RESOURCING AND TRAINING HEAD AND NECK CANCER NURSE SPECIALISTS TO DELIVER A SOCIAL REHABILITATION PROGRAMME TO PATIENTS.

Volume One.

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Preface

1.0 Format of the Doctor of Psychology (DPsych) thesis

Whilst the research quality of a DPsych is required to be the same as that required for a PhD, the content of the final thesis is designed to reflect the role of a clinical psychologist as a scientist practitioner and, therefore, includes a case history component and additional literature review. Since different courses have different requirements, the final thesis format as laid down by City University is quoted below. Further details of the course requirements can be found in City University *Research Students Handbook 2000* and *Doctor of Psychology Course Handbook, 1997-8.*

'The final thesis should comprise:

<u>Section A   Preface or Introduction (1-2,000 words).</u>
This is intended to act as a preface to what is coming next and to provide an opportunity for the student to link their professional experience with the theoretical and applied ideas contained within the various components of the study. This provides an opportunity for the student to give a summary of their career history and how this links in with various areas of study engaged in. The student will also summarise the three broad areas (Sections B, C, and D),

including information on the aims and objectives of each piece of work. The overall, perhaps implicit connection between the various pieces of work is that the knowledge and skills required by each, although overlapping, reflect different but vital aspects of the expertise required by a senior applied psychologist.

Section B Research (approx. 40,000 words).

This is the main section of the thesis comprising an original piece of research (reflecting the same level of quality and originality as a PhD thesis, but less extensive and usually with an applied focus). The study would normally be empirical, but theoretical/conceptual studies will be accepted where originality can be demonstrated. The criteria for assessment include whether the research demonstrates rigour in the methods/approaches used and whether the study adds to the existing body of knowledge in a particular field.

Section C Casework (approx. 6,000 words).

Students are required to present one case study of 6,000 words or two smaller case studies each of 3,000 words relating to teaching, supervision, consultancy or direct clinical/counselling interventions in which the student has been the primary participant. This section emphasises the skills and knowledge required to be a reflexive scientist-practitioner.

Section D Critical Review of Literature (approx. 5-7,000 words).

Students are required to submit a critical review of a specified area of clinical psychology, drawing upon their clinical experience and published literature to

do this. The area reviewed should be different to that reviewed within the main study (Section B). It should reflect an ability to review applied clinical literature in a way that would be required for publication in a peer reviewed journal. Students should state the title, aims, objectives and rationale for the review at the start of this section.'

Chapter One.

1.1 Introduction and background to the work in this thesis

The function of this introduction, as outlined in the course requirements, is to pull together all the work in this thesis. Since this work has been carried out by a clinical psychologist working within a lay-led voluntary organisation, Changing Faces, rather than within an academic or health service setting, this charity will first be described.

Changing Faces was set up in 1992, by James Partridge, following his personal experience of a severe burn injury at the age of eighteen. During the process of adaptation to severe facial disfigurement following this injury, Mr Partridge became aware that very little psychological support was available to people like himself and others, and that there was no opportunity for mutual education and support amongst people who had either congenital or acquired disfiguring conditions. The Kings Cross fire, in 1989, brought these issues sharply into the public arena. Mr Partridge was approached to write a book about his experiences in managing his own rehabilitation, and this book: *Changing Faces: the Challenge of Facial Disfigurement*, was published in 1990.

With the encouragement of plastic surgeons and Dr Nichola Rumsey, a psychologist with an international reputation for her work on the social

psychology of facial appearance, the charity Changing Faces was launched, and based in London. With the aim of: 'providing a better future for people with facial disfigurements', the charity has three main objectives.

These objectives are:

- to provide a direct service of advice and support to people with a disfiguring condition, their families and friends

- to raise public awareness of the issues involved in managing disfigurement

- to improve health and social care

From the outset, the link with Dr Rumsey has ensured that the charity bases all intervention on objective research findings; for example, the decision to run skills-based workshops for people with disfigurements was based on evidence that good social skills were predictive of better outcome for this population. The workshops were rigorously evaluated and the results published (Robinson et al 1996). The charity has continued to stress this evidence-based approach throughout the development of the service to clients and in the resources and training offered to health professionals. In 1998, Changing Faces was instrumental in setting up the Centre for Appearance and Disfigurement Research at the University of the West of England, under the direction of Dr. Rumsey. Although independent organisations, the historic link between the two has ensured a process of mutual education which has been

particularly important in informing and developing training for health professionals and in carrying out research.

