

**LONG-TERM PSYCHOLOGICAL OUTCOME OF
FACIAL RECONSTRUCTIVE SURGERY**

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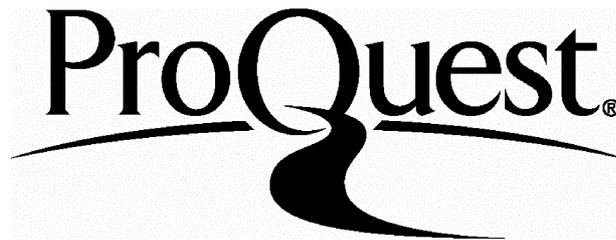
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ABSTRACT

This paper presents a study which examines the long term psychological adjustment of maxillofacial patients following surgery. Hypotheses, generated from previous research, were tested and new hypotheses generated through the development of a new theory. This was attempted using two research methods: a) quantitative and b) qualitative.

a) 32 participants, aged 16 to 33, with the congenital conditions of hemifacial microsomia and Treacher Collins were assessed from between 0.2 to 13 years post-operatively, on measures of self-esteem, body satisfaction and general psychological well-being. Participants were found to have significantly poorer mean psychological adjustment than the normal population on each of these three measures. However, adjustment was significantly better than that displayed by clinical populations, indicating that the maxillofacial population has low grade chronic difficulties. Psychological adjustment was not predicted by any of the following factors: age now; age at surgery; time since surgery; number of operations; sex; appearance before surgery; appearance after surgery; change in appearance following surgery. This study also found no evidence for any change in attractiveness following surgery, as assessed by independent observers.

b) 14 participants were also asked to take part in a telephone interview to gather simple qualitative information about their views of their surgical decision, expectations of surgery, surgical outcome and psychological support. 64% felt their expectations had been met with respect to changes in appearance, 79% stated they would repeat the procedure but 93% said they would have found psychological input helpful. 6 participants were interviewed face-to-face to generate qualitative data for a Grounded Theory analysis. The resulting theory describes a process of personal evaluation, dependent on themes of identity, awareness and management strategies.

The findings are discussed in relation to previous literature, clinical implications and future research questions.

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1.0 INTRODUCTION

The numbers and complexity of maxillofacial¹ operations are increasing all the time (Kocabalkan, Leblebicioglu, Erk and Enacar, 1995). Surgery of this kind is usually motivated by the belief that improved facial appearance will have a positive effect on psychological functioning. Shalhoub (1994) writes, "Surgical procedures usually are followed not only by changes in facial appearance but also in changes in function. These changes often lead to psychological effects on patients in addition to changes in their social life" (p181). Several assumptions are made by this statement. First, that facial disfigurement causes psychological distress. Second, that surgery is able to improve facial appearance. Third, that improving facial appearance automatically improves psychological adjustment. An associated belief which follows from the last assumption, is that early surgery will produce better psychological results. The following literature review looks at the evidence for each of these assumptions in turn, to examine the value of surgery for individuals with facial disfigurements. While it appears to be true that these individuals are at a higher risk of psychological distress, it is not clear that surgery is the most effective means of resolving these difficulties.

1.1 THE PSYCHOSOCIAL EFFECTS OF FACIAL DISFIGUREMENT

The first assumption in any intervention with a child or adult with facial disfigurement, is that having such a disfigurement causes psychological distress. This literature review examines this assumption, with reference to the literature on: attractiveness; the effect of facial disfigurement on others' attitudes and behaviour; the origins of prejudice; the effects of disfigurement on the individual, in terms of their behaviour, self-reported difficulties and measurable psychological adjustment and mediating factors in the adjustment of to disfigurement, including coping styles.

¹ Maxillofacial refers to conditions affecting the face and jaws.

1.2.1 The Benefits of Attractiveness

As Berscheid and Gangestad (1982) note, “perceptions of another’s physical attractiveness are not idiosyncratic to the eye of the particular beholder” (p.291). There does appear to be a generally accepted standard by which people judge the physical attractiveness of others. Pertschuk and Whitaker (1982) report inter-rater reliability for attractiveness of 0.94. The benefits afforded these more attractive individuals has been frequently investigated. It appears that more attractive individuals are at an advantage from the moment they are born. Nurses in charge of premature infants give a higher intellectual prognosis to those they perceive to be physically attractive (Corter, Trehub and Boukydis, 1978) and attractive versus unattractive infants receive different treatment from their mothers (Langlois, 1981).

Several studies have claimed to show a bias against unattractive children by class teachers, such that unattractive children are believed to be less intelligent and are more likely to be accused of misbehaviour than attractive children (Dion, 1972; Rich, 1975). However, these studies are based on ratings of photographs of children *unknown* to the teachers and therefore of questionable external validity. A more rigorous test, carried out by Maruyama and Miller (1981), involved a survey of children’s school performance, which was then correlated with attractiveness ratings of the children’s school photographs. These correlations were low (<0.15), indicating that if attractiveness influences initial assessment of ability, this does not translate into performance outcomes.

Other children do however appear to show discrimination against unattractive peers. Dion and Berscheid (1974) found that children aged 4-6, asked to examine photographs of classmates, perceived the unattractive children as more “scary”. There was also a sex difference, as unattractive boys were described as more aggressive, whereas unattractive females were described as more fearful. This suggests that stereotyping on the basis of an individual’s appearance begins at an early age.

Dion, Berscheid and Walster's 1972 article entitled "What is beautiful is good", appears to be a useful description of attitudes to attractive adults. The physically attractive are seen as significantly more sensitive, more sophisticated, intelligent, kind, interesting, strong, poised, modest, sociable, outgoing, exciting and sexually warm and responsive, are believed likely to capture better jobs, to have more successful marriages and in general to experience happier and more fulfilling lives than less attractive people (Bull, 1974; Dion et al, 1972).

There is also evidence that others' attitudes affect their behaviour towards attractive people. Job recommendations of experienced personnel consultants have been found to be significantly influenced by the candidates attractiveness, even when not related to possible job performance, (Cash, Gillen and Burns, 1977). Attractive people receive more assistance in general from others and others are more likely to co-operate with them (Berscheid 1981; Sigall, Page and Brown, 1971). Physically attractive people tend to be the recipients of more intimate self-disclosure from others (Brundage, Derlega and Cash, 1977).

Unattractive adults are equally *disadvantaged*, especially when little else is known about them. Efran and Patterson (1974) found that the facial attractiveness of political candidates had no influence on voter's choice of political leaders from major political parties. However, it did have an effect on minor candidates. Stewart (1980) analysed genuine court cases to determine whether the attractiveness of the defendant had an effect on jury decisions. Although there did *not* appear to be a relationship between attractiveness and guilty/not guilty verdicts, attractiveness did correlate with the length of the sentences. The more attractive defendant received shorter sentences, even when the factor of crime severity was taken into account. The exceptions to this are good-looking confidence tricksters, who got longer sentences (Bull, 1974).

Kalick, 1982 also notes that there are times "when the beautiful may be damned rather than blessed" (Kalick, 1982, p380). For example, it has been found that people may be quick to condemn the good looking for using their looks to exploit others (Sigall and

Ostrove, 1973). Also, we may be especially quick to take offence at good looking individuals when we perceive them to have slighted us (Sigall and Aronson, 1969).

In general, however, the advantages of being attractive outweigh the disadvantages and these seem to translate into positive outcomes for the individual. Physical attractiveness is associated with positive self-concept and good mental health, (Adams, 1981; Langlois, 1981). Attractive adults and children are more assertive and self-confident than their unattractive peers (Dion and Stein, 1978; Jackson and Huston, 1975). Men receive more favourable ratings when with more attractive women and are more likely to want to date them (Sigall and Landy, 1973). However, while physical appearance may be relevant in the initial stages of meeting people, there is no relationship between attractiveness and long term adjustment or satisfaction within relationships (Murstein and Christy, 1976).

The self-fulfilling nature of social stereotypes, that attractive people are treated in a way that makes them respond in a socially estimable way, is illustrated by a study by Snyder, Tanke and Berscheid (1977). Women, whose conversation partners believed them to be attractive, conversed in a manner that judges found significantly more friendly, likeable and sociable than those who were believed to be unattractive.

In sum, the literature suggests that the attractiveness or unattractiveness of an individual not only affects others expectations and their behaviour, but also the psychological status and the behaviour of the individual concerned. While it is not uniformly true that unattractive people are at a disadvantage, it is true that, especially in the absence of other information, they are discriminated against, throughout their lives.

1.1.2 The Effect of Facial Disfigurement on Others - a developmental perspective

The literature on attractiveness suggests that the individual with a facial disfigurement is at a serious disadvantage, socially, educationally, vocationally and sexually.

However, it seems that disfigurement is viewed as more than simply unattractive. Studies on social responses to the disfigured child indicate that aversive responses are significantly stronger than those shown to unattractive children, with the exception of the obese, (Lansdown and Polak, 1975; Pertschuk and Whitaker, 1982). There is also a sense of stigma associated with disfigurement, whereby the individual is marked and stereotyped and not treated as a human being (Goffman, 1963). The following review examines the effect of disfigurement on others, from the birth of the child through to adulthood. Because of the limited amount of research into children with maxillofacial conditions, the review also refers to literature on cleft lip and/or palate and craniofacial conditions. It should be noted however that these may not be entirely comparable. The cleft population have frequent difficulty with feeding and speech but their degree of deformity is less marked (Spriestersbach, 1973) and while the craniofacial population may include the maxillofacial population, it may also include individuals with major skull abnormalities and associated risks of intellectual impairment.

Difficulties for the disfigured child begin at birth. Clifford (1973) describes multiple reactions of a parent to the birth of a child with cleft lip, including grief, anger, anxiety, confusion, depression, disappointment, disbelief, frustration, guilt, hurt, inadequacy, rejection, resentment, shock, stigmatisation and withdrawal. Several authors have suggested that new parents go through a process similar to that experienced following a bereavement (Berkendorf, 1987; Drotar, Baskiewicz, Irvin, Kennell and Klaus, 1975). This is conceptualised as a grieving for the loss of the expected 'perfect' child. An alternative interpretation (Lax 1972) views these responses as a type of "narcissistic trauma", whereby parents experience the child's defect as their own which threatens their own self esteem. In either case, this predicts difficulties for the development of attachment.

In contrast to this idea, Clifford (1968) notes that the shock and depression seem to pass and become acceptable within a few days. In support of this, Clifford and Crocker (1971) report that parents show neither sense of guilt nor any feeling of being different from others as children grow up and Fishman and Fishman (1971) note that self-esteem of the congenitally defective child is determined not by the remembered amount of

maternal stress but by the subsequent handling of the child. Spriestersbach (1973) reported no effect on the parents' marriage of having a cleft child. However, Lefebvre and Munro (1978) report significant marital discord in 13% of families with a member that was craniofacially deformed, although this may not be significantly higher than the normal population.

It may be that the initial shock is over so quickly that there is no significant impact on parenting. Studies which have attempted to quantify these difficulties have found mixed results. Speltz, Armsden and Clarren, (1990) observed dyadic interactions between mothers and toddlers (aged 12-36 months) with craniofacial anomalies. They found no difference between the quality of maternal responses, when compared to a matched control group of children with no congenital problems. But Allen, Wasserman and Seidman (1990) found that mothers of pre-schoolers with congenital abnormalities exhibited a more controlling parenting style. Maternal self-reported difficulties are more consistent. Mothers of children with craniofacial anomalies reported higher levels of stress, lower evaluations of self-competence and a higher degree of marital conflict (Speltz et al, 1990) and have significant concerns about the child's future, (Brantley and Clifford, 1980). While this may seem unhelpful, Speltz et al suggest that mothers attributing caregiving problems to ineffective parenting rather than child characteristics can be a positive coping mechanism which preserves a sense of control and positive maternal feelings.

There is evidence to suggest that disfigurements affecting different parts of the body and face have differential effects on others. Greenberg (1979) studied five mothers of children with birth defects and concluded that mothers who experience the most severe sense of narcissistic trauma were those whose children had defects that interfered with feeding, eye contact, or smiling. Field and Vegha-Lahr (1984) suggest that a disfigured face is more difficult to read and that this influences sensitivity of the mother. In their study, at three months, mothers were less smiling and responsive, and less initiating of social behaviour.

The finding that the closer the disfigurement to the eyes and the mouth the greater the degree of the aversion, has been replicated in England, America and Holland, (Lansdown, 1981; Richardson, 1970). This has not been found amongst Asian cultures, where Caucasians are more likely to rate facial disharmonies as unattractive than Pacific Asians (Kiyak, 1981). Shaw, Meck and Jones (1980) noted that teeth came fourth out of 14 physical features in frequency of attracting teasing, but also noted that this caused the most distress.

Other children show negative reactions to disfigurement. Children as young as 3 months of age can recognise and discriminate among faces and show a preference for symmetric, smiling faces and a negative reaction to distorted faces, (Kagan, Henker and Hen-Tov, 1966; Vander-Zanden, 1985). Children with oral-nasal scars and other facial abnormalities are rated as less friendly, less intelligent and less popular, by their peers and adults, (Shaw and Orth, 1981). Centres and Centres (1963) found that children with amputations were named by their classmates as the saddest, least liked, least nice looking and the least fun, even after a long exposure time, although conversely, Yukar, Block and Campbell (1960) found a more positive attitude towards the disabled with increasing contact. It may be that this reflects a more positive attitude to disability rather than disfigurement, or may reflect the older sample in Yukar et al's study.

Richman and Harper (1978) looked specifically at the influence of cleft lip and palate on teachers' estimation of IQ. They found that teachers underestimated the abilities of high IQ children but *overestimated* the abilities of low IQ children, suggesting that there may not be a straightforward linear relationship between disfigurement and bias in IQ estimation. However, it may be the case that teachers always over-estimate the abilities of low IQ children and under-estimate the abilities of high IQ children, regardless of their appearance.

Lefebvre and Munro (1978) describe how most teenagers with craniofacial conditions reported cold treatment from members of the opposite sex. This situation does not necessarily improve when these teenagers become adults. Hirschenfang, Goldberg and Benton (1969) interviewed 25 patients with facial paralysis who complained of

difficulties making friends, lack of opportunities for marriage, weakening of family constellations, problems obtaining jobs and general social difficulties caused by people staring, making remarks or asking questions about the deformity.

It seems to be the case that adults with facial disfigurements are at a social disadvantage and that they are aware of the difficulties they face. It is possible that this creates expectations of negative reactions and increasingly negative interpretations of others, which in turn reinforce their beliefs about themselves. Rumsey (1983) compared the reports of disfigured subjects, non-disfigured subjects and non-disfigured subjects who falsely believed that they have been made up to look disfigured. Both the disfigured and the pseudo disfigured group made overly negative interpretations of other's reactions. This illustrates the self-fulfilling nature of negative expectations. While this may be true, there are also genuine differences in the way that people interact with people with disfigurements. Kleck and Strenta (1980) found differences in emotional arousal, gestural activity, duration of eye contact, use of personal space and time spent in face-to-face interaction.

To summarise the effects of disfigurement on others, it seems that there are many potential areas where children and adults with disfigurements experience differential treatment, right from birth, through childhood, adolescence and into adulthood, although there is some evidence that these negative reactions may lessen with time and exposure to the individual. It does appear to be the case that having the experience of rejection can also increase the likelihood of identifying discrimination, even when such discrimination does not exist. Possible explanations for the reactions to disfigurement are explored below.

1.1.3 Origins of Prejudice

As we have seen, unattractive people are also the subject of discrimination but not nearly to the same extent as that felt by people with facial disfigurements (Bull and Rumsey, 1988). It seems that the disfigured are seen as part of a separate sub-group:

“The person who is disfigured is marked, not because he fails to achieve the ideal of being beautiful, but because he has failed to achieve an unstated minimal standard of acceptability,” Clifford (1973) (cited in Lansdown, 1981, p85).

There have been several theories which have attempted to understand why it is that attitudes toward facial deformity are so negative.

The folklore surrounding facial deformity has been extensively reviewed by Shaw (1981). In Greek and Roman times, people with disfigurements were considered to be signs from the gods, usually a warning or punishment for wrong doings. In Roman times this led to the sacrifice of these infants, often with their mother, to appease the gods. In Mesopotamia, particular congenital deformities were considered to herald future events. European folklore regards physically disfigured children as either the offspring of elves or goblins, or the work of the Devil. This is particularly notable in the use of the term “hare lip” for cleft lip in English, Dutch, German, Danish, French, Swedish, Spanish and Italian. The hare is traditionally portrayed as the Devil’s familiar and mothers were often warned not to look at hares or step over their lairs while pregnant to prevent bearing a hybrid child, having the mark of the Devil (hare lip).

Modern day fairy stories, commonly portray the ‘bad guy’ as someone with a disability or disfigurement of some kind. Bradbury (1993, p2) writes, “From Grimm through Walt Disney to Nightmare on Elm Street, the message is clear.” Easson writes:

“Each culture has a built in set of values of facial appearance. In our society the small chin is supposed to denote weakness, the narrow forehead mental backwardness, the large nose alcoholism and self-indulgence, big ears the

buffoon, red hair the extrovert - against such cultural measures of pre-set values the child's face and his physical acceptability are measured and the family and society tend to react" (Easson, 1966) (cited in Lansdown, 1981, p84)

Shaw (1981) interviewed 200 women aged 20-69 to determine the extent of traditional myths in current beliefs and knowledge about facial disfigurement and found that many misconceptions about facial deformity still exist, even when the commentators know personally someone with a facial condition. All the ancient explanations were mentioned by one or more respondent, with no effect of the age of the respondent. In general, however, folklore appears to be being replaced by quasi-medical explanations, although these are not necessarily more accurate. For example, 11% believed "portwine" stains were caused by maternal cravings for red food during pregnancy. This was also believed to be produced by contact with blood and being frightened by an animal. Other explanations included intrauterine pressure, tight corsets, attempted abortion and excessive smoking and drinking.

These myths may have many effects on people's attitudes to disfigurement. They may feel it is contagious (Hastorf, Wildfogel and Cassman, 1979) or a sign of poor character in the mother. It may also reinforce guilt in the parents for something they feel they may have done to cause or deserve a disfigured child.

Other explanations for the effect of disfigurement concern the evolutionary significance of appearance. In the animal kingdom, animals who are bigger and more brightly coloured are more likely to be chosen as mates than smaller less attractive birds. In evolutionary terms, this mate is more likely to be able to compete and provide genes which will advantage the next generation. It has been suggested that we are making the same judgements on an unconscious level when we prefer more attractive partners, (Dawkins, 1976).

Individuals with severe facial disfigurements or with disfigurements which affect the eyes and the mouth may have some difficulty in communication, not only the physical production of speech, but also in the expression of non-verbal information. This

communication difficulty may make social interaction more difficult, thus these situations may be avoided. This fits with Richardson's (1970) findings that the closer the disfigurement to the eyes and the mouth the greater the degree of the aversion.

Hastorf, Wildfogel and Cassman (1979) suggest several reasons why disfigured people are avoided. The strangeness of the appearance means that people do not know how to react, they may want to examine the handicap close up or ask questions but do not want to appear rude. This causes conflict which makes people uncomfortable. This is supported by research by Rumsey and Bull (1986) into helping behaviour. They found that members of the public were willing to provide help to people with a facial port wine stain but avoided doing so if it involved lengthy interaction. Hastorf et al (1979) also suggest that people are reminded of their own vulnerability when confronted with someone else with a disfigurement. This can be likened to the narcissistic trauma experienced by parents on the birth of a disfigured child.

People with facial deformities carry low status in our society and while this does not explain the origins of this discrimination, it may explain why others do not wish to be associated with someone with a lower status than themselves; 'stigma by association', (Goffman, 1963). People with a deformity also challenge the norm of what a person should look like which may also make people feel threatened. If a person does not look as they might be expected to, people question other aspects about them; their personality, their intelligence or their identity as sexual beings. This lack of predictability, due to lack of experience with people with disfigurements, causes anxiety, (Kelly, 1955).

There seem to be many explanations for society's reaction to facial disfigurement. A strong history of discrimination has built up over thousands of years, which may have initially arisen out of biological need but has now reached a stage where it has become self-perpetuating. The persistence of historical myths about the origins of disfiguring facial conditions has implications not only for the individual but also for their families and friends.

1.1.4 The Effect of Facial Disfigurement on the Individual

While children and adults with facial disfigurements are at a disadvantage, this does not necessarily imply that this will affect their behaviour or psychological adjustment, although this has been the assumption. Frances MacGregor (MacGregor, Abel and Brynt, 1953) was one of the first clinicians to write on this subject, and she described disfigurement as “psychological and social death”, on the basis of her own clinical experience. The following is a discussion of the research findings in relation to these issues. What are the observable differences in behaviour? What are the self-reported difficulties? What are the measurable differences in adjustment?

