

**The Impact of Ablative Facial Cancer Surgery
and the Affect of Post-Operative
Facial Prostheses**

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January 2010

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ATTACHED**

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*“The love of life is next to the love of our own face, thus the mutilated cry out
for help.”*

Sushruta (6th Century BC) Hindu Surgeon

SUMMARY

“The Impact of Ablative Facial Cancer Surgery and the Affect of Post-Operative Facial Prostheses”

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This thesis examines psychosocial issues experienced by participants following a diagnosis of facial malignancy and ablative cancer surgery of the face. It investigates how participants felt about surgery and the affect that the use of postoperative facial prostheses had on each participant. Semi-structured interviews were used to capture participants' experiences of treatment. Interpretative Phenomenological Analysis (Smith 2004; Smith, Flowers & Larkin 2009) was used to perform a content analysis of the data which revealed themes and sub-themes common to all participants.

Ethical approval was granted for the inclusion of up to eight participants in the study. Initially twenty participants were randomly selected and contacted by letter. Thirteen individuals agreed to their inclusion in the study and eight were randomly selected for inclusion and contacted by letter. The five individuals not selected were contacted and thanked. Interviewing ceased after the sixth participant had been interviewed $n=6$ after no new themes relative to the study were discovered.

Some findings of the research were congruent with previous research. A supportive partner and family group make coping easier. Professional attendants who listen and allow individuals to talk have a positive impact. Findings specific to this study suggest that facial prostheses *are* useful after ablative cancer surgery of the face. Prostheses restore outward normality which was important for reasons of social acceptability. *However, the study found that feelings of normality were not restored.* This concluded with a re-definition of normality for disfigured patients who use a facial prosthesis to incorporate the wider context revealed by the study.

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GLOSSARY

Ablative	Surgical removal of tissue - part of the body or growth
Enucleation	Surgical removal of the globe of the eye
Exenteration	Surgical removal of the contents of the orbit
Immediate Prosthesis	A prosthesis fitted within 2 weeks of surgery
Implant	A small titanium screw used for the retention of a prosthesis
Neoplastic	In medicine used to describe cancerous tissue
Orbit	The eye socket and all its contents
Osseointegration	Fixation of a titanium implant in bone at a cellular level

Peripheral

At the edge

Post-operative

After surgical operation

Prosthesis

Device used to replace tissue that has been lost through surgery or trauma or congenitally absent tissue

THE STRUCTURE OF THE THESIS

The thesis consists of three parts. The first is the development of an analysis of the association between ablative facial cancer surgery, and the provision of post-operative facial prostheses which directed the development of the research focus. The second part of the thesis consists of a series of semi-structured interviews conducted with a group of participants each of whom use a facial prosthesis after disfiguring facial cancer surgery. The third part consists of the findings of the study, developed from a content analysis of the data provided by the interviews.

The purpose of this thesis is to examine, through the analysis of semi-structured interviews, the psychosocial impact of facial malignancy and disfigurement and of the affect that facial prostheses had on study participants. The thesis is a contribution to health/social science and a new tool of assessment in the understanding of how individuals react to disfiguring facial surgery and the provision of prostheses. In a 'clinically governed, patient led' NHS all these aspects should improve patient treatment standards and satisfaction (Scally and Donaldson 1998).

Chapter 1 reviews the literature and how facially disfigured individuals see themselves. How differences in an individual's appearance affect aspects of attractiveness, social acceptability and normality. The review continues with the prosthetic replacement of facial anatomy after surgery: historical treatment

regimes and contemporary options and how individuals with facial disfigurement cope, the methods used to harvest information about the situation and needs of the facially disfigured patient.

Chapter 2 sets out the aims and objectives of the study.

Chapter 3 details the methodology used in the conduct of the project.

Chapter 4 presents the transcription of one interview with analytical notes from the author's and psychologist's perspective. The full text of each interview (anonymized) can be found on Computer Disc on the inside back cover (appendix 11).

Chapter 5 presents the findings of the study.

Chapter 6 discusses the relevance of the findings within the study context.

Chapter 7 includes the study conclusions and Chapter 8 Chapter 9 and Chapter 10 discuss recommendations contribution to the literature and areas of possible further research.

The primary aim of the thesis was to discover if and to what extent, post-operative facial prostheses improved the lives of individuals who were subjected to facial cancer surgery.

Secondly, it considers the experience of participants from initial diagnosis and examines the psycho-social affects and consequences on the person as an individual.

Third, as a consequence of the findings of the study, recommendations are advanced for consideration in the treatment of facial cancer patients.

Research of a qualitative nature was considered to be the most appropriate research method because, as Smith (1995) maintains, "*there is a tendency for human individuality to be lost in the gross averaging of statistical manipulations.*" Qualitative research, he said, "*is a method more appropriate to the study of individuals and to move research back into the real world of human beings.*" Of importance was to listen to people telling of their experiences and not ask them simply to tick boxes to predetermined, narrow questions.

Carr (1997) maintains that the semi-structured interview is the most effective way of establishing a rapport with the patient. Without this rapport it is unlikely that patients will feel able to reveal or discuss details that are sensitive, or about which

they feel shame or anticipate ridicule and rejection. The superiority, Macgregor (1979) argues, of the semi-structured interview, is its ability to elucidate elements of the human struggle and what it means to be visibly impaired. The use of semi-structured interviews forms the basis of the research in an attempt to gain a detailed picture of the participant's experience following the diagnosis of facial cancer. This method also ensures much more flexibility than the more formal, structured interview or questionnaire. Avenues of interest that emerge in the interview can be explored enabling the participant to give a fuller account of their experience.

INTRODUCTION

The face forms a very special part of human existence. It is the area of the body that, outwardly, gives each and every person physical identity and individuality. Individuals recognise themselves when looking in a mirror by the features of the face and are immediately recognisable to others by these same facial features.

Facial deformity represents a marked deviation from the norm.

It is difficult for many individuals to come to terms with disfigurement following surgery for the eradication of facial cancer and some researchers have likened it to a grieving process (Bradbury 1996). Others suggest that facial disfigurement may be more difficult to incorporate into a new self image than changes that affect function (Dropkin 1989).

The restoration of facial defects is often accomplished by the use of artificial prostheses. Prosthetic restoration of facial defects is not new. Archaeological finds in Egypt and China have indicated the use of artificial noses and ears for the restoration of facial defects which were made of wood and wax.

The literature has recorded the use of facial prostheses to meet the needs of individuals with facial defects from early times and the author's professional

practise confirms that the demand for prosthetic restoration of facial defects continues. Contemporary facial prostheses are prepared using a combination of medical acrylic resins and silicones and at least one facial prosthetics centre exists in each Regional Health Authority in England and Wales (Watson et al. 2006).

Consideration of studies of how patients react to facial disfigurement, ablative surgery and prosthetic replacement gives us a somewhat confusing picture. A review of the literature suggests that facial prostheses may be of limited use and remain unused save for exceptional circumstances (Newell 1999; Dropkin and Scott 1983). However, other studies (Schoen et al 2001; Wolfaardt et al. 1993) suggest the opposite and that some prostheses are described by patients as becoming 'part of themselves' and do not feel like artificial substitutes. Honda et al. (2005) found in a study of 8 patients that a prosthesis lessened the psychological impact of a facial defect and eased anxiety in interpersonal relations.

A study by Edwards (1997) into the care of patients with head and neck cancer found that facial disfigurement was an issue that patients felt was poorly handled by professional attendants and the public. A major finding of the study, that most patients wanted but did not receive, was someone who was willing to try to understand their needs, both in practical and emotional terms and what they were going through. Patients complained of not being listened to by professionals who presented set solutions to what they perceived were patients' problems. Edwards'

findings offer an opportunity to focus the research on patients' experiences and not on preconceived ideas or research questions.

Ensuring a humanistic approach, using semi-structured interviews, this substantive study enabled a group of participants, n=6, to tell of their own story and identified how they felt about their treatment. Emphasis was placed on each individual's own assessment of treatment by allowing them to express how they felt about their experience.

BACKGROUND AND RATIONALE

Facial defects as a consequence of the surgical treatment of neoplastic disease of the head and neck are often large and debilitating from both physical and psychological aspects (Beumer et al. 1996) and rehabilitation is often difficult and complex. Facial defects threaten the concept of self-image and each patient's response to treatment is different, whether the defect is major or minor. As the physical appearance changes it is considered that body image, the way that we see ourselves, also changes. The patient may go through various stages of grief as the process proceeds and patients often develop a revised self-image (Dropkin 1981). Some patients have felt the need to document and share their experiences, possibly in a cathartic exercise, after suffering facial disfigurement through disease or trauma (Piff 1985; Partridge 1990).

Pioneering clinical research by Macgregor (1951) focused on the psychosocial phenomena of the role of self-concept or body image and patients' sensitivity to body impairment. The way in which facial disfigurement influenced social and personal interactions was included in this work. Researchers studying the psychosocial effects of psoriasis (Kent and Keohane 2001) found that quality of life and body image issues were most relevant for patients whose condition was visible on their face or hands. A strong sense of despair and depression typically accompanies the impairment or loss of a body part. This is especially true if that part of the body is in the facial region (Bailey and Edwards 1975). Often, there is

anxiety over how prosthetic treatment might affect appearance and some patients may have unrealistic expectations of prosthetic treatment, which may complicate the acceptance of a new prosthetic device. Newell (1998), one of the foremost workers in facial disfigurement in the UK held the opinion that patients were unlikely to have a prosthesis fitted or go to the trouble of wearing it “In the absence of considerable disruption.” This may be due to many factors including the lifelike quality of the device, the method of retention or the patient’s emotional state.

The patient experience of facial disfigurement and prosthetic restoration formulated the focus of this research.

CHAPTER 1

1.0 LITERATURE REVIEW

1.1 Facial Disfigurement and Prosthetic Replacement

Ablative surgery for the eradication of facial malignancy often results in facial defects postoperatively. For most individuals, this assault to the self is of major concern (Bonanno et al. 2010; Thompson and Kent 2001). Because of their complexity many defects are difficult to reconstruct surgically and are concealed by the placement of a facial prosthesis. Figure 1 shows a patient with a carcinoma of the left cheek and orbit with a prosthesis in preparation post surgically.



Figure 1 - Carcinoma of the left cheek with a prosthesis in preparation

Prostheses are fabricated from hard or soft materials or a combination of both, usually acrylic resins and medical silicones and in some instances replace both form and function. In cases where cosmetic restoration only is possible, it is the intention that this will enable patients to better cope with their situation. Figure 2 shows an adhesive retained prosthesis used to conceal the surgical defect created after surgical resection of the nose following diagnosis of a facial tumour.

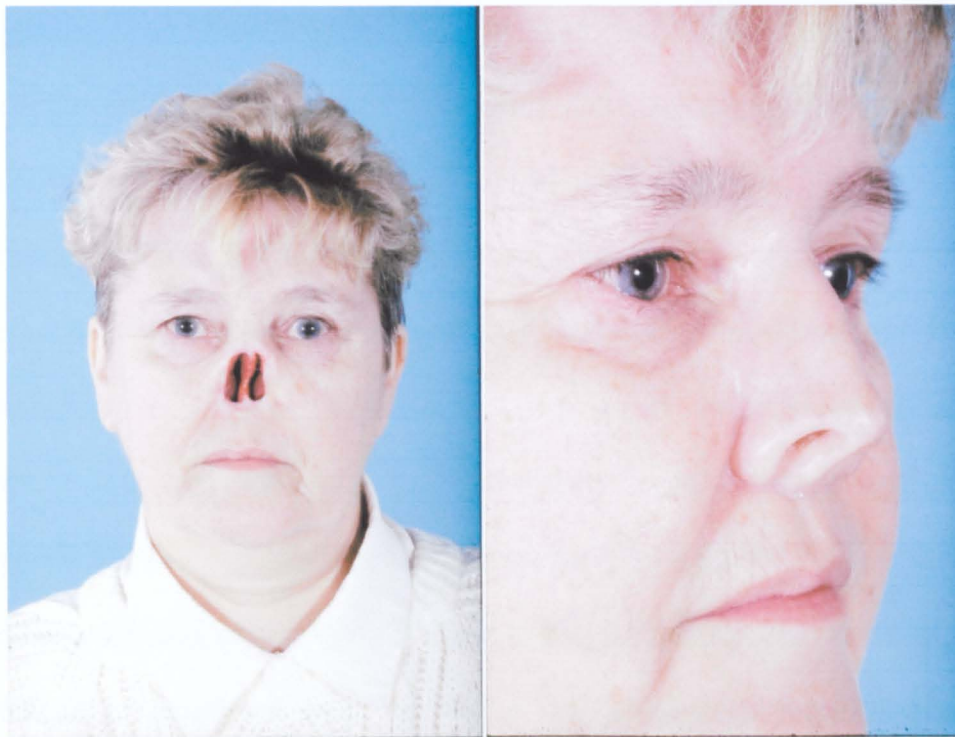


Figure 2 - Patient with an adhesive retained prosthesis

Cancer and the potential threat to life may result in emotional shock and post-traumatic stress symptoms (Ehlers, Mayou and Bryant 1998). Fear of recurrence (Campbell, Marbella and Layde 2000) and the depression caused by that fear (Bjordal and Kaasa 1995) also affect some individuals. The removal of facial

malignancy may cause additional problems because of the potential to alter facial appearance and impair communication and sensory function.

Newell (2000) investigated some of the psychological consequences of facial disfigurement that arose from various causes. He developed treatment options based on cognitive-behavioural therapy. Newell concentrated on commonly avoided situations, for example, shopping trips or social visits and developed regimes to overcome the fear felt by an individual. Newell's study is important and though much of Newell's research was quantitative he maintains that qualitative research has been of considerable importance in 'mapping the territory' with regard to the experiences of the facially disfigured, providing a valuable insight into these experiences. First hand accounts by the facially disfigured, he argued, demonstrated the range and degree of difficulty experienced more forcefully than quantitative approaches. Newell holds the opinion that health professionals who treat facially disfigured patients should have an understanding of how disfigurement affects body image to better appreciate the difficulties associated with the stress and adjustment required after facial disfigurement. He maintains that an understanding of a patient's psychological problems could be useful in treatment situations and that sympathy and a degree of empathy offered by attendants may be beneficial to the success of treatment.

Rumsey (1983) believes that people place much emphasis on the information provided within the communication triangle of eyes and mouth and reactions to

disfigurement in this area may be more extreme than to disfigurement of peripheral facial features. In later work, Rumsey Clarke and White (2003), Rumsey et al. (2004) and Rumsey, and Harcourt (2004) found that 'minor' conditions may be dismissed by health professionals in terms of a patient response that is considered to be 'out of proportion' to the disfigurement. However a study by Ong et al. (2007) into disfiguration caused by facial lipoatrophy found no correlation between the severity of the condition and the degree of psychological distress that it caused.

Research into the acceptability of orbital prostheses by Jebriel (1980) looked at a series of patients who had undergone exenteration of an orbit for facial cancer and had been treated with either an orbital prosthesis or an eye patch to conceal the surgical defect. A questionnaire was used to gather information. Orbital prostheses had been prepared for half of the patients and an eye patch had been given to the other half. The purpose of the study was to determine whether patients were dissatisfied with their orbital prostheses and might accept an eye patch more readily. Areas investigated were methods of retention, colouring technique, type of material used, comfort and cosmetic acceptability. The study concluded that given a choice, 67% of patients would prefer an orbital prosthesis and that 75% of patients who used an eye patch would prefer an orbital prosthesis. The study also found that the prosthetist may be of benefit in other ways and increase the success of prosthetic treatment. By becoming familiar with the patient's expectations, personality characteristics and his/her attitude and

emotional problems, the prosthetist can express empathy and gain the patient's co-operation. This approach often resulted in a more readily accepted restoration.

Goiato et al. (2007 & 2009) found that facial prostheses offered advantages in the treatment of facial malignancy cases in that prosthetic rehabilitation of patients resulted in earlier psychosocial re-integration. Successful rehabilitation and the patient's acceptance of the prosthesis were dependent on materials choice and colour stability and the method of retention. Satisfaction also improved if professional attendants reacted positively to patients and offered sympathy and understanding.

Markt and Lemon (2001) made similar findings in a study of 76 prosthesis users regarding the relationship between patient satisfaction, colour stability of the silicone and method of retention. In a study of 75 patients who used an implant retained prosthesis Hooper et al. (2005) found that patient satisfaction was influenced by unrealistic expectations of colour stability and longevity and that information and advice given to patients should be as complete as possible, which improved patient satisfaction.

Gritz and Hoffman (1996) studied facially disfigured patients and agreed that cancers of the head and neck produce obvious defects and although the provision of prostheses offered their users a degree of normality, most still bore negative thoughts about their appearance. However analysis by Bou et al. (2006) of two

hundred and fifteen patient files suggested a continual increase in patient demand for maxillofacial prostheses between the study dates July 1996 and July 2002. This was due in part to the development of new materials, methods of retention and techniques. The study concluded that the use of a prosthesis offers aesthetic and psychological benefits whilst allowing visual monitoring of the surgical site by professional attendants. Figure 3 shows an orbital prosthesis used to cover the defect after exenteration of the left eye and orbit following orbital exenteration for an adenoid cystic carcinoma. Removal of the prosthesis allows detailed examination of the area.



Figure 3 - Patient with an orbital prosthesis

A study by Toljanic, Heshmati and Walton (2003) of patients with facial cancer indicated that delay in fitting patients with facial prostheses post operatively increased the potential for serious adverse psychosocial consequences. Two

patients were fitted with temporary facial prostheses immediately after major facial surgery. They found that these patients were more confident and comfortable in social and family situations during the post-operative healing phase than previously operated patients who were not fitted with prostheses. Retention of the prosthesis was achieved by the use of white dressing tape, a method which would have been immediately obvious, or by the use of skin adhesives. Skin adhesives provide an effective method of retention but can be difficult to use and may be problematic for elderly or less dextrous patients. Accuracy in placement of the prosthesis at the first attempt is essential to ensure that removal and replacement is not required. Notwithstanding these difficulties, the patients in the study reported that they had felt very comfortable in family situations and when attending social events whilst wearing their temporary prostheses.

The retention of a prosthesis may be a factor in the success, or failure of prosthetic treatment. Adhesive retained prostheses as described in the literature are held to the skin surface via the use of medical adhesives (Roberts 1971). Implant retained prostheses rely on metal implants placed into bone for their retention and stability (Tjellstrom 1990).

In a study by Chang et al. (2005) of the 2 different methods of retention, higher positive ratings were reported by the group who used implant retained prostheses.

A study by Wagenblast et al. (2008) of 5 patients who used an implant retained prosthesis found similar results. The study concluded that a high degree of satisfaction and social re-integration was possible using implant retained prostheses after debilitating facial surgery.

These conclusions were re-iterated in the findings of other workers who also suggested that patients' satisfaction increased with implant retained prostheses because of a more life-like natural appearance partly brought about by enhanced peripheral integrity (Schoen et al. 2001; Arcuri and Rubenstein 1998; Parel et al. 1986). The prosthesis is rendered less conspicuous by the blending of the edge more naturally with the surrounding skin. Schoen also found that in contrast to an adhesive retained prosthesis, an implant retained device was not experienced as a foreign object by patients but experienced "*as a part of themselves.*" Westin et al. (1999) and Tollman and Taylor (1996) made similar findings. Figure 4 on page 28 shows two osseointegrated implants placed into the floor of the nose after nasal resection.



Figure 4 - Patient with an implant retained nasal prosthesis

1.2 Difficulties Associated With Disfigurement

Difference and unfamiliarity to one's peers formed the basis of a study by Perry et al. (1998) who found that during the development of an individual a small catalogue of familiar faces, of family members, friends and individuals in the local community, is built up and stored in the brain as templates. A familiar and that which is considered to be a normal face, is thought to elicit a 'safe' response in the individual and an unfamiliar and/or disfigured face an alarm response in that same individual. Macgregor (1990) conducted similar studies and concluded that the 'civil inattention' normally conferred by strangers on one another is denied to people whose appearance is different. Individuals with a facial

disfigurement were noted in many studies to report frequent exposure to stares, hurtful comments and intrusive questions for many years after the initial surgery or trauma (Rumsey, Bull and Gahagen 1982). Previous studies (Houston and Bull 1994; Langer et al. 1976; Partridge 1997) suggest that individuals who appear to others as different from that which is considered normal attract negative feedback which can include staring, personal comments and avoidance that exacerbates and compounds the difficulties for the facially disfigured individual.

Noles, Cash and Winstead (1985) and Cash and Prusinsky (1990) found that facially disfigured individuals were less satisfied with their bodies as a whole and saw themselves as less physically attractive than non-facially disfigured subjects. The expectation is that an attempt to restore the norm as far as possible, by the provision of facial prostheses, would alleviate some of the problems that patients might encounter.

McGrouther (1997) maintains that at the root of the patient's distress lies the pressure of modern cosmopolitan society to conform to an idealised appearance. The suggestion is that image and beauty are modern prerequisites for success, portraying a particular "look" as desirable, diminishing the value of individuals who deviate from the face or form of the moment.

Sarwer et al. (1999) studied 24 men and women with facial defects. All were more dissatisfied with their facial appearance than a control group. They reported

lower levels of self-esteem and quality of life and more than one third said they had experienced discrimination in employment and social settings because of how, they felt, they appeared to others.

1.3 Physical Attractiveness

The literature suggests that alterations in the facial region involve changes in the patient's sense of attractiveness. Most individuals prefer to rest in the knowledge that they present an exterior that others will find normal and attractive. Legends are commonplace in history and folklore regarding beauty and physical attractiveness. Wicked people are often portrayed as ugly, sometimes scar faced, warty or deformed. Children are introduced to this stereotype from an early age. The classic fairy tales such as Cinderella, Beauty and the Beast and Snow White and the Seven Dwarves are examples of this. The implication is that beauty or physical attractiveness is important to the majority of individuals (Bull and Rumsey 1988). Studies into Physical attractiveness (Berscheid and Walster 1974) suggest that individuals who are considered physically attractive generally enjoy a distinct social advantage compared to people who are considered unattractive. Research into why "attractive" people might be preferred was tested by participants who attempted to estimate, by scrutinising monochromatic photographs, the characteristics of men and women who varied in attractiveness (Dion, Berscheid and Walster 1972). The results confirmed that individuals who were considered more physically attractive were also thought more likely to

possess socially desirable traits such as intelligence, professional success and marital harmony than subjects of lesser attractiveness. Participants in the study were also of the opinion that more “physically attractive” people would be friendlier individuals and be easier to ‘get along with’ in social situations and Efran (1974) concluded that evidence existed to support the theory that individuals perceived to be attractive are more likely to be acquitted of a crime.

1.4 Normal Appearance

Normal appearance according to Harris (1997) is an individual concept and is accepted and defined as being “the perception of sameness in the appearances of others.” It might be presumed therefore that the provision of a prosthesis may restore the user to normality or a degree of normality if the individual accepts that his or her appearance had been restored to an acceptable sameness. The ‘sameness’ and normality seen by individuals in others is not only sought by the facially disfigured but as Gregory (2005) and Prout, Hayes and Gelder (1999), argue, sought by sufferers of other illnesses.

The concept of normality and attractiveness is highly individual. Being visibly different is also a highly individual concept that is derived from an individual’s self-comparison with the ‘normal’ appearance of others and from onlookers expressed opinions. Appearance cannot be measured objectively and there is no defined range of what is ‘normal appearance’.

1.5 Abnormal Appearance

Abnormal appearance is defined by Harris (1982) as an appearance that deviates from an individual's concept of normal appearance. "If an individual perceives that an aspect of their appearance, or that of another, is abnormal, then that perception causes them little or no concern, or it does." In the latter event, a facially disfigured individual can become preoccupied with their abnormality and become sensitive about the possibility that others might be aware of the abnormality. This reaction may cause psychological distress and a preoccupation with body image. An example of this is when individuals (especially young women) see themselves as being overweight, though of clinically normal weight and become anorexic in an effort to lose fat and regain their 'ideal' body image.

Moss (1997) reports of individuals with facial deformity who demonstrate a positive attitude and cope with their difficulties in a more constructive manner. Konradsen, Kirkevold and Zoffmann (2009) and Bronheim (1994) suggest that this feeling is due, in the case of cancer patients, to the removal of the 'bad part' imparting a feeling of elation and an increased chance of survival. But Strauss (1989) argued that feelings of increased vulnerability are also present after the 'equipment' used to deal with the world has been removed. West (1977) also argues that patients may see disfigurement as being more acceptable than death.

1.6 Body Image and its Disturbance

The head and neck region is extremely significant within the concept of body image. It is the most prominent part of the body and provides identity. The face lends animation to intellect, emotion and communication. It is the centre for the senses of vision, hearing, taste and smell and an attractive facial appearance is frequently correlated with feelings of well being (Fawzy, Secher and Evans 1994; Anderson and Johnson 1994).

The image that most individuals hold in their minds of how they appear both to themselves and to others is known as Body Image. The classic definition of body image is that described by Schilder (1938) who said that “body image is the picture of our body that we form in our minds of how we think we appear to ourselves and to others.” He said that body image is dynamic and changes in response to alterations in mood and even changes in clothing as fashion dictates. Consider how a new hairstyle might change one’s own perception of oneself and how it affects our outward appearance and behaviour when commented on by family and friends.

Dropkin (1999) agrees with this definition of body image. This perception, she believes, occurs largely at a subconscious level and is normally regulated by the condition of the body at any given time. Therefore an individual’s body image might change from day to day depending upon individual circumstances.

Cohen Khan and Steeves (1998) argue that the body is a tool of social expression and a way of existing in the world. The way in which each individual interacts with fellow human beings is connected to the picture we have of our outer self, in our minds eye. This is similar to Schilder's definition. If that outer self changes as is the case with the facially disfigured then our inner picture must also change and our interaction with others changes also.

A comprehensive account of body image is that of Price (1990). His view of body image consists of three related components: body reality, body ideal and body presentation. He sees these elements existing in a state of tension or balance that make up a satisfactory body image. Price supposes that any alteration to body reality will upset the balance and increase the tension between body reality and body ideal. Body presentation will be altered as a consequence. If this alteration to body reality is a result of surgery or disease it may well be accompanied by some degree of emotional turmoil, especially if the disease is life threatening (Neill and Waldrop 1998). To decrease the tension and compensate for the change in body reality, a person may alter the way in which he or she presents him/herself to the world or develop strategies for coping with this altered body ideal. Phobic behaviour, particularly in social situations is often the result (Newell 2002).

Facial defects threaten the concept of self-image and each patient's response is different, whether the defect is major or minor. When the external appearance

changes it is presumed that body image changes also. The patient may go through various stages of grief as the process of healing (*if healing does in fact occur. Author's italics*) progresses and patients often develop a revised self-image.

Research by Rozen et al. (1972) and Sykes, Curtis and Cantor (1972) investigated the effects of surgically acquired facial defects on body image and the quality of life of patients. The study found that aspects such as employment status and the amount of social interaction enjoyed by patients after surgery were considerably lower. A study of 28 patients by Vickery et al. (2002) into facial disfigurement after surgery for head and neck cancer found that participants did not experience lower quality of life compared with other cancer patients or normal populations but in some instances their partners reported greater distress.

Klein et al. (2005) studied the quality of life of 58 patients who used a facial prosthesis after facial surgery. The findings suggested that the quality of life of participants was reduced and that their body image was significantly altered. Participants also felt that their sexual attraction was remarkably diminished and that they emitted an unpleasant odour. Work by Papadopoulos, Bor and Legg (1999) into disfiguring skin conditions found similar results.

1.7 Facial Prostheses: Historical Perspective

The prosthetic restoration of facial defects is not new. A report (Cowell 1973) of a text from 2nd century Buddhist history tells of a Brahmin who lost the tip of his nose in an accident with a sword and, “wore a prosthesis which was attached to his face with a glue-like ointment.” Ears, noses and lips made of wax were known to the ancient Egyptians. Sufficient literature exists (Conroy 1983) to prove that ancient Indians used nasal prostheses “which were made of lacquer and had a tendency to come loose when their wearers were sweating.” Leather eye patches worn in Greco-Roman times were painted with eyes and lashes and retained using wax and twine (Niiranen 1947) and the Chinese made facial prostheses using wood, wax and clay.

In the 16th century a French Surgeon, Ambrose Pare and Falcinelli, a surgeon from Florence tried to overcome the problems associated with the retention of facial prostheses and attached leather covered metal bands to some prostheses, which fitted around the back of the head. Orbital prostheses included natural sponges on their fitting surfaces that engaged anatomical undercuts to provide retention.

Due to the increased use of vulcanised rubber in dentistry in the 19th century, Vulcanite together with celluloid, introduced in 1869, were used for the

fabrication of prostheses until the middle of the 20th century and porcelain, gold, silver and glass together with gelatine have been used as prosthetic materials.

The introduction of the acrylic resins and the silicone elastomers by F.S. Kipping in the 1940's led to their widespread use in facial prosthesis fabrication. They remain the materials most often used today, however, no material presently used is ideal for the replacement of human tissue (Roberts undated manuscript: personal communication 2006).

Contemporary prosthetic treatment is compromised by inadequate retention. Skin adhesives provide adequate retention but can be difficult to use. Mechanical retention may allow the prosthesis to slip out of position and often is supplemented by adhesives to maintain a reasonable marginal fit.