Changing Faces now employs twelve staff, some of whom have a personal experience of facial disfigurement. All staff who offer direct services to clients have a relevant training whether in counselling or psychology. This thesis describes some of the work carried out by the author since joining Changing Faces as a clinical psychologist and member of the adult service team, in 1995.

1.2   Building a service for people with disfiguring conditions

The first step as a health professional within a lay-led group is to find a way of channelling the enormous energy and flow of creative ideas into a managed and focused strategy for support. Fortunately, the importance of building a service that was underpinned by research, had been established by Dr Rumsey during the evaluation of the workshop programme. The extension of the evidence-based model to everyday practice was easier given this start. Thus it is important that there are standard procedures and protocols to be followed when people contact the charity. Anyone who chooses to come in and meet one of the counselling team needs to undergo a formalised assessment to ensure that each member of staff is able to formulate an assessment of need and work out a way forward. Where this can be provided

by the charity itself, an intervention package is designed. Where the issues raised can be dealt with best by some other agency, the appropriate steps are in place to ensure that this referral can be organised. Contact with GPs and other agencies is now formalised, and clear guidelines about exactly what an agency like Changing Faces can offer and what it cannot, are now in place. Knowledge of outcomes and monitoring of the service is a second requirement. It is important to have some standardised monitoring of change so that the charity can demonstrate its effectiveness. Standardised questionnaires are useful for one to one sessions, and a routine monitoring exercise is important in ensuring that all first contacts are followed up. A database has been set up and common requests and problems are monitored and standard responses developed. This ensures both consistency and time saving. The development of both the managerial aspects of establishing a service and careful monitoring of the clinical content of the service together with research into the main problems and concerns of people who have disfiguring conditions, has proved both a challenging and rewarding introduction to the voluntary sector. This work and its evaluation are presented as chapter two, the literature review of this thesis. Because this work forms the logical foundation for the rest of the thesis, it is presented first, followed by the case history section and finally the original research.

1.3   Building an information resource

From the outset, it was clear that many people who contacted Changing Faces were requesting basic information, and that this could best be achieved

by providing this information in a standardised form. An analysis of information needs was very helpful in demonstrating that people were more commonly accessing the charity to find out how they could manage issues themselves rather than asking for medical information or advice. This stimulated a project focused on defining and meeting the information needs of the charity. Funding for this project was made available by sponsorship from British Gas, and a series of booklets designed and piloted. In addition to developing a self-help format for the booklets, fiction was used to develop materials that could be used by young children and their parents. The whole information project proved very successful and led to some unexpected developments. Although designed for use by the client group, it soon became clear that the charity was regarded as an important resource for health professionals. Booklets were being used, both to inform and facilitate practice, in particular by nurses. International audiences requested permission to translate the booklets for use in their own countries, notably in the USA, Australia and in Russia. A major international drug company provided funding to write a condition specific package of patient information for people recovering from burn injuries and this was developed using the basic Changing Faces information framework. Defining the information needs of the charity's clients, devising a model for meeting these needs and writing much of the self help information was one of the most challenging aspects of the role at Changing Faces over the last two to three years. This project is presented in chapter three as the practical casework section of this thesis.

1.4   Meeting the needs of health professionals

Although the primary goal of the charity centres on supporting the client

directly, the dissemination of the work to health professional audiences and

the publication of resources has led to the growth of the Outreach function of

the charity, and in particular, an interest in how health professionals can work

to support people with disfiguring conditions at the point of discharge from

hospital. For example, the charity has suggested a three-point standard

(Clarke 1998) which can easily be met before discharge. It is recommended

that patients:

- Have access to relevant information about their condition

- Have details of the appropriate lay-led support group

- Can answer the question "what happened to your face?"

The increasing contact with health professionals led to the establishing of a

study day, and to the first study outlined in chapter four of this thesis, an

investigation of how skilled nurses perceive themselves to be in meeting the

psychosocial needs of their disfigured patients. From this study, it became

clear that it might be possible to design a rehabilitation programme for

patients that could be delivered by specialist nurses. This meant the

development of condition specific resources and a model of care which allows

nurses to provide the same kind of support that Changing Faces can provide

to those clients who live near enough to attend the centre. The development

of this training programme for head and neck cancer nurses, and its

evaluation, is described in chapter four, as studies two and three of the research section of this thesis.