1) Observable differences in behaviour

As young children, there is little evidence that disfigurement has an impact on behaviour. Speltz, Armsden and Clarren (1990) found no difference between the behaviour of their toddlers with craniofacial anomalies and a control group. Equally, Allen, Wasserman and Seidman's (1990) sample were just as likely to approach mum, entertain themselves, were as happy, talkative and compliant as the other children. They were however, less likely to initiate social interactions with other children.

As they get older, differences in their behaviour become more noticeable. Kapp (1979) found that children with cleft lip and palate aged 5-8 were more likely to play alone were frequently teased and chased away by other children. Richman and Harper (1978) examined children with cleft palate and cerebral palsy and both displayed greater inhibition of impulse and lower educational achievement (using teachers behavioural ratings and test-scores). They suggest the inhibition is an adaptive response in trying to avoid negative responses, but that this may increase the likelihood of low achievement.

Van Denmark and Van Denmark (1970) found adults with cleft lip and palate marry less often, have more difficulties meeting people and are more likely to have lower vocational ambitions.

There is little research which specifically and systematically examines the differences in behaviour exhibited by children and adults with facial disfigurements. However, it seems that any differences which do exist seem to change with the age of the individual.

2) Self Reported Difficulties

There appears to be some agreement about the time when children become aware of their disfigurement. Harris (1982) reported that children with congenital abnormalities became self-conscious around the age of 5-6, usually by another person commenting on it. Kapp (1979) found that children with cleft lip and palate aged 5-8, expressed desires to want to blend in and identified more frequently with a picture of an unhappy child. Teasing seems to become a problem at this age, which most facially disfigured children report (Pertschuk and Whitaker, 1982).

However, while this seems to be the time at which children first become aware of their difference, their concern about their appearance usually peaks at the onset of adolescence (Heldt, Haffke and Davis, 1982; Pertschuk and Whitaker, 1982), despite the fact that overt teasing diminishes (Lefebvre and Munro, 1978). By the early teens, craniofacial patients report feeling depressed and receiving cold treatment from the opposite sex (Lefebvre and Munro, 1978).

Harris (1982) asked patients with various abnormalities of appearance, to give written accounts of their experiences. Common patterns emerged from all groups. Negative self-evaluation, including unsuccessful rationalisation of the deformity, hostile teasing, awareness of covert reactions from others, negative assumptions about the origins of the deformity, defense mechanisms, such as camouflage techniques - especially hairstyle and restrictions to lifestyle, (particularly in the taking of photographs), unavoidable distressing activities, (occupational, social, domestic, recreational and other) and difficulties with interpersonal relationships.

There is a consistent amount of literature which describes the difficulties reported by the facially disfigured. This is perhaps not surprising, given the majority of research is carried out on the assumption that people with facial disfigurements have mainly negative experiences to report. It might however be useful to ask specifically about any positive experiences which people feel may have come out of their disability.

3) Measurable Difficulties in Psychological Adjustment

“Any kind of facial deformity is likely to lead to an increased psychological strain. Life is just that little bit harder if you have got a face that is out of the ordinary. But we are not going to find ourselves surrounded by children who are neurotic, aggressive, bullies or delinquent” (Lansdown, 1990, p450).

Clifford (1983), entitles his article on the psychological adjustment of adolescents with cleft lip and palate, Why are they so normal?. Indeed, the majority of studies have shown no differences in self-concept, self-esteem or body-percept between the ages of 8 and 18, although reported dissatisfaction with appearance is high (Kapp, 1979; Richman, 1983). In complete contradiction to expectations, some studies have even indicated higher than average self-esteem and self-concept (Brantley and Clifford, 1979; Leonard, Brust, Abrahams and Sielaff 1991).

Studies looking specifically at the adjustment of craniofacial children, have found slightly different results. Pertschuk and Whitaker (1982) found that all of the 32 pre-surgery children, aged 6-13, with craniofacial anomalies, scored within normal limits on measures of self-concept. Two of these children scored as exceptionally introverted on the Junior Eysenck Personality Inventory and one scored significantly high on the State-Trait Anxiety Scale for Children. Four children were considered to be socially isolated and four were considered by parents to have behaviour problems. This seems somewhat in contrast to an older group, aged 14 and up. Of the total of 19, 8 scored significantly poorly on the Tennessee Self-Concept Scale. Of these 8, two had concurrent depression and two concurrent anxiety.

It seems that younger children with craniofacial anomalies make social-psychological adjustments within normal limits despite serious appearance handicaps. (Tobiasen, 1988). However, as the children grow older, they have greater difficulties. This is supported by Pertschuk and Whitaker's 1988 study which noted that their (non-disfigured) control group, showed more extroversion and fewer negative encounters with age, whereas their disfigured group didn't. This indicates that the gap between disfigured and non-disfigured adolescents increases with time. Lefebvre, Travis, Arndt and Munro (1986) also report that pre-operative self-esteem in their sample of children with Apert's syndrome was negatively correlated with age.

Why should age make a difference? Pertschuk and Whitaker (1982) suggest several interpretations. First, that younger children are better at denying their problems. However, the confirming statements of their parents make this unlikely. Second, that appearance is less salient for younger children. Young children rate facial deformity as more acceptable than other handicaps, older children take a more negative view of facial deformity (Richardson, 1969). Third, that this may reflect a difference in the worlds in which they have to function. The world expands dramatically during adolescence and thus so are the opportunities for rejection. Parents express concerns that problems could develop later as dating and vocational pursuits become issues. Heterosexual relationships are an increasing concern for the late adolescent and young adult patient whereas relationships with peers are infrequently a problem (Pertschuk and Whitaker, 1982). It could however, be that older children with disfigurements are considered less attractive, either because the deformity increases with age or because younger children are considered more 'cute'. However, the relationship between appearance and adjustment is not a simple one and is discussed separately below.

Adjustment may also be related to gender. Kapp (1979) found no overall difference in self-esteem between cleft lip and/or palate 11-13 yr olds and controls. However, girls with clefts reported greater unhappiness and dissatisfaction, less success in school and more anxiety. Leonard, Brust, Abrahams and Sielaff (1991) suggest that there is an interaction between age and gender such that older girls (12-18) have lower self-concept than younger girls (8-11) but older boys have higher self concept than younger

boys. This pattern may simply reflect trends in the general population (Offer, Ostrov and Howard, 1984) but nevertheless, these children have generally average or above average self-concept. Why might this be the case? Leonard et al suggest this may be due to poor reality testing, denial, supportive parents or an emphasis on developing other competencies. It is also worth noting that many of the participants in this study received professional intervention.

Despite the relatively good adjustment of many adolescents with facial disfigurements, some authors have suggested that the questionnaires used to evaluate adjustment are not sensitive to the 'real' difficulties. For example, Pillemer and Cook (1989) report that children with craniofacial abnormalities are more likely to show inhibited personality style, low self-esteem, impaired peer relationships and greater dependence on significant adults but that these are more easily identified using projective tests such as the Tasks of Emotional Development. Lansdown, Lloyd and Hunter (1991) describe a child with facial disfigurement, who scores in the normal range on measures of self-esteem but drew pictures of people with masks on and who covers his face with his hand whenever he goes out.

This is supported by Blakeney, Meyer, Moore, Murphy, Broemeling, Robson and Herndon (1993), reporting on the psychological consequences of burn injured children, who found that although adjustment was generally good on the Child Behaviour Checklist and PSCS, projective measures still indicate emotional distress.

There are several possible explanations for these discrepancies. It could be that the questionnaires are not sensitive enough. Alternatively, it may be that the children are aware of their disfigurement but are generally well adjusted. Or, it could be that children are likely to be less honest on questionnaires. This issue relates to that of defining adjustment. There does not appear to be an accepted definition and therefore no accepted measure or measures of adjustment for these individuals. Some studies look at behaviour, others self-report and others standardised questionnaires but all seem to suggest differences in their findings.

In general, it seems that children with facial disfigurements are more psychologically well adjusted than adolescents in terms of standardised psychological measures. However, psychological difficulties are not an automatic consequence of having a disfigurement.

It is worth noting that several studies has shown the high incidence of psychological difficulties in the cosmetic surgery population. Edgerton and Knorr (1971) report that 72% of cosmetic surgery patients have psychiatric diagnoses. While this may reflect the perceived unacceptability of cosmetic surgery, which is now changing, (Kiyak, 1992), the results from the orthognathic surgery population are quite different.

General findings are that adults with orthognathic² deformities are psychologically well adjusted. Kiyak (1993) reports that orthognathic pre-surgery adult patients, men and women, were within normal range in self-esteem (TSCS), body-image and neuroticism (EPI). Flanary, Barnwell, VanSickels, Littlefield and Rugh (1990) also found normal scores in pre-operative orthognathic surgery patients on the Tennessee Self-Concept Scale, The Eysenck Personality Inventory and the 16-Personality-Factor Questionnaire, although 33% of patients had high scores on the Number of Deviant Signs indicator of personality disturbance, from the TSCS. These findings have been replicated by Auerbach, Meredith, Alexander, Mercuri and Brophy (1984) and Finlay, Atkinson and Moos (1995).

The exception to these findings are those of Pertschuk and Whitaker, (1987). They tested 60 adolescents and adults, aged 14-50, who had not had surgery. Almost half had an abnormal score on one or more tests (self-concept, extroversion, anxiety, depression and social adjustment), with approximately equal frequencies. Over 30% had an abnormal score on two or more tests. There was considerable variation in the test findings, with half the patients having entirely normal test profiles. A majority reported self-consciousness in social situations, difficulties with staring and remarks and problems with heterosexual relationships. However, on interview, only a few of them appeared sufficiently distressed to merit a psychiatric diagnosis and less than 5% had

² Orthognathic - pertaining to the teeth and jaw

sought psychotherapy. Pertschuk and Whitaker (1987, p166) summarise the emotional difficulties of this group as “low grade and chronic”.

It is not clear why the studies reveal differences in adjustment. However, it seems that there is a wide variation in adjustment within studies and the differences may reflect random differences in the sample populations. It could also reflect differences in populations which are actively considering surgery and those who has not been offered surgery (as in Pertschuk and Whitaker’s sample).

4) Summary

Overall, there is consistent evidence that the presence of a facial disfigurement affects the individuals behaviour, self-reported functioning and to a lesser extent, their adjustment in terms of standardised psychological measurements. That disfigurement is "psychological and social death", (MacGregor et al, 1953) does not appear to be the case for every individual. Perhaps a more fruitful question is under what circumstances individuals have difficulty adjusting to their disfigurements.

1.1.5 Mediating Factors in Adjustment to Facial Disfigurement

1) The Relationship Between Degree of Deformity and Degree of Psychological Distress

There is little literature which examines the relationship between the degree of disfigurement and the psychological adjustment of the person themselves. Lansdown, Lloyd and Hunter (1991) suggest that the relationship is complicated and not linear as one might expect.

Several studies have suggested that there is no relationship between degree of disfigurement and psychological adjustment. (Bradbury, Hewison and Timmons (1992), children with prominent ears; Hay (1970), adult cosmetic rhinoplasty patients). This is consistent with the finding that there is no relationship between adjustment of parents of children with facial disfigurements and the degree of the child's disfigurement (Bradbury and Hewison, 1994).

However, Arndt, Travis, Lefebvre, Niec and Munro (1986), assessing 22 children with craniofacial disfigurements, found that the self-esteem of the severely disfigured group was twice as high as that of the mildly disfigured group. This is consistent with the finding of Harper and Richman (1978), that children with mild physical impairments show a greater behavioural inhibition than those with severe impairments or non-impaired children. Lansdown, Lloyd and Hunter (1991) assessed 27 facially disfigured children and although they found no association between degree of deformity and total self-concept, when they looked at seven items relating to appearance and popularity, there was a trend for the mildly deformed to have the lowest self-concept.

Frances MacGregor et al (1953), writing from clinical experience, first suggested that a mild deformity might be harder to cope with than one that is more severe. She also noted in 1978 that mild disfigurements that provoke ridicule, such as prominent ears, cause more behavioural problems than more serious disfigurements. Why might this might be the case? It could be argued that children with mild disfigurements are still considered by others and by themselves as members of the "normal" population. They are therefore compared with other members of this group, unfavourably. Children with severe disfigurements could be considered as so different that they do not belong in the "normal" group but in a different "out" group. They therefore are not compared in the same way, as others do not have the same expectations of them. An alternative explanation may be that the public react to people with a mild disfigurement inconsistently, sometimes staring, sometimes not noticing. This may lead to an inability to predict others' reactions and increase pressure in social situations to try and hide the deformity (Lansdown et al, 1991). Reich (1969) notes that the severely deformed can confidently predict a negative response whereas responses to minor disfigurement are

unpredictable and an inability to predict other people's responses is well known as an underlying factor in anxiety (Kelly, 1955).

Should it prove to be the case that degree of disfigurement is inversely related to psychological outcome this has major implications for surgical intervention. Before suggesting surgery it would need to be proved that altering a person's appearance did in fact have a beneficial effect on their psychological state as well as their objective appearance. The current literature suggests that improving facial appearance such that a major disfigurement becomes a minor disfigurement may have a detrimental effect on the individual's psychological well-being.

2) Other Mediating Factors

If there is no clear linear relationship between appearance and psychological adjustment, what are the reasons why some people with facial disfigurements seem to adjust better than others? As we have seen, age and gender may be important but what are the others factors which influence adjustment?

Lansdown (1981) suggests that disfigured children are less likely to maintain a positive self image in the face of peer discrimination if the family has negative feelings about their child. Bradbury and Hewison (1994) carried out a study which attempted to determine the predictors of adjustment in parents of children with cleft palates, compared with parents of children with congenital hand deficit. Adjustment was measured using their own semi-structured interview which assessed attitudes to the condition, social contact with the child, the taking of photographs, attitude to surgery, the effect on their decision to have more children and the effect on the parental relationship. They found a wide range of adjustment in both groups but no significant difference in their overall adjustment. The severity of the anomaly had no effect on the level of adjustment. The only significant predictor was perceived family support.

The importance of family support is supported in part by the literature looking at the effects of burn injury on a child's adjustment. Good adjustment to deformity (as measured by self-esteem and the suicide probability scale) was predicted by family factors such as strong family commitment, ability to express conflict and encouragement to be independent (Beard, Herndon and Desai, 1989; Blakeney, Portman and Rutan, 1990).

Burn injury, while producing severe facial disfigurements, is also the result of a discrete trauma and therefore likely to produce different psychological reactions. A child growing up with facial disfigurement will have always been perceived as different, whereas a child with burn injury will have had a previous identity as a 'normal' child. Caution should be exercised in interpreting findings from other population groups.

Interestingly, Benson, Gross, Messer, Kellum and Passmore (1991) found that parents of facially disfigured children who had more severe physical impairments and were rated as less attractive reported having less available and less satisfying social support. The social competence of the child was the most important predictor of parental social support. Benson et al give several possible reasons for this. Others may feel uncomfortable around a facially disfigured child and avoid them, parents may wish to protect their child and thus alienate themselves, parents may be embarrassed about taking their child out or the additional financial burden may place financial restrictions on social activities.

Social support from peers may also have an effect on adjustment. Varni, Setoguchi, Rubinfeld-Rappaport and Talbot (1991) found that perceived classmate social support single was the biggest predictor of depressive symptomatology in children with limb deficiencies.

Other mediating factors in adjustment have been suggested. Padwa, Evans and Pillemer (1991) looked at children with symmetrical vs asymmetrical facial disfigurements and found that those with symmetrical disfigurements did more poorly on projective psychological measures. However, these children had also had a greater

number of operations and more major operations. The presence or absence of functional impairments was not found to be related to adjustment.

There has been very little research on mediating factors in adjustment to congenital maxillofacial disfigurement in particular. However, at present, the literature suggests the most important variable is family support.

3) Coping Styles

While life for someone with a facial disfigurement is arguably difficult, how one individual copes will depend to a great extent on their own coping abilities. Although these individual characteristics will be shaped by the actions and reactions of others, they are not absolutely determined by them.

So how do people cope with the difficulties they face? MacGregor (1974) describes three coping styles employed by disfigured patients: the ostrich technique; overt aggression; taking the initiative. Not surprisingly, the latter is considered to be the most adaptive. Positive behaviour in one person tends to elicit positive behaviour in others. Encouragingly, Rumsey, Bull and Gahagan (1986) found that social skill variables had more effect on observers than the presence or absence of a disfigurement.

There has been very little theory relating to the adjustment and/or coping styles of children growing up with a facial disfigurement. One exception to this is Belfer, Harrison, Pillemer and Murray, (1982). From their clinical observations they suggest that children with severe deformities tend to defend against their painful influence through the use of massive denial. Children with less severe objective deformities are believed to still use the psychological defense of denial but to focus more on an unconscious sense of badness (expressed as willfulness or anger) or neediness (defectiveness equated with emptiness). They state that “the deformity can interfere with normal psychological maturation and result in the persistence of primitive and

maladaptive psychological defense structures.” (p311). For example, dependent relationships with parents or hostile dependent relationships.

There is little research which directly addresses these hypotheses and little other theory to explain the process of adaptation which the child undergoes. This would be extremely valuable in helping to bring together the findings on adjustment and mediating factors and in predicting future psychological difficulties in older children and adults.

1.1.6 Summary of Findings

What is the evidence for psychological difficulties experienced by people with facial disfigurements? There is in general very little literature or theory directly relating to this issue and much of what there is, has been based on self-report. However, several patterns seem to be emerging. Although negative reactions to individuals with congenital facial disfigurements begin from birth, it seems to take several years before these reactions begin to have an observable effect on the individual. Negative experiences and difficulties with self-esteem seem to peak at adolescence, when the social world and the potential for rejection increase at a time when other sources of self-esteem, such as academic and vocational skills, have not yet fully developed. In adulthood, it seems that while there are pervasive low grade difficulties, there are fewer acute problems. Within these generalisations, there are huge variations between individuals, with many functioning normally. At various times, adjustment seems to be related to age, sex, family support, peer acceptance and asymmetry of the disfigurement.

1.2 SURGERY

Surgery for the maxillofacial conditions of Treacher Collins and hemifacial microsomia can involve multiple operations to the ears, cheekbones, cheeks and jaw (Calvert, 1988). These can involve both soft tissue and bone and some require several days in intensive care following the procedure. Post-operatively, patients often experience initial swelling, pain and other longer-term complications (Kiyak, 1993). In general, these operations are carried out as early as possible, within the restrictions imposed by a child's continuing growth. Putting a child through an operation can also have implications for the family. These include time off school, financial stress, child care difficulties, travelling and frequent medical appointments (Phillips and Whitaker, 1979). Surgery, particularly involving early hospitalisation, also carries potential risks for child development. Ludman, Lansdown and Spitz (1992) found that the quality of mother-infant attachment and the behaviour of three year olds was predicted by lengthy and repeated admissions to hospital in early life. Given the risks associated with surgery, the benefits and alternatives need to be clear before an informed decision can be made.

1.2.1 Motivations for Surgery

When surgeons describe indications for craniofacial surgery, psychological benefit is usually high on the list (Pertschuk and Whitaker, 1982). Other reasons, such as improving mastication or breathing, are usually secondary. As Straith states:

“any deformity or blemish, however slight, which constitutes a source of distress to the patient should be corrected whenever possible..... A proper appreciation of the fact that these unfortunate individuals are at the same time mentally unwell, will enable the physician to advise treatment that will remove both physical deformity and mental stress” - (Straith, 1932, p13)

Traditionally, desire for reconstructive surgery has been viewed by psychologists as a projection of other concerns onto the physical self (e.g. rhinoplasty as over-genitalisation of the nose in sexual disturbances, Friedman, 1951). MacGregor (MacGregor et al, 1953) was one of the first Psychologists to consider the reality of social factors contributing to psychological distress in those with facial disfigurement.

“While not downplaying the importance of warmth, acceptance, and calm handling by family members, MacGregor has maintained that such treatment is not to be viewed as a substitute for correction of flaws that are likely to elicit ridicule from outsiders. A social scientist by training, she has helped to expand the context in which plastic surgery patients are considered.” (Kalick, 1982, p380).