1.8 Adhesive Retained Facial Prostheses

Spirit gums have been used for many years and latex rubber adhesives are still used by some patients. The majority of patients who use adhesive retained prostheses employ some form of solvent-based silicone adhesive. Many adhesives are available under different trade names but all are of a similar chemical composition. Short chain dimethylpolysiloxane polymers are combined with a solvent, and are supplied in either an aerosol can or in a brush capped bottle (Hulland, Hulland and Turner 1983). A thin layer of adhesive is applied to

the fitting surface of the prosthesis and the solvent allowed to evaporate for up to five minutes before the prosthesis is positioned on the face and figure 5 shows an orbital prosthesis retained in an exenterated orbit by silicone adhesive following exenteration of the right orbit in the treatment of meningioma.



Figure 5 - Patient with an adhesive retained prosthesis

The area around the defect site may be wiped with isopropyl alcohol or similar agent to degrease the skin. This increases the adhesive to skin bond. After the prosthesis is positioned, pressure is applied to the margins to strengthen the adhesive bond. The adhesive remains waterproof and the strength of the bond ensures that, if used correctly, the prosthesis will remain in position for many hours. Bond strength is the main advantage of solvent-based adhesives, and, patients can confidently rely upon the prosthesis remaining in position after application. Among the disadvantages of adhesive retention are: -

1. reduction in the aesthetic acceptability and longevity of the prosthesis due to colour and texture changes induced by the frequent use of adhesive and cleansing agents used to remove adhesive layers from the fitting surface.
2. the need to increase the cross sectional dimension of the periphery to prevent the silicone from tearing on removal renders the prosthesis more conspicuous.
3. the contact nature of the adhesive requires the patient to position the prosthesis correctly at every application. Failure necessitates that the prosthesis be removed and cleaned before re-application.
4. the use of adhesive and cleansing agents on the skin may result in a contact dermatitis and together with the impervious barrier produced by placing the prosthesis directly on to the skin surface may result in dermal intolerance. Barrier creams and tissue conditioners may be used to prevent or treat these conditions.
5. the force required to break the adhesive to skin bond may have a traumatic effect on the skin especially where tissues have been irradiated.
6. elderly patients may not possess the manual dexterity required to apply adhesive and correctly place the prosthesis on the face.
7. accumulation of dust particles at the periphery through the inaccurate and over application of adhesive renders the prosthesis more conspicuous than it might otherwise have been.

1.9 Anatomical and Mechanical Retention

Skin adhesives remain relatively inexpensive and readily available. Presently, the majority of patients who require facial prosthetic rehabilitation will be treated with some form of adhesive retained prosthesis (Johnson et al. 2000). In patients where favourable anatomical undercuts are present, soft silicone flanges or compressible silicone sponge may be incorporated within the prosthesis to engage the undercut areas and provide retention. Figure 6 on page 41 shows an orbital prosthesis prepared with soft silicone flanges on the upper and medial aspects of the fitting surface that engage anatomical undercuts in the exenterated left orbit. The retention is completed by the application of a small amount of medical adhesive applied to the lateral or outer edge of the prosthesis and direct pressure applied to secure the prosthesis into position. Retention of this type must be monitored carefully as pressure from flanges can result in ulcerated areas of tissue that the patient may be unaware of through the surgical interruption of sensory innervation. Where none of these systems is possible, purely mechanical means of retention may be employed (Udagama 1983).

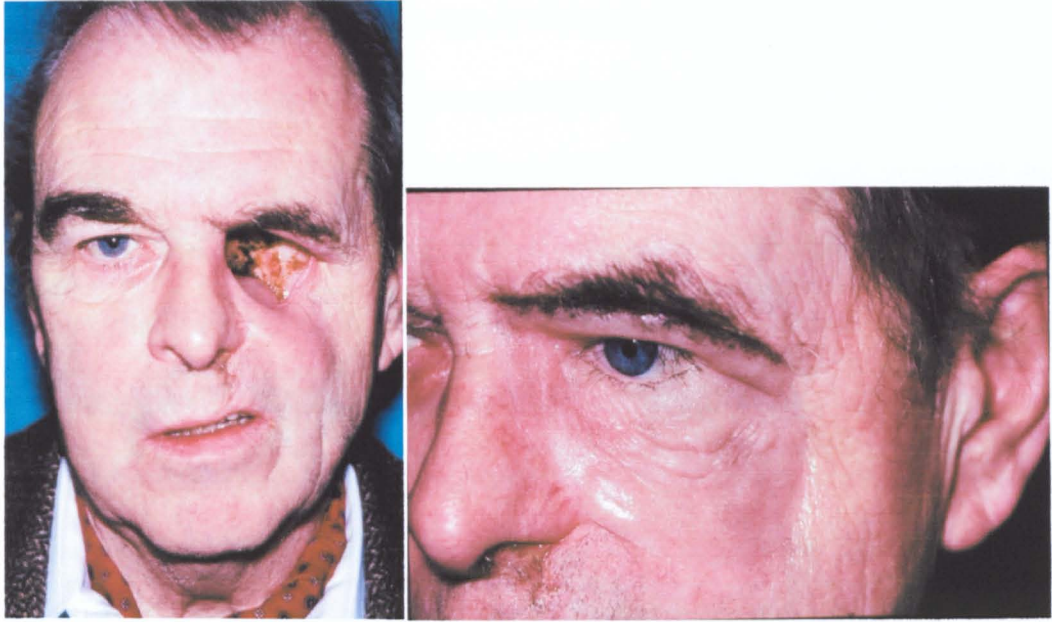


Figure 6 - Patient with an orbital prosthesis prepared with soft silicone flanges

The fixation of a prosthesis to spectacles may be used as a method of retention. Slippage of the spectacle frame during use may result in a space appearing between the face and the prosthesis which may detract from the aesthetics of the prosthesis.

1.10 Implant Retained Facial Prostheses

Osseointegrated implant retention of facial prostheses has been available since the mid 1970's (Tjellstrom and Granstrom 1995). The retention of a facial prosthesis via implants is enabled by the use of commercially pure titanium implant fixtures placed into a suitable bone site to which percutaneous abutments are connected. The abutments permit the attachment of retentive elements that retain and support a facial prosthesis. Osseointegration is defined as a "Direct structural and

functional connection between ordered, living bone and the surface of a load carrying implant.” (Branemark, Zarb and Albrektsson 1985). Osseointegration is dependent on the use of an atraumatic surgical technique which preserves the blood supply and encourages the growth of osteoblasts in the tissue that surrounds the metallic implant. A stabilized and unloaded implant fixture until osseointegration is complete is essential to prevent fibrinolytic activity in the operative site. The use of implants permits the retention of extra oral prostheses. Patients who exhibit defects after surgery to remove tumours of the head and neck may be treated with facial prosthetic restorations that are aesthetically pleasing and may enjoy a longer lifespan than their adhesive retained counterparts. Implant retained prostheses can be easier and quicker to position than adhesive retained prostheses and may be more retentive than anatomically or mechanically retained prostheses. The advances in the application and appearance of restorative prostheses may offer the patient better options.

The introduction of the Branemark extra oral implant system (Branemark et al. 1977) provided patients with a means of retention for facial prostheses together with improved marginal fit. Component systems include gold alloy bars attached to the percutaneous abutments of the implants over which gold clips, contained within the prosthesis, fit.

For patients who find difficulty cleaning under the bar and in situations where multiple implant fixtures are placed, closed field magnet retention may be

employed. Figure 7 shows a patient with two osseointegrated implants placed into the lateral wall of the orbit. Medical magnets, attached to osseointegrated implants, provide the retention. The ease of placement ensures that even the less dextrous patient can position the prosthesis quickly and accurately.

This system of retention is not suitable in every case. Implants placed in medically compromised patients may not enjoy the usual levels of success (Leonardi et al. 2008). Bone that has received high doses of radiation becomes hypocellular and the success of osseointegration is reduced (Roumanas, Chang and Beumer 2006).



Figure 7 - Patient with two osseointegrated implants

This, combined with cellular and vascular effects, as a result of late tissue changes, demineralises bone and renders it more susceptible to infection and avascular necrosis. The success of osseointegration has been reported by some workers (Granstrom, Tjellstrom and Branemark 1999; Benateau et al. 2001) to be increased by the hyperbaric oxygenation of tissue. This, it is felt, promotes osseointegration by the encouragement of fibroblastic activity and collagen production which creates a matrix for capillary budding and neovascularisation. But a study by Toljanic et al. (2005) found no evidence to suggest that implant survival rates were increased by the use of hyperbaric oxygen treatment. Egusa et al. (2008); Sicilia et al. (2008) and du Preez, Butow and Swart (2007) suggest that a titanium allergy might prevent the use of osseointegrated implants in some patients. Allergic responses were diagnosed in some patients who had received titanium dental implants with complete remission of symptoms demonstrated after removal of the implants. Maintenance of the implant site via a regular cleaning regime is essential. The interface of abutment and soft tissue is a focus for infection and may result in overgranulation (Hampton 2007) of tissue. The skin should be thinned and hair follicles removed or a split skin graft placed at the time of abutment connection. Guo, Schwedtner and Klein (2008) found that skin depth was an important and valuable indicator for the evaluation of peri-implant soft tissue.

1.11 Coping

The literature suggests that the loss of body parts can give rise to feelings of grief similar to those experienced when a relative, friend or loved one dies (Maguire and Murray-Parkes 1998). It is suggested that for recovery from the loss to occur, an individual learning to successfully cope with the removal of a body part passes through different stages of mourning. Dysfunctional coping strategies (Vos and Haes 2007; Rabinowitz and Peirson 2006) such as rejection or denial (Hardy and Kell 2009) of the situation and a yearning for the restoration of the previous situation; followed by anger, confrontation and the “why me” comments are often made. Depression may ensue, followed by acceptance of the new situation (Stanton, Danoff-Burg and Huggins 2002). If acceptance does not occur, Shultz (2009) argues that the depressive state will continue and some individuals will continue to rely on dysfunctional or emotional coping strategies (Miceli and Castelfranchi 2001) and possibly develop anxiety symptoms. For others, acceptance of their altered situation, possibly through problem focused coping strategies, and new body image leads to a more successful process of coping.

Lazarus and Folkman (1984) defined coping as “the cognitive and behavioural efforts used to manage demands appraised as stressful or exceeding resources.” Similarly, Dropkin and Scott (1983) believe that patients with facial disfigurement combine cognitive and behavioural efforts to manage external and/or internal demands that are taxing their resources. The ability to cope adequately with the

defect both emotionally and physically reduces the chance of infection while increasing compliance with follow-up care and reducing social isolation. The facial disfigurement and dysfunction associated with surgery for head and neck cancer predisposes patients to unique physiological problems and psychosocial needs. Recovery from head and neck cancer surgery can include relentless debilitating, long term, physical, emotional and behavioural problems (Gamba et al. 1992; McDonough et al. 1996; Morton 1997).

List et al. (2002) found, in a study of patients diagnosed with head and neck malignancy, that the most common coping mechanism was seeking social support. Finding someone to talk to about their situation and predicament and/or making an action plan to follow and trying to focus the problem(s). The least common strategy, List found, was behavioural escape-avoidance in which patients would adopt a wait and see attitude or take the stress and strain out on other people. The findings suggest that as treatment progressed, quality of life declined but for many study participants, quality of life levels had returned to near pre-treatment levels within 1 year of the start of treatment. Further; most participants did not have a pre-treatment strategy. This suggests that patients find ways of coping with a corresponding improvement in their situation and quality of life. Furness (2005); Furness et al. (2006) and Vidhubala et al. (2006) in similar studies made similar findings.

A study of 25 patients by Sommerfeld and Drepper (1985) with facial disfigurement which included patients with port wine stains and surgically acquired defects underwent in-depth interviewing. The study concluded that not only was it essential to take into account the psychosocial problems confronting these individuals but that early intervention of health professionals in a supportive role alongside emotional support given by family and friends considerably alleviated the coping process.

Research into the recovery of women after breast cancer (Neuling and Winefield 1987) found that patients come to terms with their situation and better coped if they received emotional, sympathetic support from their partners and family members. The same study also showed that coping was enhanced if patients received empathetic support from their professional attendants. Lemon et al. (2005) found that patients who were aware of a positive interaction between members of the surgical/prosthetic team and the attention to detail paid by the team to every aspect of care resulted in a more satisfactory prosthetic outcome and an improved patient quality of life. Gastmans (2002) and Lutzen (2006) argue that morality and the care of the sick are interlinked and are essential prerequisites for the successful and sensitive treatment of those in need.

Good interpersonal communication between patient and professional attendants has shown a reduction in psychological morbidity (Fallowfield 1995). Families and partners were thought to be particularly important in helping patients cope

(Ell 1996) and Ford, Lewis and Fallowfield (1995) suggested that the lack of sympathetic support from a partner was not compensated for by support from other sources. Bushkin (1995) found that professional attendants who treat cancer patients have been referred to by some patients as guides, accompanying and supporting them through the treatment journey and are there for them at various stages of that process. Bowers (2008) maintains that the support provided to patients should also continue for as long as the patient wishes. Walker, Risvedt and Haughey (2003) also found that professional attendants who were caring and attentive to the psychosocial needs of cancer patients increased their level of satisfaction with treatment overall. Patients with malignancy who have been through the treatment journey are convinced that the journey is made easier by staff who are prepared to simply allow the patient to talk and listen.

The provision of facial prostheses, including temporary prostheses in the early post-operative phase may help patients to cope. A study of 75 adults (Dropkin 2001) suggested that the ability to cope effectively with facial disfigurement, pre and post surgery, mediated the stress often associated with major facial surgery.

1.12 Quantitative methods of Analysis

Previous quantitative studies (Sherman et al. 2000; Katz et al. 2000, Terrell et al. 1997) of facial disfigurement attempted to assess, identify and measure the extent of patients' problems and needs in an attempt to answer research questions and/or

prior to forming an effective treatment plan. Carr argues that effective assessment rests upon researchers and clinicians having a clear picture of what they need to know in order to make informed decisions about the problem(s) and, if it is to be offered, subsequent care and treatment. Generally, in quantitative research, there is a greater reliance on structured interviews and questionnaires which elicit answers to questions which have been formulated from pre-determined categories. These answers may then be numerically analysed. The interviewer or questioner will aim to use short specific questions, asked in a particular order keeping exactly to the schedule. This method of data capture deliberately constrains the participant into answering in a specific way and areas considered important by the participant might not be predicted or prioritised by the investigator.

1.13 Qualitative methods of Analysis

Carr views the semi-structured interview as the most effective way of establishing a rapport with the patient. Without a degree of rapport, it is unlikely that patients will feel able to reveal or discuss details that are sensitive, or about which they feel shame or anticipate ridicule and rejection. A paradigm shift (Smith, Jarman and Osborn 1995) was emerging in the mid 1990's that was concerned more with persons and individuals rather than statistics and variables. Psychosocial research was becoming more open to areas which were central to everyday life and research into these areas conducted in the 'real world' of human experience. For many years some workers in the field had felt discontent and become concerned

with the narrowness of research. The emphasis on laboratory studies, experimental design and statistical analysis led a number of researchers to criticise the limitations of its practise and call for a new, non-experimental paradigm (Gergen 1973; Harre and Secord 1976; Shotter 1975). This paradigm shift arose from a frustration with academic psychology's failure to address human individuality, which is lost in the averaging of statistical data. Semi structured interviews and qualitative analysis are especially suitable where the interest is in issues that are complex, controversial and/or personal. Smith and Osborn (2003) and Smith and Eatough (2006) argue that the advantages of the semi-structured interview over a less flexible regime are that it facilitates rapport and empathy with the participant whilst at the same time, allowing greater flexibility. This enables the interview to access novel areas encountered during the course of the session which tends to produce richer data and gives the patient the knowledge that they are being listened to.

Macgregor (1953, 1979), one of the most influential researchers into facial disfigurement has carried out her work for over 50 years from a humanistic, qualitative standpoint. She maintains that the superiority of the in-depth semi-structured interview lies in its ability to elucidate elements of the human struggle with visible impairment and of aspects such as social disadvantage and adjustment to the altered situation.

Qualitative methods can elicit the understanding and meaning that individuals attach to thoughts.. Qualitative methods also allow people to describe their experiences and the impact of a condition or treatment on their lives in the subtlety and depth that a quantitative method may not capture. The 'what' and 'why' questions rather than the 'how much.' The patient can explore issues that are relevant to them rather than responding to a predetermined research theory which can produce insight into an issue rather than measuring it, and are more concerned with validity than reliability (Pope & Mays 1995). Open questions or topic suggestions should be used to prevent participants from being 'led' into particular aspects of discussion (Kvale 1996).

Using Smith's analytical tool, Interpretative Phenomenological Analysis or IPA, the transcript of each individual's response can be read several times. Aspects which are considered of interest and significant can be noted from which a table of sub-ordinate and super-ordinate themes may be produced. The aim of the analysis is to understand the experience of individual participants. IPA is a methodological tool which allows the researcher to focus on the data and explore an individual's personal account and perception of their experience. It is a method which is increasingly being used in health related research if a project is centred on the experiences of individuals (Shaw 2001). "The approach is phenomenological as it is concerned with an individual's own perception of their experience rather than someone else's attempt to produce an objective account of

their experience and it avoids making assumptions. In other words, it allows them to talk. It is also interpretative because as one tries to get close to the participant's personal world this access is unavoidably complicated by the researcher's own conceptions during this interpretative activity.”

1.14 Research focus

The research method has, as its focus, the patient experience and considering previous literature, the most appropriate should be qualitative research utilising semi-structured interviews. The aim of this study was to allow participants to talk of their experiences in an unconstrained manner in an attempt to enter, as far as possible, the world of the participant and capture the richness of the emerging themes and the experience of the individual.

CHAPTER 2

2.0 AIMS AND OBJECTIVES

2.1 Aims

To investigate:

- if and how post-operative facial prostheses improved the lives of individuals who were subjected to facial cancer surgery
- the psycho-social effects and consequences on the person as an individual

2.2 Objectives

- to establish the validity of the research method used
- to establish if and how facial prostheses improved the lives of individuals who were subjected to facial cancer surgery
- to establish any psycho-social effects and consequences on the person as an individual who were subjected to facial cancer surgery

- to make recommendations on the factors to be considered in the treatment of facial cancer patients

CHAPTER 3

3.0 METHODOLOGY

The Anaplastology and Facial Prosthetics Unit at the Northern General Hospital is a supra-regional provider of prostheses and appliances for patients who have undergone ablative facial cancer surgery and is placed to discover how individuals feel about their situation after major facial surgery and the fitting of a facial prosthesis.

All researchers should consider factors that will ensure their research is valid. The debate over qualitative versus quantitative is particularly important in social science research and was given careful consideration in the planning of this study. To ensure validity, the research protocol was subjected to independent scientific review.

3.1 Design

This study invited a random selection of National Health Service patients to tell of their experience after being diagnosed with malignant disease of the face and who used a post-operative facial prosthesis. As identified by the Local Research Ethics Committee, the risk of causing emotional upset and distress during

interview was considerable. It was essential to comply with and fulfil the requirements of Sheffield Teaching Hospitals NHS Foundation Trust Research Department. Application was made to the Local Research Ethics Committee for ethical review of the study. The process is set out below.

3.2 Ethical Review

The Central Office for Research Ethics Committees (COREC) form version 5.5 was completed and submitted online via the NHS Research Ethics Service (NRES). Reference number: 06/Q2306/19.

Application was made to Rotherham Local Research Ethics Committee for ethical review of the study which was scheduled for Friday 2 June 2006. Attendance of the principal and chief investigators was requested to answer concern that the committee had relating to the management of distress potentially caused to participants during interview. The committee also voiced concern regarding the venue selected for the interviews. These concerns were addressed (appendix 7). The Committee felt that this was an important and fascinating study and that the application had been superb (appendix 6).

3.3 Project Registration.

- Registration of project with Sheffield Teaching Hospitals NHS Foundation Trust Research Department who acted as sponsor of the project and

registered with the Trust Medical Director. Project reference number:
STH 14054.

- Curriculum Vitae of Principal Investigator and Chief Investigator logged with research department.
- Protocol (final version) logged with research department.
- Authorisation of Project (appendix 8).

3.4 Project Finance

Finance and costs of the project arranged with the University of Sheffield who was the project funder. Sheffield Teaching Hospital NHS Foundation Trust finance documents were completed and logged with research department.

3.5 Project Management

Monthly Tasks

- Advisory/feedback meeting with supervisor
- Interim reporting re: interview progress/status conference/seminar attendance
- Publication/Lecture planning and delivery

Writing Up

Writing up of project - ongoing

Further work

Partner/family studies
Possible effects on professional attendants
Temporary prosthesis provision

May 2006

Submission of proposal to Research Ethics Committee

July 2006

Review and revision of proposal if required. Ethical clearance sought

July 2006-Dec 2006

Data collection and analysis

Jan 2007 – Oct 2008

Writing up, binding and submission to examiners

3.6 Data Protection: Security and Risk

Sheffield Teaching Hospitals NHS Foundation Trust Data Protection Officer was informed of the study. The officer requested a meeting to discuss protocol.

The audio-taped interviews were transcribed by an individual who had signed a confidentiality agreement (appendix 5). Interview data were stored electronically, access to which was by electronic password known only to the researcher. In compliance with ethical review requirements, tapes were destroyed at the end of the transcription. Anonymized, unannotated full text digital copy of each interview was stored on compact disc (appendix 11) and shall be kept for 10 years in line with the Medical Research Council Ethics Series: Good Research Practice (Medical Research Council 2000). Guidelines set out in COREC regarding confidentiality and privacy were followed. Consent was obtained to use photographic images within the thesis and in further related publications/lectures by the author but not for any other reproduction or use without prior authorization.

3.7 Rights to Information, Confidentiality and Privacy

Using the updated version of the 'Guidelines for researchers; information sheets and consent forms' (COREC 2005), a participant information sheet was compiled (appendix 3). Prior to the interview, each participant was given an information

sheet and the implications of taking part in the study were discussed. Each participant was given the opportunity to ask questions about the study. Each participant was required to complete a consent form (appendix 2) after involvement and were advised that they could withdraw from the study at any time. Each participant was advised that subsequent treatment would not be compromised in any way if they decided to withdraw from the study.

3.8 Independent Scientific Review

It is a requirement of Sheffield Teaching Hospitals NHS Foundation Trust that all potential patient centred projects be submitted for Independent Scientific Review to two anonymous reviewers (appendices 9&10). The research proposal and protocol were submitted in respect of this requirement. The reviewers commented on the usefulness of the research. The study was also subject to ethical review and was highly commended by the Committee and seen as a valuable and important addition to the knowledge base (appendix 6).

3.9 Expert Validation and Reliability Assurance

On completion of interviews and analyses, a random one third of the data were reviewed by a clinical psychology colleague. The relevance of emergent themes was discussed.

3.10 Participants

Access to and recruitment of participants was negotiated with consultant surgeons within Sheffield Teaching Hospitals NHS Trust (appendix 4). It was agreed that interview of known participants may increase bias but that the potential for distress would be reduced. English speaking participants with surgically acquired facial defects and who use a facial prosthesis were randomly selected and invited for interview. Participants were offered reimbursement of their travel expenses and each participant was given a gift voucher to the value of £10.00 as thanks for taking part in the study. It is usual for studies employing Interpretative Phenomenological Analysis to include a small number of participants and the opinion is that six to eight is an appropriate number in health related postgraduate programmes (Turpin et al. 1997). Ethical approval was granted for the inclusion of a maximum of eight participants in the study. Initially twenty participants were randomly selected and contacted by letter. Thirteen individuals agreed to their inclusion in the study and eight were randomly selected for inclusion and contacted by letter. The five individuals not selected were contacted and thanked for their time. Interviewing ceased after the sixth participant had been interviewed $n=6$ after no new themes were discovered. The relevant case history of each participant is shown on page 62.

Table 1 - Relevant case history of study participants

Patient Code	Age (at diagnosis)	Sex	Diagnosis	Prosthesis Type	Immediate
G	54	F	BasalCell Carcinoma	Nasal Adhesive: 1992;1994;1995 Implant: 1996;1999;2003	12 days post-operatively
H	58	M	Olfactory Neuoblastoma	Orbital Anatomic/Adhesive: 1998;2000 Implant: 2001;2004;2006	8 days post-operatively
B	53	F	Adenoid Cystic Carcinoma	Orbital Adhesive: 2004 Implant: 2004;2007	No
J	64	F	Meningioma	Orbital Adhesive: 1997;1999;2001 Implant: ;2004;2006	No
D	59	F	Squamous Cell Carcinoma	Nasal Adhesive: 2004 Implant: 2006	No
C	42	M	Adenoid Cystic Carcinoma	Orbital Adhesive: 2000;2002 Implant: 2003;2005	No

3.11 Risk Assessment

It was agreed that interviews would be conducted in private, at a mutually convenient, neutral location away from the unit at which participants usually received treatment. It was anticipated that this would not only allow participants to relax but would also help to remove the potential bias caused by the patient/practitioner role. Further concerns highlighted under ethical review in respect of potential distress during interview were addressed via the ease of access to on-site nursing and clinical psychology services. These services were contacted prior to commencement of interviews. All participants were offered post interview briefing and any participant who became distressed could be referred to the appropriate help. This issue was addressed in the information sheet that was given to patients before interview.

3.12 Data Capture

The study included a series of semi-structured interviews with participants who had undergone surgery to remove facial cancer and who had subsequently been treated with facial prostheses.

An approach of listen and respond encouraged affected individuals to talk about their experiences pre and post surgery and after the fitting of prostheses, the flow

of conversation guided by the participant's responses. No attempt was made to offer any suggestion or advice.

The interview schedule was piloted on the first participant to assess how adequately it addressed the area of research and minor modifications to the questions and topic areas were made as a result. A journal was kept in an attempt to monitor the process and any influences on data capture and analysis. Regular review meetings with advisors were scheduled and notes kept for reference.

One-to-one semi-structured interviews were audiotape-recorded. Audio-taping was agreed to be the least intrusive method of recording each interview. Each participant was aware that the interview was being recorded but the microphone could be hidden from view in an attempt to increase reliability. Participants were informed of their right to review the tape.

3.13 Transcription and Analysis

Each transcript was read several times and emergent themes were identified which were condensed or clustered according to the thematic relevance to the research topics. These clusters were then subjected to further analysis and a master list of themes or codes produced which captured most strongly each participant's view of a particular aspect or concern. Similarities and or differences were noted together with any identifiable anomalies. Shared themes and categories could be

more intensively examined and analysed. An example, using a section of text from G's interview is shown on pages 66 and 67. The left margin is used to note anything of significance or interest which becomes more complete after subsequent readings. The next stage of the analysis transforms these notes and ideas into phrases or themes.

Table 2 - Example of the first stage of analysis

<p><i>Holding hand – comfort and support</i></p> <p><i>Looked – dreadful hole middle of face</i> <i>Pauses at recollection – vivid</i> <i>recollection laughs (nervously)</i></p> <p><i>Awful really really (twice) awful</i> <i>Immediate prosthesis – feels human like</i> <i>a person – regains human image –</i> <i>comparison with pre-operative state –</i> <i>image</i></p> <p><i>Cancer – nothing I can do mutilation is</i> <i>preferable to death survival at all costs</i> <i>Nothing nothing (twice) I can do re-</i> <i>iterates to self</i></p> <p><i>Justification for facial mutilation – and</i> <i>survival death was inevitable justifies</i> <i>to self</i></p> <p><i>Social comparisons real people do not</i> <i>do this wants to be real –may see</i> <i>herself as unreal (without a nose) or</i> <i>abnormal - denial of situation get angry</i> <i>and frustrated not real</i></p>	<p>eh I had to stand on me tiptoes and I remember her holding my hand and I looked you know and I just thought it was dreadful I thought it was awful because it is just like a hole in the middle of your face with (pause) a section down it as I now know what it is (laughter) I didn't know what you called it then it was just awful really really awful and the only time I started to feel human was when I came down here and you put that nose on me. I went back onto the Ward and I felt like a person.</p> <p>G There was there was all helping me but the thing is its your mind and its you that's got to get your mind into that situation where there is nothing I can do about this, you know, it I had cancer I've had to have me nose off and I've got down to get on with it because there's nothing there's nothing I can do about it.</p> <p>G If I hadn't have had me nose off if I'd just stayed I'd refused to have had me nose off would it have gone up and gone into me brain and killed me.</p> <p>and I thought what the hell am I doing with all this stuff and this nose and everything and there again I wanted to throw everything through the window because it wasn't real you know and I remember saying to me daughter to me son-in-law and I just said 'this this is just not real what I'm doing its just not real people don't do this' you know and it was a really bad morning a really really bad morning.</p>
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Table 3 - Example of turning initial notes into themes

<p>eh I had to stand on me tiptoes and I remember her holding my hand and I looked you know and I just thought it was dreadful I thought it was awful because it is just like a hole in the middle of your face with (pause) a section down it as I now know what it is (laughter) I didn't know what you called it then it was just awful really really awful and the only time I started to feel human was when I came down here and you put that nose on me. I went back onto the Ward and I felt like a person.</p>	<p><i>Feeling fearful</i></p> <p><i>Shock at appearance (image)</i></p> <p><i>Horror at situation</i></p> <p><i>Appearance concerns</i></p>
<p>G There was there was all helping me but the thing is its your mind and its you that's got to get your mind into that situation where there is nothing I can do about this, you know, it I had cancer I've had to have me nose off and I've got down to get on with it because there's nothing there's nothing I can do about it.</p>	<p><i>Wants rid of disease</i></p> <p><i>Justification of treatment for survival</i></p>
<p>G If I hadn't have had me nose off if I'd just stayed I'd refused to have had me nose off would it have gone up and gone into me brain and killed me.</p>	<p><i>Treatment at all costs</i></p>
<p>and I thought what the hell am I doing with all this stuff and this nose and everything and there again I wanted to throw everything through the window because it wasn't real you know and I remember saying to me daughter to me son-in-law and I just said 'this this is just not real what I'm doing its just not real people don't do this' you know and it was a really bad morning a really really bad morning.</p>	<p><i>Feelings of anger and frustration</i></p> <p><i>Unreal situation</i></p> <p><i>Social comparisons</i></p> <p><i>Denial of situation</i></p>

The establishment of connections between sub-ordinate themes allows clustering under a super-ordinate title or theme. Some initial themes may be deleted at this stage if the evidence for their inclusion, for example infrequent occurrence, is weak. A systematic method of analysis called Mind Mapping was developed by Buzan (2009). This is analogous to IPA as the process involves an initial main theme which leads to smaller themes and concepts as shown in figure 8. Mind Mapping aims to present knowledge in a structured picture or map to enhance the memory and the retention of knowledge. Whilst Mind Mapping and IPA offer the same rigour of analysis and discipline to maintain objectivity, the two processes differ in both their aim and method. IPA is, in effect, a reversal of the process of mind mapping with sub-ordinate themes progressing to super-ordinate themes as shown in figure 9 on page 69. In some studies super-ordinate themes are found sufficient.