1.5   Current and future developments

This social rehabilitation study and its presentation for a Doctor of Psychology degree have led to many new opportunities. The head and neck cancer resource pack is being published by the charity and a designated training course for head and neck nurses is scheduled to begin this year. Funding for a similar resource pack for burns nurses has just been obtained and will form the basis for a similar resource development and training programme. In response to interest from the Shriners Hospital in Galveston, which is an international centre for the rehabilitation of burn injuries, a shorter resource pack has been developed for psychologists working with adolescents who have had severe burn injuries. The effectiveness of this four day weekend rehabilitation programme is being evaluated in a controlled trial which will demonstrate the effectiveness of the coping skills model with a defined 'problem' group who have not responded to any previous form of psychosocial intervention. This kind of partnership with a leading academic and clinical institution is a very positive development in the evaluation and dissemination of work that has originated in a lay-led setting.

A further interesting development of the work at Changing Faces has come through the link with self-management programmes. Within the UK, patient led organisations have championed the growth of lay-led self-management

programmes, with a rapid pace of development from the mid 1990s.

Changing Faces is only one of a number of organisations including Arthritis

Care, The Manic Depression Fellowship and the British Liver Trust who have

developed their own self management programmes. All these groups are

members of a UK network of over 20 organisations (all involved in developing

their own programmes) which has been established by the Long Term

Medical Conditions Alliance, the umbrella organisation of almost 100 voluntary

organisations supporting people living with long-term conditions. This direct

involvement in healthcare provision parallels the increasing political activity

and importance of lay-led groups, as health policy looks more and more to the

user groups in defining health care objectives and helping set the agenda for

new health care approaches (Wilson and Dickinson 1998). The LMCA is

currently running a 'Living with Long Term Illness' project with Changing

Faces represented on the steering committee. This project is enabling eight

member groups to set up and run their own self-management programmes.

This potential role of lay-led self-management in the management of chronic

disease has been described in a paper (Cooper and Clarke, 2000), and has

led to the inclusion of LMCA as a member of the Expert Patients' Task Force,

a body chaired by the Chief Medical Officer to design the expert patients'

programme to address the needs of people in the UK with a chronic disease,

in line with the 1999 white paper, Saving Lives: Our Healthier Nation (DOH

1999).

In summary, the experience of working with a small voluntary organisation has

offered tremendous opportunities to develop the role of a psychologist. The

work presented in this thesis demonstrates the clinical, managerial, research and teaching opportunities that have been explored in this setting. In presenting and in publishing this work, the aim is not only to develop the standard of psychosocial care available to people with disfiguring conditions, and in particular head and neck cancer, but to demonstrate the role for psychologists in facilitating the important work of lay-led organisations.

1.6   References

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CHAPTER TWO. PSYCHOSOCIAL ASPECTS OF FACIAL DISFIGUREMENT; PROBLEMS, MANAGEMENT AND THE ROLE OF A LAY-LED ORGANISATION.

2.1 Abstract:

The problems of facial disfigurement are becoming more widely understood as information from different research areas becomes better integrated. This chapter reviews this research, describing the problems faced by people who have a disfigurement and the results of intervention studies.

The 'package' of care provided to this population by a lay-led organisation is described, and a framework proposed which integrates the development of coping skills with the more traditional role of providing support and information. This framework uniquely recognises the potential therapeutic role of the ex-patient for the population served, and builds this role into the package. It is proposed as a potentially useful model for health professionals providing a service in other health care settings.

2.2 Introduction: the causes and incidence of facial disfigurement

250,000 people in Great Britain have a severe facial disfigurement (OPCS 1988). Causes include congenital abnormalities such as cleft lip and palate, other craniofacial syndromes, birthmarks, haemangiomas etc., and acquired disfigurement through burns, facial paralysis, surgery, trauma and disease. In terms of prevalence, these numbers equate to approximately one child per primary school; the implications in terms of feelings of isolation, and lack of available role models are clear. Health professionals too, unless working in specialist units, are likely to encounter this group infrequently; GPs may perhaps care for two or three people per practice.

In addition, there is a separate group, who are not classified in this severe category, but who can be said to have a minor disfiguring condition. Figures of a total of up to 400,000 have been quoted in some sources (Lansdown et al 1997). This group includes smaller birthmarks, skin conditions such as acne scarring and eczema, vitiligo, facial scars from minor accidents, dog bites etc. In psychological terms, this too is an interesting group. Because medical models assume a relationship between severity and disability or handicap, 'minor' disfiguring conditions may easily be dismissed as less important, yet evidence of psychological distress has been well documented (Papadopoulos et al 1999).