This stance understands desire for surgery as a very real reaction to social ostracism and providing that appearance is improved, predicts psychological improvement. The potential for psychological improvement has seemed obvious. The surgeon, by correcting the deformity, would make the patient more acceptable to others and thus, eventually to him or herself. This is consistent with the main reason that patients themselves give for surgery - to improve their appearance (Flanary, Barnwell, VanSickels, Littlefield and Rugh, 1990; Heldt, Haffke and Davis, 1982). Other reasons include improvement in mastication and speech, with slightly more males than females reporting functional reasons (Kiyak, 1993). However, all patients, regardless of gender, reported the major cause of long term dis-satisfaction with the surgery was poor aesthetic results, indicating that this may have been of more concern than previously indicated.

1.2.2 Change in Appearance Following Surgery

Since change in appearance is the primary motive for having facial reconstructive surgery, there have been several studies which have tested the success of operations in

these terms. Arndt, Travis, Lefebvre, Niec and Munro (1986) asked independent observers to rate photographs of 22 craniofacial patients aged 8-17 from before and after surgery. Photographs were presented in a random order. The raters noticed a significant improvement in appearance for those patients with mild disfigurement but a non-significant difference in the severely disfigured group. In a similar study, Pillemer and Cook (1989) found no significant improvement in independent ratings of hospital photographs.

A more thorough study, carried out by Barden, Ford, Wilhelm, Rogers-Salyer and Salyer (1988), using 30 raters and well standardised photographs, found an overall significant improvement in appearance, from 1.69 - 2.51, on a 5 point scale, following craniofacial surgery. However, a closer analysis of these results found that in only 21% of cases was there a dramatic change for the better. In 30% of cases there was no change and in 8% there was change for the worse. It seems that improved appearance is by no means guaranteed.

One of the most striking aspects of the literature is the lack of consistency between clinicians, patients, parents and independent raters on ratings of change in appearance before and after surgery. Heldt et al (1982), Lefebvre and Munro (1978), Lefebvre and Barclay (1982) and Arndt, Travis, Lefebvre, Niec and Munro (1986) found poor correlations between clinician or observer ratings and the ratings of patients or parents. In general, patients and parents reported much higher ratings of change in appearance following surgery than the 'objective' ratings of the clinician and observers suggest, although the degree of improvement in Lefebvre and Munro's study was the same for each group.

There have been several studies which have looked at the change in appearance of children with Down's Syndrome following cosmetic surgery. These have similar findings to that from the craniofacial literature. Arndt, Lefebvre, Travis and Munro (1986) found that parents rated an improvement following surgery whereas independent raters believed the majority looked worse after surgery than before. Parents also reported happier personal, family and social lives. This suggests that people's beliefs

about surgery are more important in terms of satisfaction with outcome, at least in the short term, than the clinical outcome.

The second assumption of surgery, that it can lead to improvement in facial appearance, does not seem to be supported by the evidence. On average, there does not appear to be an improvement to the extent that observers, unaware of the surgery, can recognise. When individual improvement is assessed, appearance does noticeably change for some individuals, but they seem to be in a minority. The finding that patients themselves notice a much greater degree of improvement suggests that either the rating scales are not sensitive enough to record a small difference, or that patients are not evaluating themselves in the same way as observers. Given that surgeons are attempting to improve appearance in order to change others' reactions to the individual, this research suggests it has failed.

1.3 CHANGE IN PSYCHOLOGICAL FUNCTIONING FOLLOWING SURGERY

The third assumption of surgery, that improved appearance will lead to improved psychological adjustment, seems a little misplaced, if there is no noticeable change in appearance. However, since the patients themselves report an improvement, it is useful to examine the evidence that surgery itself leads to change in psychological functioning.

1.3.1 Self Report: Satisfaction and Improvements.

Despite the apparently poor 'objective' results, the majority of patients report satisfaction with the surgery. Kiyak (1993) reported 84% satisfaction in their orthognathic surgery group. 92% of their sample would also recommend the surgery to others. Similar results have been found by Phillips and Whitaker (1979) who report that 92% of their craniofacial patients would make the same decision and Flanary et al

(1990), who report 77% would do it again and 89% would recommend it to others. The only caveat to these comments is from Strauss, Broder and Helms (1988) who report that despite the fact that 91% of cleft patients felt surgery had achieved expectations, 50% expressed occasional or frequent concerns about appearance and 28% still felt their speech was difficult to understand.

Patients also report other benefits. Heldt et al (1982) found 11 of their 16 adult orthognathic patients were aware of personality changes after the operation and 14 of 16 were aware of significant changes in appearance. 91% of adult patients in Phillips and Whitaker's sample reported more confidence and 27% reported observable change in social functioning. 94% of parents noticed affective improvement in their children and 50% reported less teasing. Arndt, Travis, Lefebvre, Niec and Munro (1986) found all their craniofacial patients reported increased self-confidence and social acceptance. Lefebvre and Munro (1978) reported increased social activities, increased heterosexual contacts, improved self-confidence and improved assertiveness. Lefebvre and Barclay (1982) report 96 of their 125 patients described increased comfort in public places, diminished self-consciousness when meeting strangers, increased interest in appearance and grooming and a general feeling of being more appealing to others. One 6 year old boy described himself as a frog pre-operatively and as a "six billion dollar man after surgery" (p581). In a third of these patients, they also reported improved academic or work performance, promotions, beneficial job changes and increased heterosexual activity.

In general, studies have indicated that surgery is a huge success in terms of self-reported satisfaction and functioning. The only exception to this is a finding of Lefebvre and Barclay (1982) who report that 19 of their 125 families reported increased friction between family members and 12 sets of parents reported being displeased with the personality changes which accompanied surgery. It is not clear if these findings are significant, in that Lefebvre and Barclay had no control group, but it may indicate that negative consequences are either not asked about or not reported.

1.3.2 Measurable Psychological Adjustment

As we have already seen, there appears to be a discrepancy between the patient's perceptions of change in appearance and the surgeon's or outsider's perceptions of change. So, while patients report improvements in psychological functioning, what is the evidence for measurable psychological change? Studies which have attempted to quantify the long term psychological changes which accompany surgery have been less conclusive than the initial self-report suggests. Of the studies looking at psychological outcome in children having craniofacial surgery, two have found positive results, Arndt, Travis, Lefebvre, Niec and Munro (1986) and Lefebvre et al (1986).

Arndt et al studied 22 craniofacial patients, aged 8-17, who had surgery for malocclusion and Crouzon's syndrome. Self-esteem, measured by the Piers-Harris Self Concept Scale, (PHSCS) rose significantly, for both the severely and the mildly disfigured groups, over two years post-surgery. Post-operative scores for these two groups were not significantly different, although the severely disfigured group had pre-operative scores twice as high as the mild group. Patients' parents in this study also reported more social adeptness and acceptance at home and school. Raters noticed only subtle change in appearance, while patients rated appearance as significantly better.

Lefebvre et al (1986) followed 10 patients with Apert's syndrome before and 1, 2 and 4 years after surgery. Self-esteem, as measured on the PHSCS, improved significantly after surgery, mean increase 29%. Although pre-operative *means* were not significantly lower than normal, *all* scores at 4 years were within the normal range. Parents ratings of appearance improved significantly 1 year after surgery, no objective ratings were made.

A series of studies by Pertschuk and Whitaker (1982), on child craniofacial patients, have found less positive results. They compared two age groups, 6-13 and 14+, with 32 in the younger group and 19 in the older. In the older group they found no change in extroversion or social function, a non-significant trend towards improved self-

concept and reduced anxiety (they have no pre-op measures for the younger children). There was no change in either of the age groups in appearance. Parents of both groups report less inhibition and hyperactivity.

In 1987, Pertschuk and Whitaker published the results of another study, looking at comparisons between patients <4 and 6-13 years. Again, they took no pre-operative psychometric measures for the younger children, but took post-op at 3-5 years after surgery for the younger children and 18 months after surgery for the older group. At post-op, they report the older children show poor self-concept, greater anxiety, more introversion, more problem behaviours and more frequent negative encounters than the younger children. The younger children show no statistically significant differences from the control group. The older children show little change in personality traits and a possible deterioration in social interactions after surgery. They conclude from these results that surgery should be carried out as soon as possible.

However, as we have seen, younger children are likely to have fewer psychological difficulties anyway, therefore the improved psychological functioning in this group may simply be a function of their age. Pertschuk and Whitaker also note that their younger group had had fewer operations. Comparisons are therefore difficult to make, if not impossible, between the two groups.

Pertschuk and Whitaker (1988) confirm their previous findings that older children show little change after surgery. 43, 7-15 year olds were tested pre and 12-18 months post surgery. Before surgery, subjects showed wide-ranging but no severe psychosocial deficits and after surgery, no change on the PHSCS, the Junior Eysenck Personality Inventory, the Childhood Experience Questionnaire or the Missouri Behaviour Checklist. There was a change in the State-Trait anxiety scale, but no change in social functioning.

Lefebvre and Barclay (1982) report on a mixed group of 76 congenital and acquired craniofacial anomalies, aged 6 weeks to 39 years. They report that pre-surgery, 40 patients showed average self-esteem, 18 were above average and 18 below. Post-

surgery, they have results for only 35; 10 were average, 20 above average and 5 below, a non-significant difference between the pre-operative PHSCS scores and post-operative scores. However, they do not state the composition of the group, their ages, conditions or time since surgery.

In adults, only two studies have been completed, which look at measurable psychological changes following orthognathic surgery. Flanary et al (1990) found an improvement on self-esteem (Tennessee Self-Concept Scale) after surgery. However, their population had very mild congenital deformities, were psychologically normal before surgery, had extremely good preparation, less painful procedures than the children and no visible post-operative scarring. Kiyak (1993) reports on studies which show a decline in the facial dimension of body image at 9 months and an improvement beyond pre-surgical levels at 24 months. Anticipatory anxiety was high before surgery and depression scores highest just after. Social and overall self-esteem were not improved.

The studies to date which have attempted to answer the question of whether surgical intervention improves psychological functioning have been inconclusive. Some report improvements in self-esteem, others no change. Most studies suffer from a multitude of methodological problems, which are discussed in more detail later. But given that we know that there are several mediating factors in adjustment to disfigurement, there are likely to also be mediating factors in adjustment following surgery. Current literature and findings are discussed below.

1.3.3 Mediating Factors in Change Following Surgery

Several studies have indicated that different factors influence psychological outcome following surgery. These are described first in relation to self-reported outcome and second, in relation to measurable outcome.

1) Satisfaction

A difference between what the patient expected and what he or she experienced, predicts dissatisfaction and mood disturbance immediately after surgery and at the 2 year follow up (Kiyak, 1993; Lefebvre and Munro, 1978; Olson and Laskin, 1980). In one study, of the 13% dissatisfied, two thirds of these had unexpected postoperative complication (Finlay et al, 1995), including pain, swelling and numbness and problems with post-op diet and inter-maxillary fixation. Heldt et al (1982) report that the most common complaints were not being told about possibility of having a numb lip and not understanding the amount or duration of post-operative swelling. Despite this, Shalhoub (1994) notes, that “information related to the surgical procedures, the post-operative difficulties and possible complications often did not receive adequate attention” (p183). The possibilities of long term complications are quite high, Kiyak (1993) found 49% of the adult orthognathic sample experienced some degree of paraesthesia at 2 years follow up.

Other factors which affect satisfaction in the short term are neuroticism and external locus of control, but not in the long term (Finlay et al, 1995; Kiyak, 1993). Heldt et al (1982) suggest that satisfaction following surgery for congenital conditions is higher than that for acquired deformities, that patients who are highly motivated do better and those with severe disfigurements are more satisfied than those with mild. However, they give no evidence to support these claims.

2) Psychological Adjustment

Research findings suggest that there is no direct relationship between change in appearance and psychological adjustment after surgery (Arndt, Travis, Lefebvre, Niec and Munro, 1986; Bradbury et al, 1992). However, it may be that appearance after or before surgery predicts adjustment. Pillemer and Cook (1989) found that the children that were rated more attractive post-surgery had higher self-concept.

Age may be another factor in psychological adjustment. This is not to say that surgery at a younger age will produce better results. Children with facial disfigurements appear to have more psychological problems as they get older. Pillemer and Cook (1989) found that older children had poorer self-concept. Whether surgery can avoid this remains to be proven. Tobiasen (1988) states that “social rejection does indeed increase for adolescents with unacceptable appearance, and this suggests that adolescents with craniofacial anomalies should be studied separately from younger children” (p745).

If age is a factor, then time since surgery may also be a consideration. The follow-up time for the majority of studies is between 1 and 4 years. Perhaps this is an insufficient period of time to assess the long term effects of surgery as adjustment changes with time. Given the discrepancy between ratings of others post-surgery versus ratings of the patient, it may be that over time the ‘reality’ of the outcome becomes more apparent and initial positive effects wear off.

The number of operations a child has may have an effect on their overall adjustment, given the stresses associated with going to hospital and surgery itself (Tobiasen, 1989). Fisk, Pearl, Schulman and Wong (1985) found that as the number of operations increased, children with facial disfigurements were more likely to identify with a picture of a disfigured child and describe them as a friend and more likely to have blind judges identify emotional indicators in their drawings.

Family factors are almost certainly relevant to adjustment following surgery. Pillemer and Cook (1989) found that parental stress was significantly associated with reported adjustment and Lefebvre and Munro (1978) found that parental attitudes to the disfigured child also predicted the child’s confidence and assertiveness.

It is also possible that surgery has a placebo effect. Kleck and Strenta (1980) found that normal subjects made to believe that they are disfigured anticipate and believe others reactions are negative. Presumably, if the physical flaw is diminished and one acknowledges this fact, the tendency to perceive inordinate attention from others will

also be alleviated. If confidence has risen, the individual is more likely to go out and widen possibilities for positive reinforcement.

There is very little written on the effect of decisions to have surgery on adjustment. The exception to this is from Belfer et al (1982). They describe the decision to have surgery as the “start of the dissolution of what for many is a pathological denial” (p312) therefore the motivation for treatment may be projected onto the physician or to some greater good for the child. It is therefore a sign that “parents were willing to accept risk for change... a subtle manifestation of the parents’ less conscious negative view of their child’s deformity” (p312). While this may be the case, there is little evidence to support their claim. This theory also fails to address the issue of multiple surgery, as is the reality for the majority of these patients. Does denial cease after one operation, or the last one of a series. What happens if someone decides to re-commence surgery after a long break? Lefebvre and Barclay (1982) also question whether denial is always a pathological reaction or whether it can be seen as a useful coping strategy. They also question whether the decision to have surgery is always necessarily a healthy one. Could surgery merely represent a desire and unrealistic expectation that the child will become completely normal?

Belfer et al (1982, p312) go on to explain why the immediate post-operative period can precipitate psychological crisis, because it leads to increased rather than decreased disfigurement, pain and the “disruption of prior psychological defences”, in that they can no longer deny their deformity. They cite evidence for this in “acting out” behaviour following surgery. They describe one young man who displayed “a shift to modish dress, the use of alcohol and minor physical altercations”. This was understood as his expression of pent-up aggression, anger and sadness of previous years, “delayed adolescent reaction”. The difficulty of testing this theory is that explanations to the contrary stand accused of continuing denial. For example, Pertschuk and Whitaker (1988) report that virtually all of their patients denied having difficulty adjusting to their altered appearance. Of course, Belfer et al’s example could also be interpreted as enjoying new confidence and social freedom.

1.4 METHODOLOGICAL WEAKNESSES OF RESEARCH - QUESTIONS UNANSWERED

There is very little research which has specifically addressed the question of whether surgery is of benefit to people with facial disfigurements. The studies which have been carried out suffer from a number of methodological problems which limit the applicability of their findings and leave many questions unanswered. The major issues are described below:

1) Small numbers.

People with maxillofacial conditions represent a small subgroup of the population. Therefore research within this group is often limited by the small numbers. Those studies which involve larger sample sizes often compromise by including many different conditions, with many different difficulties, or a wide range of ages, sometimes even young babies to adults. This makes the drawing of meaningful conclusions extremely difficult.

2) Multiple operations

Single surgeries do not appear to result in immediate measurable personality and social adjustment changes. However, this does not reflect the reality of the average maxillofacial patient, who may have between 1 and 50 operations over the course of their life. Any theory which attempts to explain the impact of surgery on adjustment needs to incorporate the reality of multiple hospital admissions and surgical procedures.

3) Pre-operative measures

Some studies, especially those examining young children have not used pre-operative measures because of the difficulties in testing a child this young. Again, this makes it difficult to draw conclusions, especially given that adjustment seems to change with age even without surgery.

4) No long term follow up

Tobiasen (1988) states, "there is no evidence from past research that craniofacial patients become more facially attractive or even less facially impaired following surgery....even if attractiveness were improved, many of these children would still have facial stigmata of sufficient seriousness to result in social rejection" (p745). Longitudinal studies are needed to examine the social effects of decreased facial impairment as well as increased facial attractiveness. Most studies follow up patients during routine medical visits and therefore tend not to follow up longer than medically necessary. The changes in adjustment over time following surgery would be useful to evaluate.

5) Definition of Adjustment

There is no consensus about what constitutes adjustment. Future research needs to include body dissatisfaction, self-esteem and general well-being. The discrepancies within the findings on self-report, quantitative and projective measures and behaviour changes suggest that it is important not to look at one in isolation from the others.

6) Effect of Appearance on Adjustment

It seems that the relationship between appearance and adjustment is unclear. If there is no relationship between *change* in appearance following surgery, there may however be a relationship between pre-operative *or* post-operative attractiveness and adjustment. Adjustment is therefore determined by the individuals' attractiveness, at any one time, as perceived by others, rather than the degree to which the individual's appearance changes, from before to after surgery.

7) Timing of Surgery

Although several researchers have suggested that age at which surgery takes place is crucial, there has been no hard evidence to support this claim. Clearly it is important to justify this assumption before carrying out potentially unnecessary surgery on young children.

8) Lack of overall theory

There is no accepted overall theory which addresses the adjustment of maxillofacial patients following surgery. Future research needs to be multi-factorial and address as many of the potential mediating factors as possible. Clifford (1988) notes that the literature displays “conceptually naïve attempts to describe a set of patients sharing the same anomaly in familiar psychological terms” (p174). The assumption has been that each anomaly imposes its own psychopathology but it seems more appropriate to take a more individualistic and multifactorial approach to the theory.

1.5 PRESENT STUDY

The present study attempts to avoid some of the criticisms outlined above by using a large but relatively homogenous group, looking at long term follow, and using several measures of adjustment. Factors such as multiple operations, timing of surgery and appearance are also taken into account.

The three core research questions are:

- 1) How do maxillofacial patients compare with the normal population on quantitative measures of psychological adjustment i.e. self-esteem and general psychological well-being, and measures of body dissatisfaction *long term* post-surgery (i.e. as adults)?
- 2) Is long term psychological adjustment predicted by any of the following: age at surgery, age now, number of operations, number of years since surgery completed, appearance before surgery, appearance after surgery or change following surgery?
- 3) What are the patients’ views of their operations, the advantages and disadvantages, their appearance, their coping styles and their adjustment?

In general there is a paucity of methodologically sound research and psychological theory relating to psychological adjustment to facial reconstructive surgery. This study is therefore attempting to:

- (i) test the few hypotheses which have been suggested in the literature
- (ii) generate new theories which may be evaluated by future research.

The methodology best suited to these pursuits is different in each case. Hypothesis testing is the traditional remit of the positivist hypothetico- deductive approach and is well suited to looking at generalisable findings in groups as a whole. However, it could be argued that in the absence of any coherent theory, this approach may ignore too much potential information, by asking only very circumscribed questions. In the interests of developing new theory, it may be better to gather more information initially and use this to generate theory (inductive), rather than pre-selecting particular hypotheses (deductive). In this study, face-to-face interviews with the participants, using open ended questions, are used to generate text, relating to the broad areas of interest. This qualitative approach provides the detail needed to develop new ideas and theory, while staying close to the data.

The quantitative, hypothesis testing component of this study is restricted by time limitations. Given these time restrictions, it is not possible to carry out both pre and post-operative measures over a long follow-up period. While it is interesting to note the absolute levels of adjustment in this population, in comparison to normative data, a more useful question is what factors mediate this outcome. This study therefore attempts to collect information about long term adjustment and potential mediating factors, (such as number of operations, age at surgery, appearance before, appearance after surgery, change following surgery) to determine whether these factors predict psychological outcome.

Adjustment in this study is assessed in several ways: self-esteem, body satisfaction and general psychological well-being. These measures were chosen to examine specific factors as well as global adjustment, given the lack of consistent findings from previous

studies. The sample population is selected to be relatively homogenous, consisting of patients with one of only two conditions, hemifacial microsomia and Treacher Collins syndrome³.