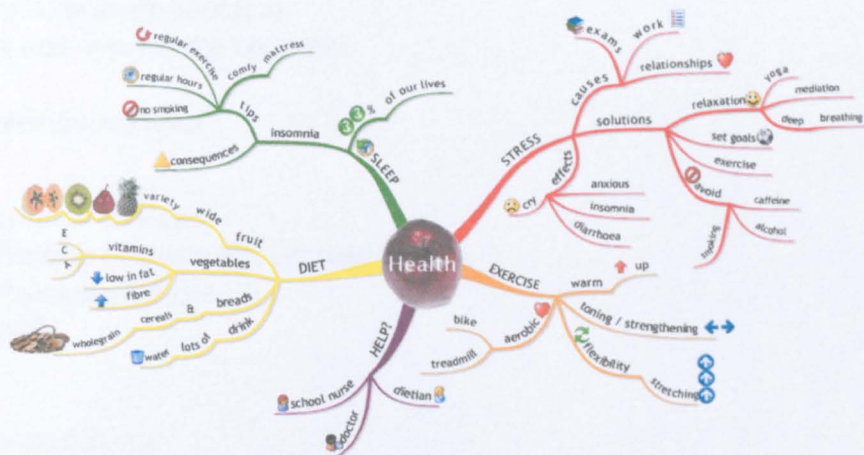


Figure 8 – A Mind Map of 'Health' (Buzan 2009)

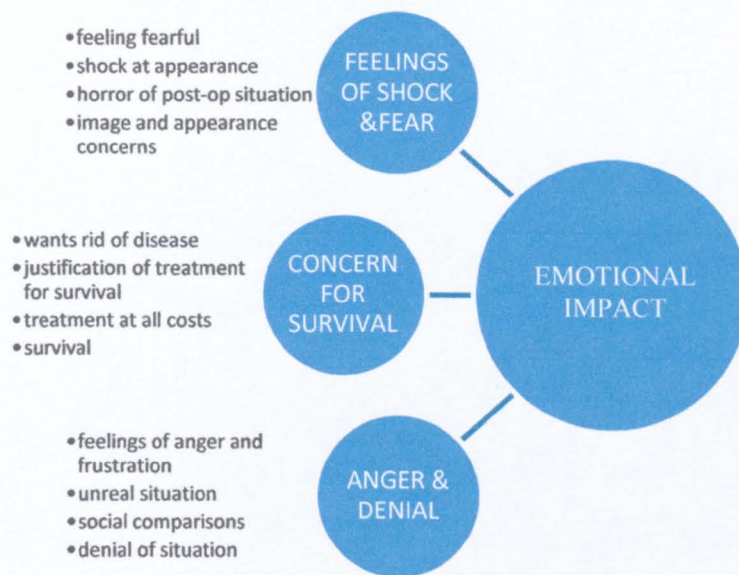


Figure 9 A reversal of the Mind Map process

Superordinate theme: Emotional impact

Feelings of shock, fear

Feeling fearful
 Shock at appearance
 Horror of post-op situation
 Image and appearance concerns

Concern for survival

Wants rid of disease
 Justification of treatment for survival
 Treatment at all costs
 Survival

Anger and denial

Feelings of anger and frustration
 Unreal situation
 Social comparisons
 Denial of situation

3.14 Validity and Reliability

The requirement to ensure that questions were 'open' and did not direct the participant in any particular way was of paramount importance (appendix 1). Furthermore, participants were allowed to develop topics and aspects of their story which they felt were important to them. Regular meetings with advisors were scheduled to review the results and discussion took place regarding the relevance of the interview content and emergent themes. A computer disc of the anonymised, unannotated interview transcriptions (in compliance with ethical approval advice and requirements) is included with this study (appendix 11).

Denzin (1978) suggests that the setting in which the meeting takes place might influence the outcome of the encounter. Too formal a setting may not encourage intimacy whilst a very casual meeting place encourages inadequate responses. Pope and Mays (1995) suggested that familiarity with participants may, in fact, increase accuracy.

The interviews in this study were conducted in a hospital setting but removed from the department where the participants were usually treated. Easy chairs and refreshments were provided. Each participant was previously known to the author as a patient.

3.15 Bias

There is an unavoidable trade-off in assessment method between flexibility and accuracy. The more flexible and sensitive a method is the more subject it is to bias: the less subject it is to bias the less flexible it is in use (Smith, Harre and Van-Langerhove 1995). Semi-structured interviewing is a flexible and sensitive method of data capture but it has been argued that, as such, it is more subject to bias.

Edwards (1997) had found that professional attendants had presented set solutions to what they perceived to be problems, thereby adding their own interpretation of what they were hearing, because they had not listened to patients. What patients most wanted was to talk and have someone listen. Semi-structured interviewing assists this objective.

Qualitative research depends very much on producing a convincing account of the subject under research (Silverman 1989). Qualitative studies generate a great volume of data and it has been suggested that this raw data, in the form of interview transcripts, should be made available on computer disc (Waitzkin 1990). This protocol has been adopted in this study. To ensure rigour, Mays and Pope (1995) suggested the presentation of sequences of text from the original data which includes commentary by the researcher. This protocol has also been adopted in this thesis.

CHAPTER 4

4.0 CONTENT ANALYSIS

After transcription of the interviews, each full text version was subjected to content analysis using Interpretative Phenomenological Analysis as described in Chapter 3 Section 13.

The author's analysis (scanned copy) of the interview conducted with G is shown on page 73 followed by the analysis (scanned copy) of the same interview transcript, completed by a colleague, shown on page 103. The relevance to the study of the emerging themes was discussed.

The remaining five transcripts were subjected to content analysis by the author with one further transcript randomly selected and subjected to content analysis by a colleague.

INTERVIEW G

11 F If you can tell me, how did you first discover you know that you had something
12 wrong?

13 G I had you know me nostrils I had a little spot come under there I mean the story
14 even before that was as a baby I had a little spot come in this place here just under
15 me nostril and me mother noticed this little spot and so she took me to the doctors
16 and he said if it got any bigger I'd got to go to the hospital which it did and I went
17 to the old Infirmary and there they put four radium needles in the soft part of me
18 nose, there, and then apparently it all scabbed over and they put some purple stuff
19 on it and the scab came off which left me scarred I used to cover that up with
110 make-up. So as far as I was concerned that was that and then one day that little
111 spot appeared here and I don't pick me nose usually (laugh) but it annoys you so
112 you know and it wouldn't heal up so I went to my doctors and he said he looked
113 at it and he said oh doctor so and so will burn that off.

114 F How old were you at that ...

115 G 54 yep and eh he said the doctor will burn that off and I know I went home
116 thought about it and I thought no no I want more information about this so I went
117 back and I saw a different doctor down at the local GPs. He looked at it and I
118 said Doctor so and so said Doctor (name) is going to burn this off because I had
119 some antibiotic cream which hadn't done anything so eh he looked at it and then
120 he said nobody's touching that and I said to him well you know what it is and I

past life
childhood
experience

recalls
precise
childhood
treatment

remembers
first treatment

issues with
appearance
concerned

recollects 'scar'
& covers up
uses make-up

annoyed by
spot

concerned
GP-treatment

Burn off spot
not happy
diagnosis
unconvinced
by GP
- sees different GP

wants more
information
(confirmation)

Suspicion at
that stage
- wants to
confirmation

- can't remember
 pays wants
 confirmation
- 21 can't remember his exact words what it was but anyway from there I know I paid
 22 to see a Specialist eh a Doctor (name) at Thornbury Annexe and while I was there
- skill seeking
 an answer
- 23 suddenly and I don't know why out of the blue I looked at him and I said 'have I
 24 got cancer?' And he said I can't I can't answer that one he says we wont know he
- Suspects
- 25 says but I'd like to do three biopsies he said I'd like to do them while you're here.
- cancer
- 26 F Why did you think that at that stage G?
- 27 G I don't know it something just come into me head and something just clicked
 28 and I don't know where it came because before that I never even thought about
- Snap thoughts
- 29 cancer at all and it I just came out with it and he did these three biopsies and it
 210 turned out that the two out of the three was cancerous one at the side of me nose
- "never thought
 about cancer"??
- 211 because that had started flaking a little bit and the one that he did inside that
 212 nostril and another one that he did which was alright. And I don't know what
- remembers
 symptoms
- 213 happened from there but I had to go to my own GP and from there I was sent to
 214 Dr (name) at the (hospital) a skin specialist. Now going through all this story he
- referral to
 specialist
 links to childhood
- 215 told me that this was an overdose of radium as a baby it was called an naevous
 216 this burnt mark thing that was in me nose and so I said well you know what do I
- wants info
- 217 do from here and I was very upset you know he didn't say cancer but I already
 218 knew because I had got the results from Mr thing and um.
- upset knows
 it's cancer
 confirmed her
 suspicious
- 219 F How were you feeling about it at that stage?
- 220 G A bit upset, a bit upset but I mean I'd had my breast off in 1983 so I was eh eh
 221 a bit upset but not not really to start sobbing and going off. I think I just shed a
- upset compares
 situation
 with previous
 treatment

Seeking
 information

Suspicion
 Fear of
 diagnosis

never?
 denial

Emotionally
 upset

Emotion
 upset

go from here in a hurry 31 few little tears but nothing nothing I would call anything and then from there I said
 "right" - get on with it 32 well where do I go from here and he said well you will have to go and see a Plastic
 Surgeon and I said 'right' and that was here because they didn't have any at the 33
 34 (hospital) and that is when I came to see Mr (name) the first time and Mr (name)
 35 must have read the notes and he wanted me to come in overnight because he
 Another biopsy 36 wanted to do another biopsy but much further up so I came in overnight and he did
 37 this biopsy and I went home the next day but I had to come back the following
 family support / horrid bit 38 Wednesday which I did with me daughter and that's when we come on to the
 39 horrid bit and we came in and I sat down and I says 'have you got the results of the
 eager for result 310 biopsy' so he says 'yes I have' and he says 'I am afraid' he says 'we've got to
 Now off - numb 311 take your nose off' and I was numb I felt as though all that room and everybody
 horrid, unreal 312 in it was unreal it was (pause) it was just horrid and the nurse said to me 'would
 313 you like a drink of water?' and I said 'yes please' and she fetched me this drink of
 remembers vividly - think about recon. - shocked 314 water and I had a bit and he started explaining about reconstruction about what
 315 they do and me daughter that was with me she said 'my mum wont like that' and
 knows about prosthesis comparison - previous treatment 316 he mentioned about a prosthesis well with having a prosthesis for me breast I
 317 knew what one was otherwise I probably wouldn't have really known what it was
 318 and I just looked at him staring really I just looked and I said I'll have a
 not knowing about prosthesis 'doesn't want to know' 319 prosthesis and not knowing anything anything about prosthetics nothing nothing
 320 at all I thought that I'd gone that day knowing that I'd have to have some sort of
 321 operation to remove this cancer probably cut a bit off my nose there and probably
 Was not expecting such radical treatment / horrendous 322 go inside me nose under a general anaesthetic and they'd do what they'd got to do
 323 cut it out probably stitch it up and that was going to be that. But to be told that
 324 you've got to have the main feature on your face cut off was absolutely
 325 horrendous.

'Right' anxious to start treatment survival removal of tumour

shocked unreal situation denial

shocked horror of situation emotional upset

41 F Did you feel any different, you know you mentioned that you had a breast off
 42 some years previously. How did you feel when you were told that you had to have
 43 your breast off?

'eh'eh'eh'
 -rumor

44 G I wasn't I eh I eh eh I was just had to sign the consent form in case eh well I
 45 think he he knew but I didn't know that I was going to have me breast off to have

past treatment

46 surgery um I signed the consent form that if whatever they were doing was

mentions
 cancer
 comfort in
 daughter
 support

47 cancerous they were doing a frozen section if it was cancer they were going to take
 48 it off but at that particular stage I didn't know my daughter did because she worked
 49 at Claremont at the time and she knew that she knew Mr (consultant) and eh I
 410 didn't shed a tear over that.

previous
 treatment
 recollection

411 F What about after your operation to remove your breast, how did you feel?

412 G The only the only time I shed a tear over that was when the nurse a lady came
 413 in with a prosthesis she wanted your bra so that she could she started showing

upset at
 breast prosthesis
 reality
 anger, denial
 frustration

414 prostheses and I broke down and so did the lady at the side of me as well we both
 415 cried you know I I went angry and I wanted to get hold of these prostheses and
 416 throw them you know I really did I didn't want to know about it at all and in fact
 417 she came back a couple of days later and to see how I was and I said to her what

anger
 frustration
 denial

reflects on
 action
 time to think

418 would you have done if I had thrown that prosthesis flying across this ward so she
 419 says I'd have gone and picked it up you know so I says well very sorry I am not
 420 an aggressive person like that I said I don't know what on earth came over me to

comparisons 51 to do that . So she said its quite a natural you know eh people are different yes so I
 upset & angry 52 think I was more angry than upset really and I never cried any more about that.

angry
 & upset

53 F Was your nose any different to when you had your breast removed?

much x 3 worse 54 G Oh god the removal of my nose was much much much worse oh it was

much worse
 fearful shock

horrendous 55 absolutely horrendous that because you can cover your breasts up you can cover

can't cover 56 that up with clothes you know you get a prosthesis for it and its measured and you

image
 concern

covered - look 57 just look normal you know but to think that you've got to have your nose off you

normal 58 say what the hell am I going to look like I'm going to look a monster its its just

concerned for
 appearance
 unthinkable 59 something that its so hard to describe unless its you.

difficulty
 in describing
 feelings 510 F You can't it's difficult to know how.....?

concerned for
 appearance 511 G You can't I mean like you've seen me umpteen hundreds of times without it on

512 and it doesn't bother you but if it was you you would feel you would feel so you

social
 comparisons 513 would probably feel like I you really would because and I mean everybody has

professional
 staff support

514 been absolutely marvellous with me and which I you know I mean people are

staff "been
 marvellous" 515 aren't they because such a horrible thing it really really is but I mean I remember

? taken a
 distance 516 Mr (consultant) sending for you and then we came down here with me daughter

517 and I had to have this impression which was all everything was so real about that

518 afternoon because it went on into the evening really didn't it? Half past sixish

'and er' - 519 going on seven you know and then I had got to go home and er then tell the

'and er'

horrid news
 to tell family 520 family you know.

61 F And how did you feel then, how did your family react?

tell herid 62 G I said to our well we went back to me other daughter's and I said to fetch me
news 63 husband up because I don't want to have to tell one and then have go and tell him
dislikes idea 64 which they did they rang and and he came up to me daughter's and I went I think I
of repeating 65 went up to the toilet eh and my daughter told them.
daughter tells
family

*Frankly really upset
Denial of situation*

66 F Ah right so you didn't you didn't tell them anything.

Couldn't tell 67 G No no I just couldn't I just couldn't I felt (pause) oh just I don't know it was just
horrendous 68 horrendous it was really awful.

*horror of situation
couldn't deny*

69 F So how long then after that news did Mr (consultant) leave it before your
610 operation?

611 G Oh not long not long do you know I don't know whether it was the following
612 week

613 F So pretty quick.

family support 614 G It was very quick ye I think it was the following week and me daughter brought
 615 me in me eldest daughter brought me in and eh (long pause) and then they did it
"did it" 616 at ??/ and I think it was a Wednesday morning that it was done and I remember
did not want to look 617 eh for I wouldn't look I wouldn't look at all and when I wanted to go to the toilet
mirrors covered 618 they had to put newspaper up at the mirror even though I'd got a dressing a big

family support

Post-op fear of image

refuses to look at reflection
 "Staff good"
 remembers individuals

71 dressing over it. When I went to the toilet I asked if somebody would put either a
 72 towel or some newspaper because I didn't want to see anything of meself at all
 73 when I went to the toilet which they were very good and did that and I remember
 74 the Sister I think she's left now and I have forgotten her name.

refuses denies
 staff help

75 F Was it Sister (name)?

remembers staff individuals
 write down goals

76 G Ye ye she was a lovely lady she would even come and massage my feet
 77 underneath to try and relax me she was wonderful and she even gave me a paper
 78 and asked me to write down me goals what I wanted you know and I eh eh put to
 79 see myself and also to go home because I was in hospital about a fortnight I think.

helpful staff professional support

710 F Did you find that helped? Did you find that input from Sister (name) helped?

"wonderful" Sister (staff)
 fond memories
 didn't want to look
 good impression by staff
 staff supporting her
 remembers hugs

711 G Oh I mean from her oh she was wonderful because I asked her to draw could
 712 she draw me a picture of what I would look like without a nose on and I
 713 remember she drew this picture and obviously now I know it was exactly what
 714 she had drawn but you couldn't envisage what was on that paper that you were
 715 going to look ye ye and I didn't look first and cor for about 10 days I think and
 716 then one day there was one of the little wards there was no one in it and she asked
 717 me if I wanted to go and look and I said well I know I've got to face this but I
 718 don't really want to she said that she would she would be with me you know I
 719 mean you'd already got the impressions and everything and was making me nose
 720 weren't you while I was in hospital and anyway she took me in this this ward and
 721 hugging me ??? the mirror was high so all I could see was me eyes (laughter) and

supportive staff
~~staff~~
 staff support (professional)

holding hand - support 81 eh I had to stand on me tiptoes and I remember her holding my hand and I looked
 82 you know and I just thought it was dreadful I thought it was awful because it is just
 dreadful hole 83 like a hole in the middle of your face with (pause) a section??? down it as I now
 vivid recollection
 84 know what it is (laughter) I didn't know what you called it then it was just awful
 awful awful 85 really really awful and the only time I started to feel human was when I came
 immediately replacement - real person 86 down here and you put that nose on me. I went back onto the Ward and I felt like
 87 a person.

at shock
 appearance
 Comparison
 feels human

88 F You felt a lot better than

feels better 89 G oh god ye

adhesive retained 810 F That was a glue-on prosthesis wasn't it?

Negative
practical
comparison
(prosthesis)

awful but felt human 811 G Oh it was awful that glue I had. Did I do it for about four years?

812 F I think you did.

813 G I must have done ye ye

814 F Even though it was a glued-on prosthesis how did think about that, how did you

815 um when you went out into general public areas shopping and things like that?

adhesive alright 816 G Well it was alright but there were certain times when the glue started to come
 unstuck 817 unstuck from the bottom, you know, just above me lip and you could feel it
 problems & retention

Practical
problem
- prosthesis

no security
"the thing
m"

91 loosening and that was awful because you had to keep like as though you was
92 wiping your nose but you wasn't really you was holding the thing on you know the
93 gluing was an awful awful thing.

security
anxious
confidence

94 F As far as how it looked G, how did you feel about it?

but looked
very well
pleased &
appearance

95 G It looks very well, it really really looked very well so it did ye and you did give
96 me some glasses and I wore those glasses for quite a long time.

prostatic
compromise

97 F So how did you feel then when you were shopping and things like that?

feels alright

98 G I felt alright.

99 F You felt alright.

anger at
staff individuals

cleaning
regime

pushed into
cleaning

at daughter's

anger at
situation

individual
stuff
problems

anger
denial

910 G Ye, I think I think it took me a long time because you know the District Nurse
911 used to come and clean the cavities out and um I remember she hurt me one
912 morning because I said to her 'how long will you be coming to have to do this'
913 and she said 'well for as long it as long as you feel you can't do it yourself' you
914 know and I know she came for about a fortnight and then one day she she really
915 hurt me and I thought I'll have a go at doing this meself which I did and I've
916 done it ever since but there was one particular morning and I can remember that
917 very vividly and er I was at me daughter's and I er er slept there actually I was
918 there a while and er I I'd got a this big mirror on a pillow and all the stuff I got
919 out and all of a sudden I got this ??? feeling just like the feeling that I got in me

comparing 101 breast and I thought what the hell am I doing with all this stuff and this nose and
frustrated 102 everything and there again I wanted to to throw everything through the window *anger*
at situation 103 because it wasn't real you know and I remember saying to me daughter to me son *frustration*
wasn't real 104 in-law and I just said 'this this is just not real what I'm doing its just not real *unreal*
social comparison 105 people don't do this' you know and it was a really bad morning a really really bad *situation*
bad morning 106 morning.

107 F So you felt angry about this?

unnatural 108 G Ye, I just wanted to throw the nose through the window and all the cleaning *unreal*
gets angry 109 stuff with it everything I just wanted to get rid of everything because it wasn't *situation*
 1010 natural because it wasn't real. *anger*
denial

1011 F What were the members of your family saying round about this time?

support from 1012 G Eh all my daughters were, my youngest daughter I I stayed there because my *family*
daughters' 1013 husband hadn't got much idea of what to say and when I did go home I used to *support*
cries whilst 1014 cry a lot I cried a lot about it and eh (sigh) he used to to be quite honest with you
at home 1015 he said I remember one day I was crying I had got my tea and I didn't want it *no partner*
-husband 1016 I was crying and he said 'oh I can't cope with this' he said 'I'm going to ring *support*
husband can't 1017 Janet up' and he rang Janet up 'you will have to come and fetch your mother I
cope 1018 can't cope with all this'. Now that didn't give me that much support but I didn't
no partner 1019 want to be in that place with him I wanted to be with me daughter and me son *family*
support 1020 in- law as you know with (name) he was absolutely fantastic with me and they *support*
-want to
be with
daughter
-support

- family support - emotional
- 111 were wonderful if he hadn't have been for me two daughters and a son-in-law I
- 112 think I would have gone crackers.
- 113 F So you felt that they helped....?
- daughters' fantastic
- 114 G They was absolutely fantastic but me husband had just got no idea, no idea at
- 115 all. You know and I stayed there quite a long time, you know before I I'd until
- accepted everything - returned home
- 116 really I I'd accepted everything I could do everything and then then I went back
- 117 home.
- 118 F So when you say you started to accept things did you feel different about
- 119 yourself? How did you feel?
- acceptance??
feels better
asks questions
- 1110 G I suppose yes, I suppose I did a little bit but (pause) there again if you look at
- 1111 things very logically it's you that's gone through it all and if people can't accept
- 1112 you for who you are you are still the same person, you know, and if people can't
- 1113 accept you for who you are then I couldn't care two pence, you know what I
- doesn't wear glasses
- 1114 mean (pause) and now I don't even wear the glasses. I have got some glasses in
- 1115 there but that that I get to make things look a bit sharper but its very rare that I
- 1116 wear them.
- 1117 F And you feel confident in walking?
- regain confidence
"time heals"
- 1118 G I do yes, because I couldn't care less what anyone else thinks now, you know,
- 1119 when its fourteen years on, fourteen years on now aren't we, you know and I
- family support
emotional support
- family support
- acceptance
(of situation)
- Confidence
Body image
awareness
- Confidence
returning
time heals

horrible
job-cleaning
awful

121 just think its me that has to do this horrible job every morning of cleaning out the
122 cavities every morning, its me that has to do it an when I've got cold its
123 horrendous. That is awful.

awful
horrid
but accept
situation

124 F See all your mucous and things like that.

horrible
face but
accepts

125 G Aw (sigh) even horrible it really is horrible, you know, it makes meself feel
126 sick (laughter) it really does but I mean that is just something now that I have
127 come to accept.

128 F So have you accommodated the fact that you have got this to do and you just
get on with it?

14-years
?? reference to
survival
social comparison

129 G Ye, I get on with it now and fully fully well after fourteen years you do accept
1210 it don't you? But I don't know whether everybody still does or not.

time as a
harder
survival
(rat to 14-years)

1211 F Well, not everybody does.

aware of
appearance

1212 G Well, I mean I still know and I still look and I try to make eh me nose feel as
1213 though its gone into like a (pause) crevice, a frown, if you like, eh eh a line if
1214 you know what I mean on me face so that it kind of fits in there but as I say then
1215 I put the make-up on and put make-up on that to match me face and then I feel
1216 quite confident.

accepts
prosthesis

Confidence
returns
helps self
? acceptance

1217 F You feel.....?

131 F You've had both types of prosthesis, G, you've had the implant prosthesis that
132 you wear at the moment.

*prefers implant
prosthesis* 133 G, oh ye, that's wonderful.

*implant
prosthesis
prefers
implants*

134 F And then we started off with an adhesive, glue-on stick-on prosthesis which I
135 think you had for about, I think you said four years.

136 G It must have been about four years that, ye.

137 F What would you say the differences just between one and tother?

*implants
fantastic* 138 G There's no comparison whatsoever, I mean the the magnets are absolutely
*feels confident
retention* 139 fantastic they really really are, I mean, you do it, you click it on and it doesn't
*appreciates
imitation* 1310 come off unless somebody cracks you on the side. The pull is very very good,
1311 the pull that way forward but if somebody give you a crack with the elbow or
1312 their hand sideways then obviously it would come off, you know, but eh, in fact
1313 I was at on Bonfire night this week on Monday night I was sat in this house and
1314 there was two people in the room as well as me and I don't now how it
1315 happened but all of a it must have been meself it was meself and I don't know

*implants
preferred
security
concern*

*able to find
humour in
"embarrassing"
situations* 1316 how I did it I knocked it and it came off so quickly but you know me reflexes, it
1317 fell, like that, I picked it up and put it on and turned round and nobody was the
1318 wiser, no, nobody knew (laughter). I just got you know....

*humour or
embarrassment
didn't exist
confidence
acceptance*

141 F So practically, Is it a lot easier to to.....?

Social
comparison

142 G Oh, it is absolutely wonderful, oh it's wonderful, if you could talk people into
143 having it done.

Social
Comparison

144 F Any differences in say how it...it.....?

adhesive retained
appears OK
annoyed with
adhesive

impacts on
social life

Magnetic
retention
"wonderful"
"fantastic"

145 G Well, when you first glue it on, I mean, it sticks down and it looks alright, its

146 just the annoyance of it coming unstuck, I remember once I was going to a eh eh

147 an aerobic class thing and we was laid down on this mat and it wasn't very far

148 from where I lived, it was only round the corner and I just got laid on this mat

149 thing and all of a sudden I could feel it starting to come away and I just said to me

1410 daughter I am sorry, I said, we will have to go home and reglue this, you know,

1411 and I had to run home, take it off, reglue it all, stick it back on and then go back.

1412 Where, with with magnets there is nothing like that, oh ye, them magnets are

1413 wonderful oh I have never regretted I have never regretted them for one minute,

1414 oh I haven't. Absolutely, fantastic.

Image
Comparison
Security
Concerns

Prosthetic
Comparison
~~Prosthetic~~

1415 F Would you feel unhappy about going back to a an adhesive retained

1416 prosthesis?

hate a
return to
adhesive
retained

1417 G I would, oh, I'd hate it, I would hate it, ye. I mean its like if anything

1418 happened to me then they had to come out and had to have it redone I would

1419 have it redone because the difference is, there's just no comparison at all.

definite
preferences

151 F That's ok?

Secure quite

152 G You feel such a lot safer with this one, ye, oh ye.

Security concern
Confidence in
situation,

153 F And you wouldn't want to go back to a dressing?

image
concern with
dressing

154 G No I wouldn't go out, no, oh no. Do you mean just a eh eh dressing over that.

155 I wouldn't go out.

156 F You wouldn't.

public know
-flat

157 G No way, oh no, no I wouldn't. No, because everybody would know, because it

158 is flat, you know, like at night when I take it off I put a dressing over it, you

creator 'nose'
at night
from dressing
-appearance

159 know, I cut triangles out of the melolin dressings and put micropore on, you

1510 know, stick a bit on the top an a bit on the side so that it could breath at night

1511 and I do that and then obviously take it off first thing in the morning and put it

1512 straight on. Have me breakfast and then go back up and clean it all. You know.

Appearance
Concern
Image
Concerns
"feels"
whole

1513 F Yeh I know?

wouldn't go
out without
now

1514 G No I wouldn't like that, I wouldn't go out unless I looked as though I'd got a

1515 nose on, I know I wouldn't because you would know that everybody was

concerned at
appearance

1516 looking at you and even though I've said, you know, they can please themself it

1517 is because I feel confident in what I have got on but I wouldn't feel confident if

Must have
nose in place
for confidence

1518 I'd got what you just suggested with a dressing over it, oh no, no.

Returning
Reviving?
confidence
(in public
places)

dislike
dressings 161 F So it is fair to say then that you are much happier with a prosthesis than with a
162 dressing on? dislike of dressings

prosthesis preferred 163 G Ye oh ye, hundred percent, hundred and ten percent, ye. Implant preferences

implant retained 164 F And as far as the thing that you prefer most of by these implants?

comparisons with others 165 G Definitely, most definitely ye and anybody that won't have them, I mean, I just
166 cannot understand it, you know, I really can't. They just don't realise how
167 brilliant they are, I mean I can't thank the NHS enough for what they've done for
168 me.