2.3 Sources of information about facial disfigurement

Although it is an area that is beginning to receive more attention, the psychological aspects of facial disfigurement and their management can still be said to be relatively unreported in the clinical/ health psychological literature, with most reports appearing in medical journals specific to a given condition, or in the social psychology literature. However, evidence from different disciplines using different methodological approaches is remarkably consistent in terms of results, producing a coherent picture of the kinds of difficulties that people with a disfigurement encounter in their day to day lives. There is less reported information on effective management of problems whether in terms of self-reported coping strategies or reports of clinical intervention, but this is changing with the development of better validated measuring instruments and better designed studies. This chapter therefore introduces the psychological aspects of facial disfigurement and looks at how the problems can be managed. It then describes the treatment package established in a lay-led setting and discusses the implications of this package for managing facial disfigurement in other health care settings.

2.4 The problems of facial disfigurement

Research studies are remarkably consistent in describing the problems that people with a disfigurement face. The predominant difficulties lie within the area of social interaction, with people being subjected to unwanted intrusions such as staring or comments. Macgregor (1974), working with people who have experienced disfiguring burns, has highlighted these issues. Her summary encapsulates these difficulties very succinctly:

> "In their attempts to go about their daily lives, people are subjected to visual and verbal assaults, and a level of familiarity from strangers.....(including) naked stares, startled reactions, 'double takes', whispering, remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, laughter, ridicule and outright avoidance.'

This perceived hostility from other people has led McGrouther to describe facial disfigurement as "the last bastion of discrimination" in this country (McGrouther 1997), although Partridge (1998) suggests that there is more evidence to support uncertainty rather than hostility on the part of the observer. Drawing on his own experience of severe facial burns, Partridge emphasises the role of the disfigured individual in managing the success or failure of social situations, illustrating this with a feedback model (figure 1).

Figure 1. The negative feedback loop.

Self-image

Negative reactions
from other people

Own behaviour

Shy   Vulnerable   Aggressive

Avoidance
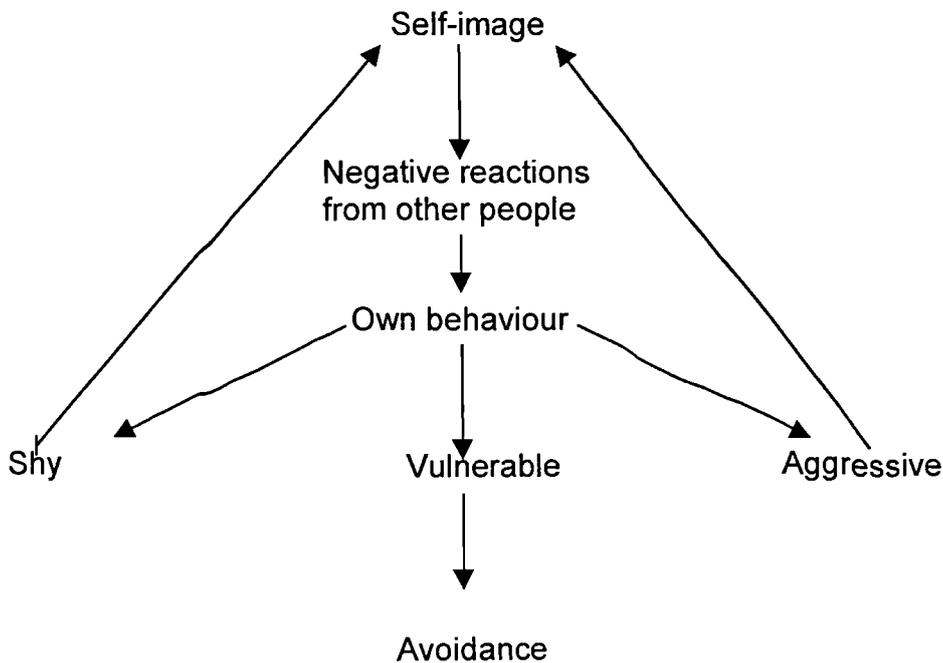
(It is curious that Partridge does not suggest that negative reactions impact on

self-image; the model could be adapted to illustrate this idea if a double

headed arrow was used to link these two constructs). Interestingly, the same

explanation was suggested by Bull and Rumsey (1988), drawing on evidence

from a series of well designed and controlled studies in laboratory and field

settings. They too proposed the hypothesis that the breakdown in the

reciprocal behaviour of social encounters accounted for much of the distress

both on the part of the disfigured individual and the observer.