³ These conditions are types of Branchial Arch Disorders, of which the predominant features are either facial asymmetry or mandibular retrusion.

2.0 METHOD

Participants

The initial sample consisted of 20 (33%) men and 41 (67%) women, mean age 22.8, S.D. 5.2 (range 16-33). All had been patients at the Maxillofacial and Dental department of the same Children's Hospital and had received facial reconstructive surgery for the congenital conditions hemifacial microsomia and Treacher Collins syndrome. Thirty two participants (52% of the original sample) responded to the initial request to be involved in the study. Of these, 11 (34%) were men and 21 (66%) were women, mean age 21.9, SD 5.3, (range 16-33). 28 had a diagnosis of hemifacial microsomia, 4 had Treacher-Collins Syndrome. Of the initial sample, 13 were not known at the address held on record, 14 gave no response, 1 had died and 1 had severe learning disabilities and would have been unable to complete the questionnaires.

Ethical Approval

Ethical approval was given by the hospital Research Ethics Committee following submission of the research proposal.

Procedure

The research was carried out in several stages, as follows:

Stage 1: Information from medical files

Patient information; type, number and timing of operations and information about diagnosis was obtained from the medical notes. The variables were measured as follows:

Age now

Age now was taken as the age of the participant in months, at the time when the questionnaires were sent out.

Age at surgery

Age at surgery was measured in months from the date of the last operation at the children's Hospital, up to the time when the questionnaires were sent.

Time since surgery

Time since surgery was calculated as the difference between age now and age at surgery.

Number of operations

This measure was calculated on the basis of the number of operations the participant had while under the care of the children's Hospital. All operations requiring hospital admission were included.

Stage 2: Photographic ratings

Two photographs of each participant *in the original sample* were selected from the hospital records. Photographs were taken from before the first operation and at least 3 months after the final operation in the Hospital. All photographs were taken using colour film and all were frontal views.

Ten raters, selected from medical (non-maxillofacial) and non-medical staff were asked to take part. They were told that they were participating in a study to test for perceptions of attractiveness. Their instructions were as follows:

“We are exploring the manner in which people judge physical attractiveness. We will be showing you a number of photographs of children and adults. Please rate these

photographs as to how attractive you think the person in the picture is. Mark your answer sheet using the 1 to 7 scale for each photograph.

1 means that you found the person in the photograph extremely unattractive

2 means you found the person very unattractive

3 means that you found the person slightly less attractive than average

4 means that you found the person of average attractiveness

5 means you found the person slightly more attractive than average

6 means that you found the person very attractive

7 means that you found the person extremely attractive”

The photographic stimuli were then presented in the same randomised order to each of the raters. Each photograph was presented for approximately 10 seconds. All ten raters rated each photograph.

The raters were asked to focus on attractiveness, rather than disfigurement, because it was felt that the latter would encourage raters to anticipate and focus on the disfigurement. In everyday situations, people meeting the person with a disfigurement do not usually anticipate the disfigurement, therefore this was felt to be a more realistic indication of others' judgements.

Appearance before and after surgery were assessed by calculating the mean rating from the ten raters for the pre and post operative photographs.

Change in appearance following surgery was calculated by subtracting the mean rating from the pre-operative photograph from the mean rating from the post-operative photograph.

Stage 3: Questionnaires

A questionnaire pack was sent to the 62 participants in the original sample containing three questionnaires, the Body Satisfaction Scale, the Rosenberg Self-Esteem Scale and the General Psychological Well-Being Scale, described below. Included with the questionnaires was a covering letter and a patient information sheet explaining the purpose of the study (see Appendix). After six weeks, a second questionnaire pack was sent to those participants who had not returned the first. 32 questionnaires were returned.

- Body Satisfaction Scale (Slade, Dewey, Brodie and Kienle, 1990)

The Body Satisfaction Scale (BSS) is a measure of general body dissatisfaction and consists of 16 items concerning different body parts, half from the head and half from below the neck. Each body part is scored on a scale of 1 to 7 (1=very satisfied, 7=very unsatisfied). General body dissatisfaction is calculated by adding the ratings together to obtain an overall score. Two sub-scales, head dissatisfaction and body dissatisfaction, are calculated by summing scores from specific items. The BSS takes 2 minutes to complete.

The validity of the scale has been assessed using a Principal Components analysis. This reveals two factors, a general factor, with positive loadings (>0.4) on all items and a second bipolar factor with body items loading positively and seven head items negatively. The BSS and the two sub-scales, head and body, also positively correlate with the Body Shape Questionnaire (BSQ), 0.44, 0.26 and 0.52 respectively. BSS scores have been compared across normative and clinical populations (1015 student nurses, college students and volunteers versus eating disorder patients and overweight subjects,) and it has been shown that the BSS is capable of identifying clinical populations. Internal consistency for these populations was good (Cronbach's alpha coefficients >0.785 for all three BSS scales) (Slade et al, 1990).

- Rosenberg Self Esteem Scale (SE) (Rosenberg (1965))

The scale consists of ten items (e.g. "I feel I do not have much to be proud of") with responses on a 4 point scale from "strongly disagree" to "strongly agree". Overall scores are calculated by summing the responses to each item. It takes about 2 minutes to complete.

There is good support for the validity of the Rosenberg scale. Convergent validity was assessed by Silber and Tippett (1965), who found item correlations of 0.56 and 0.83 on this scale. Robinson and Shaver (1973) report correlations of 0.59 - 0.60 between the Rosenberg Self-Esteem Scale and the Coopersmith Self-Esteem Inventory. Kaplan and Porkorny (1969) report two uncorrelated factors, accounting for 45% of the total variance, which they labelled 'self-derogation' and 'defense of self-worth'. Rosenberg (1965) reported good construct validity, in relation to reduced shyness, depression, assertiveness and social activities.

Both internal consistency and test-retest reliability are reported to be good. Rosenberg (1965) found a reproducibility coefficient of 0.92 and a scalability coefficient of 0.72. Silber and Tippett (1965) report a test-retest reliability coefficient of 0.85 using a student population.

Ingham, Kreitman, Miller, Sashidharan and Surtees (1986) report normative data for the scale, based on a community survey of 573 women, aged 18-34. They also report mean scores for a sample of 78 women with psychiatric diagnoses of general anxiety, panic disorders, minor and major depressive disorders and intermittent depression.

- The General Psychological Well Being Scale (Dupuy, 1978)

The General Psychological Well-Being Schedule (GPW) is a quick but wide-ranging indicator of subjective feelings of psychological well-being and distress. There are 18 questions, both positive and negative and each has a time frame of "during the last

month” (e.g. how happy satisfied or pleased have you been with your personal life). The first 14 questions use 6 point response scales representing frequency or intensity. The final four questions use 0-10 rating scales. Six dimensions cover anxiety, depression, general health, positive well-being, self-control and vitality. The GPW takes about 15 minutes to complete.

There is considerable evidence for the validity of the scale. The GPW correlates with the Zung Depression Scale (0.66) and the Personal Feelings Inventory-Depression (0.78). The average correlation of the GPW and three anxiety scales was 0.64. (Fazio, 1977). Dupuy (1978) reports a factor analysis of the scale which reveals three factors accounting for 51% of the variance, one relating to anxiety and depression, one to health and energy and the third to positive well-being or life satisfaction items.

Test-retest reliability co-efficients of 0.68 and 0.85 have been reported by Monk (1981) and Fazio (1977). Internal consistency has been reported as >0.9 (Ware, Johnston, Davies-Avery and Brook, 1979). There are no published norms for this scale but Dupuy (1978) derived national reference standards from 1,209 respondents in the US. These indicate that 71% of the adult population fell into a positive well-being category, 15.5% fell into a moderate distress category and 13.5% were classified as experiencing severe distress.

Stage 4: Face-to-face interviews

Included in the questionnaire pack was a letter asking whether the participants would be prepared to be interviewed in more detail, either by attending the hospital or being contacted on the telephone. The second stage involved contacting those participants who had agreed to travel to the hospital and interviewing them using a semi-structured interview described below (see Appendix). Each interview lasted approximately one hour. These sessions were audiotaped and transcribed.

The semi-structured interview was based on that carried out by Phillips and Whitaker (1979) (Appendix). The final schedule uses nine open questions related to different aspects of maxillofacial surgery, including consent, expectations of change, perceptions of change, attitude to disfigurement and coping strategies. Within each of these broad areas, specific prompts were used to focus on particular issues. The format was flexible enough to enable the participant to discuss any other issues they felt were relevant.

Text generated from this interview was analysed using Grounded Theory. Six transcripts were analysed. These were selected at random from the 13 available.

Stage 5: Telephone interviews.

Participants who were unable to travel to the hospital were interviewed on the telephone, using a shortened and more structured version of the semi-structured interview (see Appendix). Each interview lasted approximately half an hour and responses were recorded on the interview sheet (see Appendix).

The telephone interview was developed after the face-to-face interviews had taken place (but before the Grounded Theory analysis), and questions were altered on the basis of these interviews. Specific concerns which had been raised, such as residual loss of sensation following surgery, and specific beliefs regarding the impact of disfigurement on character, such as disfigurement makes you a stronger person, were included in the telephone interviews. The questions were more direct to enable the researcher to note down responses more easily and also in recognition of the difficulties in conducting an in-depth discussion on the telephone.

Responses to the telephone interviews were intended to provide information about specific concerns, which could provide feedback to the Hospital, to enable comparison with previous research findings and to provide the participants who had been unable to travel to the hospital with an opportunity to discuss their experiences.

Data Analysis

Quantitative data was analysed using the Statistical Package for Social Sciences. Qualitative data was analysed using the Grounded Theory approach (Strauss and Corbin, 1990), described below.

Grounded Theory: Methods and Techniques

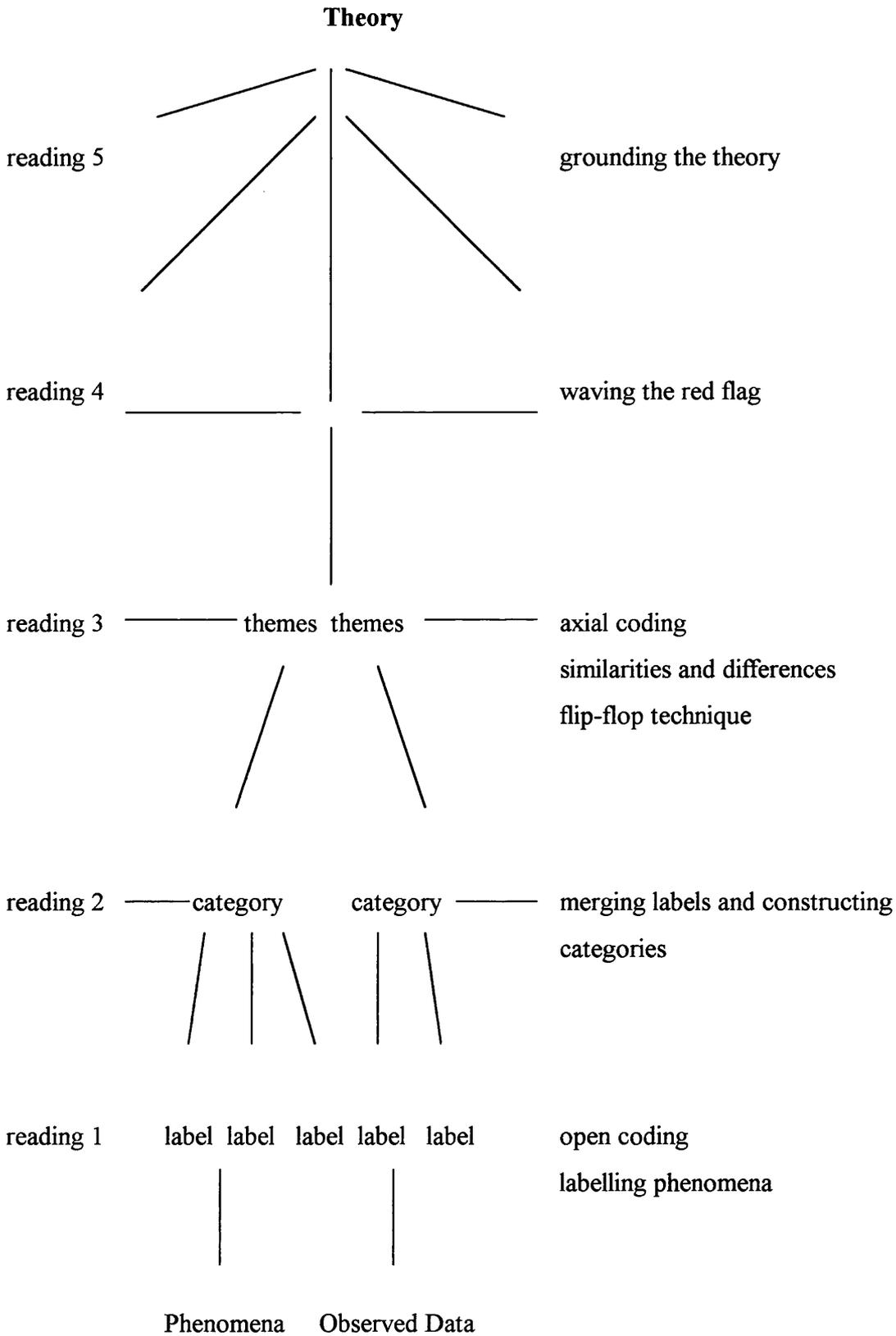
The text is subjected to at least five readings in order to categorise and make sense of the data. There are three main stages which utilise three different types of coding: open coding; axial coding; selective coding. During these stages a variety of techniques and models can be applied to assist with coding: asking questions; using comparisons (known as "flip-flop technique"); testing assumptions (known as "waving the red flag"). Each of the three coding methods and techniques are described in the following section.

Fig 1 is a diagrammatic representation of the methods and techniques involved in the research. Particular applications will vary in terms of the number of readings, the techniques used at each stage, and the number of labels, categories and themes. The lines represent the connections between the data and the subsequent stages. While lines connect the data to all higher levels, there are also lines which emerge from outside of the data at readings 2, 3, 4 and 5. These represent the emergence of new ideas from the asking of new questions.

Stage 1: Open coding, labelling phenomena.

Strauss and Corbin (1990) define open coding as “the part of the analysis that pertains specifically to the naming and categorising of the phenomena through close

Fig 1. Grounded theory methods and techniques



examination of data", (Strauss and Corbin, 1990, p62). The data are broken down into discrete parts, closely examined, compared for similarities and differences, and questions are asked about the phenomena they represent. Sections of text, single words or sentences are then labelled according to what they seem to represent, for example; body part, pain, age. This process normally requires at least two readings. As reading progresses, labels are replaced with categories which best describe groups of labels. The categorising of labels develops in a reflexive relationship with evolving ideas about their meaning. The constant movement between proposing categories and checking them against the data keeps theories grounded to the text.

Within each emerging category, there will be properties pertaining to that category and dimensions along which the properties vary. During this first stage, the properties of each category are mapped out. For example, the category "disfigurement" may have properties of "degree" and "symmetry", which themselves vary along dimensions of "mild-severe" and "symmetrical-asymmetrical".

Stage 2: Axial Coding

As categories emerge, it becomes clear that some subsume or relate to others. The purpose of axial coding is to define several main categories and then suggest and justify relationships between these categories and their sub-categories. After proposing such a relationship, the theorist must go back to the text to find several instances which justify the claim as it must be supported in the data.

Proposed relationships are based on the paradigm model. The paradigm model states that the phenomenon is brought about by causal conditions, within a particular context and in the presence of intervening conditions. The phenomenon is acted upon by further action/interactional strategies which lead directly to certain consequences. By identifying which categories relate to each stage in the paradigm model, the theory begins to take shape.

For example, the phenomenon, low self-esteem, may be brought about by the causal condition of teasing, within the context of the school playground and the intervening conditions of relationship to tormentor, frequency of teasing or type of insult.

Stage 3: Selective Coding

Selective coding refers to similar processes to axial coding but occurs at a higher conceptual level. After generating major categories and developing relationships between these categories, the theorist must identify the core category, story or theme to which the text refers. The other categories are then related to the core category, using the paradigm model, but at a higher dimensional level. These relationships are also validated by testing the theory against the original text.

For example, poor personal evaluation may be brought about by the causal conditions of rejection, within the context of poor social support and the intervening conditions of previous experience of rejection and coping strategies.

Techniques: Asking Questions, Flip-Flop Technique and Waving the Red Flag.

Using these techniques helps to generate new ideas about the data, especially when the analysis feels 'stuck'.

(a) Asking questions about the text such as who, what., why, how, when, where can broaden categories and develop properties but also assist in developing relationships between categories. For example, "when do others react negatively to the individual with a facial disfigurement?", "how does the individual recognise their reaction?" .

(b) Making comparisons between the phenomenon discussed and another, entirely unrelated, can also generate ideas and questions which would not have otherwise arisen. For example, "What are the similarities and differences between expectations of

surgery and expectations of moving house?" may generate ideas about new environments, changing friends etc. Comparisons can also be made within the same phenomenon but at the extremes of a particular dimension. For example, "What is the difference between the reaction someone with a facial disfigurement gets and Naomi Campbell when they walk into a pub?".

(c) Waving the red flag prevents the researcher from taking anything for granted. It refers to the reaction the researcher needs to have when they come across words like "always", "never" and "of course". When they see these words they are asked to ask more questions about the circumstances under which these may not be true. When, where, under what conditions, etc.

Memos and Diagrams

The final aids to developing Grounded Theory are the keeping of memos and the writing of diagrams. Memos are "the written forms of our abstract thinking about the data". Diagrams are "the graphic representations or visual images of the relationships between concepts", (Strauss and Corbin, 1990, p198). Memos and diagrams can be written at any time, whenever a new idea emerges.

None of the stages outlined above take place in strict succession. Equally, none of the techniques are rigidly applied at any particular point in the analysis. Techniques are used as "aids to analysis" and are generally useful when the researcher feels they have run out of ideas.

3.0 RESULTS

Characteristics of the sample

There were no significant differences, using independent samples t-tests, between the initial sample and the individuals who agreed to take part in terms of their age ($t(d.f.29)=1.56$, n.s.) or the number of operations they had had ($t(d.f.7)=-1.74$, n.s.). There were also no significant differences between the mean ratings of attractiveness either pre-surgery ($t(d.f.12)=-.75$, n.s.) or post-surgery ($t(d.f.5.88)=.76$, n.s.). The sample is therefore considered representative of the general maxillofacial surgery population at this Hospital.

All further reported results are based on the 32 participants who returned questionnaires. 20 out of the 32 were willing to attend the hospital to be interviewed and 11 were willing to be telephoned. Of these, 13 were seen for face-to-face interviews and 14 were interviewed on the telephone. Those who were not interviewed had not been available at the time of data collection (working, on holiday or moved away).

Participant details are presented in Table 1.

Table 1: Descriptive data for sample participants

Measure	Mean (years)	S.D.	Range
Age now	21.9	5.3	16-33
Age at surgery	17.4	5.0	4-28
Time since surgery	4.6	4.2	.2-13
No. of operations	8.7	8.8	1-50

Results from Photograph Ratings

(a) Reliability of Ratings

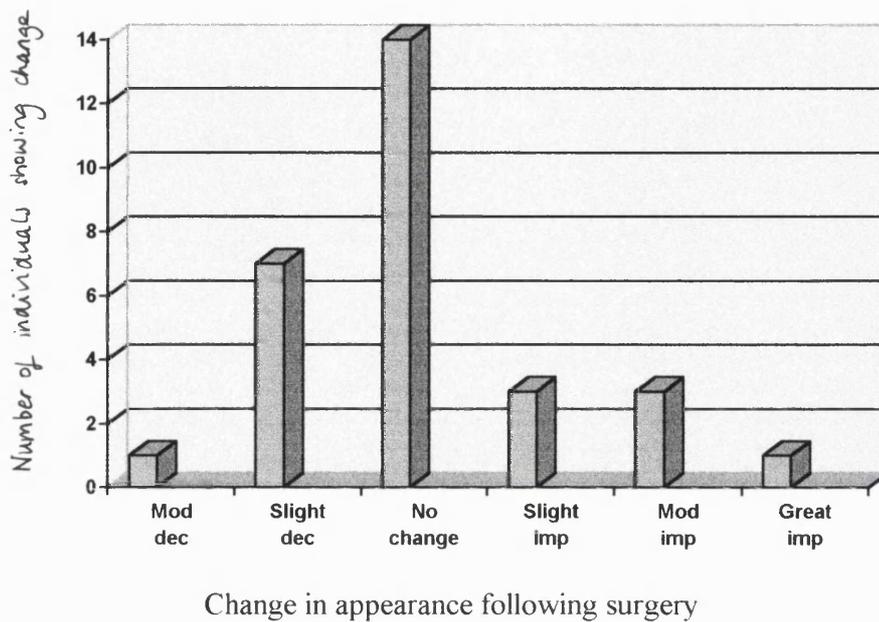
Inter-rater agreement was calculated by comparing correlations between raters. All of these, pre and post surgery, were highly significant (range $r=.5827 - .9446$, $P=.000 - .001$), therefore none of the data was rejected.