QoL difference 169 F So you'd say it has made a difference to the quality of your life? QoL.

reflects on cancer awful operation 1610 G Oh ye, I mean if you've got cancer and you have got to have a nose off it is
1611 very aggressive its awful, an awful operation, you know, but to think you can
1612 have a nose and the people that do know about it have said you would never

happy with comments from others 1613 know would you unless you'd told me I wouldn't know which is great for you,
1614 as well as for me. Is it, you know? It is a compliment for you that's making the

absolutely brilliant 1615 noses as well. But I mean I think they are absolutely brilliant, I know that that
1616 down there but I mean some people have one if they've stopped being reading

skill compares self to others 1617 or whatever. I've even noticed on the television that if I look at the television
1618 and I look at people's noses and there is one or two people that's got like a

"permanent dent"
no glasses - coverage 1619 permanent dent there and they've got no glasses on.

Quality of life issues

Social Comparison

~~excusing~~
~~downside~~ 171 F And you get things on the side of your nose as well, things like that.

?? looks for shoes doesn't think any- not bothered 172 G Ye, ye, I mean, like as I said, I come on two buses this morning and it doesn't

173 bother me one eyeota. I don't find people staring at me, I don't at all. If I did, if I

174 really did find that people was staring at me and I'd think they are looking and!?

175 they can tell then all I would do was put me glasses on.

confidence
Confidence
in public
(places)
Still worn
Dr Bodgins

176 F Right and that would just hide that....?

177 G And ye and probably a little bit there and but it wouldn't stop me going out,

178 going into town and shopping or whatever.

179 F You would not feel any different about it you would just get your glasses on?

glasses on for further "concealment" rationalises inhibition 1710 G No I would just put me glasses on that's only if I found people staring at me

1711 which people don't. You know I don't go to town and look to see if somebody

1712 has got a false ear on or a glass eye. You are too busy with your own life to be

1713 looking at people's faces. That is the way I look at it, anyway.

rationalises

1714 F Did any people and even including your own family and friends as far as what

1715 they are saying to you did that help at all to make the shock of eh having to have

1716 your nose off any different any more bearable?

???

1717 G No not really.

???
incongruous
= not fit
transcripts

181 F You were sort of lost in your own thoughts?

horrendous
situation

182 G Yes yes I was ye. It was just as I say, it was just too horrendous I was so numb

horror of
situation
denial of
situation

183 I couldn't I just couldn't get to terms with it for quite a while, really couldn't.

184 F How long would you estimate that it took

185 G Um do you mean before I started to come to terms with it?

186 F Yeh to come to terms with things.

time to
"come to terms"
with things

187 G It was I would say it must be going on a year before I I really started to come

188 come round properly, ye, I know, (cough) excuse me, it was a matter it was more

189 it was months it wasn't a matter of just a few weeks and I'd come to terms with it

1810 it wasn't that it it was months. Ye.

1811 F Did you find that you accommodated that yourself or did anybody around you

1812 help you?

help but
help yourself

1813 G There was there was all helping me but the thing is its your mind and its you

1814 that's got to get your mind into that situation where there is nothing I can do

faces up to
challenge

1815 about this, you know, it I had cancer I've had to have me nose off and I've got

get on
with it

1816 down to get on with it because there's nothing there's nothing I can do about it.

Nothing I can
do about it

1817 Everybody in the medical profession like Mr (consultant), like you you've all

Survival
concerned
for survival
remove
tumour

Professional help - self help can't cover cover breast surgery
 191 done everything you can to help me so there's only meself now that can get to
 192 terms with this another thing it does take months because its its slap bang in
 193 middle of your face this is the thing, you know, if it wasn't so prominent like I
 194 said your breast you can cover you can cover up and I got to terms with that ever
 195 so quickly even though it it was serious very serious thing but I got to terms with
denies breast surgery remembers exactly
 196 it in fact I think I've always been in denial of this in all these years its twenty
 197 twenty four years, you know.

Com in the terms - accept

denial (of Mastectomy)

198 F Since you had your breast removed.

remembers exactly horrible - get rid of it
 199 G Twenty three and a half years, ye, in 1983 and eh I've just been in denial of
 200 that and my thoughts to that was oh it was horrible there was something really
 201 wrong with it take it off its gone and I've always looked with that I've not
 202 wanted to know about cancer in me breast I didn't want to know and I've never
denies breast cancer can't recall cancer
 203 wanted to know but when something slap in your face is that's a different

Denial

Body Image Appearance Concern

1914 F That's your thoughts and?

Different
 1915 G Ye, that's different ball game all together.

1916 F So did you find at that time and do you find now that people treat you

1917 differently?

Relationships no different
 1918 G No oh no.

201 F The same?

202 G Yes its just the same now ye.

203 F Right ho.

Seem happy
in the situation

204 G Yes, I am very happy with very happy with it all.

accepts
situation

205 F So you look at yourself now and then look back on all that time?

reflect on
came slight
anxious
repeats 3.

206 G Oh ye I wouldn't want it back again (slight laugh) I wouldn't want it back

vivid memory
rid of tension
(happy)

207 again I would not want that back again.

208 F But would you say that you've recovered from it all?

"No" recovered
but constantly
reminded

209 G Um, really because it's like every morning when when I've got to clean the

210 cavities and you think oh god I've got to get that job done, you know, and it's

211 not a nice job even doing that you know so I mean I've accepted it all and

212 everything but it don't mean to say that I like it (laugh) you know what I mean.

213 I have accepted it because I can't do anything about it but I don't like it that's all

214 but I am confident with it as well am I making sense.

acceptance
-because
situation
exists

sets goals
accepts
or situation

settling
realisation

215 F I think I know what you mean, it's almost as if what you are saying is you'd

216 feel recovered is if you had your proper natural nose back.

211 G Exactly.

212 F Right oh.

213 G People don't know how lucky they are when they've got one. When you look

214 at the television these people having nose jobs done makes me so angry and I

215 want to ye because I just feel as though I just want to shout at them be thank god

216 you've got one.

*Social comparison
anger at
perfection in others
- aware of her
situation*

*anger
Social
Comparison*

217 F Rather than thinking about messing about with....?

218 G Ye, stop messing with it you've got a nose, I haven't and it really I want to

219 shout at them, ye, that does annoy me very much.

*I haven't got
a nose
with aware*

*body image
awareness
anger
Social comparison*

2110 F That's ok.

2111 G Because I mean my nose it me own nose wasn't perfect by any means it it

2112 really in a way didn't look very nice but it was mine and it was attached to me

2113 and all that all those months it was kind of a grieving process because you have

2114 lost part of your body, haven't you you know.

*My nose was
my nose
not perfect
but mine
now lost*

2115 F Do you ever see your prosthesis as being your nose?

2116 G No because it (pause) my nose didn't look anything like this I mean this is

2117 great don't get me wrong.

*prosthesis
not part of
her*

221 F We could change the shape of that....

happy with
prosthesis
but not her

222 G I think my nose was maybe maybe it was a bit smaller I don't know, this is

223 great because it is straight, mine wasn't but I wouldn't want a nose making like

224 that um (pause) I'm just happy with the way I'm happy with the way it is, ye I am

"stuff"
great

225 ye as I say and everybody's been so marvellous that you can't praise people

226 enough I just think everybody's great been marvellous with me.

Normality
"not me"
aware of
~~action~~
artificiality
?
stuck

227 F Because of that has that helped you then?

helpful
stuck
practical
help
happy

228 G Oh ye I was oh definitely definitely ye. It does because people know like you

229 you know what you're talking about and you can help like if I'd got a problem at

2210 home and I could ring you up and you would help me and the help is there

2211 straight away which is nice to know.

2212 F That is the same with other people as well?

other bits
- further small
knows
- question
source

2213 G Oh ye ye exactly ye because where all these other bits of things have come

2214 from I just don't know. It is like I nearly live here (laugh). It makes you

2215 wonder if it's all come from this you know.

situational
annoyance
! survival
concern

2216 F It's possible you know I mean maybe but at least

231 G But Mr (consultant) said you know when I was having me head done we are
 232 going off well we're not going off because we got talking about me nose actually
 233 one one when he was doing me head and I said to him I said well you know
 234 having me nose off was very aggressive surgery wasn't it and he said oh yes so
 235 he said eh we were talking about basal cell carcinomas and I said to him why do
 236 people call them rodent ulcers when they are cancers and I says can I just give
 237 you my answer before you give me yours and I said is it because it buries in one
 238 particular place and that's why you call it like a rodent and he said well ye that's
 239 it exactly so I said but I said but with me nose I said that was so such a big
 2310 surgery that one he says yes that was very aggressive he says that might have
 2311 taken five years
 2312 F To grow to that sort of size yes.

Treatment
to head
lesion?

remember
nasal surgery

fulm about
"cancers"

still think
about nasal
surgery -
chronology
& histology

vivid
recollection
of treatment

"Question"
Survival

Seeking
information
- comparison
2 previous
treatment
seek the answer
and logic

2313 G But then looking on the other hand like the storey I've just told you about the
 2314 radium needles and Dr (consultant) saying you know er about that so how did it
 2315 take fifty four years then for it to come out if it was an overdose of radium and
 2316 that I don't understand that I've never asked Mr (consultant) because he's too
 2317 such a busy man and I I wouldn't go into all that with him but I have wondered.

Wants
re-assurance

2318 F Well a lot of these things take time to alter the cells G.

?! concern
for survival
- reassurance

2319 G So that's why it would have took all them years and then something triggered
 2320 it off and then it started and as he said it must have took about five years to have
 2321 got to the stage that it got.

"Question"
Seek
re-assurance

?? do not want it to be a cancer ulcer - not like throat cancer - ulcer
 241 F Well basal cell carcinomas you know is a very slow growing tumour but it is survival
 242 also some people refer to it as a rodent ulcer cancer
 243 G They do ye

244 F Yeh.

"popping up like a rodent"
 245 G So maybe this is why they keep popping up you know in these different areas
 246 of me face I've even had them under me lip you know under there.

247 F They are annoying little things but it's.....

asks question looking for justification for rhinectomy
 248 G If I hadn't have had me nose off if I'd just stayed I'd refused to have had me ~~bride~~
 249 nose off would it have gone up and gone into me brain and killed me. ~~just~~
 survival
 justification
 treatment
 survival
 2410 F Almost certain, ye, ye.

survival
 cancer
 2411 G I thought that.

"get it out"
 survival
 don't like risk
 2412 G But it was still, well I mean I could have been dead before it had got there
 2413 really, ye, you don't take that risk do you. You get it out.

2414 F And the big advantage of getting all the treatment early G.

treatment
 justification
 survival
 and
 justification
 in definitely

Meticulous daily inspection of self - concern for appearance - surgery - survival
 251 G Mine, as I say it is still all over me face in, one day there is nothing there and
 252 then all of a sudden and I find all these as I am cleaning the cavities that's how
 253 I've found all of them as I am doing that because I've got light haven't I you
 254 know straight onto me face and I look and that weren't there yesterday so I give it
 255 I give it so long and then.

*Survival
concern*

Self diagnosis 256 F You diagnose it yourself?

Something not right
 257 G Yes, ye, I think that there is something not right there I give it so long and if it
 258 hasn't gone away then I come and

259 F Get it sorted out. That is very good, that's good. As you know a lot of these
 2510 little things turn out to be nothing.

constant self inspecting
 2511 G Oh I've had more I've had more that's turned out to be nothing but I think
remembers previous recurrences and potential consequences
 2512 I've had about six or seven that's been something you know but I'm glad you
 2513 know noticed that one with my eye because I mean there again if I had left that I
 2514 could have lost me eye.
 2515 F Oh you could have done over time.

*? Survival
concern
Image
concern*

'skating a BCC'
 2516 G Little did I know that that was starting as a basal cell carcinoma there you
 2517 know so I could have lost my eye there but its all gone anyway that's' good.
- consequences of losing eye - all gone anyway - that's good

*rid of human
survival
concern*

261 F This is the big advantage you you are looking for you get onto Mr (consultant)

262 and get it out.

happy & treated 263 G I couldn't be tret any better if I paid paid for it all everywhere in this hospital.

happy
accepting
of situation

264 F That's ok G.

supports
skill 265 G They do they do in that waiting room you know my appointment was such a
266 time I says excuse me I said Mr (consultant) is a very very good surgeon and
267 when you get in there you will find that you feel the only person that there is

Confidence
in prof
skill

Very thorough
? thinking of
her own appt. 268 something wrong with and he's very very thorough and this is why you're having
269 to wait a long time you know I just won't have anybody.

2610 F You tell them off do you?

skill number
individuals
fool 2611 G Ye, ye I do in a in a nice way but a nice but firm way really because I I
2612 mean he is so good and he is so thorough you know he is really lovely.

skill
confidence
-re-assured

2613 F He is a nice bloke and he is a good surgeon.

happy
with individual
skill number
- with men
intimate
relationship
- confidence 2614 G He is, his attitude is nice his attitude is everything. I had these on my lip done
2615 the other week and he said something Mrs G and I looked at him and I said
2616 don't you think that it is about time you started calling me G after all these years
2617 (laugh) and he just laughed and he said alright (laughter). You know, he is he is
2618 brilliant.

confidence
in
individual
skill

271 F G, that's been good talking to you G.

stuff
individuals
made a
difference

272 G He frightened me to death he did. Well because you talked to me about having
 273 these implants done and it was Mr (consultant) and he wasn't far off retiring if
 274 you remember rightly and I had a talk to him and he did his damdest to put me off
 275 and he scared me, yes he did, he really frightened me and I thought you know
 276 because he was saying when you smile and when you know when you laugh
 277 when you smile all your face alters and people will probably see a hole there and
 278 the way that he came across he made it appear as though it wasn't really worth
 279 having these implants I learned after that he's never done any implants and I
 2810 would have been his first patient to do an implant on and so I think it was you
 2811 who told me about Mr (consultant) and I went to see Mr (consultant) at Charles
 2812 Clifford because somebody gave me his card anyway and I went to see him and
 2813 I told him that Mr (consultant) had frightened me with these implants and he
 2814 was as different again and when he finished talking to me I said that's fine I said
 2815 I want them but I don't want him to do it.

individual
shall

unhappy
individuals

st all members
(individual)

2716 F So did Mr (consultant), if you had thought that Mr (consultant) was putting
2717 these in then.....?

frightened

2718 G I don't think I would have had them done. No because he frightened me, he
 2719 frightened me in the way in the way that he spoke to me the way that he was
 2720 going on about these implants and I think deep down it's because he didn't

few of
treatment

281 know how to do it because he's never done one before and I was going to be his
 282 first one so I I'm really glad that I didn't let him do it you know and it wasn't
 283 long after that he retired and Mr (consultant) took over and he was he was
 284 fantastic I mean I had to have my implants done in two but they do them in one
 285 now don't they? I had to have the two didn't I? The bottoms and then the
 286 uppers. But Mr (consultant) he wasn't I think he was scared to be honest you
 287 know looking back I think he was so scared that he thought that well if he
 288 frightened her to death she'll not have it done which he did (laughter) and then
 289 talking to Mr (consultant) who really knew what he was at he was fantastic he
 290 was you know and it was in very early stages weren't it with Mr (consultant)
 291 you know, I don't know.

*lack of
confidence
in individual
stuff*

*individual
stuff
member*

*feels confident
to allow others
to treat her*

2812 F I don't know G.

*lot of
praise*

2813 G No he hadn't it was a very new thing for him but he was absolutely brilliant
 2814 that man and eh he has got a lot of praise I have got a lot of praise for him.

2815 F Do you ever see, does he call you in for review and things like that.

2816 G Mr (consultant) no no last time I saw him he was here when you were doing
 2817 me noses and he was here once but I've not seen him since. Does he work at
 2818 (name)?

2819 F Yes, he is still over at the hospital.

291 G Doesn't he ever come here now?

292 F Not really, I mean he comes over on odd occasions.

293 G Because he used to have patients here didn't he?

294 F Ye ye he used to have a Clinic here. But he now sees patients over there.

295 G He is a professor now isn't he?

296 F Ye, Professor (name).

praise for individual still

297 G Mind you he deserves it. He really deserves it. But I am so glad that Mr

298 (consultant) retired. (laughter) I didn't like him. So I mean that's going back a

299 long time isn't it?

2910 F Oh a long time ye I mean that's as you say about

*retiree
14 years
- survival
happy & complete*

2911 G I must have had these I fourteen years I've had me nose off this September

"14 years"

2912 that's just gone and eh I must have had these in at least ten years because I was

survived

2913 gluing for about four weren't I so I've had them in for ten years. I don't regret

2914 one minute of it.

2915 F Good that's good. Thanks very much, G.

301 G Do you Know I've not told anybody about this but I'm gonna tell you that me
 302 husband has not looked at me in that way, not wanted sex since I had me nose
 303 removed. It didn't bother him when I had me breast off but he went straight off it
 304 when me nose was took off. Yeh, Yeh.
 305 F That's interesting G how did that make you feel

Confides in
 starts
 sexual relation
 husband
 aware of
 body change
 lack of support
 queer her own
 appearance & sexual
 attractiveness.

Body Image
 Change
 (sexual)
 concern
 Sexual
 attractiveness
 concern

306 G I'm not bothered because he's a no gooder anyway.

justification
 for situation
 - humor

humor
 - embarrassment
 denial.

INTERVIEW ENDS

INTERVIEW G

11 F If you can tell me, how did you first discover you know that you had something
12 wrong?

13 G I had you know me nostrils I had a little spot come under there I mean the story
14 even before that was as a baby I had a little spot come in this place here just under
15 me nostril and me mother noticed this little spot and so she took me to the doctors
16 and he said if it got any bigger I'd got to go to the hospital which it did and I went
17 to the old Infirmary and there they put four radium needles in the soft part of me
18 nose, there, and then apparently it all scabbed over and they put some purple stuff
19 on it and the scab came off which left me scarred I used to cover that up with
20 make-up. So as far as I was concerned that was that and then one day that little
21 spot appeared here and I don't pick me nose usually (laugh) but it annoys you so
22 you know and it wouldn't heal up so I went to my doctors and he said he looked
23 at it and he said oh doctor so and so will burn that off.

*1st Sig Memory
Recollection
of Childhood
poignant
Memories
mother/daughters
bond*

*apparently
forgets
left me scarred
covered it
appearance
conscious of
reflecting*

*Reflective
experience
(childhood)*

*Appearance
Body Image
Concerns*

114 F How old were you at that ...

54
115 G 54 yep and eh he said the doctor will burn that off and I know I went home
116 thought about it and I thought no no I want more information about this so I went
117 back and I saw a different doctor down at the local GPs. He looked at it and I
118 said Doctor so and so said Doctor (name) is going to burn this off because I had
119 some antibiotic cream which hadn't done anything so eh he looked at it and then
120 he said nobody's touching that and I said to him well you know what it is and I
you know what
it is? does G
suspect cancer!

*time lapse
reflections
Seeking information
unconvinced
by doctor's
diagnosis*

*Seeks
information
Making
Sense
Fear
re-assured*

pays for an answer (or confirmation)

pays-feels 21 can't remember his exact words what it was but anyway from there I know I paid
able to participate 22 to see a Specialist eh a Doctor (name) at Thornbury Annexe and while I was there
in consultation 23 suddenly and I don't know why out of the blue I looked at him and I said 'have I

requires information

Suspects cancer 24 got cancer?' And he said I can't I can't answer that one he says we wont know he
and seeks 25 says but I'd like to do three biopsies he said I'd like to do them while you're here.
confirmation or confirmation of negative

suspects/suspicious fear of diagnosis

26 F Why did you think that at that stage G?

thinking of 27 G I don't know it something just come into me head and something just clicked
cancer for something 28 and I don't know where it came because before that I never even thought about

Denies fearful

Denial/wants it not to be -suspects 29 cancer at all and it I just came out with it and he did these three biopsies and it
recollection (vivid) 210 turned out that the two out of the three was cancerous one at the side of me nose
211 because that had started flaking a little bit and the one that he did inside that
212 nostril and another one that he did which was alright. And I don't know what
213 happened from there but I had to go to my own GP and from there I was sent to

Specialist doctor 214 Dr (name) at the (hospital) a skin specialist. Now going through all this story he
refers to childhood treatment 215 told me that this was an overdose of radium as a baby it was called an naevous
216 this burnt mark thing that was in me nose and so I said well you know what do I
217 do from here and I was very upset you know he didn't say cancer but I already
becomes very upset -suspects 218 knew because I had got the results from Mr thing and um.

Emotions upset fear of treatment

Cancer (results confirm - suspicious confirmed suspected)

219 F How were you feeling about it at that stage?

A bit upset 220 G A bit upset, a bit upset but I mean I'd had my breast off in 1983 so I was eh eh
cancer confirmed 221 a bit upset but not not really to start sobbing and going off. I think I just shed a
reflects on previous cancer treatment and feelings

feeling fearful

"Where do I go from here" 31 few little tears but nothing nothing I would call anything and then from there I said
 "right" 32 well where do I go from here and he said well you will have to go and see a Plastic
 anxious to 33 Surgeon and I said 'right' and that was here because they didn't have any at the
 Start treatment 34 (hospital) and that is when I came to see Mr (name) the first time and Mr (name)
 35 must have read the notes and he wanted me to come in overnight because he
 cancer spread 36 wanted to do another biopsy but much further up so I came in overnight and he did
 Confirmation 37 this biopsy and I went home the next day but I had to come back the following
 of diagnosis 38 Wednesday which I did with me daughter and that's when we come on to the
 accompanied 39 horrid bit and we came in and I sat down and I says 'have you got the results of the
 by relative 310 biopsy' so he says 'yes I have' and he says 'I am afraid' he says 'we've got to
 daughter (suspects bad news) Composes herself
 Shocked/Unreal 311 take your nose off and I was numb I felt as though all that room and everybody
 Situation 312 in it was unreal it was (pause) it was just horrid and the nurse said to me 'would
 Avoidance/ 313 you like a drink of water?' and I said 'yes please' and she fetched me this drink of
 Dysfunctional C. 314 water and I had a bit and he started explaining about reconstruction about what
 315 they do and me daughter that was with me she said 'my mum wont like that' and
 Recollection/ 316 he mentioned about a prosthesis well with having a prosthesis for me breast I
 Comparisons 317 knew what one was otherwise I probably wouldn't have really known what it was
 318 and I just looked at him staring really I just looked and I said I'll have a
 Not knowing 319 prosthesis and not knowing anything anything about prosthetics nothing nothing
 Not wanting 320 at all I thought that I'd gone that day knowing that I'd have to have some sort of
 to know 321 operation to remove this cancer probably (cut) a bit off my nose there and probably
 denies 322 go inside me nose under a general anaesthetic and they'd do what they'd got to do
 horrendous 323 cut it out probably stitch it up and that was going to be that. But to be told that
 treatment 324 you've got to have the main feature on your face cut off was absolutely
 proposals 325 horrendous
 -unexpected
 Surprized at magnitude of treatment
 main feature of face removed
 mutilation of face - inevitable

Wants to get on with treatment

Survival of disease

Denies Situation fearful Unreal Situation

Shocked horror emotionally upset

41 F Did you feel any different, you know you mentioned that you had a breast off
 42 some years previously. How did you feel when you were told that you had to have
 43 your breast off?

not told prior to breast removed diagnosis unconfirmed prior to surgery daughter knew
 44 G I wasn't I eh I eh I was just had to sign the consent form in case eh well I
 45 think he he knew but I didn't know that I was going to have me breast off to have
 46 surgery um I signed the consent form that if whatever they were doing was
 47 cancerous they were doing a frozen section if it was cancer they were going to take
 48 it off but at that particular stage I didn't know my daughter did because she worked
 49 at Claremont at the time and she knew that she knew Mr (consultant) and eh I

Reflective experiences

Didn't shed a tear avoids/denies
 410 didn't shed a tear over that.

411 F What about after your operation to remove your breast, how did you feel?

412 G The only the only time I shed a tear over that was when the nurse a lady came
 413 in with a prosthesis she wanted your bra so that she could she started showing
 414 prostheses and I broke down and so did the lady at the side of me as well we both
 415 cried you know I I went angry and I wanted to get hold of these prostheses and
 416 throw them you know I really did I didn't want to know about it at all and in fact
 417 she came back a couple of days later and to see how I was and I said to her what
 418 would you have done if I had thrown that prosthesis flying across this ward so she

Anger and frustration Avoids Denies

anger and frustration with situation results in denial

Makes amends Seeks support Emotional focused C.
 419 says I'd have gone and picked it up you know so I says well very sorry I am not
 420 an aggressive person like that I said I don't know what on earth came over me to

Seeks pardon
 more angry
 anger Denial
 51 to do that . So she said its quite a natural you know eh people are different yes so I
 52 think I was more angry than upset really and I never cried any more about that.

feelings
 of
 Anger

53 F Was your nose any different to when you had your breast removed?

reiteration
 and emphasis
 cover breasts
 and look normal
 concerned appearance
 inhuman
 Monster
 mutilation
 54 G Oh god the removal of my nose was much much much worse oh it was
 55 absolutely horrendous that because you can cover your breasts up you can cover
 56 that up with clothes you know you get a prosthesis for it and its measured and you
 57 just look normal you know but to think that you've got to have your nose off you
 58 say what the hell am I going to look like I'm going to look a monster its its just
 59 something that its so hard to describe unless its you.
 510 F You can't it's difficult to know how.....?

horror

Concerned
 Appearance

appearance
 concerns and
 impact on others
 Staff accept
 feels good
 forgets mutilations
 - Skips to
 reconstruction
 511 G You can't I mean like you've seen me umpteen hundreds of times without it on
 512 and it doesn't bother you but if it was you you would feel you would feel so you
 513 would probably feel like I you really would because and I mean everybody has
 514 been absolutely marvellous with me and which I you know I mean people are
 515 aren't they because such a horrible thing it really really is but I mean I remember
 516 Mr (consultant) sending for you and then we came down here with me daughter
 517 and I had to have this impression which was all everything was so real about that
 518 afternoon because it went on into the evening really didn't it? Half past sixish

Staff
 Supportive

Reconstructive
 procedure

tell the family
 "bad news"
 involve the family
 upset/support
 519 going on seven you know and then I had got to go home and er then tell the
 520 family you know.

family
 relationships

61 F And how did you feel then, how did your family react?

finds it
difficult to
tell family
delegates
task
avoids
unpleasant task

62 G I said to our well we went back to me other daughter's and I said to fetch me

63 husband up because I don't want to have to tell one and then have go and tell him

Avoidance
Denial

64 which they did they rang and and he came up to me daughter's and I went I think I

65 went up to the toilet eh and my daughter told them.

daughter inparts news

66 F Ah right so you didn't you didn't tell them anything.

Couldn't
(emphasises)
horror
awful

67 G No no I just couldn't I just couldn't I felt (pause) oh just I don't know it was just

68 horrendous it was really awful.

Shock
horror
awful

69 F So how long then after that news did Mr (consultant) leave it before your

610 operation?

prefers to
forget

611 G Oh not long not long do you know I don't know whether it was the following

612 week

denial?

613 F So pretty quick.

recollects
'did it'
finality
mutilation
would not look
at image
avoids reflection
denies.

614 G It was very quick ye I think it was the following week and me daughter brought

615 me in me eldest daughter brought me in and eh (long pause) and then they did it

616 at ???/ and I think it was a Wednesday morning that it was done and I remember

617 eh for I wouldn't look I wouldn't look at all and when I wanted to go to the toilet

618 they had to put newspaper up at the mirror even though I'd got a dressing a big

finality
fear

Appearance
Concerns

avoids reflection immediate denial of situation Staff helpful

71 dressing over it. When I went to the toilet I asked if somebody would put either a
 72 towel or some newspaper because I didn't want to see anything of meself at all
 73 when I went to the toilet which they were very good and did that and I remember
 74 the Sister I think she's left now and I have forgotten her name.

Denial of situation

75 F Was it Sister (name)?

Recollects individual Staff members Write down goals Active coping strat. (problem focused)

76 G Ye ye she was a lovely lady she would even come and massage my feet
 77 underneath to try and relax me she was wonderful and she even gave me a paper
 78 and asked me to write down me goals what I wanted you know and I eh eh put to
 79 see myself and also to go home because I was in hospital about a fortnight I think.