Whatever the underlying construct, there is convincing evidence of difficulties

in social settings. First meetings are particularly difficult (Porter et al 1990),

but others report longer-term difficulties in forming friendships (Lannigan and

Cotterill 1989). Other studies report high levels of social anxiety, and evidence that not surprisingly, this group of people may have very low self-esteem and expectation about life chances. Self-report statements within these studies suggest that many believe they need to make compromises in terms of relationships, "you have to take what you can get", or believe that they have low employment prospects (Noar 1991; Partridge 1994; Rubinow et al 1987).

2.5   Factors predicting good outcome for people with disfigurements

Relatively few studies have attempted to look beyond the description of psychosocial problems in the target population to the factors associated with good adjustment in the long term. An exception has been Macgregor, who identified coping style as important. Those who cope well and report fewer problems tend to use 'positive' coping strategies; they have good social skills, are assertive and take the initiative in new settings; 'negative' coping strategies include aggression, use of alcohol, unrealistic pursuit of surgical solutions, and above all, avoidance and withdrawal from difficult situations. (Macgregor 1974; Partridge 1994; Robinson et al 1996a). More recently, Partridge et al (1997), measuring the effectiveness of the first specialist Disfigurement Guidance Unit funded by the N.H.S., report the *number* of effective coping strategies used by an individual to be a better predictor of good outcome than a particular kind of strategy per se; in other words, those who managed their disfigurement most effectively and reported fewer

problems, were those who had developed a variety of different responses that they could use.

2.6   Methodological approaches

In considering the problems of facial disfigurement, it is important to be aware of the different methodological approaches that research studies have employed. Survey and descriptive studies reported particularly within the medical literature, tend to investigate specific medical conditions. Disfigurement, in these studies, is therefore only one, (albeit an important one), of a number of problems being measured. Thus, for example, there are a group of studies looking at the psychosocial consequences of burns, (Macgregor 1974, 1990; Malt and Ugland 1989; Wallace and Lees 1988; Williams and Griffiths, 1991), cleft lip and palate, (Noar 1991), port wine stains, (Lannigan and Cotterill 1989) and vitiligo, (Porter et al 1986). This descriptive approach therefore provides one source of evidence about the importance of psychosocial issues across a range of disfiguring conditions.

Measuring quality of life is another technique for studying long term psychosocial outcome, and has been used to study the impact of dermatological conditions (Finlay and Khan 1992), burn injury (Kleve and Robinson 1999) and particularly, in cancer of the head and neck (Baker 1992; Bjordal et al 1995; Breitbart and Holland 1988; Edwards 1997; Koster and Bergsma 1990).

With the technical advances being made in the treatment of head and neck cancer, more and more people survive the illness (Edwards 1997). This has led to an awareness of a 'trade-off' between survival and severe dysfunction and disfigurement, with some sources questioning the validity of treatment where such severe outcome results (Morton and Witterick 1995). Many studies suggest long term supportive counselling for this population, and others advocate the investigation of coping skills in the rehabilitation of this group (Bjordal et al 1995). The importance of psychosocial issues for this group is therefore well established. However, whilst the interest in reduced quality of life in this group receives increasing attention, other conditions with far reaching consequences in terms of altered physical appearance and visible disfigurement have received only superficial attention e.g.: loss of an eye or eyelid, facial paralysis, endocrine disorders.

2.7 The contribution of social psychology research

In contrast to these descriptive medical studies, social psychology has provided not only an empirical basis for investigation, but also a conceptual shift towards the investigation of disfigurement per se, and the problems encountered by the disfigured population as a whole (Bull and Rumsey 1988). Whilst the description of problems in different populations with disfigurements has largely been by means of self report, social psychological research has considerably focused clinical intervention strategies by providing empirical evidence and better understanding of the problems reported. Work on

proxemics for example, has demonstrated that the subjective experience of being avoided can be objectively demonstrated (Rumsey et al 1982). Actors made up to appear disfigured, either with scars, birthmarks or bruising, were compared with a control group. Members of the public stood significantly further from them in an everyday situation (waiting to cross the road) and moved to stand on the non-affected side when they had the opportunity.