(b) Findings

29 pre and post surgical photographs were available from records. Mean age (in years) at pre-operative photographs was 10.3, S.D. 3.9, range 2.2-18.2. Mean age of post-operative photographs (in years) was 17.8, S.D. 2.8, range 12.5-26.2. Mean pre-operative ratings of the photographs were 2.88, S.D. 1.4, indicating ratings between 2 ("very unattractive") and 3 ("slightly less attractive than average"). Mean post-operative ratings were 2.81, S.D. 1.21, also indicating ratings between very unattractive and slightly less attractive than average. There was no significant difference in the ratings between the pre and post-operative appearance, ($t(d.f.28)=.37$, n.s.), on a paired samples t-test.

When the results of the photograph ratings are broken down into individual data, 14 (48%) showed no change (defined as less than plus or minus 0.5 point change), 3 (10%) showed slight improvement (between 0.5 and 1.5 point improvement), 3 (10%) showed moderate improvement (between 1.5 and 2.5 point improvement), 1 (3%) showed great improvement (between 2.5 and 3.5 point improvement), 7 (24%) showed slight deterioration (between 0.5 and 1.5 decrease) and 1 (3%) showed moderate deterioration (between 1.5 and 2.5 point decrease). See Graph 1.

Graph 1 : Distribution of the change in appearance following surgery



Question 1: How do maxillofacial patients compare with the normal population on quantitative measures of psychological adjustment at long term follow-up post-surgery?

1) Body Satisfaction Scale (BSS)

The mean score on the BSS was 40.94, S.D.16.45, (range 18-75). Mean scores on the subscales of head satisfaction and body satisfaction were 21.34 (S.D.9.79, range 9-46) and 13.75 (S.D. 6.92, range, 6-29). These results are significantly different on an independent samples t-test from the norms published by Slade et al (1990), based on a sample of 1015 student nurses, college students and female volunteers (Table 2). The maxillofacial population scored significantly lower on overall BSS scores, indicating greater general body satisfaction than the normal population ($t(d.f.1045)=6.44, p<0.01$). They scored significantly higher than the norm on the head sub-scale ($t(d.f.1045)=6.72, p<0.01$), indicating lower head satisfaction and significantly lower on

the body sub-scale ($t(d.f.1045)=16.9, p<0.01$), indicating greater body satisfaction. These results are also significantly different from a sample of 84 women with eating disorders. The maxillo-facial group scored significantly lower on general BSS ($t(d.f.114)=23.33, p<0.01$), head BSS ($t(d.f.114)=4.66, p<0.01$) and body BSS ($t(d.f.114)=30.09, p<0.01$), indicating greater satisfaction on all scales.

Table 2: Comparison of mean scores for BSS with norms and eating disorder group (lower score indicates greater satisfaction).

	Sample		Norms		Eating Dis	
	Mean	S.D.	Mean	S.D.	Mean	S.D.
BSS	40.94	16.45	45.38	14.71	61.42	18.39
BSS Head	21.34	9.79	18.21	6.64	23.95	9.92
BSS Body	13.75	6.92	22.41	8.18	31.76	8.82

2) Rosenberg Self Esteem Scale (SE)

The mean score on SE was 18.88, S.D. 6.07, range (10-31). In order to compare these results with published means, the results were re-coded on a dichotomous Guttman Scale, giving values between 0 and 10 (where 0=high self-esteem and 10=very low self-esteem). With this scoring method, the mean score was 2.16, the S.D. was 2.57 (range 0-9). These results are significantly higher than the norms published by Ingham, Kreitman, Miller, Sashidaran and Surtees (1986), indicating lower self-esteem ($t(d.f.525)=4.78, p<0.01$) (Table 3). However, they are significantly lower than a sample of 78 women with psychiatric diagnoses of general anxiety, panic disorders, minor and major depressive disorders and intermittent depression, also reported by Ingham et al (1986), indicating higher self-esteem ($t(d.f.108)=2.69, p<0.01$).

Table 3: Comparison of mean scores on Rosenberg Self-esteem Scale with norms

	Sample		Norms		Cases	
	Mean	S.D.	Mean	S.D.	Mean	S.D.
SE	2.16	2.57	1.13	1.32	2.97	1.85

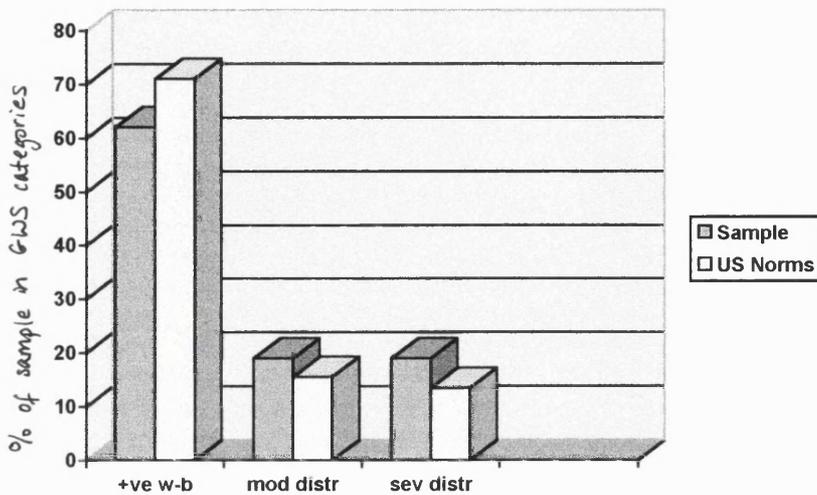
3) General Psychological Well-Being Scale (GWS)

The mean score on the GWS was 76.84, S.D. 19.25, range 35-108. Of the 32 respondents, 20 (62%) had scores indicating positive well-being, 6 (19%) had scores indicating moderate distress and 6 (19%) had scores indicating severe distress. Unfortunately there are no published normative means and standard deviations for the GWS, however, Dupuy (1978) derived national reference standards from 1,209 respondents in the US. These indicate that 71% of the adult population fell into the positive well-being category, 15.5% fell into the moderate distress category and 13.5% were classified as experiencing severe distress. See Graph 2. According to this standard, the maxillofacial sample were not significantly different from the general population ($\chi^2(d.f.2)=4.17, n.s.$).

Correlations Between Questionnaires

Using Pearson's Correlations, there was a significant correlation between scores on the GWS and SE ($r=-.8287, p<.001$) and between the GWS and BSS ($r=-.4941, p<.01$). Both the head and body sub-scales of the BSS had significant correlations with GWS ($r=-.3631, p<.05$; $r=-.5270, p<.01$). There was no significant correlation between the BSS and SE ($r=.3088, n.s.$).

Graph 2. Comparison of sample with US norms for GWS reference standards (%)



Psychological Well-Being

All of the GWS sub-scales of anxiety, depression, general health, well-being, self-control and vitality significantly correlated with each other and with SE ($p < 0.05$). The GWS sub-scales of anxiety, depression, general health and well-being significantly correlated with the BSS ($p < 0.05$). The sub-scales of anxiety and depression significantly correlated with the body sub-scale of the BSS and the sub-scales of anxiety and well-being correlated with the head sub-scale of the BSS.

Question 2: Is long term psychological adjustment predicted by any of the following: age at surgery, age now, number of operations, number of years since surgery completed, appearance before surgery, appearance after surgery or change following surgery?

As a pre-requisite to a regression analysis, correlations were examined between the dependent and independent variables. Using Pearson’s Correlations, there were no significant correlations between the GWS, any of the GWS sub-scales, SE or the BSS, or the BSS head sub-scale with any of the independent variables of sex, age at surgery, age now, number of operations, time since surgery, pre-operative appearance, post-

operative appearance or change in appearance after surgery. The only exception to this were weak but significant correlations between the body-sub-scale of the BSS and sex ($r=-.3599$, $p<.05$) and between the body sub-scale of the BSS and change in appearance after surgery, ($r=.3725$, $p=.05$).

The independent variables (pre-operative appearance, post-operative appearance, change in appearance following surgery, sex, number of operations, age now, age at surgery and time since last surgery) were entered into a step-wise Regression Analysis. However, none of these variables loaded at a 0.05 significance level, indicating that none of these variables were predictive of psychological adjustment.

Comparisons between individuals whose appearance improved following surgery and those whose appearance deteriorated.

To examine whether there were any significant differences between those participants whose appearance improved and those whose appearance was considered worse following surgery, the group was split into these two groups. 14 participants were rated as having improved appearance (i.e. change following surgery, as assessed by mean post-operative rating - mean pre-operative rating had a positive value) and 15 participants were rated as having worse appearance (i.e. change following surgery had a negative value). These two groups were compared on their scores from the questionnaires and other independent variables.

There were no significant differences on independent sample t-tests between those whose appearance improved and those whose appearance worsened on any of the questionnaire scores, or on any of the following independent factors; time since surgery, pre-operative appearance, number of operations, age now or age at surgery ($p>0.05$). The only significant variable was sex ($t(d.f.21.3)=-3.05$, $p<.01$). Significantly more females had better post-operative appearance than men.

Question 3: What are the patients' views of their operations, the advantages and disadvantages, their appearance, their coping styles and their adjustment?

This question is answered in two parts, a) the summary of information from the telephone interviews and b) the findings from the Grounded Theory analysis.

a) General Findings From Telephone Interviews (N=14)

The main findings from the telephone interviews are presented in Table 4. The results from Phillips and Whitaker (1979) are also given for comparison. They interviewed 18 adolescents who had undergone surgery for craniofacial dysostosis, hypertelorism and Treacher Collins syndrome. The results from this study and that of Phillips and Whitaker are generally similar, indicating that the two populations are broadly analogous.

In general, patients felt that it had been their decision to have surgery. Only 2 (14%) felt that the decision had been made by their parents and 2 (14%) felt that the decision had been made by the Doctors. When asked how keen they had been to have surgery, on a scale of 1 to 10, (where 1=not keen and 10=extremely keen), 8 (57%) gave figures of between 7 and 10, 3 (21%) gave figures between 4 and 6 and 3 (21%) gave figures below 3. Despite the range of motivation, the decision was also felt to be the right one, with 11 (79%) stating that they would make the same decision again.

Post-operative difficulties were common, although these were generally anticipated. 8 (57.1%) reported problems with pain after surgery but 75% of these had expected pain. Of those that did not experience pain as a problem, 83% had anticipated it. 10 (71.4%) reported difficulty with swelling after surgery but 70% of these had expected it. The exception to this was loss of sensation following nerve damage. 10 (71.4%) reported problems with numbness following surgery, but only 40% of these had been warned that this was a possibility. None of the 4 who did not report difficulties with numbness had anticipated this as a problem.

Table 4: General Findings from the Telephone Interviews (compared with Phillips and Whitaker, 1982)

Question	Current study - N (%)	Phillips + Whitaker - N(%)
I. The Decision		
A. Who made it:		
Self and parents	12 (86%)	12 (67%)
B. Would do it again:	11 (79%)	15 (84%)
II. Expected change in		
A. Social life	4 (29%)	
B. School/college	2 (14%)	
C. Personality	11 (79%)	
D. Appearance	14 (100%)	
III Expectations met in		
A. Social life	4 (29%)	6 (33%)
B. School/college	1 (7%)	3 (16%)
C. Personality	7 (50%)	11 (61%)
D. Appearance	9 (64%)	14 (77%)
IV Surgical Experience		
A. Pain	8 (57%)	
B. Swelling	10 (71%)	
C. Numbness	10 (71%)	
D. Post-op difficulties		9 (50%)
V. Psychological Support		
A. Suffered teasing	12 (86%)	
B. Would have found support helpful		
For self.	13 (93%)	
For parents	12 (86%)	

There were two other difficulties which were reported. 4 patients (29%) reported unexpected difficulties with eating and weight loss following surgery, due to fixed gold braces. One patient lost nearly three stone. One patient also reported feeling frightened by the tubes down her throat in intensive care and worried about choking. Neither of these difficulties were anticipated. Although preparation was not always adequate, all 14 (100%) reported that the staff were supportive.

Despite the post-operative difficulties, the hospital experience was not always negative, 7 patients (50%) stated they had enjoyed their time in hospital. 13 (93%) felt that seeing a psychologist would have been useful and that this would help cope with experiences outside the hospital as much as the hospital experience itself. 12 (86%) described having been teased at school. Interestingly, 12 (86%) also felt that their parents would have benefited from talking to a psychologist, as they felt they had emotional needs which were not met. Although the participants would have preferred not to have had the operations, 8 (57%) felt that they had become stronger people as a result of having to cope with their experiences.

.b) Grounded Theory Analysis of 6 Face-to-face Interviews

The results from the Grounded Theory analysis are presented below. To give a flavour of the development of the theory, the process is illustrated through the use of tables, containing examples of labels, categories and themes (Table 5; Table 6; Table 7).

Table 5 Examples of labels generated after readings 1 and 2.

Label	Text
"Smile"	"it was a bit more even, my smile"
	"I wouldn't smile in photographs"

"Eye"	"my eye doesn't crinkle up like the other one"
"Ears"	"I'd like to be able to wear earrings and put my hair up properly"
"Pain"	"I remember my ribs being quite painful"
"Fear"	"I remember being very very frightened" "terrified before my operations"
"Parents"	"I've got very very positive parents"
"Acceptance"	"because I was accepted by them and that made me feel really good"
"Men"	"Very nice guys who I'm close to now" "They never say it about me ("she's a babe")" "I'm still terrified around men"
"Coping"	"as I got older, I had a lot more to cope with"
"Siblings"	"my sister... is incredibly attractive" "my older brothers, they're both married"
"Operations"	"I sometimes had two operations a year"
"Disfigurement"	"the cheekbones didn't grow with me"
"Feelings"	"I didn't have any confidence in myself" "I'm more relaxed now about my appearance"
"Insults"	"monkey face"

	"you are the most ugly girl I've ever seen in my life"
"Needles"	"I'm actually terrified of needles" "If they give me an injection, I hate it"

Once labels had been generated, categories began to emerge through successive readings and the asking of questions about the data. Table 6 provides a list of the categories and one example of text relating to each category.

Table 6: Categories and examples of text from readings 3 and 4.

Category	Text
"Asymmetry"	"the face looks as if it's at one side"
"Avoidance"	"there was no way I'd go into something like teaching or social work or anything where I've got to deal with the public"
"Awareness of Disfigurement"	"I knew there was something wrong with me - I could see it every day"
"Change over time"	"When a child is 8 and starting Primary School, that's when it starts and the child will notice it"
"Changing Priorities"	"because of all the experiences I've had as well, it

puts your life into perspective...your appearance isn't everything...I've had boyfriends and they take me for what I am"

"Context"

"every teenager feels incredibly vulnerable"

"Comparison"

"my sister, she's very pretty, a model...I was constantly jealous of her"

"Compensation"

"I've sought out friends who are very attractive... "Oh, well, she's with someone who's attractive, so she must be ok""

"Disfigurement"

"the cheekbones didn't grow with me as I was growing up"

"Effect of experiences"

"some drunken bastard came up to me and pinned me against the wall and said, "You are the most ugly girl I've ever seen in my life...I'd had all this done...and that just...I was back at, I was back where I was when I was fifteen. All the operations that I'd had didn't mean a thing really"

"Effect on Family"

"I know it probably broke up my parents marriage"

"Emotional Release"

"my mum's sort of my counsellor. She knows when I'm upset and she'll just try and make me talk"

"Explanations of Disfigurement"

"I said I'd been in a car crash"

"Group Membership"

"you feel like you're totally different and no-one

wants to know you"

"Hospital"

"It's like an adventure, loads of fun"

"Missed Opportunities"

"I hit the teenage stage a bit late"

"Mistrust"

"I thought two guys were interested in me and it turned out they weren't. I daren't read anything into anything anymore. I don't trust myself at all"

"Mood"

"If I'm in a bad mood, I fight but if I'm in a good mood I just let them"

"Other Medical Problems"

"Hole in the heart"

"Others' Reactions"

"People used to point and say "what's wrong with her?""

"Parental Attitudes"

"My parents were very over-protective"

"Parental Attitudes Surgery"

"She gets upset when she sees me coming out of the operation generally...she saw all the tubes down my throat and she couldn't take it"

"Personal Development"

"The way forward is to concentrate on my job...and try to make a success of myself"

"Personality"

"I was a very independent child"

"Post-operative Difficulties"

"I woke up in intensive care....on a ventilator...my jaws were weird together...I don't remember much pain...I remember being very, very frightened"

"Prediction"	"Sometimes they say "Do you mind me asking a question?" and I know what they're going to say"
"Pre-empting Others Reactions"	"I said straight out, "I hope no-one has a problem with the way I look, I don't see it as a problem", which is a white lie"
"Preparation"	"I wasn't shocked by how I looked because I knew it was going to be swollen"
"Protection"	"we didn't talk about it. I was protecting them and they were protecting me"
"Psychological Support"	"you need counselling for when you are outside - not while you're in here"
"Rationalisation"	"I just have to be myself. If they don't like it tough. That's their loss not mine"
"Relationships"	"I've had counselling...cos...I've never had a relationship with a girl before, I'm 26 now and...getting a bit worried"
"Role"	"I'm a career girl"
"Self-Evaluation"	"I haven't got to like myself"
"Social Life"	"I was too embarrassed to go out"
"Support"	"I've got so many friends... they give me the main reason for going on"

"Surgery Complications"	"it kind of split open and all the stuff came out that they put in"
"Surgical Decision"	"It was up to me what I wanted"
"Surgical Expectations"	"I thought if I looked better my life would be better"
"Surgery Limitations"	"Medical science wasn't as advanced then, they left it"
"Surgical Motivation"	"I was very determined"
"Surgical Outcome"	"I can go out and get a job now, I can talk to someone like you without feeling embarrassed"
"Surgery Risks"	"It's likely it could fail again"
"Surgical Techniques"	"They moved my jaw forward so it was the same level as my top one"

After identifying categories, themes were identified through the use of questions, and other techniques (flip-flop, waving the red flag etc). Nine themes were identified: disfigurement; awareness; management strategies; identity; surgery; personal development; family; support; context. As indicated in the table below, the mapping of categories onto themes was not a perfect fit. Some categories contained elements which related to different themes. This was particularly true for the category "change over time", which contained items relating to the majority of themes.

Table 7 presents the themes and the categories which contained items relating to the themes.

Table 7: Themes and related categories.