Staff help Coping

710 F Did you find that helped? Did you find that input from Sister (name) helped?

helpful Staff important information

711 G Oh I mean from her oh she was wonderful because I asked her to draw could
 712 she draw me a picture of what I would look like without a nose on and I
 713 remember she drew this picture and obviously now I know it was exactly what
 714 she had drawn but you couldn't envisage what was on that paper that you were
 715 going to look ye ye and I didn't look first and cor for about 10 days I think and
 716 then one day there was one of the little wards there was no one in it and she asked

V. Supportive Staff

Staff helping coming to terms Support from Staff (individuals)

717 me if I wanted to go and look and I said well I know I've got to face this but I
 718 don't really want to she said that she would she would be with me you know I

professional Support

719 mean you'd already got the impressions and everything and was making me nose
 720 weren't you while I was in hospital and anyway she took me in this this ward and

recollects image - reflects on rehabilitation

hugging me emotional support

721 hugging me ??? the mirror was high so all I could see was me eyes (laughter) and

Holding hand
 - comfort and support 81 eh I had to stand on me tiptoes and I remember her holding my hand and I looked feeling
 Looked - dreadful 82 you know and I just thought it was dreadful I thought it was awful because it is just fearful
 hole middle of face 83 like a hole in the middle of your face with (pause) a section??? down it as I now Shock at
 Pauses at recollection 84 know what it is (laughter) I didn't know what you called it then it was just awful appearance
 - vivid recollection 85 really really awful and the only time I started to feel human was when I came horror of
 laughs (nervously) Situation
 Awful really really 86 down here and you put that nose on me. I went back onto the Ward and I felt like appearance
 twice) awful Concerns
 Immediate 87 a person felt like a person Compares
 prosthesis - feels human with previous
 like a person - regains human image Self
 comparison with pre-operative state - image
 88 F You felt a lot better than

emphasis 89 G oh god ye

810 F That was a glue-on prosthesis wasn't it?

prosthesis
Problems

did not like 811 G Oh it was awful that glue I had. Did I do it for about four years?
glue prosthesis

812 F I think you did.

813 G I must have done ye

814 F Even though it was a glued-on prosthesis how did think about that, how did you

815 um when you went out into general public areas shopping and things like that?

alright but 816 G Well it was alright but there were certain times when the glue started to come lack of
glue came confidence
unstuck 817 unstuck from the bottom, you know, just above me lip and you could feel it in nose glue

Nose glue
did not feel
Secure
'the thing'

91 loosening and that was awful because you had to keep like as though you was
92 wiping your nose but you wasn't really you was holding the thing on you know the
93 gluing was an awful awful thing.

insecurity
of glue

94 F As far as how it looked G, how did you feel about it?

looks very
well pleased
with appearance

95 G It looks very well, it really really looked very well so it did ye and you did give
96 me some glasses and I wore those glasses for quite a long time.

compares
prosthesis

Public situations
97 F So how did you feel then when you were shopping and things like that?

feels alright
98 G I felt alright.

99 F You felt alright.

fears physical
Pain from
cleaning out
nose

910 G Ye, I think I think it took me a long time because you know the District Nurse
911 used to come and clean the cavities out and um I remember she hurt me one
912 morning because I said to her 'how long will you be coming to have to do this'
913 and she said 'well for as long it as long as you feel you can't do it yourself' you
914 know and I know she came for about a fortnight and then one day she she really
915 hurt me and I thought I'll have a go at doing this meself which I did and I've

staff
support

Self cleaning
to avoid physical
pain

916 done it ever since but there was one particular morning and I can remember that
917 very vividly and er I was at me daughter's and I er er slept there actually I was

Family Support
angry/frustrated

918 there a while and er I I'd got a this big mirror on a pillow and all the stuff I got
919 out and all of a sudden I got this ??? feeling just like the feeling that I got in me

angry
with
situation
denies

Social Comparisons 101 breast and I thought what the hell am I doing with all this stuff and this nose and feelings of anger and frustration
 Real people do not do this 102 everything and there again I wanted to to throw everything through the window Unreal Situation
 Wants to be real 103 because it wasn't real you know and I remember saying to me daughter to me son- Social compar
 - may see herself as unreal (without a nose) or abnormal 104 in-law and I just said 'this this is just not real what I'm doing its just not real' Denial of situation
 105 people don't do this you know and it was a really bad morning a really really bad
 106 morning.
 Denial of situation just angry and frustrated not real

107 F So you felt angry about this?

angry frustrated 108 G Ye, I just wanted to throw the nose through the window and all the cleaning unnatural
 wasn't natural 109 stuff with it everything I just wanted to get rid of everything because it wasn't unreal
 110 natural because it wasn't real. Situation

1011 F What were the members of your family saying round about this time?

Support daughters 1012 G Eh all my daughters were, my youngest daughter I I stayed there because my Family Support
 husband unsupportive 1013 husband hadn't got much idea of what to say and when I did go home I used to
 cries in front of husband- 1014 cry a lot I cried a lot about it and eh (sigh) he used to be quite honest with you
 Seeking support 1015 he said I remember one day I was crying I had got my tea and I didn't want it emotional release/seeking support
 1016 I was crying and he said 'oh I can't cope with this' he said 'I'm going to ring
 husband 1017 Janet up' and he rang Janet up 'you will have to come and fetch your mother I husband
 unsupportive 1018 can't cope with all this'. Now that didn't give me that much support but I didn't unsupportive
 ~ Can't cope 1019 want to be in that place with him I wanted to be with me daughter and me son-
 ? doesn't know how 1020 in- law as you know with (name) he was absolutely fantastic with me and they for support Support family
 ? relationship

son-in-law and

daughters 111 were wonderful if he hadn't have been for me two daughters and a son-in-law I

Wonderful 112 think I would have gone crackers.

Very helpful and supportive

Emotional Support family

113 F So you felt that they helped....?

fanstatic

114 G They was absolutely fantastic but me husband had just got no idea, no idea at

husband 115 all. You know and I stayed there quite a long time, you know before I I'd until

unhelpful 116 really I I'd accepted everything I could do everything and then then I went back

'accept's and return home

117 home.

'Accepts' reframes

118 F So when you say you started to accept things did you feel different about

119 yourself? How did you feel?

things very

1110 G I suppose yes, I suppose I did a little bit but (pause) there again if you look at

logically reflects

1111 things very logically it's you that's gone through it all and if people can't accept

coping rationalises

1112 you for who you are you are still the same person, you know, and if people can't

Still same

person (physical changes)

1113 accept you for who you are then I couldn't care two pence, you know what I

1114 mean (pause) and now I don't even wear the glasses. I have got some glasses in

does not wear

1115 there but that that I get to make things look a bit sharper but its very rare that I

glasses

1116 wear them.

Question's attitudes in society

Confidence returning

1117 F And you feel confident in walking?

feels confident

1118 G I do yes, because I couldn't care less what anyone else thinks now, you know,

14 years survival

1119 when its fourteen years on, fourteen years on now aren't we, you know and I

(Emphatic C.)

emphasis

positive reframing

horrible Job
horrendous
awful

121 just think its me that has to do this horrible job every morning of cleaning out the
122 cavities every morning, its me that has to do it an when I've got cold its
123 horrendous. That is awful.

Acceptance
Active coping

124 F See all your mucous and things like that.

horrible
Sees humour
accepts

125 G Aw (sigh) even horrible it really is horrible, you know, it makes meself feel
126 sick (laughter) it really does but I mean that is just something now that I have
127 come to accept.

128 F So have you accommodated the fact that you have got this to do and you just get on with it?

fully fully
Survival
accepts
compares with others

129 G Ye, I get on with it now and fully fully well after fourteen years you do accept
1210 it don't you? But I don't know whether everybody still does or not.

14 years
Survived

1211 F Well, not everybody does.

aware of change
appearance
concern

1212 G Well, I mean I still know and I still look and I try to make eh me nose feel as
1213 though its gone into like a (pause) crevice, a frown, if you like, eh eh a line if
1214 you know what I mean on me face so that it kind of fits in there but as I say then
1215 I put the make-up on and put make-up on that to match me face and then I feel
1216 quite confident.

Acceptance
active coping
Self aware

confident
with make up
on

1217 F You feel.....?

both types of prosthesis 131 F You've had both types of prosthesis, G, you've had the implant prosthesis that
 132 you wear at the moment.

Wonderful implant 133 G, oh ye, that's wonderful.

134 F And then we started off with an adhesive, glue-on stick-on prosthesis which I
 135 think you had for about, I think you said four years.

136 G It must have been about four years that, ye.

137 F What would you say the differences just between one and tother?

Magnets fantastic 138 G There's no comparison whatsoever, I mean the the magnets are absolutely
feels confident 139 fantastic they really really are, I mean, you do it, you click it on and it doesn't
Secure in public 1310 come off unless somebody cracks you on the side. The pull is very very good,

Magnets increase security

aware of problem 1311 the pull that way forward but if somebody give you a crack with the elbow or
 1312 their hand sideways then obviously it would come off, you know, but eh, in fact
 1313 I was at on Bonfire night this week on Monday night I was sat in this house and
 1314 there was two people in the room as well as me and I don't now how it
 1315 happened but all of a it must have been meself it was meself and I don't know

Nose came off but replaced 1316 how I did it I knocked it and it came off so quickly but you know me reflexes, it
 1317 fell, like that, I picked it up and put it on and turned round and nobody was the
laughs - accepts 1318 wiser, no, nobody knew (laughter). I just got you know....

Copes with situation GFC.

Emotion foc. C.

141 F So practically, Is it a lot easier to to.....?

Wonderful 142 G Oh, it is absolutely wonderful, oh it's wonderful, if you could talk people into
good for others 143 having it done.

Social
Comparison

144 F Any differences in say how it...it.....?

glue on nose 145 G Well, when you first glue it on, I mean, it sticks down and it looks alright, its
looks good 146 just the annoyance of it coming unstuck, I remember once I was gong to a eh eh
but annoyed 147 an aerobic class thing and we was laid down on this mat and it wasn't very far
with insecurity 148 from where I lived, it was only round the corner and I just got laid on this mat
"Cramps
lifestyle" 149 thing and all of a sudden I could feel it starting to come away and I just said to me
re glue it 1410 daughter I am sorry, I said, we will have to go home and reglue this, you know,
1411 and I had to run home, take it off, reglue it all, stick it back on and then go back.

Image
Insecurity
of glue resi

not like that 1412 Where, with with magnets there is nothing like that, oh ye, them magnets are
with magnets 1413 wonderful oh I have never regretted I have never regretted them for one minute,
magnet nose 1414 oh I haven't. Absolutely, fantastic.
Wonderful

Compares
Magnets
and glue

1415 F Would you feel unhappy about going back to a an adhesive retained

1416 prosthesis?

1417 G I would, oh, I'd hate it, I would hate it, ye. I mean its like if anything

Would hate 1418 happened to me then they had to come out and had to have it redone I would
another glue
nose 1419 have it redone because the difference is, there's just no comparison at all.

Peelers
Magnets

feels a lot safer
151 F That's ok?

152 G You feel such a lot safer with this one, ye, oh ye.

A lot safer and secure

153 F And you wouldn't want to go back to a dressing?

does not like dressing either
154 G No I wouldn't go out, no, oh no. Do you mean just a eh eh dressing over that.

Would not go out - Image
155 I wouldn't go out.

156 F You wouldn't.

Wouldn't every body
157 G No way, oh no, no I wouldn't. No, because everybody would know, because it

Would know - image appearance
158 is flat, you know, like at night when I take it off I put a dressing over it, you

even in private situations
159 know, I cut triangles out of the melolin dressings and put micropore on, you

B.I.
160 know, stick a bit on the top an a bit on the side so that it could breath at night

161 and I do that and then obviously take it off first thing in the morning and put it

162 straight on. Have me breakfast and then go back up and clean it all. You know.

163 straight on. Have me breakfast and then go back up and clean it all. You know.

164 straight on. Have me breakfast and then go back up and clean it all. You know.

165 straight on. Have me breakfast and then go back up and clean it all. You know.

166 straight on. Have me breakfast and then go back up and clean it all. You know.

167 straight on. Have me breakfast and then go back up and clean it all. You know.

168 straight on. Have me breakfast and then go back up and clean it all. You know.

169 straight on. Have me breakfast and then go back up and clean it all. You know.

170 straight on. Have me breakfast and then go back up and clean it all. You know.

171 straight on. Have me breakfast and then go back up and clean it all. You know.

172 straight on. Have me breakfast and then go back up and clean it all. You know.

173 straight on. Have me breakfast and then go back up and clean it all. You know.

174 straight on. Have me breakfast and then go back up and clean it all. You know.

175 straight on. Have me breakfast and then go back up and clean it all. You know.

176 straight on. Have me breakfast and then go back up and clean it all. You know.

177 straight on. Have me breakfast and then go back up and clean it all. You know.

178 straight on. Have me breakfast and then go back up and clean it all. You know.

179 straight on. Have me breakfast and then go back up and clean it all. You know.

180 straight on. Have me breakfast and then go back up and clean it all. You know.

181 straight on. Have me breakfast and then go back up and clean it all. You know.

182 straight on. Have me breakfast and then go back up and clean it all. You know.

183 straight on. Have me breakfast and then go back up and clean it all. You know.

184 straight on. Have me breakfast and then go back up and clean it all. You know.

185 straight on. Have me breakfast and then go back up and clean it all. You know.

186 straight on. Have me breakfast and then go back up and clean it all. You know.

187 straight on. Have me breakfast and then go back up and clean it all. You know.

188 straight on. Have me breakfast and then go back up and clean it all. You know.

189 straight on. Have me breakfast and then go back up and clean it all. You know.

190 straight on. Have me breakfast and then go back up and clean it all. You know.

Concern re appearance and image (even in private)

Social Interaction Confidence

body image external appearance important for feeling of confidence

body image must be acceptable for restoration of confidence

Much happier with prosthesis nose

161 F So it is fair to say then that you are much happier with a prosthesis than with a
162 dressing on?

happier with magnetic nose

163 G Ye oh ye, hundred percent, hundred and ten percent, ye.

implant nose

164 F And as far as the thing that you prefer most of by these implants?

165 G Definitely, most definitely ye and anybody that won't have them, I mean, I just
166 cannot understand it, you know, I really can't. They just don't realise how

Commonality Social Comparison

167 brilliant they are, I mean I can't thank the NHS enough for what they've done for
168 me.

169 F So you'd say it has made a difference to the quality of your life?

experiential reflection

1610 G Oh ye, I mean if you've got cancer and you have got to have a nose off it is

1611 very aggressive its awful, an awful operation, you know, but to think you can

Awareness of Self

1612 have a nose and the people that do know about it have said you would never

appearance and body image important for societal re-integration

1613 know would you unless you'd told me I wouldn't know which is great for you,

Social Interaction and re-integration

1614 as well as for me. Is it, you know? It is a compliment for you that's making the

1615 noses as well. But I mean I think they are absolutely brilliant, I know that that

1616 down there but I mean some people have one if they've stopped being reading

1617 or whatever. I've even noticed on the television that if I look at the television

Social Comparison trying to find commonalities

1618 and I look at people's noses and there is one or two people that's got like a

1619 permanent dent there and they've got no glasses on.

Compares with others

171 F And you get things on the side of your nose as well, things like that.

Copes with situation

doesn't bother me but aware of change in appearance

172 G Ye, ye, I mean, like as I said, I come on two buses this morning and it doesn't

Self awareness

173 bother me one eye I don't find people staring at me, I don't at all. If I did, if I

~~prob. fac~~

174 really did find that people was staring at me and I'd think they are looking and

looking for stares

prob. fac Strat.

175 they can tell then all I would do was put me glasses on.

176 F Right and that would just hide that.....?

accepts her situation does not impinge on life style

177 G And ye and probably a little bit there and but it wouldn't stop me going out

Accepts Situation

178 going into town and shopping or whatever.

179 F You would not feel any different about it you would just get your glasses on?

glasses on - cover up

1710 G No I would just put me glasses on that's only if I found people staring at me

aware and looking for stares

1711 which people don't. You know I don't go to town and look to see if somebody

Coping

1712 has got a false ear on or a glass eye. You are too busy with your own life to be

Coping (Emot. fac)

1713 looking at people's faces. That is the way I look at it, anyway.

1714 F Did any people and even including your own family and friends as far as what

1715 they are saying to you did that help at all to make the shock of eh having to have

1716 your nose off any different any more bearable?

1717 G No not really.

181 F You were sort of lost in your own thoughts?

Intense Shock
at diagnosis 182 G Yes yes I was ye. It was just as I say, it was just too horrendous I was so numb
183 I couldn't I just couldn't get to terms with it for quite a while, really couldn't.

horror
denies

184 F How long would you estimate that it took

185 G Um do you mean before I started to come to terms with it?

186 F Yeh to come to terms with things.

1 year to come
to terms
months not
weeks 187 G It was I would say it must be going on a year before I I really started to come
188 come round properly, ye, I know, (cough) excuse me, it was a matter it was more
189 it was months it wasn't a matter of just a few weeks and I'd come to terms with it
1810 it wasn't that it it was months. Yc.

1811 F Did you find that you accommodated that yourself or did anybody around you
1812 help you?

Cancer - nothing
I can do
Mutilation is
Preferable to
death survival
at all costs
Nothing nothing
(twice) I can do
reiterates to self 1813 G There was there was all helping me but the thing is its your mind and its you
1814 that's got to get your mind into that situation where there is nothing I can do
1815 about this, you know, it I had cancer I've had to have me nose off and I've got
1816 down to get on with it because there's nothing there's nothing I can do about it.
1817 Everybody in the medical profession like Mr (consultant), like you you've all

wants rid
of disease
justification
of treatment
for survival

Self help and coping 191 done everything you can to help me so there's only meself now that can get to
 middle of face 192 terms with this another thing it does take months because its its slap bang in
 impossible to cover affects 193 middle of your face this is the thing, you know, if it wasn't so prominent like I
 image and appearance 194 said your breast you can cover you can cover up and I got to terms with that ever
 come to terms 195 so quickly even though it it was serious very serious thing but I got to terms with
 with mastectomy 196 it in fact I think I've always been in denial of this in all these years its twenty
 - Denies breast surgery covered 197 twenty four years, you know.

Appearance Concern

Denies Mastectomy Surgery

Denial

198 F Since you had your breast removed.

Knows exactly 199 G Twenty three and a half years, ye, in 1983 and eh I've just been in denial of
 DENIES 1910 that and my thoughts to that was oh it was horrible there was something really
 1911 wrong with it take it off its gone and I've always looked with that I've not
 Does not want to know 1912 wanted to know about cancer in me breast I didn't want to know and I've never
 1913 wanted to know but when something slap in your face is that's a different
 Dys. co. Strat.

and a half!! Dysfunctional C.

1914 F That's your thoughts and?

1915 G Ye, that's different ball game all together.

Facial cancer different - impossible to hide and cover

Appearance Concern

1916 F So did you find at that time and do you find now that people treat you

1917 differently?

1918 G No oh no.

201 F The same?

202 G Yes its just the same now ye.

203 F Right ho.

happy
QoL

204 G Yes, I am very happy with very happy with it all.

205 F So you look at yourself now and then look back on all that time?

Reflective

206 G Oh ye I wouldn't want it back again (slight laugh) I wouldn't want it back

207 again I would not want that back again. Emphasis x3

208 F But would you say that you've recovered from it all?

Recovered
um!

209 G Um, really because it's like every morning when when I've got to clean the
2010 cavities and you think oh god I've got to get that job done, you know, and it's

Emotional
acceptance
physical
acceptance

2011 not a nice job even doing that you know so I mean I've accepted it all and

2012 everything but it don't mean to say that I like it (laugh) you know what I mean.

EM. foc.

2013 I have accepted it because I can't do anything about it but I don't like it that's all

2014 but I am confident with it as well am I making sense.

learns to
live with it

2015 F I think I know what you mean, it's almost as if what you are saying is you'd

2016 feel recovered is if you had your proper natural nose back.

Coping
accepts.

211 G Exactly.

212 F Right oh.

Soc. Comp. 213 G People don't know how lucky they are when they've got one. When you look

anger/frustration

214 at the television these people having nose jobs done makes me so angry and I

Anger and
frustration
Comp. Soc.

Situational Awareness of difference 215 want to ye because I just feel as though I just want to shout at them be thank god
216 you've got one.

217 F Rather than thinking about messing about with....?

Aware and annoyed

218 G Ye, stop messing with it you've got a nose, I haven't and it really I want to

219 shout at them, ye, that does annoy me very much.

Image awareness annoyed Soc. Comp.

2110 F That's ok.

Not perfect but mini-real loss bereavement for body part grieving

2111 G Because I mean my nose it me own nose wasn't perfect by any means it it

2112 really in a way didn't look very nice but it was mine and it was attached to me

2113 and all that all those months it was kind of a grieving process because you have

2114 lost part of your body, haven't you you know.

loss/bereaves
Grief and acceptance

2115 F Do you ever see your prosthesis as being your nose?

Appearance changes altered body image

2116 G No because it (pause) my nose didn't look anything like this I mean this is

2117 great don't get me wrong.

Altered Appearance Body Image

221 F We could change the shape of that....

Accepts
Physical appearance
change and
body image

222 G I think my nose was maybe maybe it was a bit smaller I don't know, this is

Coping

223 great because it is straight, mine wasn't but I wouldn't want a nose making like

Em. foc.

224 that um (pause) I'm just happy with the way I'm happy with the way it is, ye I am

Coping

225 ye as I say and everybody's been so marvellous that you can't praise people

helpful
Staff

226 enough I just think everybody's great been marvellous with me.

Acceptance
of changes
in appearance

227 F Because of that has that helped you then?

Confidence
in professional
Staff.
on hand to
help

228 G Oh ye I was oh definitely definitely ye. It does because people know like you

229 you know what you're talking about and you can help like if I'd got a problem at

2210 home and I could ring you up and you would help me and the help is there

2211 straight away which is nice to know.

2212 F That is the same with other people as well?

other bits
other tumours

2213 G Oh ye ye exactly ye because where all these other bits of things have come

Tumours
Survival

2214 from I just don't know. It is like I nearly live here (laugh). It makes you

2215 wonder if it's all come from this you know.

2216 F It's possible you know I mean maybe but at least

other
treatments

231 G But Mr (consultant) said you know when I was having me head done we are

232 going off well we're not going off because we got talking about me nose actually

233 one one when he was doing me head and I said to him I said well you know

Reflection

Reflective
very aggressive
surgery

234 having me nose off was very aggressive surgery wasn't it and he said oh yes so

235 he said eh we were talking about basal cell carcinomas and I said to him why do

ulcers not
cancers

236 people call them rodent ulcers when they are cancers and I says can I just give

237 you my answer before you give me yours and I said is it because it buries in one

buries in one
place not all
over body

238 particular place and that's why you call it like a rodent and he said well ye that's

239 it exactly so I said but I said but with me nose I said that was so such a big

2310 surgery that one he says yes that was very aggressive he says that might have

2311 taken five years

2312 F To grow to that sort of size yes.

Still Seeking
answers
Justify
removal
of
nose

2313 G But then looking on the other hand like the storey I've just told you about the

2314 radium needles and Dr (consultant) saying you know er about that so how did it

Questions
Justification
of treatment

2315 take fifty four years then for it to come out if it was an overdose of radium and

2316 that I don't understand that I've never asked Mr (consultant) because he's too

2317 such a busy man and I I wouldn't go into all that with him but I have wondered.

2318 F Well a lot of these things take time to alter the cells G.

2319 G So that's why it would have took all them years and then something triggered

2320 it off and then it started and as he said it must have took about five years to have

2321 got to the stage that it got.

rodent ulcer cancer
 Slow growing
 - reduction in
 Severity
 and reassurance

241 F Well basal cell carcinomas you know is a very slow growing tumour but it is

242 also some people refer to it as a rodent ulcer

243 G They do ye

Slow growth
 ulcer
 Survival

244 F Yeh.

Keep popping
 up - self
 examination

245 G So maybe this is why they keep popping up you know in these different areas

246 of me face I've even had them under me lip you know under there.

247 F They are annoying little things but it's.....

Justification
 for facial
 mutilation - and
 Survival death was inevitable justifies to self.

248 G If I hadn't have had me nose off if I'd just stayed I'd refused to have had me

249 nose off would it have gone up and gone into me brain and killed me.

2410 F Almost certain, ye, ye.

Treatment
 at all
 costs.

2411 G I thought that.

Survival at
 all costs

2412 G But it was still, well I mean I could have been dead before it had got there

2413 really, ye, you don't take that risk do you. You get it out.

2414 F And the big advantage of getting all the treatment early G.

Justification
 of treatment
 for survival

251 G Mine, as I say it is still all over me face in, one day there is nothing there and
 252 then all of a sudden and I find all these as I am cleaning the cavities that's how
 253 I've found all of them as I am doing that because I've got light haven't I you
 254 know straight onto me face and I look and that weren't there yesterday so I give it
 255 I give it so long and then.

daily
 Self examination
 and inspection
 of face

Prevention
 of
 further
 Mutilation
 Survival

256 F You diagnose it yourself?
 ?? diagnose ??

257 G Ye, ye, I think that there is something not right there I give it so long and if it
 258 hasn't gone away then I come and

'not right'

259 F Get it sorted out. That is very good, that's good. As you know a lot of these
 259 little things turn out to be nothing.

'Sorted-good'
 Self-reassurance

2511 G Oh I've had more I've had more that's turned out to be nothing but I think

2512 I've had about six or seven that's been something you know but I'm glad you
 2513 know noticed that one with my eye because I mean there again if I had left that I
 2514 could have lost me eye.

lost my eye
 -image
 concerns
 Self examination

Image and
 appearance
 Survival

2515 F Oh you could have done over time.

2516 G Little did I know that that was starting as a basal cell carcinoma there you

Cancer
 Starting
 but all gone
 away - that's good

2517 know so I could have lost my eye there but its all gone anyway that's good.

261 F This is the big advantage you you are looking for you get onto Mr (consultant)

262 and get it out.

Seems happy

263 G I couldn't be tret any better if I paid paid for it all everywhere in this hospital.

Acceptance

264 F That's ok G.

Supportive
Staff and
individuals
grateful
to individuals
Thinking of
her own
Situation -

265 G They do they do in that waiting room you know my appointment was such a

266 time I says excuse me I said Mr (consultant) is a very very good surgeon and

Staff
Characteristic
(individuals)

267 when you get in there you will find that you feel the only person that there is

268 something wrong with and he's very very thorough and this is why you're having

269 to wait a long time you know I just won't have anybody.

requires thoroughness

2610 F You tell them off do you?

So thorough
- Survival

2611 G Ye, ye I do in a in in a nice way but a nice but firm way really because I I

2612 mean he is so good and he is so thorough you know he is really lovely.

Confidence
(Survival)

2613 F He is a nice bloke and he is a good surgeon.

Staff
rapport
esp individual
intimate
rapport
guarantees
Good treatment

2614 G He is, his attitude is nice his attitude is everything. I had these on my lip done

2615 the other week and he said something Mrs G and I looked at him and I said

Individual
Staff

2616 don't you think that it is about time you started calling me G after all these years

2617 (laugh) and he just laughed and he said alright (laughter). You know, he is he is

2618 brilliant.

271 F G, that's been good talking to you G.

272 G He frightened me to death he did. Well because you talked to me about having

273 these implants done and it was Mr (consultant) and he wasn't far off retiring if

difference
in Staff
Members
esp. individuals
Staff
put off
treatment

274 you remember rightly and I had a talk to him and he did his damdest to put me off

Staff
Concern

275 and he scared me, yes he did, he really frightened me and I thought you know

276 because he was saying when you smile and when you know when you laugh

277 when you smile all your face alters and people will probably see a hole there and

278 the way that he came across he made it appear as though it wasn't really worth

279 having these implants I learned after that he's never done any implants and I

2710 would have been his first patient to do an implant on and so I think it was you

2711 who told me about Mr (consultant) and I went to see Mr (consultant) at Charles

Rapport
different
with other
Staff
instills
confidence

2712 Clifford because somebody gave me his card anyway and I went to see him and

Individuals

2713 I told him that Mr (consultant) had frightened me with these implants and he

2714 was as different again and when he finished talking to me I said that's fine I said

2715 I want them but I don't want him to do it.

2716 F So did Mr (consultant), if you had thought that Mr (consultant) was putting

2717 these in then.....?

Frightened
into not
having
treatment

2718 G I don't think I would have had them done. No because he frightened me, he

fearful
of

2719 frightened me in the way in the way that he spoke to me the way that he was

treatment

2720 going on about these implants and I think deep down it's because he didn't

as a result
of
Individuals

Staff
 differences
 281 know how to do it because he's never done one before and I was going to be his
 282 first one so I I'm really glad that I didn't let him do it you know and it wasn't
 283 long after that he retired and Mr (consultant) took over and he was he was
 284 fantastic I mean I had to have my implants done in two but they do them in one
 285 now don't they? I had to have the two didn't I? The bottoms and then the
 286 uppers. But Mr (consultant) he wasn't I think he was scared to be honest you
 287 know looking back I think he was so scared that he thought that well if he
 288 frightened her to death she'll not have it done which he did (laughter) and then
 289 talking to Mr (consultant) who really knew what he was at he was fantastic he
 2810 was you know and it was in very early stages weren't it with Mr (consultant)
 2811 you know, I don't know.

Sympathetic
 Staff
 Support

2812 F I don't know G.

absolutely
 brilliant
 lots of praise
 2813 G No he hadn't it was a very new thing for him but he was absolutely brilliant
 2814 that man and eh he has got a lot of praise I have got a lot of praise for him.

Staff
 Support

2815 F Do you ever see, does he call you in for review and things like that.

2816 G Mr (consultant) no no last time I saw him he was here when you were doing
 2817 me noses and he was here once but I've not seen him since. Does he work at
 2818 (name)?

2819 F Yes, he is still over at the hospital.

291 G Doesn't he ever come here now?

292 F Not really, I mean he comes over on odd occasions.

293 G Because he used to have patients here didn't he?

294 F Ye ye he used to have a Clinic here. But he now sees patients over there.

295 G He is a professor now isn't he?

296 F Ye, Professor (name).

Staff Praise
deserves it
feels confident

297 G Mind you he deserves it. He really deserves it. But I am so glad that Mr
 298 (consultant) retired. (laughter) I didn't like him. So I mean that's going back a
 299 long time isn't it?

Professional Support increases Satisfactor

2910 F Oh a long time ye I mean that's as you say about

14 years
Implant
nose much
preferred

2911 G I must have had these I fourteen years I've had me nose off this September
 2912 that's just gone and eh I must have had these in at least ten years because I was
 2913 gluing for about four weren't I so I've had them in for ten years. I don't regret
 2914 one minute of it.

2915 F Good that's good. Thanks very much, G.

Questioning
 appearance
 and sex
 appeal in
 relationship
 (husband)

301 G Do you Know I've not told anybody about this but I'm gonna tell you that me
 302 husband has not looked at me in that way, not wanted sex since I had me nose
 303 removed. It didn't bother him when I had me breast off but he went straight off it
 304 when me nose was took off. Yeh, Yeh.