Themes	Categories
"Disfigurement"	Disfigurement Asymmetry Other medical problems Context Change over time
"Awareness"	Awareness of Disfigurement Comparison Others' Reactions Relationships Context Missed Opportunities Change over time Context Effect on Family Relationships Mistrust
"Management Strategies"	Avoidance Emotional Release Compensation Pre-empting Others Reactions Prediction Personal Development

Context
Explanations of Disfigurement
Preparation
Protection
Psychological Support
Rationalisation
Change over time
Effect of Experiences

"Identity"

Role
Group Membership
Self-evaluation
Missed Opportunities
Change over time

"Surgery"

Surgical Decision
Surgical complications
Surgical Expectations
Surgery Limitations
Surgical Motivation
Surgery Outcome
Surgery Risks
Surgical Techniques
Hospital
Post-operative Difficulties
Preparation
Change over Time

"Personal Development"

Changing Priorities
Personal Development
Change over time

"Family"	Parental Attitudes to Surgery Parental Attitudes
"Support"	Support
"Context"	Mood Personality Context Change over time

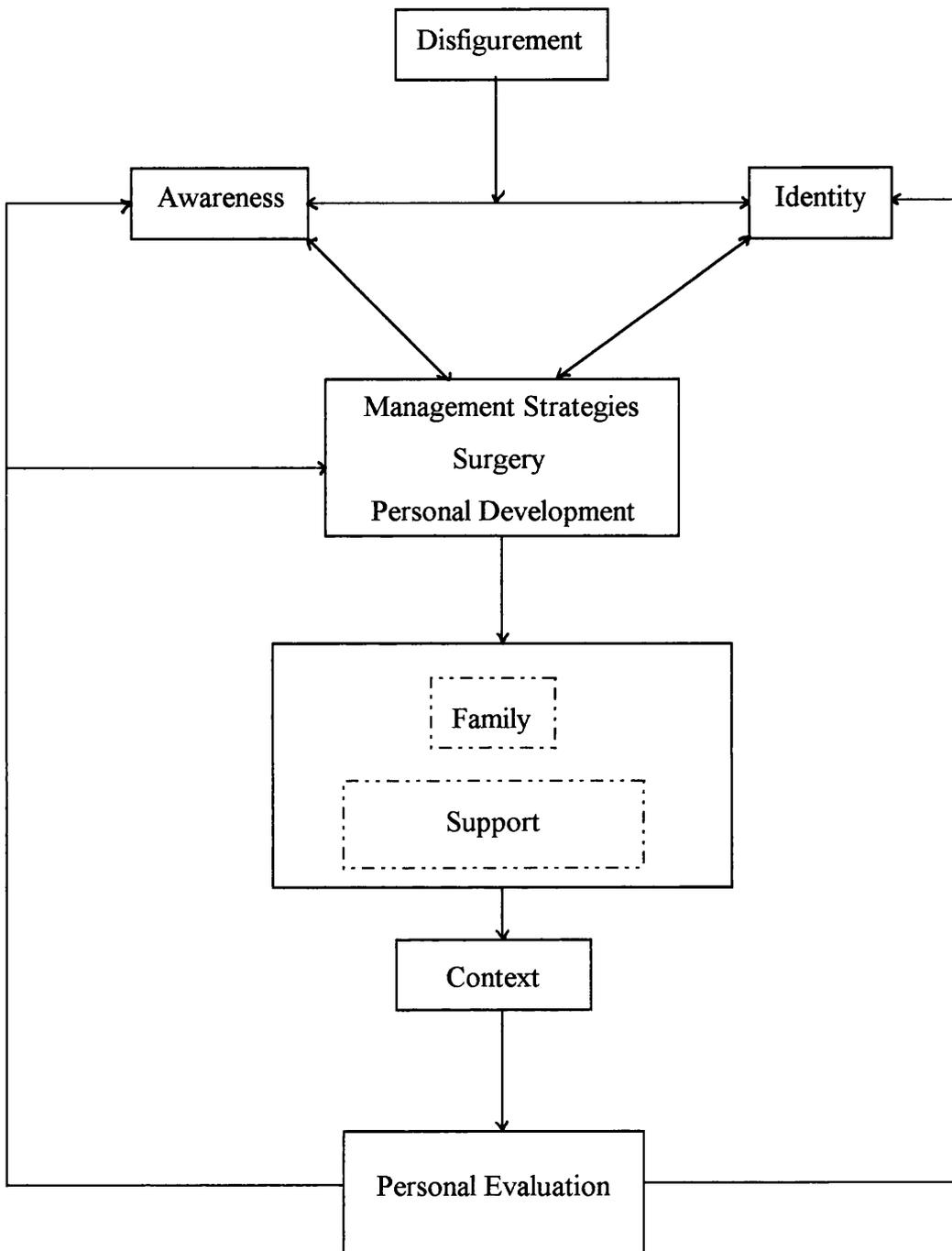
During the process of developing categories and themes, properties and dimensions of both the categories and themes were identified, where applicable. For example, the categories within the theme of "management strategies" vary along dimensions of "degree of action required" (along a dimension of active-passive), "timing of action", (along a dimension of proactive-reactive) and "effect on self-evaluation" (along a dimension of useful-not useful).

Finally, the themes were linked together around a core theme using the paradigm model. The core theme which was identified was that of personal evaluation. A secondary theme was that of surgery. The final theory therefore relates to how maxillofacial patients evaluate themselves and the relationship between evaluation and surgery.

The Grounded Theory analysis is summarised in Fig.2.

Within the paradigm mode, the causal condition is "disfigurement". The phenomenon is the effect of disfigurement on the individual, which consists of "awareness" and "identity". The consequences of awareness and identity on "personal evaluation" are mediated by the action/interaction strategies "management strategies", which include the strategies of "surgery" and "personal development". The intervening conditions of

Fig 2. The Process of Personal Evaluation



"family" and "support" and the "context" also influence the relative contributions of awareness, identity and management strategies on personal evaluation.

4.0 DISCUSSION

4.1 INTERPRETATION OF RESULTS

Ratings of Appearance

This study indicates that there are no significant changes in appearance following facial reconstructive surgery, in terms of mean ratings of attractiveness by independent observers, for the conditions hemifacial microsomia and Treacher Collins. This is consistent with the findings of Pillemer and Cook (1989), who also found no significant improvement in observers' ratings of appearance following craniofacial surgery. When the present findings were examined individually, 24% were rated as improved, 48% showed no change and 28% were rated as being less attractive following surgery. This is in contrast to Barden et al's (1988) craniofacial sample, for which 62% were rated as improved, 39% as not changed and 8% as decreasing in attractiveness following surgery. This may reflect differences in either the rating scale (Barden et al used a less sensitive 5 point scale) or the scoring criteria for determining no change (which is unstated in their paper).

Although this study did not directly attempt to compare the ratings of observers with ratings of improvement by the patient, the findings from the telephone interviews suggest that all of the patients (100%) anticipated changes in appearance following surgery and that the majority (64%) felt that these expectations had been met. This suggests that there was a discrepancy between the ratings of the observers and the views of the patients with respect to perceived improvements. This is consistent with several previous studies (Arndt, Travis, Lefebvre, Niec and Munro, 1986; Heldt et al, 1982).

While this study is generally in line with previous research findings, it is confounded by the fact that there was no control group in this study. It is possible that ratings of

attractiveness are moderated by age and that disfigurement is seen as less severe in children, i.e. that young children elicit a positive response, simply due to their age. This would mean that post-operative photographs were automatically rated as less attractive. The mean age at pre-operative photograph was 10.3, but the range was large, between 2.2 and 18.2, so this may not have been an issue for all participants. It is also possible that facial disfigurements which are related to inadequate growth, such as those associated with hemifacial microsomia and Treacher Collins, become accentuated by growth over time. In this case, surgery hopes to prevent the natural deterioration with age but not necessarily improve overall appearance.

Because the individual data relating to change in appearance following surgery was so varied, the participants were analysed separately with respect to whether or not their appearance was rated as better or worse. This revealed a significant difference in gender between those whose appearance improved and those whose appearance deteriorated, with significantly more women being judged as attractive following surgery. This finding may indicate that women are more likely to request surgery which has aesthetic components or that they have more available to them in the way of camouflage techniques, such as make-up and hairstyle. It is also possible that women are generally considered to increase in attractiveness in comparison to men as they age. As there are no norms for the attractiveness scale, this explanation cannot be validated at present.

1) How do maxillofacial patients compare with the normal population on quantitative measures of psychological adjustment, long term post-surgery?

The results have shown that this population of maxillofacial patients are not significantly different from the general population on a measure of general psychological well-being, although there was a non-significant trend towards poorer psychological well-being in this sample. On more specific measures, self-esteem and general body satisfaction, the picture reflects that suggested by the literature, that this group has low grade psychological difficulties.

Their self-esteem was slightly but significantly lower than a normal population but not as low as that in a group of adults with diagnoses of anxiety and depression. Their general body satisfaction was significantly better than a normal population, as was their specific body satisfaction (as measured on the body sub-scale) although their facial satisfaction was significantly lower. However, they were more satisfied with their general body, body alone *and facial* appearance than a comparison group with eating disorders.

As there are no pre-operative measures it is difficult to say whether this last finding, that the maxillofacial group were more satisfied with their facial appearance than a group with eating disorders, represents positive changes following surgery. It could also be the case that the eating disorder group have a particularly poor general body concept. However, it is consistent with the general picture that the maxillofacial population has difficulties which are chronic, but not severe (Pertschuk and Whitaker, 1987).

Self-esteem and general body dissatisfaction, including both the head and body subscales, correlated with general psychological well-being, such that high self-esteem and high satisfaction were associated with improved general psychological well-being. Although correlations do not imply causality and need to be interpreted with caution, this may suggest that high self-esteem and greater body satisfaction improve psychological well-being. It could also be that psychological well-being improves self-esteem and body dissatisfaction through more positive self-evaluation and reduced focus on the head and body, or that these two processes work reciprocally. However, since there were no correlations between self-esteem and general body dissatisfaction, their contributions appear to be independent of each other.

2) Is long term psychological adjustment predicted by any of the following: age at surgery, age now, number of operations, number of years since surgery completed, appearance before surgery, appearance after surgery or change following surgery?

Long-term psychological adjustment, as measured by general psychological well-being, self-esteem and body dissatisfaction, was not predicted by any of the following factors; age now, age at surgery, number of operations, time since surgery, appearance before surgery, appearance following surgery, change after surgery or sex. This indicates that specific factors directly associated with surgery have little effect on long-term psychological adjustment. Each of these findings is discussed below.

Age now had been considered as a predictor of psychological adjustment on the basis of findings that adjustment is inversely related to age during adolescence (Lefebvre, Travis, Arndt and Munro, 1986; Pertschuk and Whitaker, 1988). It may be that this is no longer the case once the adolescent reaches adulthood. As the age range in this study was 16-33, the participants may have been too old to detect an age effect.

Age at surgery was assessed in relation to psychological adjustment because of the suggestion and assumption by many researchers, that earlier surgery is of more benefit than later (Pertschuk and Whitaker, 1987). This study suggests that age at surgery does not relate to long-term psychological adjustment. It may be that previous research has confused 'natural' changes in adjustment through adolescence with outcome following surgery.

Time since surgery was indicated by two factors. First, the finding of Kiyak (1993), that body image changed over time after surgery, declining at 9 months after surgery but rising beyond pre-surgical levels at 24 months. Second, the absence of any studies examining long term adjustment in adults, who had undergone surgery as children. The finding of this study, that time since surgery was not related to adjustment, suggests that changes following surgery, if any, are consistently maintained with time. This does not fit with the idea that initial gains 'wear off' as the patient continues to experience social difficulties.

The number of operations was included as a predictor variable because of the finding of Fisk et al (1985) that as the number of operations increased, children with facial disfigurements were more likely to identify with a disfigured child. However, Fisk et al

used projective tests to measure adjustment and the fact that this study found no relationship between the number of operations and psychological adjustment may reflect the use of questionnaires. Previous research has suggested that different measurement techniques suggest differences in degree of maladjustment (Lansdown et al, 1991).

This study found no significant relationship between attractiveness before surgery, attractiveness after surgery or change following surgery and adjustment. This is consistent with the findings of Arndt, Travis, Lefebvre, Niec and Munro (1986) and Bradbury et al (1992) that there is no direct relationship between change in appearance and psychological adjustment but inconsistent with the finding of Pillemer and Cook (1989) that those children with higher post-operative ratings of attractiveness were associated with higher self-concept. This may reflect the longer-term follow up of this study, or a difference in the overall ratings of attractiveness between this study and that of Pillemer and Cook.

This is also inconsistent with the suggestion that degree of disfigurement is inversely related to psychological adjustment (Lansdown, Lloyd and Hunter, 1991). However, as the participants in the present study had undergone surgery, it is possible that any relationship between disfigurement and adjustment was affected by the surgical process. It does however indicate that there is no risk in increasing psychological difficulty if appearance changes from severely to mildly disfigured following surgery.

Despite the general lack of significant findings, a positive correlation was found between the body sub-scale scores and change in appearance following surgery. This indicates that the greater the increase in rated attractiveness following surgery, the greater the long term body dissatisfaction. This is interesting because it suggests that following effective surgery the focus of dissatisfaction shifts to other parts of the body.

There are two possible explanations for this finding. The first suggests that this is a reflection of the finding from the psychodynamic literature on cosmetic surgery that views desire for plastic surgery as a reflection of other emotional issues. This predicts

that cosmetic surgery will be unsuccessful as it will not address the core issue, which would need to be worked through with psychotherapy. Friedman (1951), cited in Kalick (1982, p380), comments, "It would be extremely interesting if a thorough statistical study could be made of persons who have undergone plastic operations of the nose and who have not sought the help of psychoanalysis in order to determine how many of them presented sexual disturbances and had unconsciously genitalised or overcathected their noses".

This idea, that some reconstructive surgery is a representation of other psychiatric difficulties, has recently been formalised in the form of a new diagnostic category in DSM-IV of "Body Dysmorphic Disorder" (BDD) (Cunningham, Bryant, Manisali, Hunt and Feinmann, 1996). The diagnostic criteria refers to excessive pre-occupation with a defect in appearance which causes significant distress in social, occupational or other areas of functioning (American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 1994). Cunningham et al describe 'Doctor shopping' and frequent requests for surgery as clinical aspects of BDD.

However, the finding that the maxillofacial population has significantly greater body satisfaction than the general population, as measured on the body sub-scale of the BSS, indicates that this is unlikely. A more plausible explanation may be that change in appearance shifts priorities such that 'normal' concerns about body shape become more salient. This sets the maxillofacial population apart from the cosmetic surgery population, who are generally considered to have a high incidence of psychiatric difficulties (Kiyak, 1993).

Correlations were also found between scores on the body sub-scale of the BSS and gender, with women reporting higher levels of dissatisfaction than men. Unfortunately, there are no norms available, with respect to differences on gender, which would indicate whether this is a reflection of the usual gender bias in the general population. Given the significantly higher incidence of eating disorders in women (Raphael and Lacey, 1992) this seems a likely explanation.

3) What are the patients' views of their operations, the advantages and disadvantages, their appearance, their coping styles and their adjustment?

a) Telephone Interviews

Information gleaned from the telephone interviews indicated that the majority of maxillofacial patients felt that their surgical experiences were worthwhile, with 79% stating that they would make the same surgical decisions again. However, there are certain aspects of the surgical experience which could be improved through better preparation. The major unexpected difficulty concerned loss of sensation, usually around the lower lip and chin, which often persisted for several years.

Interviewees reported different expectations of surgery, with the exception of change in appearance, which was important for everyone. The next frequent expectation was change in personality (79%), less important was change in social life (29%) and changes at work or college (14%). Similar patterns were found when interviewees were asked whether their expectation had been met. 64% felt that their expectations had been met in terms of their appearance, 50% felt there had been changes in their personality, 29% changes in their social life and 7% noticed changes at work or college. This pattern of findings is consistent with that of Phillips and Whitaker (1979).

The majority also felt that having a psychologist available within the maxillofacial and dental department would have been helpful. 93% felt this would have been helpful for themselves and 86% felt this would have been helpful for their parents. In general, they felt that a psychologist would be helpful in learning to deal with issues outside of the hospital, such as bullying, rather than concerns to do with surgery. All found the staff were extremely supportive, while they were in hospital.

b) Grounded Theory

A full description of the hypotheses generated from the Grounded Theory analysis is given below. In order to illustrate the origin of concepts, themes are represented in **bold**, categories in *bold italics* and properties and dimensions in *italics*. The core theme relates to: how maxillofacial patients evaluate themselves and the relationship between evaluation and surgery.

Facial disfigurement is a broad term which covers a variety of physical differences. The *location* of the disfigurement varies from ears, cheeks, jaw, eyes and nose and varies in the *degree of disfigurement* as compared to an unstated but accepted norm. The disfigurement also varies along a dimension of *symmetry*, from completely bilateral to unilateral. Disfigurement can *change over time* through natural growth patterns which further distort the face. Facial disfigurements are also frequently associated with *other medical problems*, such as breathing difficulties, feeding problems, speech problems, hearing difficulties and less frequently with syndromes which may also affect other organs (e.g. the heart) or developmental processes (e.g. no breast development on one side). These functional difficulties are usually managed through the use of hearing aids, speech therapy and surgery.

Maxillofacial patients appear to go through a process of **personal evaluation** which can be on a continuum from *positive* or *negative* and depends on three related categories; **a) awareness, b) identity** and **c) management strategies**.

a) Awareness refers to the salience of the disfigurement in the individual's life. This seems to be composed of different *types of awareness*, the *awareness of the disfigurement* itself and the *awareness of others' reactions* to the disfigurement. Awareness of disfigurement seems to begin from around the age of 8, arising from negative *comparison* with family members, peers and media images and from the *reactions of others* to the disfigurement. Other people who come into contact with someone with a facial disfigurement react in different ways (*type of reactions*).

Responses can range from curiosity, teasing, pity, staring, rejection, avoiding, verbal abuse or in some cases physical violence.

The *reaction of others* in interactions is reported to be affected by several mediating factors. First, how *obvious* the disfigurement is, including the degree that it is hidden by hairstyle. The *relationship* between the observer and the person with a facial disfigurement is also thought to be important. The *quality* of the relationship, including the two properties of *intimacy* and *duration* affect *others' reactions*. The longer and better someone is known, the less likely they are to react *negatively*. Contact with strangers occurs in many situations (*context*), using public transport, socialising or starting a new school. Particular difficulties also seem to occur when the individual is being *evaluated*, such as at job interviews. *Relationships* appear to be the only factor which is not affected by the mediating factors. With time and contact, friendships with both sexes may develop but these seem more likely to be considered by the non-disfigured party as *asexual*.

b) **Identity** refers to the sense of *group membership*. People with facial disfigurements appear to have a sense of group membership depending on their *role*. There are different types of *role*, wife, mother, professional, peer leader which interact with the *role* as someone with a facial disfigurement. Having an identity which is focused primarily on the **disfigurement** is reported as *negative*, "spoiled" and having no sense of *group membership*, being an outsider.

The impact of other *roles* on **identity** seems to depend on several mediating factors. First their *presence* or *absence*, which also *changes over time*. Second, the degree to which they challenge ideas about a disfigured identity, a kind of *role dissonance*. Roles which are *valued* (e.g. white-collar worker) and roles which relate to and acknowledge *relationships*, (sexual partner or parent) appear to have a greater impact on **identity** than those which are not *valued* or not related to *relationships*. Third, **identity** is affected by the degree of **awareness**. The greater the *awareness of disfigurement* and the *awareness of others' reactions*, the greater the impact of the disfigured identity. Fourth and finally, **identity** is also reported to be affected by a sense of *missed*

opportunities, stemming from perceived discrepancies between self-and others in developmental processes and shared experiences; socialising, sexual experimentation and relationships. It appears that the greater the sense of *missed opportunities* ("missed out on teenage years and hit adolescence later", "grew up quickly") the greater the impact of the disfigured *role* on *identity*.

c) **Management strategies** refer to the attempts of the individual to modify the effects of **awareness** on **personal evaluation**. Participants presented five *types of strategy*: *avoidance*, *compensation*, *emotional release*, *pre-empting others' reactions* and *rationalisation*.

1) *Avoidance* refers to any strategy which avoids negative interactions with others, such as changes in lifestyle (e.g. choosing a job which does not involve contact with the public) or attempts to camouflage the affected area (e.g. always wearing hair long and covering disfigured ears). *Avoidance* includes the category *protection*. This refers to any attempt to protect the self or others' from negative experiences. For example, not talking to parents about bullying.

2) *Compensation* strategies are strategies which decrease the likelihood of negative evaluation by assuming other valued characteristics, e.g. choosing attractive friends, or building a career.

3) *Emotional release* involves strategies which allow expression of the individual's reaction to others' negative reactions, such as crying, getting angry, getting drunk. This includes the category *psychological support*, which refers to emotional support either from professionals, friends or parents, which facilitates *emotional release*.

4) *Pre-empting others reactions* in social situations allows the individual to respond in a manner which influences others' responses, both to avoid confrontations and protect others from awkward moments. Responses include *explanations of disfigurement*, smiling or making a joke or getting angry. *Pre-empting others reactions* relies on accurate *prediction* of *others' reactions*. However, it is not always possible to

accurately predict others reactions (*low predictability*) and this can lead to *mistrust* of *others' reactions* (e.g. "The only reason he's asking me to dance is because he's drunk").

5) Finally, *rationalisation strategies* are those that involve intellectualising *others' reactions* to minimise their effect (e.g. "that's their loss, not mine").

Management strategies appear to be *active* or *passive*, in that they require action or absence of action, *proactive* or *reactive*, in that they occur before or after others' reactions, *useful* or *not useful*, in that they improve **personal evaluation** or detract from it and *purposeful* or *not purposeful*, in that they are designed to improve **personal evaluation**. The strategy which is most useful seems to depend on the *context* and also the *sense of purpose*. An example would be some *avoidance* strategies. Using **management strategies** is, in itself, stressful and people sometimes need to have time off from coping, which may involve temporarily avoiding some difficult situations. The effect of this on **personal evaluation** depends on the *sense of purpose* the person has. If this is viewed as *purposeful*, this is a *useful* strategy. If this is seen as *not purposeful*, the only possible response to a difficult situation, then it is *not useful*. The *sense of purpose* seems to be mediated by *prediction*, which is in turn affected by the *effect of previous experience*. If a child or adult with a disfigurement has found that *purposeful management strategies* affect experience, they seem more likely to take *purposeful* action in the future. It seems to be also mediated by *personality* types, ("extrovert", "risk-taker") and by current *mood*. The more extrovert and happier the individual the more positive the *prediction*.

Personal evaluation appears to be most positive if **awareness** is *low*, **management strategies** are *useful* and **identity** is not solely based on a disfigured *role*. **Personal evaluation** seems most negative if **awareness** is *high*, **management strategies** are *not useful* and **identity** is solely based on a disfigured *role*.

Personal evaluation also appears to be influenced by other factors such as *family attitudes* to disfigurement and coping, *support* networks and *context*, including life events.

Family members can encourage *purposeful* and *active management strategies* (e.g. dealing with bullies) or be *protective* and encourage *avoidance* (e.g. keep child isolated). The parents influence seems to depend on the *effect of* the child's own *experiences* on *prediction*. In families where the facially disfigured child has no experience of managing their situation, the child seems likely to grow up with fewer **management strategies** and poorer **personal evaluation**. Siblings' appearance and degree of *comparison* between siblings can influence **personal evaluation** through the development of **awareness and identity**. If the family treats all children equally, they are more likely to develop a sense of *group membership* and more *positive predictions*.

If the child/or adult can build up a *support* network of loyal friends and family this appears to act as a protective factor in **personal evaluation**. *Awareness of disfigurement* seems to decrease in an environment where others know the person well and do not react towards the disfigurement, thus potentially reducing *awareness of others' reactions*. **Identity** may then begin to be defined as a member of a group, rather than an individual outsider, different from others with no sense of *group membership*. Others can also be used for *emotional release* and *pre-empting others' reactions* (e.g. friends challenging bullies). Existing friendships can also provide the experience of *positive* reactions, thus increasing *positive predictions* and *rationalisation* (e.g. "if my friends can have a positive attitude, other's will too"). Equally, if the individual has no friends, they may lose their *positive predictions* and confidence in *purposeful management strategies*. Family members cannot always be a useful source of support if they express their concerns to the child, who then is reluctant to confide in them for fear of upsetting them (*protection*).

Personal evaluation seems to be influenced by the *context*. Context refers to both situations and life events. Positive and negative life events include bereavements,

achievements, parental divorce and having children. The impact of these events seems to depend on their relative effect on each of the categories of **awareness**, **identity** and **management strategies**. For example, *changing priorities* following life events may influence **awareness**. In much the same way as the influence of a disfigured *role* on **identity** can depend on other *roles*, **awareness** may depend on awareness of issues raised from other events, whose impact will change with their *presence* and with *time*.

Surgery is an **management strategy** intended to make **personal evaluation** more *positive*. This is the belief of the patient, the parents and the doctors. Many different *surgical techniques* are used. These include cleft palate repair, jaw surgery involving rib bone grafts, ear reconstructions and soft tissue implants. *Surgical decisions* depend on the effect of physical growth on the disfigurement (*change over time*) and **surgical expectations and limitations**.

The *surgical decision* is usually primarily made by the patient, in consultation with the parents. The decision is reported to be made on the basis of a *risks / expectations* analysis. In some cases, *risk* is *unpredictable* (e.g. "it could look worse, it could relapse, it could look better"). Patients hold particular *surgical expectations* that surgery can make them look better, more symmetrical, more normal, that people will not notice their difference and that this will prevent others from treating them differently. They expect that they will have more friends, that they will feel better about themselves and that they will be able to get on with their lives and careers. This seems to provide *hope*. In some cases these beliefs are held even when information is given to the contrary before surgery (e.g. explanations of *surgical limitations*). Even when it is clear that there are no guarantees of improved appearance, individuals sometimes feel that it is better to take the *risk* because "anything would be better", it is better to take the risk than have *missed opportunities*.

Surgery is generally experienced as *negative*. This appears to depend upon *post-operative difficulties, complications, preparation* and *changes over time*. Anxiety about the surgical experience seems to be managed by **management strategies**, often *rationalisation* "what's six weeks of your life". Most patients report experiencing pre-

operative anxiety. Reported *post-operative difficulties* include *pain* (although this is usually well managed with *pain killers*) and *anxiety* about choking because of the tubes inserted down the throat. Patients also report having a worse *appearance*, until the *swelling* goes down. They describe managing the impact of this by *preparation* before looking in a mirror and *avoidance* of mirrors until the *swelling* has reduced. Patients also complain of difficulties *eating* up to 3 months afterwards, due to the appliances which fix jaws together after major jaw surgery (*surgical techniques*). Some patients report losing a great deal of *weight*, some several stones. *Surgical Complications* are not uncommon and are understood by the patient as due to *tissue rejection* or persistent *loss of sensation* from nerve damage. There are usually uncertainties expressed at this stage about whether the surgery was justified, an evaluation of the *post-operative difficulties/surgical outcome*, ("why have I done this" "I'm never going through this again").

Despite the *negative* surgical experience, the *hospital* experience is generally considered very *positive*. This is reportedly due to the *acceptance of disfigurement* within the hospital and the *special attention* received by the children from parents, friends and staff. When negative experiences are reported they are usually associated with *fear of needles* and *negative family attitudes to surgery*. *Family attitudes* were seen as most negative immediately following surgery when *appearance* was worst and the child was in *intensive care*. In general patients feel that they have *lower personal evaluation* outside, rather than inside, the *hospital*.

Evaluation of *surgical outcome* is mainly *positive*, both from improvements in *disfigurement* and more *positive predictions*. These improvements seem to reduce *awareness* of disfigurement, improve *management strategies* and sometimes lead to a change in *identity* to one in which disfigurement is not the core *role* (e.g. "now I'm the leader of the pack"). When there was no change in *disfigurement*, patients described not looking any worse as a *positive outcome*. Negative evaluation of *surgical outcome* appears to result from the realisation that *others' reactions* haven't changed and that personal evaluation is *context* dependent (e.g. "hasn't stopped ignorance", "still terrified around men", "I go to a club and get up on stage but certain

people I still find it hard to talk to"). Whether evaluation of *surgical outcome* is *positive* or *negative* seems to depend on the individual's experiences following surgery.

The decision for further **surgery** is reportedly influenced by *surgical limitations*, when the patient continues to reject implants or previous scar tissue prevents further work, new *surgical techniques* or because of the re-evaluation of *surgical expectations*. Re-evaluation seems to depend on the *effect of experiences* on the *risks/expectations* analysis. If either the predicted degree of *risk* or the *expectation* changes, so that the risks outweigh the predicted benefits, further surgery is less likely. *Risks* are seen to change if the *negative* experiences (*anxiety, pain, complications* etc) associated with previous **surgery** were greater than expected. *Expectations* are seen to change if the *positive* experiences following **surgery** (change in *appearance*, change in *awareness*, change in **management strategies**, change in **identity**) were less *positive* than expected. For example, "there will always be room for improvement and the small difference it will make is not worth it" and "I have to face the fact that people find it difficult to cope with".

Patients still left with a facial **disfigurement** after **surgery** describe a process of **personal development** which follows **surgery**. This involves three stages. First, acknowledging **others' reactions** will continue to be negative. Two, recognising that **identity** and **personal evaluation** do not have to be based on *disfigurement*, that "appearance isn't everything". Three, gaining a sense of *purpose* taking responsibility for changing **personal evaluation**. This last step involves *action* to change **awareness** and **identity** by changing **management strategies** to improve **personal evaluation**. Examples given include developing skills, developing a career (*compensation*), meeting new people (*support*) and *changing priorities*, "as long as I'm happy and healthy and I've a roof over my head and food on the table and have some fun with my friends, that's ok". Patients describe the outcome of this as not necessarily being happier with appearance, but feeling more relaxed about it (reduced **awareness**). Despite improvements in **personal evaluation** through **personal development**, *others reactions* in regard to sexual *relationships*, continued to have an impact.

The process of **personal development** seems to be on-going, throughout the life of the individual with a facial disfigurement.

According to this Grounded Theory analysis, the two major components of personal evaluation are identity and awareness. Awareness is thought to be directly related to awareness of others' reactions to the disfigurement. There is some support in the literature for the suggestion that others' reactions depend on the type of relationship and situation in which they meet the individual with a disfigured face (Hirschenfang, Goldberg and Benton, 1969; Lefebvre and Munro, 1978). Previous research has suggested that first impressions are usually negative but that this changes over time. Situations where the individual is evaluated, i.e. job interview or by prospective partner have been found to be more difficult.

The concept of identity is interesting. Being identified as a disfigured individual appears to be consistently experienced as negative. This creates a dilemma. Unless surgery can completely eliminate any trace of disfigurement, the individual will continue to evaluate themselves negatively, unless they develop an identity as something else. However, in this society, appearance is considered to be of great importance and research has indicated that those with facial disfigurements are at a distinct disadvantage. This predicts an ongoing struggle to maintain a positive identity while everyday experience highlights the disfigurement.

Unlike other stigmatised groups, such as the deaf community or the lesbian and gay community, there appears to be no development of a positive identity, which is still focused on the stigmatised element, i.e. a positive disfigured identity. This may reflect the small size of the facially disfigured population and their geographical spread, or point to possible cultural developments in the future. However, given the relative persistence of difficulties with regard to sexual relationships, despite generally positive adjustments, perhaps this indicates the strength of the public and media's emphasis on appearance and the difficulty a disfigured individual faces in reclaiming their identity.

The use of different "management strategies" suggests that people with disfigurements have a wide range of coping skills. The hypothesis relating to the value of "purposeful" strategies fits with previous research on attribution and learned helplessness (Kelly, 1955; Seligman, 1975). If attributions for outcomes are related to the individual's own ability to cope, rather than to external influences, they are more likely to be able to cope in the future. Equally, learning that outcome is beyond that individuals' control may lead to "learned helplessness" and no purposeful action in the future.

The influence of the family's attitudes in the development of positive person-evaluation is also supported by research findings (Beard et al, 1989; Blakeney et al, 1990; Bradbury and Hewison, 1994) and may indicate why the findings of the factors relating to surgery had such little influence on long term psychological adjustment. It may have been of value to include a retrospective measure of family attitudes in the analysis.

The theory also suggests that the decision making process before surgery is not always dependent upon the risk/benefit analysis. In these cases, the possibility of surgery seems to provide a sense of hope, a focus, which acts as a support in itself. This means that although preparation is reported to be helpful, a discussion of the limitations and/or complications associated with surgery may not always be 'heard'.

It may be the case that hope allows a negative cycle of negative evaluation and negative expectations of change to be broken. Surgery tends to take place in adolescence, when teasing is at its height and appearance is becoming more important. As such, it may provide an emotional crutch which gets the individual through these difficult years. It is suggested that adults have more resources to cope than adolescents, have developed other roles and skills and they may no longer need to pursue surgery.

This analysis suggests that surgery is helpful, not because it changes others' reactions but because it improves an individual's self-evaluation and subsequently their confidence in their ability to cope. The literature supports this idea that expectations of negative encounters become self-fulfilling prophecies (Rumsey, 1983). It begs the question, however, of whether the same benefits could be obtained without the use of

surgery. It may be that small improvements in appearance, non-significant to an observer, are the most important factor in positive self-evaluation. Or, it could be that the sense of hope is sufficient to instigate changes in behaviour which ultimately lead to more positive interactions with others.

4.2 CLINICAL IMPLICATIONS

1) Challenging Assumptions

This study began by outlining the three assumptions made by surgeons in advising maxillofacial patients to have reconstructive facial surgery. One, that facial disfigurement causes psychological distress. Two, that surgery improves facial appearance. Three, that improving facial appearance leads to improved psychological functioning. However, the literature review and findings of the present study suggest that these three assumptions may be misplaced.

It seems to be the case that maxillofacial patients do have some psychological difficulties. However, these difficulties seem to be of a magnitude significantly different from those of the normal population, but not as severe as clinical populations. In general, people with facial disfigurements appear to manage well on a day-to-day basis. However, certain situations appear to be more difficult than others. These tend to be situations where the individual is being formally evaluated, e.g. at an interview or in the context of a potential sexual relationship. It is unclear whether these relatively positive adjustments are the consequence of surgery, or not, as very few studies have assessed an adult population who have not had surgery.

It is the finding of this study that surgery for the conditions of hemifacial microsomia and Treacher Collins, surgery does not consistently, significantly, improve appearance, according to the ratings of independent observers. Neither do specific factors

associated with surgery (time since surgery number of operations, age at surgery, appearance after surgery or change in appearance following surgery) predict psychological adjustment. It is important that this is made clear to both surgeons working in this field and the patients themselves, so that an informed opinion can be made. It may be that some surgical techniques are more effective than others and this would need to be communicated to the individual. Identifying realistic outcome may become more of a clinical possibility using moire topography and interactive imaging systems, recently described by Chen and Iizuka (1995).

Finally, it does appear that surgery has a beneficial effect on psychological functioning, according to the reports of the patients themselves. The lack of pre-operative measures means that these benefits are not measurable. However, any change which occurs does not seem to be a direct result of improvements in appearance, as seen by others. This also needs to be made clear to any individual seeking surgery, so that they can make an informed decision about whether the risks associated with the operations are justified. It may be that some patients would prefer to seek psychological support in developing confidence in other ways.

2) Psychological support

Regardless of whether or not individuals opt for surgery, psychological support should be available to both patients and their parents, as the majority of patients feel this would be useful. Broder and Richman (1987) report on a survey of mental health services offered by cleft/craniofacial teams and conclude that although directors stated that mental health intervention was important, and was available in theory, it tended not to be offered to patients routinely.

Patients in this study report that psychological support would be valuable for dealing with everyday stresses, rather than concerns relating to surgery or surgical decision making. Although no questions were asked specifically about these everyday stresses,

it appears these concerns might relate to bullying, relationships, social skills or preparation for job interviews.

Lefebvre and Arndt's 1988 paper, entitled "Working with facially disfigured children: a challenge in prevention" provides a comprehensive list of the contributions which can be made by psychologist working with the facially disfigured. It describes interventions from birth, with the family, the child and the school. These are briefly described below:

Identification

- At birth, give correct diagnosis, its embryology and aetiology, to dispel myths which promote parental guilt
- Outline specific surgical steps and promote realistic hopes
- Identify early functional difficulties (hearing, speaking etc)
- Provide genetic counselling

Early Intervention with the family

- Promote communication and problem solving in social situations
- Model infant stimulation, cuddling and affective response
- Model open discussion about the child's attractive and less attractive features

Early Intervention with the Child

- Encourage exposure to 'normal peers'
- Teach the child to answer simple questions about his/her appearance
- Use dolls and drawings to talk about the child's understanding of their disfigurement

Cohort Programs

- Particularly at school entry and after surgery

Later Intervention with the Child

- Preparation for surgery (also important to do this with parents)

- Specific training around social skills, dealing with negative encounters, developing other skills, getting information from professionals, interview skills and handing genetic counselling

Lefebvre and Munro particularly mention adolescence as "a period of maximum insecurity and self-doubt, in which the need for support from peers is at its peak. Therefore it is the optimal time for specific life skills training in a group therapy context" (p457). This is consistent with the findings of this study, that adolescence is a time of great stress for any young person, but particularly so for an adolescent with a facial disfigurement because of the increased focus on appearance.

In the context of the Grounded Theory analysis presented in this paper, Lefebvre and Munro's suggestions are consistent with the concept of developing positive personal evaluation, through developing other skills, encouraging open discussion of the disfigurement (developing positive identity), encouraging positive reactions of others (reducing awareness) and giving specific advice about managing difficult situations (management strategies).

3) Better preparation

It is clear from patient reports that some aspects of post-operative care are not fully explained before surgery. These mainly relate to the possibility of post-operative loss of sensation in the lower lip and jaw. Other reported anxieties relate to waking in intensive care and feeling unable to breathe or swallow properly because of naso-gastric tubing or the splints applied to fix together the upper and lower jaw. The splint also restrict food intake over the next three months and the subsequent weight loss, although sometimes welcome, is not always anticipated.

4.3 METHODOLOGICAL LIMITATIONS

There are several criticisms which can be made of this study. These relate to both the research methods and the theoretical assumptions behind the Grounded Theory analysis.

1) Control Group

There was no control group in this study. Ideally, two control groups would have been used, one group of maxillofacial patients, matched for degree of disfigurement and age, who do not have surgery and a matched control group of people without facial disfigurements. Without these, there is no way of knowing whether ratings of appearance change with age and whether people who do not have any surgery fare better or worse psychologically long term. However, the current reality is that almost all maxillofacial patients do request surgery, therefore it would be extremely difficult to provide a large enough sample to provide adequate controls.

The lack of control groups was partly compensated for by the use of normative data for the questionnaires. Unfortunately, there are no norms available for the attractiveness rating scale. It has been suggested by Berscheid and Gangestad (1982) that "the media in recent years have so emphasised physical beauty and set standards so high that the distribution is skewed in the opposite direction, that most of us are regarded below the neutral point on an attractiveness dimension" (p295). This would be an important suggestion to verify.

2) Small Numbers

The numbers are relatively small. Although the response rate was very high, considering the length of time since participants had been involved with the hospital, the low numbers mean that findings need to be interpreted with caution. Given the size

of the maxillofacial population and the need to maintain a relatively homogenous group, this difficulty is unlikely to be overcome. Using a Grounded Theory approach enables the maximum detail to be retained, while still drawing some general conclusions.

3) Pre-operative Measures

There were no pre-operative measures available for the participants. Ideally a longitudinal research design would have been used, but in reality this is expensive and time-consuming. By making use of the natural variability in scores, the question, "what predicts outcome?" was answered, rather than "what change occurs?". In the absence of pre-operative measures this study relied on self-report to assess gains following surgery, which may not have correlated with questionnaire ratings.

4) Multiple Operations - Coding

The maxillofacial sample used for the study had undergone different numbers of operations and a wide range of type of operations. In deciding how to code these differences, it was decided that the number of hospital admissions was of more relevance than the type or complexity of the operation. It could be argued that operations which require extensive stays in intensive care are more traumatic than those which are day cases. However, the task of making comparison between operations in this way would have been complex and not based on any known research.

5) Photographs

The photographs which were used to assess pre-and post-operative appearance were not as uniform as they could have been. Facial expression and hairstyle varied, in some hair was pinned back to enable the disfigurement to be seen more clearly. The rating scale used to measure the degree of attractiveness was also fairly crude, with only 3

potential responses with the domain of "unattractive". This did not allow for detailed responses which may have detected small changes following surgery.

For a few participants, the post-operative photograph was not an accurate reflection of their current appearance, as some had undergone minor cosmetic operations after leaving the Children's hospital. Unfortunately, more recent photographs were not available. As these later operations were generally very minor, such as titanium implants for bone anchored hearing aids, it was felt that they would not have a great impact on responses to the questionnaires. Questions relating to surgical experiences were phrased with reference to operations at the Children's hospital. However, given that the relationship between surgical experience and psychological outcome is so complicated, it is possible that these further operations had a greater impact than anticipated.

6) Age Since Surgery

In relation to the above point, age since surgery was defined as the time since last surgery at the Children's hospital. Since some participants had further surgery, this may be an irrelevant measure. This measure also bears little relationship to the time elapsed since the last major operation, which for most patients, involved bone grafts from the rib, to the jaw. This rib graft was often reported to have had the greatest impact on appearance and it may, therefore, have been more appropriate to measure time since this operation. However, as the relationship between degree of disfigurement and adjustment is not clear, this was not considered essential.

7) Grounded Theory Analysis

The Grounded Theory analysis can be criticised on several counts. These are summarised by Rennie, Phillips and Quartaro (1988): a) the emphasis on theory-

generation; b) the effect of researcher subjectivity; c) the dependence on verbal report as data and d) the generalisability of the findings. These issues are discussed below:

a) The emphasis on theory generation appears to be at odds with the traditional hypothetico-deductive approach, which is concerned with verifying propositions. There are advantages and disadvantages to both of these approaches. The freedom of the grounded theory approach allows researchers to explore phenomena, in detail, without the constraint of particular pre-formed ideas. Hypothetico-deductive researchers need to base their hypotheses on a theory and in the absence of theory, this may be little more than skilful guessing. The grounded theorist develops theory in a systematic and reflexive manner, ensuring that theory comes from and remains close to, "grounded in", the data. It should therefore be of particular use in circumstances where there has been little previous research.

b) The credibility of grounded theory is threatened by its self-declared subjectivity. The assumption here is that hypothetico-deductive approaches avoid subjectivity by the use of random assignment, large numbers, experimental control and statistics. This assumption is challenged by theorists coming from a social constructivist framework by their assertion that all research is inherently subjective, because there is no such thing as an objective reality. The common misinterpretation of this view is that research exists in a value vacuum and all research is therefore as good as any other. Strauss and Corbin (1990) argue that although research and theory can merely provide an approximation to our perceived reality it can be measured by its usefulness and relevance.