305 F That's interesting G how did that make you feel

306 G I'm not bothered because he's a no gooder anyway.

ridicules
 husband
 making light of situation E.M. Foc. C.

INTERVIEW ENDS

Appearance
 Concern
 and sexual
 appeal

Coping Strat.
 humour
 Em. Foc. St.
 improve sit.

CHAPTER 5

5.0 FINDINGS (CASE WITHIN THEME)

Table 4 – Theme 1

Superordinate Theme 1: Emotional impact
Subtheme 1: Feelings of shock and fear
Subtheme 2: Concern for survival
Subtheme 3: Anger and denial

Table 5 – Theme 2

Superordinate Theme 2: Help and support
Subtheme 1: Family support
Subtheme 2: Professional support

Table 6 – Theme 3

Superordinate Theme 3: Return to normality
Subtheme 1: Post prosthetic experience
Subtheme 2: Acceptance and reflection

Specific cross-references detailed in the text may be followed by accessing the computer disc containing the text transcriptions (raw data) of each interview at appendix 11.

5.1 EMOTIONAL IMPACT

This superordinate theme comprised three subthemes; feelings of shock and fear on learning of the diagnosis of a facial malignancy; concern for survival which was uppermost in participants' minds and anger and denial.

5.1.1 Feelings of shock and fear

Participants experienced emotion and turmoil after the diagnosis of facial cancer was made. No less of an impact was the effect that surgery or the prospect of surgery had on each participant's view of the image they held in their mind and that which they projected to the world. Participants were frightened of what the immediate and long term future held for them.

G describes the moment she was told that she should have her nose removed as horrid and describes it in similar terms throughout her narrative "*.....that's when we come to the horrid bit....*"(G 3.9). She had suspected that she might have cancer (G 2.4) although tried to distance herself from the possibility by later denying she ever thought of it (G 2.8). She tries to distract herself from the situation and describes a cognitive shift of her perception of the room and of those in it (G 3.11) in an attempt to distance herself from the reality of the situation.

Though G denies the situation she felt that she had to inform the rest of her family of the news (G 5.19) and she did not want to keep reminding and upsetting herself by telling each member of the family separately so she asked her daughter to gather the family members together before imparting the news (G 6.3). The shock and horror of the situation continued to pervade her feelings and her daughter was left to tell the rest of the family the news (G 6.5; 6.7).

When H was told that he had facial cancer he had already spent two weeks in hospital undergoing diagnostic tests and drug therapy for the pain around his nasal area. He said that he already had suspicions that he might have cancer (H 3.10) and he appears to have taken the news calmly (H 3.13). H attributes this to the analgesic medication he was taking (H 4.1), although the news appears to have had some impact as he said that his mind was put "*more or less at ease*" (H 4.5) when told that he had a fifty fifty chance of survival. H implies that he was grateful for a one in two chance of survival at that stage. He copes by positive reframing and looking for the positive aspects in the situation. H admits to feeling "*dreadfully worried*" over forthcoming treatment (H 7.17). Later H again describes the point at which his consultant delivers the news (H 19.17) and reflects on the severity of the situation "*you know what cancers like*", easing the situation with laughter and re-iterates the comment (H 19.18; 19.19). He reflects on his chance of survival (H 20.2) and refuses to contemplate an unfavourable outcome and makes a definitive statement, "*it can't go the other way that was it*" (H 20.3).

J said that she did not know what was meant by the word tumour (J 2.17) and describes herself as being “*very naive*” (J 2.13). Her concern was for a return to normality. Though J claims that the word tumour held no meaning for her and describes herself as “*not medically knowledgeable*” the phrase “*brain tumour*” seems to have been well understood (J 2.10). Naivety, or simply putting dreadful news to the back of one’s mind may be her defence mechanism; a way of distancing oneself from unpalatable news or events; a denial of the situation and distraction from reality. Evidence of these dysfunctional coping strategies may also be seen in J’s use of alcohol.

B describes her feelings of utter devastation and imminent demise on receiving the news that she had a facial malignancy (B 2.6; 2.7; 2.19; 3.4; 3.9; 11.11). B denies and questions the fact that as a nurse who attended cancer patients in the community, felt that cancer always happened to someone else and as a carer of the sick, immune to the disease.

D describes feelings of being “*quite shocked*” (D 6.6) on receiving the news that she had cancer in her nose. She remained, she said, “*quite calm*” and was adamant that she was not going to break down and cry at the news (D 6.9). D had been convinced for several months that something was wrong inside her nose and had been attending outpatient appointments for approximately one year previous to her diagnosis. She wished to appear steadfast and exhibit little or no emotion

whilst in the company of her professional attendants. Later D talks of the shock being “*so great*” (D 8.6).

C found talking of the moment he was told that he had cancer and would need major surgery very upsetting (C 2.20). Later reflection still causes C great heartache (C 12.14).

5.1.2 Concern for survival

Participants felt that treatment on such a major scale was inevitable. In their mind was eradication of the disease, regardless of the extent of treatment and survival at all costs.

G reflected on the inevitability of treatment (G 18.13) and seemingly, in an attempt to prove to herself and justify the need for such radical surgery and mutilation, she poses questions and offers herself scenarios which would have entailed a much graver outcome (G 24.8; 24.12).

H appeared satisfied that his consultant thought his chances of survival at least were even (H 4.5) and he comments that he was never concerned that he had a facial malignancy (H 9.2) but was acutely aware that, potentially, he had a life

threatening illness and other patients had not survived (H 6.11; 6.18; 7.1). He felt his chances of survival increased when he was discharged from hospital (H 7.2).

Although B thought that she had little chance of survival (B 3.1; 5.5) she used her experience of nursing cancer patients in the community and she felt, improve any chance of survival by staying focused and as normal as possible (B 5.12). When B required a second operation to remove residual tumour she readily agreed to the surgery, not needing time to think it over even though she knew it meant the loss of her left eye (B 6.13). B wanted rid of the tumour (B 7.5; 7.7; 8.3).

D also wanted to be rid of the tumour (D 9.10) and felt that she did not have a choice in respect of subjecting herself to disfiguring surgery (D 10.4). Some of D's relatives had succumbed to cancer and it was important for her to survive (D 15.14; 16.7) and she felt, important for her family to have someone survive the disease, possibly to prove that a member of the family could conquer a life threatening illness which had caused the death other members of her family. Though she has researched and considered it, D ruled out surgical reconstruction as an option as frequent examination of the operative site for recurrence would be compromised.

Survival and the fear of recurrence is uppermost in C's mind (C 3.5). He cried throughout the early stages of the interview. Crying can be a means of emotional release but it can also be an attempt to manage feelings of frustration and

powerlessness. C talks of death, blindness and his desire to see his children (C 3.6; 3.10; 4.11; 12.14; 14.6) whilst crying profusely. Medical opinion that his chance of survival would be dramatically increased with a course of radiotherapy are met with obvious delight (C 4.16) which is repeated later in the narrative (C 18.10) but he is preoccupied with thoughts of recurrence and death (C 16.3; 16.9; 16.15).

5.1.3 Anger and denial

Participants became angry with their situation and with themselves when the reality of the situation began to sink in.

G did not want to look at her reflection and asked for mirrors to be covered wherever she went (G 7.1). She felt the situation was too horrendous (G 18.2) and difficult to accept. She was angry at the daily placement of a prosthesis and considered it unnatural (G 10.1; 10.8) “.....*and I thought what the hell am I doing with all this stuff and this nose.....and I just said this this is just not real what I'm doing its just not real people don't do this you know and it was a really bad morning a really really bad morning.*” G felt that it was a year before she began to accept her situation (G 18.7). Acceptance for G was a realisation that although she had family support and professional help, her appearance had permanently changed. She felt that she had to get on with life but was still very much aware of her situation and is angered by the thought of facial plastic surgery to which some

individuals subject themselves in an attempt to increase their beauty and attractiveness.

H was well aware of the severity of a facial malignancy (H 19.18) and he uses emotion focused coping strategies by thinking of other, 'more enjoyable' aspects of treatment (H 20.12). H makes several references in his narrative to his family, especially his wife and the effect that the situation had on her (H 3.7; 3.13; 4.4; 5.21; 6.16; 9.2). His distraction from his predicament may be his own defence mechanism; his making light of the situation with the pretence of "*everything's fine*" suggests dysfunctional coping strategies and continuing denial.

Facial disfigurement had a profound effect on J. Her situation overwhelmed her and she drank excessive amounts of alcohol in an attempt to hide from her predicament (J 5.9). She refused to look at her reflection after operation (J 9.4; 9.9) and she admits to many episodes of grief and crying both before and after her operation (J 24.5).

Preserving as much normality in her life was B's mechanism for dealing with her predicament after she was diagnosed with facial cancer (B 5.7). Keeping focused and as normal as she could whilst putting the thought that she had cancer "*on a back burner*" (B 5.14). After her surgery B refused sternly to have anything to do with her wound (B 9.9) for some time after her operation. She finds that she gets very angry if she feels that onlookers are staring at her (B 14.7).

Denial of the situation in which she finds herself is used by B as a defence mechanism (B 22.4; 22.10; 22.16).

D found herself angry (D 6.6) at treatment she had received before her referral for specialist treatment but relieved that her condition had been diagnosed and that surgery to rid her of her tumour was imminent (D 8.8). Her anger had given way to relief and carrying on as normal was important to her (D 18.12; 19.5). She becomes frustrated with everyday tasks that her situation renders more problematic (D 20.10; 20.15) but finds the release of anger to be therapeutic (D 24.8).

As noted above, C's frequent episodes of crying (C 2.21; 3.6; 3.10; 4.11; 12.14) may be an emotional release mechanism or an attempt to manage his frustration he feels for the situation he finds himself. His frustration, at certain times, turns to anger (C 15.1) and aggression which is directed towards his relatives as the easy conduit, possibly also a form of frustration management. Talk of death or of listening to music which C relates to death and dying are anathema to him (C 12.3) and aspects of life that would be considered happy (C 13.6), are equally unacceptable to him. His constant denial of the situation in which he finds himself results in him not wanting to be reminded of the prospect of an imminent and early death and the life he might leave behind.

5.2 HELP AND SUPPORT

Two subthemes were identified here. Support from family and friends and from professional groups. The latter category included aspects including staff attitudes both positive and negative, staff awareness of the situation, approachability and staff making time to talk and listen. These components seemed to make a difference to how participants felt about and coped with their situation. Of interest was the fact that only one participant had been referred by a doctor who felt the need for professional psychiatric intervention.

5.2.1 Family support

After discharge, G found her husband less than supportive despite her emotional upset. Her constant crying may have been a combination of emotional release and frustration management but might also have been a signal to her husband that she needed, and wanted, his support (G 10.13). Support from her husband was not forthcoming so G stayed with her youngest daughter and son-in-law (G 10.12; 10.19). Despite having the opinion on reflection (G 17.17) that she had to and did help herself to accept her situation she said that the situation would have been difficult to bear if it were not for their support and that of her eldest daughter (G 11.1). Towards the end of the interview, G, without prompting, re-introduces her relationship with her husband (G 30.1) and concludes her narrative (G 30.6) with a mild verbal assault on her husband. This attempt by G to ridicule and 'hit back'

at her husband as “a no-gooder” may be a response to him not finding her physically and sexually attractive after her facial surgery. She purports to be unconcerned; and uses humour as an emotion focused strategy to try to cope with the situation.

H refers to his wife on several occasions throughout his narrative and how she is affected by *his* situation (H 2.3; 3.14; 4.4; 4.8; 5.21; 6.2; 6.9; 6.16; 9.2). His concern for her well-being may be an attempt at his drawing comfort and support from their relationship and coping with the situation i.e. an emotion focused coping strategy, as well as protecting her from a situation he finds frustrating and can do little about.

J relied on her husband for everyday practicalities as well as emotional support (J 14.11).

Close family and friends were very important to B and she feels were essential to her well-being (B 3.11; 20.1). As the mother of two grown-up sons she felt maternal, protective instincts towards them (B 4.1) but she felt that she had benefited emotionally from her imparting the knowledge of her illness to one of her sons (B 4.12) That her husband was very supportive and still found her physically attractive after her surgery (B 9.12; 20.10) brought her great comfort.

D also found help and support from family and friends invaluable (D 24.6).

C comments that his wife was always positive (C 5.2). He also talks of his mother as being a strong person (C 5.8) and she commented on meeting him after his operation that he would be alright. Positive attitude and the lack of a sharing of emotion may be detrimental to emotional well-being. Although C feels comfortable with his wife and children (C 7.6) he comments that his wife took a positive, optimistic view of any situation, rarely showing any emotion. This may have been an attempt by C's wife to help him or it may have been an emotion focused coping strategy to help herself through a very testing situation. C would probably have welcomed his wife's tears and gained strength and closeness from her vulnerability and the demonstration of sympathy for his plight shared by both of them.

5.2.2 Professional support

Professional support made G feel better (G 5.14; 22.5; 22.8; 26.12) and individual staff members at times of vulnerability made a great contribution to her welfare (G 7.6; 7.11; 8.1).

H reports that staff generally made the situation very much easier to cope with (H 4.15; 7.5; 7.15; 20.6).

Professional staff also played a part in making B's care as successful as possible (B 11.7; 14.1) but she found a visit by the Macmillan nursing service (B 11.13) immediately after admission to hospital as unhelpful.

D also found great support in her professional attendants and in the care that she received (D 11.9; 11.18; 24.6). She commented that she felt she was being listened to (D8.14).

C finds support in professional attendants (C 17.5; 18.19; 19.8) and being able to talk and feel that he is being listened to is important for him (C 19.14; 20.2).

5.3 RETURN TO NORMALITY

This superordinate theme comprised the restoration of the physical changes created by surgery and the affect of that restoration on individual participants. Two sub-themes were identified; post prosthetic experience and acceptance and reflection.

After debilitating and mutilating facial surgery the restorative and rehabilitative process included the individual preparation and fitting of a facial prosthesis. Most participants had an idea of what a prosthesis was and had been told that some form of restoration would be provided for them. Two participants were fitted

with an immediate temporary prosthesis prior to leaving hospital. Other participants had dressings placed.

5.3.1 Post Prosthetic experience

G had been provided with a breast prosthesis following mastectomy a number of years previously but was very much aware that prosthetic reconstruction after facial surgery may present greater problems (G 5.4). She was fitted with an immediate, temporary prosthesis soon after surgery, “.....*and the only time I started to feel human was when I came down here and (name) put that nose on me. I went back onto the Ward and I felt like a person.*” (G 8.5). G was fitted with a permanent adhesive retained prosthesis which she found aesthetically pleasing (G 9.5; 14.5) but problematic in application and security (G 8.11; 9.3; 8.16; 14.6). After approximately four years of using an adhesive retained prosthesis, G was fitted with an implant retained prosthesis which she found, for practical reasons, preferable (G 13.8; 14.12).

H was fitted with an immediate, temporary prosthesis, adhesive retained after surgery (H 10.1). H continued with adhesive retained prostheses until he was fitted with an implant retained prosthesis. He found the implant retained prosthesis preferable for practical reasons (H 11.5; 11.12; 13.4) but also found that as dirt was not attracted to the periphery, the prosthesis looked better (H 12.10).

J felt happy not to have to apply dressings after being fitted with an implant retained prosthesis (J 15.6) She said that the prosthesis allows her to “*pretend to be normal*” (J 15.5; 15.10) and would be annoyed if she did not have a prosthesis (J 17.16).

B was relieved to find that she could be helped with a prosthesis after thinking the situation impossible to reconstruct (B 10.6; 13.4).

D found the use of a prosthesis to be “*far preferable*” to dressings (D 17.14) and although she felt that she would never look as she did previous to her surgery (D 18.1) she found the return to society to be “*an absolute delight*” (D 18.9). D also prefers a prosthesis to any possible reconstructive surgery as she feels it far easier for her medical attendants to review her situation (D 28.15).

C was fitted with an adhesive retained prosthesis soon after surgery which he did not like because of problems with retention (C 5.16) and prefers an implant retained prosthesis for increased security (C 6.4). Socially, he feels less conspicuous whilst wearing a dressing (C 6.6).

5.3.2 Acceptance and Reflection

Participants wanted to look and feel as normal as possible. They felt that the use of a facial prosthesis restored appearance to some extent and allowed a degree of social interaction similar to that enjoyed pre-operatively.

It is important to G that she appears and feels as normal as possible (G 15.7; 15.14). As a user of a facial prosthesis she takes a rational view of her life and those around her (G 11.10; 11.18). Whilst still aware of her disfigurement (G 12.12) she accommodates situations as they arise (G 17.2; 17.10) "*I mean, like as I said, I come on two buses this morning and it doesn't bother me one iota.*" G poses her own question regarding her acceptance (12.9) and re-iterates the fact that it is a "*full fourteen years*" since her surgery. Although G did not have a partner who was supportive, she was supported by her children and their families and grieved for the loss of her nose (G 21.13). In contrast, the removal of her breast some years previously was an aspect of surgical treatment that she chose to ignore and still denies today (G 19.6; 19.9) because it was easy to cover and appear normal (G 5.6; 19.4) she may never have accepted her mastectomy but simply put it out of her mind. Her reference to a full fourteen years may be a demonstration to herself that she has survived facial cancer, having the knowledge that, without treatment, she may have died (G 24.8; 24.11) But though she accommodates her disfigurement and the benefits of a prosthesis she does not accept that her prosthesis is part of her "*Because I mean my nose it me own nose*

wasn't perfect by any means it really in a way didn't look very nice but it was mine and it was attached to me." (G 21.16).

H is aware that some people notice a difference in his appearance (H 14.2) but he also notices that many do not (H 14.5; 14.10). He remains unconcerned and says that his lifestyle is similar to that he enjoyed pre-operatively (H 15.17; 16.20) and he talks of it freely (H 17.4) and is happy with his appearance whilst wearing his prosthesis (H 17.10). H questions whether the diagnosis of facial cancer could have been made earlier (H 20.16) but takes a pragmatic view of the situation as "*it turned out alright*" (H 21.16).

J talks of her prosthesis as helping her in a pretence of normality (J 15.5; 15.10). One of the biggest hurdles for J was acceptance by her grandchildren of her altered appearance. She likened her orbital prosthesis to that of her full dentures (J 16.2; 16.7) and describes her prosthesis as "*presentable*" (J 18.9) although J feels that she could not function without a prosthesis (J 18.11; 18.13; 19.2) and uses her prosthesis without spectacles when at work (J 22.3). J is very much aware of her altered appearance and whilst engaged on activities of a personal nature, requires "*camouflage*" (J 22.9), at work she maintains that she is "*too busy*" to become concerned over what onlookers may think (J 23.4). It appears that the more personal and intimate a situation becomes the more threatening it may seem. J refers to her "*psychological*" on occasions (J 21.8; 23.12) as her explanation of how she is more aware of her altered state in these situations.

After her surgery B thought that a prosthesis would be impossible in her situation because of the size of her defect (B 10.6). She was surprised to find herself thinking of her image and how she might have appeared to others (B 13.4). She was happier when she learned that a prosthesis could help in her situation. B felt that she was going to “*look normal*” (B 13.12) but she questions normality and what normality means to her; settling with the idea that she was to appear as much as she did pre-operatively. B locked the thought of appearing normal again into her mind, almost promising herself the possibility which was very important to her (B 13.13). B becomes (very) angry and upset if she finds (*or thinks she finds*) people looking at her (B 14.7). This reaction is possibly due to B remaining very much aware of her situation and constantly feeling abnormal. Upon making eye contact with an onlooker, B fully expects that individual to notice differences in her appearance even if that is not the case. She holds eye contact and B grows very angry (B 14.10) as she becomes convinced the onlooker has noticed a difference in her appearance. Later B rationalises these thoughts (B 17.11; 18.4; 20.21; 23.5; 23.12; 23.17). She feels that her appearance and consequently her body image has changed but takes a pragmatic view of her situation and feels that her situation could not be improved (B 15.10; 17.5). Professionally, her prosthesis allows her to function normally (B 16.3) and be treated normally (B 16.14; 16.19) which is very important to B (B 22.4). Normality in B’s life is possibly a means of helping her to forget her situation and life threatening cancer as well as returning to society as a normal individual.

Survival for D was paramount (D 15.15). She explains that *“later the physical bits hit you when you’re left looking like that.”* Although she had resigned her thoughts to the inevitability of the situation she still finds aspects distressing (D 16.2). D developed skin rashes after the application of post-operative dressings and the prospect of an implant retained prosthesis obviating the need for adhesive dressings was her first consideration (D 17.14). She took a pragmatic view and realised that the extent of the surgery would present difficulty in any prosthetic reconstruction and held opinion that, however faithful, the prosthetic replacement would not restore her appearance to that of her pre-operative state (D 18.1). D readily accepted her facial prosthesis when she gained family approval and demonstrated to herself that many onlookers did not notice any difference in her appearance, though she looked for a reaction in onlookers (D 29.3) and finds her confidence restored (D 18.9; 19.1; 19.5; 24.19; 25.12). It was demonstrated to her by her own public exposure, probably brought about by a growing inner confidence, that her altered body image caused by the change in appearance was her view alone and not shared by onlookers. Though D finds that her lifestyle has returned to that of her pre-operative state her thoughts of the prosthesis are mixed, *“I don’t think of it as me, I don’t think of it as any attempt to get back to how I looked, it’s a way of not drawing unwanted attention to myself immediately so that I can carry on with a normal life and this works just fine.”* (D 20.3). *“Yes, yes it’s like a simply top-class dressing.”* (D 21.8). D had researched future surgical reconstruction of her defect and possibly as a guarantee of survival, decided against it *“But I’m quite happy it does reassure me this sounds really silly*

it does reassure me that if something is happening round the site of the operation it can be taken off and seen. I know that's not foolproof but it's something quite reassuring now. (D 28.15).

C was fitted post-operatively with an adhesive retained prosthesis which he found difficult to accept. An implant borne prosthesis, that C uses presently, is practically more acceptable as it enjoys greater retention and therefore C is more confident in its use. C is acutely aware of his altered appearance and in some situations he says that he prefers to use a dressing rather than his prosthesis “.....*but if I had my eye in and they noticed I would feel strange because it's not me.....*”(C 6.6; 8.13). If asked, C feels that he could easily explain the reason for the dressing rather than any difference in appearance an onlooker might notice. This may be due to C feeling that he does not wish to explain that he had facial cancer to anyone and in the process, reminding himself of the fact or the prosthesis may be too painful a reminder of his situation. Inevitably, wearing a facial prosthesis, C would be required to divulge his medical history, not only to a curious onlooker but to himself. Using a dressing, C finds it beneficial to claim that he has a ‘problem with his eye’ whilst claiming that a dressing is very rarely used and is impractical (C 6.12; 8.1; 11.2). C is mindful of the fact that his appearance may not be noticed “*they might not notice but I would think that they might notice.*” (C 6.9) but remains unconvinced and finds the situation difficult to accept. The image of his body has altered and he finds it difficult to convince himself, despite being aware of the possibility that his prosthesis may go

unnoticed (C 8.14). C offers his own explanation (C 9.1; 9.9) and the reaction that he feels should be forthcoming from onlookers is possibly a product of the feelings of abnormality he has about himself. The fact that the prosthesis is unnatural is difficult for C to accept and is unconvinced by words of encouragement *“Because its not me and its like false it its false because its not me is it its not me its just something what’s thereit’s a lump of synthetic material trying to do a job as best it possibly can”* (C 10.1; 10.6). But C thinks that the unacceptability of the situation is not solely due to his altered appearance and the fact that he uses a facial prosthesis, but that he is preoccupied with survival (C 11.15) and wishes to avoid being reminded of his cancer. C talks of the situation becoming progressively worse over time rather than improving (C 12.13) and reflects on ‘the sands of time running out’. A reference to his own finite and he feels, inevitably shortened lifespan (C 14.6) which he finds difficult to accept (C 15.18; 16.9; 16.15).

CHAPTER 6

6.0 DISCUSSION

Evidence exists in ancient texts and from archaeological finds to prove that prostheses have been used by mankind for thousands of years to repair, using artificial means, facial defects caused by trauma, surgical excision and congenitally absent tissue. A piece of wood carved to the shape of an ear and held in place with a length of twine or leather band; wax sculpted to resemble a nose and retained using sticky ointment have all found a place in the fabrication and use of early facial prostheses and prosthetic rehabilitation. This suggests that individuals living in ancient times were as concerned about their appearance and any alteration to that appearance as individuals living in the modern era. Facial disfiguration, as Dropkin (1999) pointed out, permanently affects our body image; the picture each and every one of us holds in our mind of the way we think we appear to the outside world and many facially disfigured individuals seek help to regain, as far as possible, that previous image and appearance. Often, this is only achievable through the artificial replacement of lost or absent tissue and the 20th Century witnessed a variety of materials and techniques used for the preparation of 'modern day' facial prostheses. Vulcanised rubber, moulded gelatine and swaged metal were used in the construction of facial prostheses until the introduction of acrylic resins and later, the silicone elastomers in the latter half of the century. Fixation, or retention of the prosthesis to the face or head, relied to a

great extent on mechanical means; metal bands incorporated into the substance of the prosthesis which encircled the head and spirit or latex adhesives applied to the fitting surface of the prosthesis before placement, into position, on the face. The development of silicone adhesive systems improved adhesive retention and a majority of patients who use facial prostheses today will use some form of silicone adhesive retention (Johnson et al. 2000). The discovery of osseointegration, by P-I Branemark et al. (1977) and the subsequent introduction and development of implants for dental treatment led to their later use in the retention of facial prostheses for suitable patients.

This study investigated the affect that facial prostheses had on participants after facial cancer surgery and the psychosocial effects of treatment and disfigurement relative to the use of a facial prosthesis. A facial prosthesis enables a disfigured individual to mask the disfigurement and the indications from this study are that coping is made easier and the quality of life for patients is improved by the use of a prosthesis in terms of the restoration of an acceptable, normal appearance. It does not however, improve the *feeling* of being normal.

Findings from this study of patients' need for a facial prosthesis were similar to the findings of Jebreil (1980) who conducted a study of patients who had been provided with either an eye patch or a prosthesis to conceal the defect after exenteration of an orbit. He found that the majority of patients preferred to use a prosthesis rather than a patch to cover the defect area and a later study by Bou et

al. (2006) on two hundred and fifteen patients confirmed that the demand for facial prostheses from facially disfigured individuals continued unabated. However, these findings contrasted with other studies (Newell 1998) findings that facial prostheses are of little use and remain largely unused unless the defect is large and in the centre of the face. Rumsey et al. (2004) also found in a study of body image and appearance that some health professionals considered patients' concerns were 'out of proportion with the disfigurement' and they felt that the disfigurement exhibited by some patients, although visible, was 'minor.'

The question of 'what is large' and what defines 'the centre of the face' is subject to individual interpretation, but it is important that the interpretation should be the patient's interpretation as investigated in this study. The findings of this study are supported by Ong et al. (2007) who found during a study of patients with facial lipoatrophy that there was no correlation between the severity of the condition and the degree of psychological distress caused by the disfigurement and even 'minor' disfigurement had the potential to cause considerable distress. An increase in distress was also reported by Goiato et al. (2009) and Toljanic, Heshmati and Walton (2003) who found that the delayed provision of facial prostheses for patients who had undergone recent resection of facial malignancies had the potential to cause considerable distress. Two participants in this study were provided with immediate temporary prostheses. They expressed feelings similar to those in the studies by Goiato et al. and Toljanic, Heshmati and Walton that coping with their situation, immediately post-operatively, had been easier than it

appeared for others. Sentiments such as returning to the hospital ward after placement of the prosthesis looking like a human and feeling 'fabulous' suggested a greater, more immediate acceptance. Still very much aware of the situation their later feelings of normality were similar to fellow participants and later coping mechanisms did not differ greatly from those exhibited by other participants, but is worthy of further study.

The rationale to use semi-structured interviews and Interpretative Phenomenological Analysis in this study was determined by a number of concerns. Professional preconceptions and the inattention shown to patients' concerns and needs was reported by Edwards (1997) in a study of facially disfigured individuals. Health professionals, she found, did not allow patients the time to talk, and of greater importance, did not listen to what patients were saying about their situation, feelings and needs. And Walker, Risvedt and Haughey (2003) and Lemon et al. (2005) had argued that treatment delivered with a caring attitude, a degree of sympathy and listening to patients' needs and concerns, increased treatment satisfaction for patients with facial malignancy. Findings from this study of the prevalence of dysfunctional as well as emotion focused coping strategies contrasted with, questionnaire based, related studies (Vidhubala et al. 2006; List et al. 2002) of patients with facial disfigurement that had found more problem focused, therapeutic approaches to coping with facial cancer amongst some individuals. Questionnaires employed as the method of data capture, by their very nature, confine the data, to predetermined, narrow research

questions and do not allow individuals to give a fuller, more personal account of their human predicament. Qualitative research, Smith (1995, 2003) argued should be carried out in the 'real world' of human experience and Macgregor (1979) maintains that the semi-structured interview is superior in its ability to elucidate elements of human suffering and is the method of data capture most useful in establishing a rapport with the patient. Without that rapport, Carr (1997) argues, it is unlikely that facially disfigured individuals will feel able to reveal and discuss sensitive feelings and concerns. Listening and recording an individual's 'lifestory' is an established technique in social studies and the use of the semi-structured interview in this study allowed participants to talk freely and reflect on their experience from diagnosis to date. Smith's Interpretative Phenomenological Analysis was used as the analytical tool. It is a method which is being increasingly used in health related research studies as it is based on the 'real world' experience of the individual. It enabled the exploration and interpretation of the accounts and perception of the study participants' experience, without preconception, and allowed a wider insight of that experience than would otherwise have been possible. Acknowledgement, of course, should be made to the fact that the analysis is interpretative and the researcher's prior knowledge of participants may potentially influence the process. But the reverse argument can also be made and participants who are comfortable with someone who is well known to them may feel that they can be more open and truthful with their comments as Pope and Mays (1995) had suggested.

It appears clear from the findings in this study that the diagnosis of facial cancer had a major impact on participants. Feelings of impending demise were coupled with thoughts of survival at all costs. The consensus amongst participants was that even major disfigurement seemed infinitely more preferable to death as Konradsen, Kirkevold and Zoffmann (2009) had also found. Participants remained focused on the implications of the diagnosis in terms of survival and the consequences of major facial surgery essential for the (potential) eradication of the malignancy.

Participants found difficulty accepting the diagnosis and the denial of a threatening situation, a cognitive avoidance, is often categorized, as a potentially unhelpful, dysfunctional coping strategy. But it can also be argued that it may be an adaptive coping strategy, a defence mechanism that individuals use to protect themselves against unwanted information or threatening thoughts as Rabinowitz & Peirson (2006) and Vos & Haes (2007) had indicated. For example, 'being very naïve' and 'not medically knowledgeable' and 'putting it (cancer) on a back burner' were feelings expressed by participants in the study, possibly in an attempt to put out of mind the thought of having developed a life threatening disease and its consequences; the refusal simply to contemplate a scenario which included thoughts of death as the final outcome. Hardy & Kell (2009) also suggested that denial may be a strategy used by some individuals to better cope with a threatening situation. An adaptive or coping function may allow individuals the time to accommodate an overwhelming situation or unwelcome

news and time may be a factor in the healing process for some patients. Stanton, Danoff-Burg and Huggins (2002) had indicated a reduction in denial over time in a study of breast cancer patients (*although reduction may not occur in every case. Author's italics*) with a corresponding development of other, more helpful, coping strategies such as emotion focused and/or problem focused strategies. Long term dysfunctional coping strategies, for example, constant denial and disengagement with the reality of the situation, often lead to continuing anxiety, depression and episodic crying. Participants reported episodes of crying during times of emotional upset. Crying may be used, as seen in this study, as a means of emotional release but it can also be an attempt to manage and cope with feelings of frustration, anger and powerlessness and crying may also be a signal that sympathetic help is required as Miceli & Castelfranchi (2001) suggested.

Support, both physical and emotional, help individuals diagnosed with facial malignancy and its affects and input from two distinct sources were identified by participants in this study; family members and professional attendants. Coping with the situation may be influenced and made easier for individuals by loved ones and relatives who demonstrate an understanding of the situation and offer sympathy for their predicament as Neuling & Winefield (1987) had argued. Ford et al. (1995) and Ell (1996) had suggested that lack of sympathetic support from a partner was not compensated for by support from other sources. Participants in this study wanted the knowledge that their partners still found them not only attractive but also sexually attractive which was also reported by Klein et al.

(2005). Findings from this study are complemented by a contemporary study by Bowers (2008) that partners and relatives impact positively on the wellbeing and ability to cope. But it may be too convenient an assumption that partners and loved ones can give of this help freely and without difficulty. The family may also require help and support to cope with their new found situation and individually tailored professional help; treating patient and family may be required to mitigate or overcome coping difficulties to enhance 'symbiosis' and achieve a more positive outcome. This aspect is worthy of further investigation. Seeking advice and planning for the future and also the sharing of emotions at stressful times may prove beneficial to emotional wellbeing. Coping by participants in this study appeared to include different aspects. Rabinowitz & Peirson argue that coping is part of a process (often lengthy) by which individuals, in the case of cancer victims, "sculpt a more acceptable reality for themselves." It appears from this study that participants may see coping as an end in itself 'have I coped' not 'am I coping' which suggests that coping strategies as they see it stop or become less of an issue when their 'end point' determined by how they feel at a particular stage in their lives, is reached. This aspect may have treatment implications not only for providers of care but also support implications for members of an individual's own family group.

Gastmans (2002) views health care as "a moral enterprise because the overarching aim is to ensure the wellbeing of persons in need of medical treatment." Lutzen et al. (2006) concurs with Gastmans view and also argues the case for morality in

care regimes and for the development of a concept of moral sensitivity in the treatment of patients. She defines this as “a genuine concern for the welfare of others, which is experienced as caring about others.” Moral sensitivity she believes, not only has a theoretical basis but also a cognitive one. She advances the theory that individual conscience forbids or allows certain actions and requires individuals to examine their thoughts, actions and self when treating patients. Lutzen believes that this explains why some health care professionals appear to be more aware of the needs of patients from patients’ perspectives. It may also explain why individual patients, as seen in this study, ‘prefer’ to be treated by particular staff members during treatment episodes. This not only has implications for the day to day care of patients but also impacts on researchers and research methods as it may be argued that the ‘favouring’ of a researcher or researchers may place undue bias on any findings made during the study. Though, as we have seen previously, the reverse argument can also be made.

Inter professional referral should be made with forethought and prior explanation. A seemingly innocuous but well meant referral to the Macmillan nursing service in the case of one study participant (a community nursing sister) had a detrimental effect because it was taken as a threat to her notion of survival. The Macmillan nursing service provides care and support for patients with cancer and their families. The service is seen by many to be providers of care *only* for the terminally ill and the referral set the idea in the participant’s mind that death was inevitable even before treatment had begun.

The artificial restoration of facial defects using facial prostheses is an attempt to restore the pre-operative appearance as far as possible and help patients to better cope with their situation. Retention of the prosthesis is achieved by the use of medical adhesives, anatomical or mechanical retention, or osseointegrated implants. Participants in this study thought that their appearance had been restored to what they considered as near normal as possible by the use of a prosthesis and felt that they could not function as human beings without prostheses to conceal the operative site but that their feeling of normality had not been restored. In public situations, their use of a prosthesis went largely unnoticed save for when participants incited reactions in onlookers. This, Harris (1982) suggested, was a preoccupation with the notion that others *might* be aware. This was manifest in this study in that participants would *stare at others* and hold the gaze until an onlooker *looked*. This may have treatment implications and cognitive behavioural therapy programmes (Newell 2000) may help in these situations.

Participants in this study were able to socialize and function as near normal previous to their surgery. Although very much aware of their predicament, they were unhappy with thoughts of living without a prosthesis and though Newell's opinion that some prostheses may be of little or no use, Schoen et al. (2001) and Arcuri and Rubenstein (1998) argue that implant retained prostheses, by virtue of their appearance, enjoy an increased psychological acceptability than prostheses retained by other methods. Schoen's study, based on a standardized

questionnaire, found that patients fitted with implant retained prostheses described the devices as not feeling artificial or foreign but part of themselves. This contrasted with findings of this study. All participants in this study preferred an implant retained prosthesis for ease of placement and greater stability rather than increased aesthetic acceptability. No participant voiced opinion that an implant retained prosthesis was more psychologically acceptable or restored feelings of normality or appearance to any greater extent than adhesive retained prostheses. Participants in this study suggested that the type of retention used to keep the prosthesis in place has less relevance for aesthetic and psychological reasons than practical advantages.

To look normal and to feel normal are fundamental human needs and the participants in this study were anxious for a return to normality. They were acutely aware that their appearance had changed and consequently the picture they kept of themselves in their own mind. These changes in body image appear to be permanent as Price (1990), Neill and Waldrop (1998) and Cohen Khan and Steeves (1998) had suggested. Gregory (2005) had studied sufferers of chronic illness and suggested that normality is governed by how people regard their everyday lives. The normality that people seek, she argues, is related to how patients view their lives before illness and the 'normality' that they see in the lives of others. Prout, Hayes and Gelder (1999) reported similar findings in a study of asthma sufferers and their families. These findings are congruent with themes from this study. But this study also showed that though participants had a desire

for a return to normality which, as Gregory argues, is possibly a coping mechanism as much as an ideal; they never reached a state of *complete* normality. Harris (1997) defined normality in terms of appearance. He proposed that normality for an individual was the perception by that individual of the sameness in the appearances of others. In effect, a normality based on a perceived, external or social normality. Findings in this study suggest that 'normality' for the facially disfigured who use a prosthesis includes more than one aspect, in essence, an 'internal' and 'external' normality. Variation exists in the length of time that study participants had used a facial prosthesis, however, the responses would indicate that none of the participants reached a state of *complete normality* and that these feelings appear to be unmitigated by time as all participants gave similar responses. All the participants in this study felt that they would never, or could never, achieve their previous state of normality, they redefined themselves and their new found situation; and were aware of the loss of their previous appearance. The use of a facial prosthesis was essential for each participant to better cope and function in society in so far as it allowed the conveyance of a 'normal' appearance but *feelings* of normality remained absent. Comments, for example, "*it's an absolute delight not to be stared at*" and "*a pretence of normality*" suggested a sense of normal appearance but did not correspond with feelings of normality and comments, for example "*Its not me*" and "*I don't think of it as me*" were made. It appears that normality for individuals who use a prosthesis is not simply 'the perception of sameness' as Harris had defined but is also concerned with inner feelings which, in turn, influence coping strategies.

The restoration of an outward ‘sameness of appearance’ had failed to instil a corresponding feeling of ‘inner normality’; an important distinction and words like ‘superpatch’ and ‘expensive rubber’ were used to describe the prostheses. The prosthesis conveyed an external appearance of normality allowing the users, they said, to re-integrate into society and function normally but that they never *felt normal* within that society. Participants in this study suggest therefore a state of normality re-defined by their experience and that a normal appearance was not synonymous with feelings of normality.

Findings from this study suggest that the feeling of normality is a product of an individual’s self perception. This internal aspect of normality indicates that participants have learned to cope with their loss and disfigurement in both social and private situations but are aware of their disfigurement as a constant. This is distinct for the need to be accepted as normal which is external to the inner self and feeling the need to be socially accepted. The use of a facial prosthesis facilitates social acceptability and allows participants to cope with their disfigurement in everyday situations. This contrasted with Schoen’s (2001) findings that implant retained prostheses, which all study participants used, were psychologically more acceptable and felt more a part of the user. Nor did they influence the inner feeling of normality or improve coping with disfigurement any more than prostheses retained by other means. Normality for the participants in this study extends beyond Harris’s “perception of sameness,” which is necessary for social acceptance and is achieved by the provision of facial prostheses. We

can call this “Functional Normality” and facilitates the ability to cope, psychologically and socially, after acceptance of the loss and function in personal life.

CHAPTER 7

7.0 CONCLUSIONS

- The qualitative methodology and IPA analysis used in this study re-affirmed previous findings in the literature and revealed new insight into the patient experience.
- Listening to patients' through semi-structured interviews allowed a greater insight into the patient experience.
- Facial prostheses contributed to patients' re-integration to society, improved quality of life and enabled patients to better cope with their situation.
- Family members influenced coping strategies and assisted patients' recovery and enhanced their quality of life.
- Professional attendants influenced overall treatment satisfaction, coping and quality of life.
- Implant retained facial prostheses were preferred for ease of application and security not improved psychological advantage.

- A novel definition of normality derived from the experience of patients who use facial prostheses. The use of a facial prosthesis enabled social re-integration through 'Functional Normality' but did not improve the feeling of normality.
- The use of immediate temporary prostheses enhances short term coping strategies and quality of life.

CHAPTER 8

8.0 RECOMMENDATIONS

Recommendations are suggested which should lead to improved patient treatment standards and satisfaction.

- Patients should be allowed time to talk and professional attendants should listen without prejudice. Listening should lead to a better understanding of patient concerns and needs and lead to a more successful treatment outcome.
- Patients and their relatives should, if possible be treated as a family group or unit. Coping strategies of patients and their family groups may be influenced and monitored and intervention initiated if required to achieve the best possible long term outcome.
- Patients and relatives should be encouraged with an empathetic and sympathetic approach during and after treatment which should lead to better patient satisfaction.

- Facial prosthetic devices should be considered, if the situation allows, for patients post-operatively.
- Immediate temporary prostheses should be fitted wherever practicable. Implant retained prostheses should be considered wherever practicable.
- Cognitive behavioural programmes specific to users of facial prostheses may be designed and promoted in patient/family groups.

CHAPTER 9

9.0 CONTRIBUTION TO THE LITERATURE

- **Demonstrated the successful use of an established research methodology within a new research context.**
- **Established that facial prostheses contribute to patients' coping strategies which enable re-integration to society and quality of life.**
- **Describes a new construct of Functional Normality derived from the patient experience and coping strategies. Functional Normality describes the social re-integration of patients who use a facial prosthesis after ablative facial cancer surgery.**

CHAPTER 10

10.0 FURTHER WORK

This study has identified areas where further investigation may add valuable information in understanding the concerns and difficulties endured by facially disfigured individuals and their families and learn of their coping strategies.

- Partner/family focused study and the effects that a diagnosis of facial cancer has on the family group including coping strategies and the development of professional intervention strategies.
- The effects that the treatment of facially disfigured patients might have on professional attendants and possible reciprocation which may influence treatment options and outcomes.
- Further research into the affect of temporary prostheses fitted immediately or very soon after surgery and the possible short/long term psychosocial benefits.

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APPENDICES

Appendix 1. Interview topics

1. Could you tell me something about what led up to your treatment at the hospital?

feelings, thoughts about treatment

feelings, thoughts after surgery

2. You have been given a prosthesis to wear. Could you tell me about that?

process

felt at the time

3. What do you now think/feel about the prosthesis?

does it affect you?

and your relationships?

4. What does the future look like to you?

Possible Additional Questions

- 1 Can you tell me a bit about your experience of learning about your illness when you came to hospital?
- 2 What were you expecting/ did you expect something serious?
- 3 What happened at the appointment what did the doctor say and do?
- 4 How did you react to being told about your illness and your treatment?
- 5 Did the surgery affect how you see yourself or how others see you?
- 6 Have your family and friends helped you in any way after surgery?
- 7 What do they think and feel?
- 8 Can you tell me a bit about how you felt and what you thought about having a prosthesis made?

Appendix 2. RESEARCH PARTICIPANT CONSENT FORM

This form is to help me check that I have mentioned everything to you that you might want to know about this study. It is also to show that you have agreed to being interviewed and that I have explained to you what is involved in taking part. One copy will be kept for my records and one copy is for you to keep.

Please read the following statements and circle 'Yes' or 'No'

I have read the information sheet regarding the study	Yes	No
I have had the opportunity to ask questions and discuss the study	Yes	No
I have received satisfactory answers to all my questions	Yes	No
I understand that the interview will be audio taped	Yes	No
I understand that I am able to withdraw from the study at any time without giving a reason and that this will not affect my treatment in any way	Yes	No
I have received enough information about the study	Yes	No
I agree to take part in the study	Yes	No

Name :

Date :

Signed :

Researcher

Name :

Date :

Signed :

Contact details :contact details given on form

Appendix 3. RESEARCH PARTICIPANT INFORMATION SHEET

Research study: Facial Cancer Surgery and Prosthetic Devices

Researcher: Frank Johnson, Principal Anaplastologist

What the study is about

The aim of this study is to ask people who have had an operation to remove facial cancer how they felt after they were told they had cancer. I am interested in talking to people about their feelings after they were told and how they felt before and after their operation to remove the cancer. I would also like to talk to you about your facial prosthesis, how you use it and what you feel about it. I hope that this information will help other people like you and also the health service staff who look after people like you.

This study has been approved by a Research Ethics Committee.

What will be involved if I take part?

I would like to interview you about your experiences. The interview will take about 1 hour and will take place in a quiet room at the hospital away from the department where you usually receive treatment unless you wish it to be conducted in another place e.g. your own home. You will only be interviewed once.

Can I leave the study at any time?

You can change your mind about being interviewed at any time. You do not need to talk to me for any longer than you want to. You may leave the study at any time and will not be asked for a reason. Deciding not to be involved or leaving the study at any time will not make any difference to the treatment or care that you receive. If you wish, any tape recordings that have already been made will be destroyed immediately.

Will the interview be confidential?

The interview will be kept completely confidential. It will be taped but the tapes will be destroyed as soon as the transcription is finished. The tapes will not be shared with anyone else. The tapes will be transcribed (typed on paper) for the study but the person who does the typing will have signed a confidentiality form before starting the transcriptions. Any details that identify individuals or organisations (such as hospitals) will not be included in the final report.

What will happen to the results of the study?

Findings from the study may be published in medical journals or given in lectures to medical or related staff. It will be impossible for anyone attending a lecture or reading a journal to identify you. At the end of the study you can, if you wish, be sent a condensed copy of the report's conclusions.

Will my own Family Doctor know that I am taking part?

With your consent, your own General Practitioner will be sent a letter telling him or her that you have decided to take part in the study. No other information will be exchanged with your general practitioner or any other doctor that you have seen without your consent.

Where will the interview take place?

The interview will be conducted at a time convenient for you, here in Sheffield at the Northern General Hospital in a room away from the department where you were treated unless you wish it to be conducted in another place e.g. your own home. Your travel costs will be refunded.

What can I do if I would like to talk further about things discussed in the interview?

You can be put in touch with organisations such as 'Let's Face It' or 'Changing Faces' who provide help and support for people with facial disfigurement.

Specialist nurses are also available if you wish to talk to them and the Department

of Psychology is on site as well as a cancer support centre near the Royal Hallamshire Hospital.

What if I wish to complain about the way in which this study has been conducted?

If you wish to make a complaint about any aspect of this study, normal NHS complaints procedures are open to you. The University of Sheffield's complaints procedures are also open to you and in this instance please contact Dr Giuseppe Cannavina in the Department of Adult Dental Care, University of Sheffield, Claremont Crescent, Sheffield. Tel: 0114 2717941.

Thank you for taking the time to read this information sheet.

If you would like to talk to me about being involved in this study or have any questions I would be very pleased to hear from you. I can be contacted at the address below,

Contact details given on form

Appendix 4.

Anaplastology & Maxillofacial Surgery
Northern General Hospital
Sheffield
Tel: 0114 2714830
E-mail frank.johnson@sth.nhs.uk

Dear Mr/Dr (Consultant/GP)

Participant name date of birth and address

I should like to invite your patient **NAME** to take part in a study that I am conducting together with the University of Sheffield of patients who have had facial cancer.

The project will look at the effects of the diagnosis, how major surgery affects individuals and which factors helped in a patient's recovery including the fitting of post-operative facial prosthetic devices. A research participant information sheet is included for your information.

If you feel that your patient should not be involved in this study, I should be grateful if you could contact me as soon as possible.

Yours sincerely

Mr Frank Johnson
Principal Anaplastologist

Appendix 5.

Anaplastology & Maxillofacial Surgery
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Tel: 0114 2714830

Mrs J Smith
Dept. of Oral & Maxillofacial Surgery
School of Clinical Dentistry
Claremont Crescent
Sheffield
S10 2TA

15 June 2006

Dear Judy

FACIAL CANCER AND PROSTHETIC DEVICES – PhD THESIS

Thank you for agreeing to transcribe the data from the interviews that I shall be conducting for my study into the effects of facial cancer and prosthetic devices.

The information will relate directly to patients and be of a sensitive nature and of course, must be kept confidential.

If you agree to this condition I should be grateful if you would sign and date the foot of this letter and return it to me. Thank you.

Kind regards

Yours sincerely

Frank Johnson
Principal Anaplastologist

Appendix 6.

Rotherham Local Research Ethics Committee
The Rotherham NHS Foundation Trust
Ward B11 Corridor
Moorgate Road
Oakwood
Rotherham
S60 2UD

6 June 2006

Mr Frank Phillip Johnson
Principal Anaplastologist
Sheffield Teaching Hospitals NHS Trust
Northern General Hospital
Department of Anaplastology and Maxillofacial Surgery
Sheffield
S5 7AU

Dear Mr Johnson

Full title of study: The Impact of Ablative Facial Cancer Surgery and the Effect of the Fitting of Post-operative Facial Prosthetic Devices

REC reference number: 06/Q2306/19

The Research Ethics Committee reviewed the above application at the meeting held on Friday 02 June 2006.

Summary of Discussion

Many thanks to you and to your supervisor Dr Cannavina for presenting your fascinating and important study at our meeting on the 2 June 2006. If I may say so your application is superb; the fact that there was so much discussion simply reflects how fascinating we all found your study and the importance we attach to it.

There were two specific matters raised which I have summarised below for your convenience.

1. Distress during interview

Your patients have been through a difficult (and perhaps disfiguring) physical change and are likely to have suffered emotional stress. You are obviously a warm hearted and sympathetic person so it would not be surprising if a one-to-one detailed interview might not precipitate an emotional catharsis and general upset, it was pointed out. You clarified you were aware of this risk. In such an event you yourself will try and help (transcending from being a professional to the patient's friend) and that you have access to specialists in this field at the Northern General if necessary.

2. Venue for interview: Hospital or home?

Bearing in mind the difficult circumstances I wondered if the interviews might not be better conducted in the patient's own home i.e. on his or her own patch, where they might feel more free to express the true depths of their feelings.

Dr Cannavina commented that

this would undoubtedly be the ideal *but* logistical and financial restrictions would make it very difficult. Furthermore, in the event of an emotional catharsis, you would be less well placed to offer help.

Let me turn to a different but related matter. The role humans attach to the face is as remarkable as it is fascinating: it is indeed the path to the soul as Dr Cannavina implied. This would be a wonderful topic for you to speak on at the British Association for Science Schools' Week. I have taken the liberty of writing to my colleague Dr Richard Walton, (Sheffield Hallam University) about this and would be grateful if you would get in touch with him, please. You will of course be writing scientific articles for peer review journals during and after your PhD. But do please seriously consider writing a more general article for the intelligent layman: it certainly will be widely read - and I personally would be very grateful if you could send me a copy.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	15 May 2006
Investigator CV		
Protocol	5	01 January 2006
Covering Letter		15 May 2006
Peer Review x 3		
Interview Schedule	4	01 March 2006
Letter of invitation to participant	1	01 February 2006
Participant Information Sheet	4	01 March 2006
Participant Consent Form	2	01 January 2006
Consultant/GP Letter	1	01 February 2006
Supervisor's CV		

Research governance approval

You should arrange for the R&D Department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final research governance approval before commencing any research

procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2306119

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Brown

**Professor K D
Bardhan, Chair**

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

Standard approval conditions SL-AC2

Copy to: The Medical Director's Department, Sheffield Teaching Hospitals NHS Foundation Trust, 8 Beech Hill Road, Sheffield, S10 2SB

The Research Governance Administrator, Research Department, STH NHS Foundation Trust, 305 Western Bank, Sheffield, S10 2TJ

Rotherham Local Research Ethics Committee

**Attendance at Committee meeting on 02 June 2006
and members who submitted written comments**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present?</i>	<i>Notes</i>
Professor K D Bardhan	Consultant Gastroenterologist	Yes	
Mrs Liz Booth	Retired	Yes	
Mr Ian Cawthome	Chief Pharmacist	Yes	
Mr Indranil Chakrabarti	Consultant Orthopaedic Surgeon	Yes	
Dr Peter Macfarlane	Consultant Paediatrician	Yes	
Mrs Margaret Oldfield	Chairman	Yes	
Dr Sam Muthusamy	Consultant Cardiologist	Yes	
Miss Jo Abbott	Senior Nurse Manager	No	
Dr A Abdelhafiz	Consultant Physician - Medicine for the Elderly	No	
Mr Derek Bainbridge	Nurse Consultant - Critical Care	No	
Miss Helen Barlow	Knowledge Manager	No	
Dr Jonathon Cobb	General Practitioner	No	
Dr Ken Ruiz	Consultant Anaesthetist	No	
Dr Paul Spencer	Consultant Radiologist	No	
Dr Grace Warren	Consultant Psychiatrist	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
-------------	---

Appendix 7
Department of Anaplastology and Maxillofacial Surgery
Northern General Hospital
Sheffield
S5 7AU

Telephone: 0114 2714830
Email: frank.johnson@sth.nhs.uk

28 June 2006

Professor K D Bardhan
Chairman Rotherham REC/Consult. Gastroenterologist
Ward B11 Corridor
The Rotherham NHS Foundation Trust
Moorgate Road
Rotherham
S60 2UD

Dear Professor Bardhan

The Impact of Ablative Facial Cancer Surgery and the Effect of the Fitting of Post-operative Facial Prosthetic Devices

REC reference number 06/Q2306/19

Thank you very much for your letter received recently informing me of the favourable ethical opinion given by Rotherham Local Research Ethics Committee and thank you also for your kind words and support for the study.

I have noted your comments concerning the potential for distress during interview and the venue for the conduct of interviews. Both Dr Cannavina and myself agonised at length over these two areas of the study and concluded that, although not ideal, the best place to carry out the interviews would be at the Northern General with specialists on hand if required.

I have made contact with Dr Richard Walton of Sheffield Hallam University regarding involvement with the British Association for Science Schools' Week.

Kind regards

Yours sincerely

F P Johnson
Principal Anaplastologist

Sheffield Teaching Hospitals

Mr Frank Johnson
Principal Anaplastologist
Department of Anaplastology and Maxillofacial Surgery
Northern General Hospital
Herries Road
Sheffield
S5 7AU
Dear Mr Johnson

NHS Foundation Trust

Authorisation of project

STH ref: STH 14064
Study title: Facial prosthetic devices and the effects of ablative cancer surgery.
Chief Investigator: Dr Giuseppe Cannavina, University of Sheffield
Principal Investigator: Mr Frank Johnson, STH
Sponsor: Sheffield Teaching Hospitals NHS Foundation Trust
Funder: The University of Sheffield

The Research Department has received the required documentation for the study as listed below:

1. Sponsorship IMP studies (non-commercial)	N/A
Sponsorship responsibilities between institutions	N/A
Responsibilities of investigators	N/A
Monitoring arrangements	N/A
2. STH registration document: completed and signed	Mr F Johnson, 15/05/06
- COREC Form	
- STH Finance Form	Dr G Cannavina, 11/07/06
3. Evidence of favourable scientific review	STH, 10/01/06
4. Protocol-final version	V5, 01/01/06
5. Participant information sheet-final version	V4, 01/03/06
6. Consent form-final version	V2, 01/01/06
7. Signed letters of indemnity	N/A
8. ARSAC/IRMER certificate	N/A
9. Evidence of hosting approval from STH directorate	Prof I Brook 14/07/06
10. Evidence of approval from STH Data Protection Officer	Mr P Wilson 17/07/06
11. Rotherham LREC,	06/Q2306/19 06/06/06

Ref: STH 14054

12. Proof of locality approval	N/A
13. Clinical Trial Authorisation from	MHRA
	N/A1
4. Honorary Contract	N/A
15. Associated documents	
- CV Dr G Cannavina	
- CV Mr F Johnson	
16. Signed financial agreement/contract	N/A

The project has been reviewed by the Research Department and authorised by the Medical Director on behalf of STH NHS Foundation Trust to begin.

Yours sincerely

1 Dr G. Davies

Medical Director, Sheffield Teaching Hospitals NHS Foundation Trust

Telephone +44 (0) 114 2712178

Fax +44 (0) 114 2713765

Appendix 9.

Reviewers' checklist for STH (STH14054)

Please enter text into cells; these will expand as required. Please elaborate as the comments you make will be useful to the Researcher and the Research Department.

No.	Criteria
1	<p>Project details: Has appropriate information been included? (Investigator details, STH number and project title, protocol version number and date, STH Programme affiliation)</p> <p>yes</p>
2	<p>Research question: Is there a clearly defined, answerable question?</p> <p>Yes – his is a quality of life study the outcomes of which will be qualitative</p>
3	<p>Is the research original?</p> <p>(Student project: does the study fulfil course requirements?)</p> <p>Yes in so far as there is limited data on UK patients none of local region who have been studied</p>
4	<p>Background: Is the research question an important one?</p> <p>1. Is the study useful to clinical practice?</p> <p>Yes greater understanding of patients experience / social-physiological difficulties</p> <p>2. Is there a real problem/ knowledge gap that needs filling?</p> <p>Yes little knowledge on the effect of facial surgery on patient self image</p> <p>3. Is the project in alignment with the strategic objectives of the programme with which it is associated?</p> <p>yes</p>
5	<p>Plan of the investigation:</p> <p>1. Methods: are these appropriate to the aim, will they address the question being asked and are they likely to produce an answer?</p> <p>yes</p>

2. Design: is the study designed to reduce the risk of bias?

yes

3. Analysis: have any analysis techniques, such as statistical methods, been defined, where appropriate?

yes

4. Outcome measures: Are these appropriate and achievable?

yes

5. Setting: will the project setting appropriate

yes

6. Participants: have the methods used to identify, approach, recruit and consent participants been clearly defined

yes

7. Sampling issues: Will the proposed sample be large enough for significant findings to be detected? Will the sample collected be reasonably representative of the population in question? Is there sufficient evidence to indicate that it will be possible to obtain the numbers required for the study?

yes

8. Intervention: Is the intervention clearly delineated, where appropriate?

yes

9. Screening tools and questionnaires: are these relevant to the project and have they been thoroughly tested?

Yes a pre project pilot will be undertaken to refine methods

	<p>10. Project plan: Has an appropriate plan of the study in the form of a flow chart / diagram been included? Is the estimated duration of the project appropriate?</p> <p>yes</p>
6	<p>Project management: have adequate arrangements been specified?</p> <p>yes</p>
7	<p>Expertise: Does the research team include the necessary expertise?</p> <p>yes</p> <p>Has access to people with relevant expertise at the appropriate points of the project been agreed?</p> <p>N/A</p>
8	<p>Ethical issues: Have ethical issues been addressed?</p> <p>Risk - safety issues. Rights to information and consent, confidentiality and privacy. Issues concerning data protection; in what form, how long and where will data be stored, and security? Issues concerning racial and cultural diversity</p> <p>yes</p> <p>Have patient information sheets and consent forms been included? Are these satisfactory for the lay person and is advice given should the participant become distressed?</p> <p>yes</p>
9	<p>Service users: where appropriate, have they been consulted about the design and outcome measures of the study?</p> <p>yes</p>
10	<p>Dissemination: Have suitable plans for dissemination been included, where appropriate?</p>

	yes
11	Taking the work forward: Is there, where appropriate, a strategy for developing the study? yes
12	IntellectualProperty: If the research is likely to generate any commercially exploitable I.P. have appropriate arrangements been made? N/A
13	Costing schedule: Has an Itemised costing been included? Are the resources requested appropriate? yes
14	Funding arrangements: have these been made clear? Has agreement from the host team / clinical area been obtained for the use of resources in particular where there is no funding associated with the project? yes
15	References: Has a suitable list of references been appended? yes
16	Abstract: Is the abstract clear, concise and appropriately structured? yes
17	Curriculum Vitae: Has a CV been attached? yes

18	Statistical opinion: Has a statistical opinion been included, where appropriate? yes
Overall project grading: A. No changes required; minor suggestions at discretion of the researcher; take the study forward Any additional comments: Study valuable to gain an insight in patients problems following disfiguring surgery	

Appendix 10

Reviewers' checklist for STH (STH14054)

Please enter text into cells; these will expand as required. Please elaborate as the comments you make will be useful to the Researcher and the Research Department.