However, it should be noted that compared to other qualitative research methods, such as the American phenomenological approach and the British new paradigm research, (Keen, 1975; Reason and Rowan, 1981), grounded theory is relatively more systematic and places less emphasis on the role of the researcher in co-constructing the respondent's accounts. For this reason, it is considered less open to bias than other methods (Moon, Dillon and Sprenkle, 1991) and to fit more comfortably with a "post-positivism" stance. This accepts that there is a reality 'out there' but that our

understanding of this reality will always be imperfect because of the limits of our perception, our subjectivity. This is usually known as 'critical realism'.

It can also be argued that traditional research is not in fact exempt from subjectivity and experimenter bias. Stevenson and Cooper (1997) argue that all research takes place within a social, moral and political agenda. Research is only ever carried out because someone believes the subject is worth knowing about. They suggest that it is better to be open about one's subjectivity than pretend that the research exists in an objective vacuum. Acknowledgement of one's subjectivity can be incorporated into the research by researcher reflexivity. Grounded theory is based on the assumption that there is a constant reflexive process occurring between data, method, theoretical propositions and methodological assumptions (Fig 1). This is reflected in the research method by the use of various techniques (waving the red flag, flip-flop etc.) designed to challenge assumptions and maintain a questioning attitude towards the data (Strauss and Corbin, 1990).

c) Using verbal reports as data relies on participants being able to communicate all relevant information about conscious and unconscious processes. It also relies on participants being open about feelings or thoughts of which they are aware. However, this criticism is also true of much quantitative research which relies on self-report, such as questionnaires or interviews. The close attention to detail and constant comparison within and between individuals in qualitative research may reveal discrepancies in self-report, which traditional methods may not be sensitive enough to detect.

d) The final concern often raised with qualitative research is its lack of generalisability. Ideally, grounded researchers systematically compare contrasting groups to identify common themes. In practice, this is often limited by time-constraints. This places grounded theory somewhere between the single case study and the traditional group comparisons approach. Like the case study it gives the opportunity to study a phenomena in detail but unlike the single case design it replicates the events over several individuals. Traditional research continues this attempt at replication but

produces results which may be generalisable, yet so dilute of detail that the findings may be meaningless to individuals.

Whereas hypothetico-deductive research emphasises criteria and empirical testability and generalisability, Rennie et al (1988) suggest four alternative criteria against which to evaluate Grounded Theory which are:

- 1) believable, in that it should seem to the examiner to be a plausible explanation
- 2) adequate, in that it should present a comprehensive account that does not omit large or important portions of the data
- 3) grounded, in terms of the appropriate procedures and thereby inductively tied to the data
- 4) applicable and should lead to hypotheses and additional investigation.

The present Grounded Theory analysis is believable, in that it fits well with the previous literature and the findings from the quantitative elements of the study. The procedures, although applied flexibly, were rigorously followed. The grounding process ensured that all of the data are adequately represented in the final theory. Finally, there are many hypotheses generated by the theory which can be further investigated. These are described within the Future Research Questions section.

In summary, there are benefits to be gained from both the traditional and grounded theory approaches, provided the researcher is clear about the limitations of each. Any results from any approach or technique in Psychology need to be understood and interpreted within the context in which they arise. For this reason, the approaches may be complementary, each providing a different kind of knowledge, which the other is missing.

4.4 FUTURE RESEARCH QUESTIONS

1) Normative data for attractiveness with respect to age and gender.

The attractiveness scale used in this study is an adaptation of one used by Barden et al (1988). It has the advantage of making judgements based on attractiveness, as it was assumed that this better reflects the response of the average individual in the street, rather than asking specifically about the disfigurement. However, this assumes that the mid point (4=average attractiveness) is a true reflection of a population average. It is possible that media images are so influential that the true average is rated as less than the mid point. To test this, it would be useful to collect normative data for the scale, including the separate norms for men and women and young children through to adults. It would then be possible to test the hypotheses made in the discussion that younger children are rated more favourably than adults and that women are rated more favourably than men.

2) Assessing attractiveness

This study found no evidence for significant changes in rated attractiveness following surgery. One possible explanation for this finding is that the rating scale was too crude to detect the small changes which were significant to the individual patient. One approach which circumvents this difficulty would involve presenting the pre and post surgical photographs simultaneously side-by-side but randomly assigning the photos to the left or right side. The rater would then be asked to select the photograph which was considered more attractive. While this method may detect small changes, it is probably less likely to reflect the gut reaction of others to the disfigurement and would not provide a comparison with an average.

It would also be of interest to ask the patients themselves to give a rating along similar scales to the observers, to enable direct comparisons.

3) Without surgery, how does adjustment change over time?

One of the difficulties in carrying out research into the effects of surgery is the lack of non-surgical control groups. Very few patients elect not to have surgery. However, should the opportunity arise, it would be very useful to examine the changes in adjustment over time for those individuals who do not have surgery. This information would assist decision making in patients seeking treatment and also provide a baseline against which to measure the benefits (or not) of surgery.

4) How do particular individuals adjust to disfigurement and/or surgery?

Given the wide variation in individual scores on measures of attractiveness and adjustment, it may be more useful for future research to focus on incidence of 'caseness' rather than using population means for comparison. An individual approach to research would also benefit from further case-level analysis, such as that of the Grounded Theory approach. Such analysis could attempt to identify the precise contribution which surgery makes to improve psychological functioning

5) The relationship between types of disfigurement and distress.

Lansdown (1990) reports that it is psychologically more damaging to have a 'funny voice' than a 'funny face'. Having a 'funny voice' was found to be a more powerful determinant of low ratings by others. This study has not addressed the relative importance of particular types of disfigurement, or the influence of disfigurement on communication, despite the fact that the location of the disfigurement has been shown to have an effect on the reactions of others. It would be interesting to look at the relationship between types of disfigurement and psychological distress. This may have implications for the types of surgery which have the greatest impact on psychological functioning. For example, having an artificial ear fitted might have a much greater

impact on psychological adjustment than having a rib graft to the lower jaw and yet be a much less complex operation.

6) Focus on the strengths of people with disfigurements

Tobiasen (1989) states “It is time to move on to study how the development of children with CF anomalies compare to that of healthy children and children with other chronic disabilities. Are there areas in which coping with a chronic physical disability actually helps patients to become more psychologically and socially resilient?” (p208).

In the present study, 57% of the participants in the telephone interview stated that they felt they had become a stronger person as a result of their experiences. It would be useful to explore the positive consequences of having a facial disfigurement to acknowledge the relatively healthy adjustment of the majority of these people and also to establish a strong basis for the development of further management strategies.

7) Other predictors of adjustment e.g. attribution, family attitudes and peer support?

The present study found no significant predictors of psychological adjustment from a range of measures relating to surgery. There may however, be many other factors which do predict adjustment, assuming it is not a random process. Alternative predictors suggested by the current study and previous literature include attributional style, family and peer support or family and peer attitudes to disfigurement.

8) Alternatives to surgery

Encouragingly, Rumsey, Bull and Gahagan (1986) found that social skill variables had more effect on observers than the presence or absence of a disfigurement. Some researchers are already beginning to suggest possible psychological approaches to

working with people with facial disfigurements but these have not generally been formally evaluated. Future research could examine the efficacy of psychological interventions in terms of standard psychological measures or in terms of the themes identified in the present study: awareness; identity; management strategies; personal development.

9) The relationship between theory and other psychological measures

In order to evaluate the theory suggested in this paper, it would be useful to examine the relationship between the identified themes and standardised psychological measures, in order to provide a measure of the concepts. However, it may be that it would be more valuable to develop new scales which are more conceptually linked to these themes.

10) Longitudinal studies

Finally, many of the questions raised above would be best answered using a longitudinal research design to facilitate pre and post surgical comparisons, to answer the question what changes as well as what predicts change.

In summary, a quote from Tobiasen (1988).

“Many of them, especially adolescents, experience regular social rejection. The question of how these children make relatively healthy adjustments and the role of surgery and facial alteration in this process over time are still poorly understood and deserve continued scientific attention” (p746)

5.0 CONCLUSIONS

Maxillofacial surgery is performed with the following three assumptions in mind:

(i) that people with facial disfigurements suffer psychological difficulties as a result of their difference; (ii) that surgery improves appearance; (iii) that improving appearance through surgery will lead to improved psychological functioning

This study has attempted to challenge these three assumptions. In contrast to previous research, this study has followed up individuals into adulthood, who had surgery for maxillofacial conditions as children. Using a combination of semi-structured self-report and questionnaires, this study attempted to test the few hypotheses already suggested by the literature. Perhaps more importantly, it also generated new theory and new ways of thinking about the process of adjustment which offer possibilities for future research and clinical practice.

People with facial disfigurements do seem to have difficulties which are associated with their condition but these difficulties do not in the majority of cases, appear to reach clinical proportions. As this study cannot determine whether these relatively positive adjustments are due to the surgery they have received, it remains to be seen whether long term psychological difficulties in a non-surgery population are significantly greater.

Surgery does not, in general, improve appearance to the extent that others' ratings of attractiveness change. However, the majority of maxillofacial patients feel their surgery was worthwhile. The question is therefore, by what process does surgery have a beneficial effect on psychological functioning and is surgery the best means by which to confer these benefits? The model of personal evaluation presented in this paper suggests that surgery may act to provide hope, which breaks negative cycles of negative expectations and negative experience, sufficient to provide a lasting psychological effect.

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7.0 APPENDIX

7.1 Recruitment Letter

7.2 Patient Information

7.3 Consent Forms

7.4 Ethical Approval

7.5 Semi-structured Interview

7.6 Telephone Interview

7.1 RECRUITMENT LETTER

8th July 1996

Dear Sir/Madam,

We are carrying out a study to look at the effects of facial surgery performed by the Maxillofacial Department at X Hospital and we are writing to you in the hope that you will be able to help us with our research. Please find enclosed an information sheet which explains in detail what we are hoping to achieve and how you will be involved, should you choose to take part. Please read this sheet carefully first and keep it for reference later.

The enclosed questionnaires form the first part of our research. They should take about 30 minutes to complete. We would be grateful if you could fill them out and return them in the envelope provided, within the next two weeks.

We would also value talking to you in person, either at (name of hospital), or by telephone. This will help us to get your views about your experiences, in detail. When you return the questionnaires, please complete both sides of the consent form, indicating whether you would prefer to come to the hospital or to talk on the telephone. We would also be grateful if you could give your current name, address and telephone number (this will not be kept with your questionnaires).

Thank you very much in anticipation of your support. Please feel free to contact us if you require any further information or clarification. We can be contacted on the following number....

We look forward to hearing from you.

Yours sincerely,

Naomi Adams
Research Psychologist

Mary Calvert
Consultant Orthodontist

7.2 PATIENT INFORMATION

THE LONG-TERM EFFECTS OF FACIAL RECONSTRUCTIVE SURGERY

1. The aim of the study

The aim of the study is to investigate the long term psychological effects of facial reconstructive surgery. We are interested in people who have been treated for the conditions craniofacial microsomia and Treacher Collins.

2. Why is this study being done?

Some people who have facial surgery seem to feel more satisfied with the results than others. We are interested on finding out why this happens so that we can improve the experience for others.

3. How is the study being done?

The first part of our study involves filling out three questionnaires. These will be sent by post and should take about 30 minutes to fill in. Some of the questions are about your views about your appearance since you had surgery, some are about your feelings in general.

4. What are the risks and discomforts?

There are no anticipated risks to this study. The only inconvenience should be the time taken to complete the questionnaires and talk to the researchers. This will involve travelling to (name of hospital) unless you would prefer to talk on the telephone.

5. Who will have access to the case/research records?

Your participation will be completely confidential. Any identifying information will be removed before the information is entered onto our computers. Your hospital files and photographic records will be seen by staff at the hospital only and will not be taken out of the hospital.

This research has been approved by an independent Research Ethics Committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be fully informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study. No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital and/or any manufacturer involved.

6. What are the potential benefits?

You will have the opportunity of discussing the advantages and disadvantages of surgery and how it has affected you. Everyone will be interviewed by a Clinical Psychologist in Training, supervised by a Clinical Psychologist. Should you wish, advice and information can be provided about support groups or counselling. When we have completed our study we will contact everyone who has taken part and provide a summary of our findings.

As patients of the hospital, your satisfaction with our work is of the greatest importance. Very little research has been carried out on the emotional impact of surgery and we feel this is a very important area to consider if we are to do our job well. Your views about your experiences of treatment with us, both good and bad, will help us to plan our services for the future.

7. Do I have to take part in this study?

If you decide, now or at a later stage, that you do not wish to participate in this research project, that is entirely your right, **and will not in any way prejudice any present or future treatment.**

8. Who do I speak to if problems arise?

If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researchers. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via the Research and Development Office, (address), or if urgent, by telephone, on (telephone number).

9. Researchers who will have contact with you.

You will be contacted by Naomi Adams, Research Psychologist and Mary Calvert, Consultant Orthodontist.

10. Details of how to contact the researchers.

Mary Calvert can be contacted at the Maxillofacial and Dental Department, at (name of hospital), on (telephone number). Naomi Adams can be contacted at (telephone number).

7.3 CONSENT FORMS

7.3.1 CONSENT FORM FOR PARENTS OR GUARDIANS OF PARTICIPANTS 16-17 YEARS OLD

NOTES FOR PARENTS OR GUARDIANS

1. Your child has been asked to take part in some research. The person organising that study is responsible for explain the project to you before you agree to take part.
2. Please ask the researcher any questions you like about this project, before you decide whether you wish to participate.
3. If you decide, now, or at any other stage, that you do not wish your child to participate in the research project, that is entirely your right, and if your child is a patient it will not in any way prejudice any present or future treatment.
4. You will be given an information sheet which describes the research. This information is for you to keep and refer to at any time. *Please read it carefully.*
5. If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post to (address), or if urgent, by telephone on (telephone number).

CONSENT

I/We _____, being parents(s)/guardias(s) of
_____, agree that the Research Project named
above has been explained to my/our satisfaction, and I/We give permission for our child to
take part in this study. I/We have read both the notes written above and the Information
Sheet provided, and understand what the research study involves.

SIGNED (Parent(s)/Guardian(s))

SIGNED (Researcher)

7.3.2 CONSENT FORM FOR ALL PARTICIPANTS

NOTES FOR PARTICIPANTS

1. You have been asked to take part in some research. The person organising that study must explain the project to you before you agree to take part.
2. Please ask the researcher any questions you like about this project, before you decide whether to join in.
3. If you decide now, or at any other time, that you do not wish to be involved in the research project, just tell us and we will stop the research. If you are a patient your treatment will carry on as normal.
4. You will be given an information sheet which describes the research. This information is for you to keep and refer to at any time. *Please read it carefully.*
5. If you have any complaints about the research project, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post to (address), or if urgent, by telephone on (telephone number).

CONSENT

I _____ agree that the Research Project named above has been explained to me to my satisfaction, and I agree to take part in this study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

SIGNED

SIGNED (Researcher)

Please indicate below whether you would be willing to come to (name of hospital) to talk to us about your experiences.

Yes No

If this is not possible, please indicate whether you would be able to talk to us on the telephone.

Yes No

Please fill out the sections below, so that we can contact you again. (This information will only be used to contact you if you have answered yes to either of the above questions. It will not be kept with your completed questionnaires).

Name:

Previous name if married:

Address:

Post Code:

Telephone Number (daytime) :

Telephone Number (evenings) :

7.4 ETHICAL APPROVAL

14th June 1996

Mrs M L Calvert
Maxillofacial and Dental Department
GOS Trust

96SG12 A study of the psychological effects of reconstructive surgery on patients with craniofacial microsomia and treacher collins: Mrs M L Calvert.

Notification of Ethical Approval

The above research has been given ethical approval after review by the Great Ormond Street Hospital for Sick Children NHS Trust / Institute of Child Health Research Ethics Committee subject to the following conditions.

1. Your research must commence within twelve months of the date of this letter and ethical approval is given for a period of 15 months from the commencement of the project. If you wish to start the research more than twelve months from the date of this letter or extend the duration of your approval you should seek Chairman's approval.
2. You must seek Chairman's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature, i.e. using the same procedure(s) or medicinal product(s). Each research project is reviewed separately and if there are significant changes to the research protocol, for example in response to a grant giving bodies requirements you should seek confirmation of continued ethical approval.
3. It is your responsibility to notify the Committee immediately of any information which would raise questions about the safety and continued conduct of the research.
4. Specific conditions pertaining to the approval of this project are: the use of the enclosed standard consent forms for the research. A copy of the signed form must be placed in the patient's clinical records and a copy must be kept by you with the research records as our insurers may demand access to them.

Your sincerely,

Anna Jenkins
Secretary to the Research Ethics Committee

cc Ms N J Adams

7.5 FACE-TO-FACE SEMI-STRUCTURED INTERVIEW QUESTIONS

1. How was the decision to have surgery made? (open question)

Who's decision was it?

How keen were you to have surgery (on a scale of 1 to 10)?

How keen were your parents for you to have surgery (on a scale of 1 to 10)?

2. What were your expectations of surgery? (open question)

What changes did you expect in your life at work/college/school?

Have you noticed any change in your life at work/college/school since surgery?

What changes did you expect in your social life?

Have you noticed any change in your social life since surgery?

What changes did you expect in your family life?

Have you noticed any change in your family life since surgery?

What changes did you expect in your romantic relationships?

Have you noticed any change in your romantic relationships since surgery?

What changes did you expect in your personality / temperament? e.g. confidence

Have you noticed any change in your personality / temperament since surgery?

What changes did you expect in your physical appearance?

Have you noticed any change in your physical appearance since surgery?

Did you expect anything to be worse in your life as a result of surgery?

Has anything been worse in your life since surgery?

3. Did the surgery meet your expectations? (open question)

Did the surgery meet your expectations in terms of:

your life at work/college/school

your social life

your family life

your romantic relationships

your personality

your physical appearance?

4. What were the difficult aspects of the surgery?

(Prompt....e.g. pain, swelling, post-operative care)

5. What were the difficult aspects of the hospitalisation?

6. What made this easier?

(Prompts....Who helped you? E.g. mum, dad, nurses?

What helped you to cope? E.g. talking to others, thinking about other things)

7. What or who could have made your experience of surgery less difficult?

(Prompt....e.g. preparation)

8. Have you ever had counselling? Would you have considered this if it had been available? Do you think we should provide this now?

9. Would you make the same decision to have surgery again?

10. What would you tell other people who are thinking about having the surgery?

Would you recommend it to others?

If you would, what would you tell them?

If you would not, why not?

11. When you look back on your life,

a) What are the difficulties you have had to cope with apart from the surgery?

To what extent do you feel that difficulties in your life have been due to your appearance?

How have you coped with these difficulties?

e.g. talking to others, being active, problem solving

b) What are your achievements?

To what extent do you feel these are due to your appearance?

How have you managed these?

7.6 TELEPHONE INTERVIEW QUESTIONS

- 1) How many operations did you have? At what age?
- 2) Who decided for you to have surgery? You Parents Doctors Other
- 3) How keen were you to have surgery? (1-10)
- 4) Had you had any teasing? Yes/No
- 5) Did you expect changes in your
work/college/school? Yes/No Expectations met Yes/No
social life? Yes/No Yes/No
family life? Yes/No Yes/No
relationships? Yes/No Yes/No
personality? Yes/No Yes/No
physical appearance Yes/No Yes/No
- 6) Did you have any trouble with post-op swelling? Yes/No Expected Yes/No
- 7) Did you have any trouble with pain? Yes/No Yes/No
- 8) Did you have any trouble with numbness? Yes/No Yes/No
- 9) Did you dislike the time in hospital? Yes/No
- 10) Did you find the staff supportive? Yes/No
- 11) Do you think being able to talk to someone
 like a Psychologist would have helped? Yes/No
- 12) Do you think your parents would have liked this? Yes/No
- 13) Would you make the same decision again? Yes/No
- 14) Do you feel like your experiences have made you a stronger person? Yes/No