No.	Criteria
1	<p>Project details: Has appropriate information been included? (Investigator details, STH number and project title, protocol version number and date, STH Programme affiliation)</p> <p>Yes apart from protocol version number</p>
2	<p>Research question: Is there a clearly defined, answerable question?</p> <p>Yes, the aims of the project are appropriate.</p> <p>This appears to be a study to be undertaken as part of a course (higher degree) but this is not stated explicitly. It would be helpful for the researcher to make this explicit as this carries implications for how the project is reviewed.</p>
3	<p>Is the research original?</p> <p>(Student project: does the study fulfil course requirements?)</p> <p>I do not have expertise in the field in question so cannot comment fully on this. However the researcher presents a logical account as to why this particular study is justified in exploring what appears to be an under-researched area.</p>
4	<p>Background: Is the research question an important one?</p> <p>1. Is the study useful to clinical practice?</p> <p>Yes, the study could provide some useful insights which could inform the preparation and support of patients who are fitted with a facial prosthesis following surgery for cancer.</p> <p>2. Is there a real problem/ knowledge gap that needs filling?</p> <p>See point 3 above. It appears that there is a genuine gap in knowledge however someone with expertise in the field would be better able to comment.</p> <p>4. Is the project in alignment with the strategic objectives of the programme with which it is associated?</p> <p>The proposal does not make explicit the links to the research programme on the 'Patient experience' however, it does fit with the strategic objectives of the programme</p>
5	<p>Plan of the investigation:</p> <p>1. Methods: are these appropriate to the aim, will they address the question being asked and are they likely to produce an answer?</p> <p>Adopting a qualitative approach using semi-structured interviews is appropriate to this exploratory study and should provide some insightful data for analysis.</p>

2. Design: is the study designed to reduce the risk of bias?

It is not clear whether the researcher has also acted as a practitioner providing care to patients who will form the sample. If possible it is best to avoid this in order that participants may feel more open in sharing their experiences of care. However, in small scale educational projects this may not be feasible and provide the researcher acknowledges the potential issues this raises it should not be problematic.

3. Analysis: have any analysis techniques, such as statistical methods, been defined, where appropriate?

An overview of the strategy for qualitative analysis has been presented which is adequate but does not go into detail

4. Outcome measures: Are these appropriate and achievable?

Outcome measures are not appropriate in a qualitative study of this nature.

Setting: will the project setting appropriate

Yes

6. Participants: have the methods used to identify, approach, recruit and consent participants been clearly defined

It would be helpful to provide a little more detail on how the researcher will approach and recruit participants to the study. The brief account in the proposal is supplemented with some information in the letters of invitation appended however a clearer account would be helpful.

7. Sampling issues: Will the proposed sample be large enough for significant findings to be detected? Will the sample collected be reasonably representative of the population in question? Is there sufficient evidence to indicate that it will be possible to obtain the numbers required for the study?

A sample of 8 is suitable for a study of this nature, especially if it is being undertaken as a part of an education programme. It is not clear from how many patients the sample will be drawn – it may be helpful to state how many patients are treated each year.

8. Intervention: Is the intervention clearly delineated, where appropriate?

N/A this is a qualitative study

9. Screening tools and questionnaires: are these relevant to the project and have they been thoroughly tested?

The interview agenda is a little confusing. It is not clear how the first 4 questions relate to the following 21 questions – there appears to be some overlap. The number of questions does appear rather long for a semi-structured interview agenda for an interview lasting one hour, especially if the researcher intends to probe.

10. Project plan: Has an appropriate plan of the study in the form of a flow chart / diagram been included? Is the estimated duration of the project appropriate?

Yes although the analysis may take a bit longer than specified. However the overall time scale following the necessary approvals looks appropriate

6	<p>Project management: have adequate arrangements been specified?</p> <p>Yes although a little information in the expertise of the academic supervisor would be helpful.</p>
7	<p>Expertise: Does the research team include the necessary expertise?</p> <p>It is not clear what expertise the supervisory team have in qualitative research methods.</p> <p>Has access to people with relevant expertise at the appropriate points of the project been agreed?</p> <p>It appears to be the case</p>
8	<p>Ethical issues: Have ethical issues been addressed?</p> <p>Risk - safety issues. Rights to information and consent, confidentiality and privacy. Issues concerning data protection; in what form, how long and where will data be stored, and security? Issues concerning racial and cultural diversity</p> <p>These will be reviewed by the LREC. However I suggest that the applicant gives more consideration to the possible psychological distress that some participants could encounter during the interviews and explain how he intends to minimise this and what support mechanisms are in place should participants request this. More information on data storage/security (university, trust or home computer) needs to be provided but these issues will be addressed on the LREC form.</p> <p>Have patient information sheets and consent forms been included? Are these satisfactory for the lay person and is advice given should the participant become distressed?</p> <p>PIS / consent forms letters of invitation will require a date, version number and to be on headed note paper. It may be helpful draw upon some more of the sections in the sample PIS given on the COREC website, e.g. to include the introductory statement about the project, details as to why the individual has been approached, do they have to take part, who has reviewed the proposal (STH scientific review panel and LREC) etc.</p>
9	<p>Service users: where appropriate, have they been consulted about the design and outcome measures of the study?</p> <p>It does not appear that they have been involved.</p>
10	<p>Dissemination: Have suitable plans for dissemination been included, where appropriate?</p> <p>It would be helpful to know if the researcher intends to feedback a summary of the project to research participants.</p>
11	<p>Taking the work forward: Is there, where appropriate, a strategy for developing the study?</p> <p>N/A</p>
12	<p>IntellectualProperty: If the research is likely to generate any commercially exploitable I.P. have appropriate arrangements been made?</p>

	N/A
13	<p>Costing schedule: Has an itemised costing been included? Are the resources requested appropriate? yes</p>
14	<p>Funding arrangements: have these been made clear? Has agreement from the host team / clinical area been obtained for the use of resources in particular where there is no funding associated with the project? This appears to be the case</p>
15	<p>References: Has a suitable list of references been appended? Yes</p>
16	<p>Abstract: Is the abstract clear, concise and appropriately structured? Yes</p>
17	<p>Curriculum Vitae: Has a CV been attached? Yes</p>
18	<p>Statistical opinion: Has a statistical opinion been included, where appropriate? N/A</p>
<p>Overall project grading:</p> <p>A. No changes required; minor suggestions at discretion of the researcher; take the study forward B. Changes required; decision at the discretion of the Reviewer after receipt of amendments C. Substantial changes; a re-submission required D. Complete re-think required; a new submission required</p> <p>Any additional comments:</p> <p>A/B – I have recommended some areas where the proposal would benefit from development prior to submission to the LREC however I do not think that it is necessary for me to see it again if the researcher takes these points on board.</p>	

PROFESSIONAL ACTIVITY

GUEST LECTURE

“Craniofacial Prosthetics for the Oncology Patient; Psychosocial Aspects.”

Postgraduate Oncology Nursing Course. University of Sheffield School of Nursing and Midwifery. 21 February 2007.

KEY NOTE LECTURES

“Maxillofacial Prosthetics; Restoration and Rehabilitation.” The Society of Limb

Prosthetists and Orthotists Annual Conference 2006. Sheffield Hallam University, 25 November 2006.

“Maxillofacial Prosthetics; Restoration and Rehabilitation.” The Tissue Viability

Society Regional Conference 2006. Don Valley Stadium, Sheffield, 23 November 2006.

"The use of Branemark Implants in Facial Reconstruction and Rehabilitation"
International Conference on Otolaryngology. B Braun Conference Centre, Thornhill
Business Park, Sheffield. 5 October 2005.

"Facial Prosthetics after Ablative Cancer Surgery." The Japanese Society of Head
and Neck Surgeons. University of Tokyo School of Medicine. Tokyo. Japan. 6
April 2005

"The use of Extra-oral Implants in Prosthetic Rehabilitation." Portugese Institute of
Oncology. Lisbon. 27-28 October 2000

ABSTRACTS

Watson, J., Johnson, F.P., Brook, I., Walsh, T.F and Cannavina, G.(2001) *The
psychological impact on health professionals treating patients with facial
disfigurement. Br. Soc. Study Pros. Dent Abs.*

Johnson, F.P., Watson, J., Brook, I., Walsh, T.F., Cannavina, G. (2002)
Psychological aspects of patients with facial disfigurement. *Br. Soc. Study Pros.
Dent. Abs.* 17.

PAPER

Overleaf

Facial Prosthetics: Techniques used in the Retention of Prostheses following Ablative Cancer Surgery or Trauma and for Congenital Defects

Frank Johnson*, Giuseppe Cannavina†, Ian Brook‡, and Jason Watson§

Abstract – *The retention of facial prostheses is a major factor influencing the successful outcome of rehabilitative treatment following ablative cancer surgery or trauma and for the prosthetic replacement of congenitally absent tissue. Since the sixteenth century to the present day, facial prosthetic devices have been retained by methods including adhesives and spectacle frames. The introduction of the Branemark extra oral implant system enhanced the stability of life-like prostheses thus giving patients more confidence in their use. This paper outlines the retention systems commonly used at the authors unit and the benefits gained by the use of implants to retain facial prostheses. The use of a single stage surgical technique instead of the usual two stage procedure is detailed.*

KEY WORDS: Maxillofacial prosthesis; Dental implantation, Endosseous

INTRODUCTION

The development of facial silicone elastomers and prosthetic colouring systems has enabled prosthetists to fabricate life-like restorations for patients who have lost parts of the face through trauma or disease. Equally, patients who require prosthetic replacement of congenitally absent facial tissues can benefit from similar materials and techniques.

Successful prosthetic treatment is often marred by inadequate retention or adhesive systems which are difficult for patients to use. Prosthetic adhesives provide adequate retention but are messy and difficult to use for the less dexterous patient. Mechanical retention sometimes fails, allowing the prosthesis to slip out of position, and often has to be supplemented by adhesives to maintain a reasonable marginal fit.

The introduction of the Branemark (Entific) extra oral implant system^{1,2} provides patients with an excellent means of retention for facial prostheses together with stable marginal fit and excellent aesthetic possibilities. The reproducible placement ensures that even the least dexterous patient can position the prosthesis quickly and accurately.

Adhesive-Retained Facial Prostheses

The retention of facial prostheses by adhesive compounds is not new. The Danish astronomer Tycho Brahe lost much of the central part of his nose in a sword duel in 1566 and wore a small metal prosthesis, held in place by a glue like ointment³. Spirit gums have been used for many years and latex adhesives are still used by some patients.

The majority of patients who wear adhesive-retained prostheses today use some form of solvent based adhesive. Many adhesives are available under different trade names but all are of a similar chemical composition. Short chain dimethyl polysiloxane polymers are combined with a solvent, usually trichloroethane, and are supplied in either an aerosol can or in a brush capped bottle. A thin layer of adhesive is applied to the fitting surface of the prosthesis and the solvent allowed to evaporate for up to five minutes before the prosthesis is placed into position on the face. The area around the defect site can be wiped with isopropyl alcohol to degrease the skin which will increase the adhesive to skin bond. After the prosthesis is positioned, pressure is applied to the margins to strengthen the bond. The adhesive is waterproof and the strength of the bond ensures that the prosthesis will remain in position for many hours. The majority of prostheses fitted in the authors unit are made from silicone elastomer. A silicone appliance provides the patient with a soft prostheses which can be coloured to offer a life-like appearance. Some mimicking of movement during facial expression will also be observed.

Among the disadvantages of adhesive retention are:

- reduction in the aesthetic acceptability and durability of the prosthesis due to colour and texture changes induced by the frequent use of adhesive and cleansing agents used to remove layers from the fitting surface (*Figure 1*).
- the need to increase the cross sectional dimension of the periphery to prevent the silicone from tearing on removal, renders the prosthesis more conspicuous.
- the contact nature of the adhesive requires the patient to position the prosthesis correctly at every application. Failure necessitates that the prosthesis be removed and cleaned before re-application.
- the use of solvent based adhesive and cleansing agents on the skin may produce a contact dermatitis or allergic reaction. This may be seen as a slight reddening of

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Figure 1. Discolouration of a silicone prosthesis following repeated use of adhesive and cleansing agents.

the skin or, in severe cases result in excoriation. In such cases, patients are instructed in the correct use of adhesives. The solvent should be allowed to fully evaporate before placement. A tissue conditioner and barrier cream can be prescribed for use between the skin and adhesive layer (Comfeel Barrier).

- the force required to break the adhesive to skin bond may have a traumatic effect on the skin especially where tissues have been irradiated.
- elderly patients may not possess the manual dexterity required to apply adhesive and correctly place the prosthesis on the face.
- the accumulation of dirt at the periphery through the inaccurate and over application of adhesive renders the prosthesis more conspicuous than it might otherwise have been.

Anatomical and Mechanical Retention

Skin adhesives remain relatively inexpensive and readily available and the majority of patients who require facial prosthetic rehabilitation will be treated with some form of adhesive retained prosthetic device. In patients where favourable anatomical undercut areas are present, soft silicone flanges or compressible silicone sponge may be incorporated within the prosthesis to engage the undercut areas and provide retention. Retention of this type must be monitored carefully as pressure from flanges can result in ulcerated areas of tissue of which the patient may be unaware as a result of the surgical interruption of sensory innervation.

Where none of these systems are possible, purely mechanical means of retention can be employed. The fixation of the prosthesis to spectacles is a method which should be used as a last resort. Slipping of the spectacle frame during use results in a space appearing between the face and the prosthesis which detracts from the aesthetics of the restoration.

Implants

Osseointegrated retention of facial prosthetic devices has been available since the mid 1970s. Each silicone prosthesis includes a rigid acrylic section which incorporates the retentive attachment to the implant, visible from the fitting

surface. The flexible silicone part of the prosthesis is bonded to the acrylic shell by the use of primers and bonding agents. Patients who undergo surgery to remove tumours of the head and neck or who exhibit congenitally absent facial tissue can be treated with facial prosthetic restorations which are not only more aesthetically pleasing, but enjoy a longer lifespan than their adhesive-retained counterparts. Implant-retained prostheses are easier and quicker to position than adhesive-retained prostheses and are usually more retentive than anatomically or mechanically-retained prostheses. They instil confidence and self esteem in the user. Component systems including closed field magnets and wrought gold bar and rider clips increase the versatility of the system and allows the retention to be tailored to individual patient needs.

Cases reported

In our unit we have 18 patients, six female and 12 male aged between 11 and 58 years, with a mean follow up of 36 months (range 4–103 months). Nasal and orbital prostheses were provided following tumour excision. Ear prostheses following tumour excision (1), burns (3), human bites (2), road traffic accident (3) and congenital deformity (8). Details of patients and implants are set out in *Table 1*.

Initially, seven cases were treated using a two stage technique, the implants being left between four and 11 months (mean 8 months) before being uncovered. In 1995 we started placing percutaneous/mucosal abutments at implant placement and started prosthesis construction three months post operatively. Exceptions to this have been in a burns patient and in an orbital case where bone quality was judged poor at the time of surgery. One implant, placed using a two stage technique, functioned for three years. The prosthesis was then converted from bar to magnet retention on two further implants, the former implant being converted to a sleeper. Subsequently this caused repeated skin infection and after a further year was removed using a trephine. Two of our patients, both with ear prostheses, developed pain at nine months and 57 months, respectively, which they attributed to the implants. The pain proved to be psychosomatic and resolved with supportive therapy. The majority of prostheses (15) were magnet retained, the magnets mounted directly on the abutments. Bars were used in two early cases and for children (4) where greater retention was desirable to prevent embarrassment in games and the classroom. Hyperplasia of skin around the abutments occurred in three patients. This was attributed to a lack of personal hygiene which contributed to a localised infection. Insufficient surgical reduction of subcutaneous tissue may have permitted tissue mobility around the abutment⁴. In all three cases surgical thinning of the tissue followed topical application of Terra Cortril ointment (Pfizer). One early case had a

Table 1.

	No of implants placed	No of implants used	No of prostheses	No of Patients
Nasal	4	4	2	2
Orbital	11	10	2	2
Auricular	42	40	17	14
Totals	57	54	21	18

skin graft at second stage surgery; the remaining cases had radical thinning of the skin around the implants at placement.

Implant Placement

The placement of implants can be carried out wherever suitable bone exists i.e. where an adequate thickness of cortical and cancellous bone is located⁵.

The usual sites for placement of implants are :

- the temporal bone or mastoid process for auricular prostheses.
- the supra orbital ridge and zygomatic buttress in orbital prostheses.
- the floor of nose and/or the nasal aspect of the frontal bone in nasal cases.

The ideal implant site is determined after careful reference to diagnostic wax sculptures to ensure the implant abutments are placed within the confines of the planned prosthesis (Figure 2). For auricular prostheses the positioning of implants described by Tjellstrom⁶ may also be adopted. In orbital cases it is essential that an accurate wax sculpture of the prosthesis is tried on the patient and impressions obtained from which study casts are made. The wax sculptures and the study casts can be used to determine the best position of the implants to prevent incompatible alignment. In the majority of cases a single stage procedure avoids a secondary operation to place percutaneous abutments⁶ (Figure 3). Results of the single stage technique in our unit demonstrate that it is equally as effective as the two stage procedure.

Selection of Retention

Two systems, available for connection to osseointegrated implants, were used:

- A 2 mm diameter wrought gold bar soldered to platinumised gold cylinders which are screwed on to each abutment (Figure 4). Gold bar rider clips are incorporated into the fitting surface of the prosthesis which in turn fit over the wrought bar and anchor the prosthesis into place (Figure 5).



Figure 3. Implant fixtures and percutaneous abutment placed during the same surgical procedure.



Figure 4. A two millimetre diameter wrought gold alloy bar soldered to abutment cylinders connected to the implant abutments.

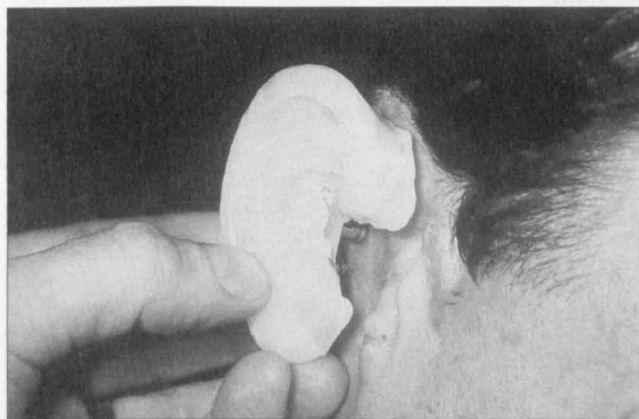


Figure 2. Use of diagnostic wax sculptures ensures the accurate placement of implant fixtures.

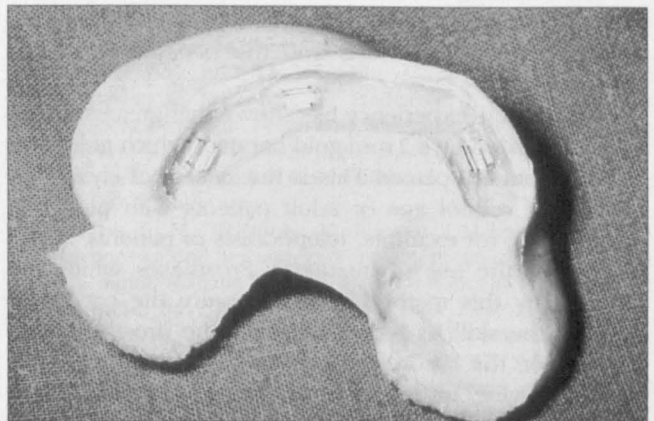


Figure 5. Gold alloy bar rider clips located in the fitting surface of a silicone prosthesis.

- Magnetic retention whereby magnet keepers or magnacaps (Technovent) are screwed into the abutments and powerful closed field magnets, processed into the prosthesis, provide retention (Figures 6 and 7).



Figure 6. Magnacaps connected to implant abutments to provide magnetic retention for a large orbital prosthesis.

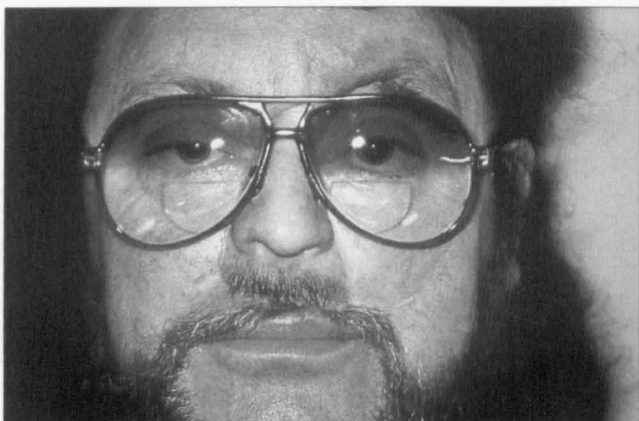


Figure 7. The orbital prosthesis fitted and retained magnetically.

The selection of retention is based on factors such as the patient's age; the degree of dexterity exhibited, the location of the prosthesis and the occupation of the patient.

The authors experience has shown that greatest retention is provided by a 2 mm gold bar over which gold clips or bar riders are placed. This is the system of choice for patients of school age or adult patients with particular occupations, for example, telephonists or patients whose job entails the use of headgear. Prostheses which are retained by this method usually require the patient to develop the skill to accurately place the prosthesis into position on the bar before pressure is applied to finally seat the device. In elderly or arthritic patients the development of this skill may be a problem. Some elderly patients, or patients who live alone, may also find that cleaning under the bar is a problem and that cleaning around the abutments is impossible. Magnet retention does not require the implants to be joined and therefore cleaning is greatly simplified. The degree of retention provided by maxi lipped magnets is more than adequate for nasal and orbital prostheses where two or more implants are placed and is satisfactory for auricular prostheses in adults who follow a sedentary occupation and do not engage in active leisure pursuits which make the stronger retention achieved with clips advisable. The access afforded to the abutments for cleaning and the ease by which the

prosthesis can be placed, as well as the adequate retention provided for the majority of prosthetic situations, means that magnet retention is usually the first choice for most patients in our unit.

Fabrication of the silicone prosthesis follows standard practice with a space for air circulation developed wherever possible (Figure 8). The periphery should also be made very thin to allow the silicone to blend with the surrounding tissue⁷ (Figure 9).

DISCUSSION

Although the success of facial prosthetic rehabilitation depends largely on the aesthetic acceptability of the final prosthesis, a device which is difficult to position or retain is likely to fail. Research into new prosthetic adhesives is lacking⁸. Adhesive provides excellent retention but is not, by any means, ideal in most cases. Adhesive retention is provided for the majority of patients who require facial prosthetic rehabilitation simply because it is cheap and readily available. Adhesives are messy, require the patient to be skilled in their use, are time consuming to apply and remove and reduce the longevity of the prosthesis.

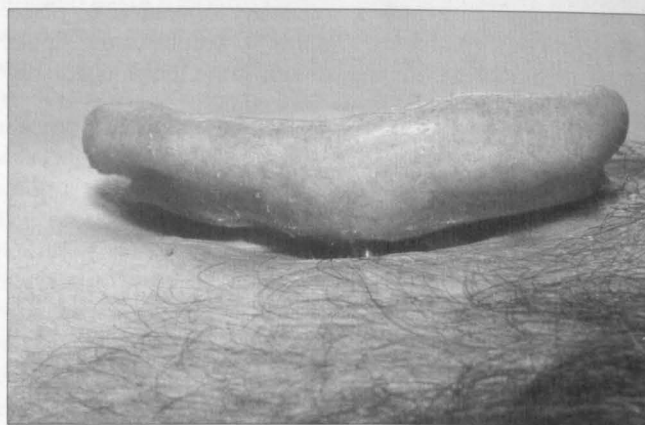


Figure 8. Space between the fitting surface of the prosthesis and the tissue allows circulation of air around the implant site.

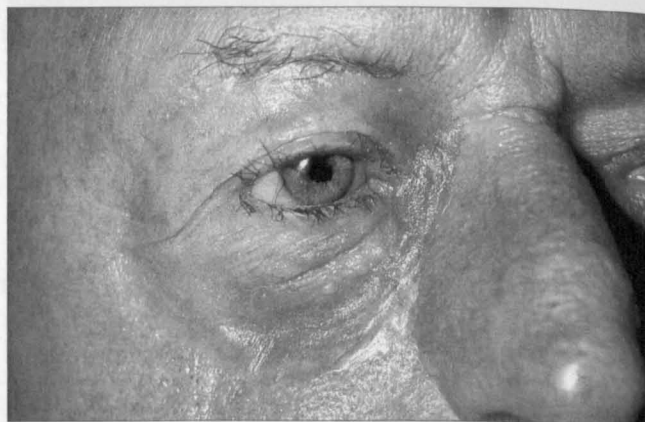


Figure 9. The periphery of an orbital prosthesis made very thin and blended against the skin using white soft paraffin.

Marginal integrity is compromised and consequently the aesthetic acceptability of the prosthesis. Wherever possible indirect, or adhesive/magnetic retention should be employed to overcome at least some of these problems⁹.

Anatomical retention is a technique which should be employed whenever favourable tissue undercuts are found. Prostheses designed with retentive silicone flanges or tissue engaging impervious silicone foam exhibit excellent retention. Patients find this type of prosthesis easy to fit, the correct positioning of the device is almost automatic and the margin of the prosthesis can be made very thin allowing it to blend to the skin with good aesthetic results. Frequent review is essential to check for pressure sores but in practise this is unlikely to be a major problem. Longevity of the prosthesis is improved due to the absence of surface adhesives and chemical cleansers. A prosthesis which is attached to spectacles enables the patient to easily position the device and the patient can be confident that when the spectacles are resting in the correct position on the face the prosthesis will, automatically be in the correct position. Slipping of the spectacle frame will readily occur which will result in a space appearing between the periphery of the prosthesis and the face. This can be overcome to some extent by the use of an elasticated sports band worn around the back of the head and attached to the spectacle sidearms. Many patients find the idea of a prosthesis fastened to spectacles psychologically unacceptable and almost comical. Nevertheless, for elderly, less dextrous patients, spectacle retention can be a useful tool in prosthesis retention when other systems are impossible or prove difficult to cope with. Mechanical linkage to an intra oral obturator can be made where maxillectomy has been combined with facial surgery such as rhinectomy or orbital exenteration. Maximum stability of the obturator is a prerequisite if retention of this type is to be successful.

Implant retained prostheses enjoy a much longer lifespan than their adhesive retained counterparts. The implant retained prosthesis gives the patient a greater degree of confidence and patients often remark that the prosthesis feels more a part of themselves. The prosthetist is able to thin the edge of the prosthesis to such an extent that blending of the periphery occurs at each and every fitting with a much improved cosmetic result. Patients are automatically directed by the placement of the retentive elements to place the prosthesis correctly and confidence in appearance is restored. When implants are placed into irradiated bone osseointegration is less than that of fixtures placed into normal tissue. Irradiation makes the bone tissue hypocellular and together with combined cellular and vascular effects as a result of late tissue changes the bone becomes demineralised and has an increased susceptibility to infection and avascular necrosis. The success of osseointegration has been reported to be increased by hyperbaric oxygenation of tissues. This promotes fibroblastic activity and collagen production creating a matrix for capillary budding and neovascularisation¹⁰. The technique should remain very much a consideration especially when major loss of facial tissue is encountered.

CONCLUSION

The success of a facial prosthesis owes as much to the method of retention as it does to the cosmetic appeal of the device. Modern skin adhesives will keep a prosthesis confidently in place but do not add to the longevity of the restoration. Adhesive retention remains an under researched area and more user-friendly compounds may have a great influence on the choice of retention for future facial prostheses. Anatomical retention can be utilised only where favourable anatomy exists and mechanical retention is acceptable for a small number, usually elderly, patients. The success of modern facial prostheses owes much to the use of extra oral implant systems, whose use world-wide is rapidly increasing. In suitable patients the final result is aesthetically and functionally excellent.

MANUFACTURERS' DETAILS

- Entific, Didcot, UK
- Comfeel Barrier, Coloplast, Humlebaek, Denmark
- Pfizer, Kent, UK
- Technovent, Leeds, UK

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