In a series of further studies, both in controlled natural and laboratory settings, the level of face to face contact and social interaction have been varied. Rumsey et al (1986) reported the effects of covarying social skill and disfigurement in an interview task. Not only did subjects report feeling more comfortable in the presence of an actor with good social skills, whether or not the actors were disfigured, but their own social skills were better when rated by an independent observer.

These empirical studies are important in demonstrating, unequivocally, that the *behaviour* of the individual rather than physical appearance can be instrumental in influencing the response from other people and in doing so can substantially reduce the perceived threat. Social skills are a better predictor of successful outcome than disfigurement, and social skills training can therefore be seen as a logical and potentially very powerful intervention strategy in the clinical setting.

Whilst it is easy to see how repeated exposure to negative events can lead to behaviour change, particularly the increasing avoidance of social situations,

the role of individual beliefs is also important. In addition to the evidence that people behave differently in response to someone who is visibly different, the *expectation* of a negative response is enough for the visibly different person to perceive and report events differently. Strenta and Kleck (1985) examined the impact of beliefs about disfigurement. Actors were made up to look disfigured, but under the guise of having fixative added, and unknown to them, the experimental group had that make-up removed before being exposed to the experimental situation. Subjects who believed themselves to be scarred reported stronger reactions from other people than the control group. This finding could be due to heightened sensitivity leading to the misinterpretation of events, or to subtle alterations in the subjects' behaviour - poor posture, eye contact etc. producing genuinely stronger reactions from the onlooker, in which case it is not simply a matter of inaccurate reporting. However, sensitivity to the disfigurement and the tendency to attribute all negative experiences to facial appearance, even where unrelated, is a common clinical observation (Partridge 1994), and a possible explanation for the significance to the individual of apparently only minor disfigurement.

Other areas of research in social psychology provide evidence that people are selective in their interpretation of feedback in social situations, with a tendency to focus on information that supports their internalised view of themselves (Kenny and DePaulo 1993). In the wider context of information processing, Wason (1974) reported the bias towards seeking evidence for an existing hypothesis rather than seeking evidence that challenges it. Clearly there is

ample evidence of the need to fully assess the *beliefs* as well as the

behaviour of the individual in planning psychological intervention.

2.8   Studying disfigurement across different conditions

The conceptual shift towards the study of facial disfigurement as a

phenomenon independent of medical condition has a number of advantages.

Grouping different medical conditions together produces a larger research

cohort, and makes it possible to set up a specialised service to a substantial

clinical population (Partridge 1994, 1997). However, it can only be justified

given a level of homogeneity in the problems encountered by different groups,

and although so far, there is a remarkable consistency in the kind of problems

reported by people with different conditions (Partridge et al 1997), there are

some difficulties. One of these is the measurement of the relative severity of

a disfigurement. Given the impact and prevalence of the medical model in

generating treatment options, it can be argued that severity is one of the most

important variables in studying the psychological impact of any disfigurement.

It is therefore important not only to know whether it is a term that is meaningful

in a psychological sense, but that it can be measured in a reliable and valid

way.

The classification of different conditions into 'severe' and 'minor' categories

has already been illustrated. However, within these categories, a condition

may still be relatively severe or minor. If these populations are to be studied

together, then there needs to be a way of comparing, for example, the severity of acne scarring with the severity of facial palsy. In most studies, judgements based on size, location and visibility all contribute to what is usually a highly subjective measurement standardised by inter-rater agreement across very simple categories. Thus, whilst it is widely reported that severity of a disfigurement does not predict psychological distress, this is a finding that is perhaps less convincing from studies *between* groups with a variety of disfigurements (Robinson et al 1996b), than from studies *within* groups having a unitary medical condition (Baker 1992; Love et al 1987; Malt and Ugland 1989). A second major problem with research into disfigurement is the fact that many disfiguring conditions involve associated dysfunction. Dropkin et al (1983,1989) in an attempt to standardise rating of severity of disfigurement and dysfunction after head and neck cancer demonstrated high inter-rater reliability in a study of 100 nurses. Disfigurement was rated most consistently severe where the central part of the face was involved, and in particular where audio-visual function was impaired.

Whilst acknowledging these measurement difficulties, and in particular, the absence of standardised scales for use across conditions, it is reasonable to say that a simple medical model is unhelpful in predicting psychological distress from the severity of a disfigurement. Perhaps the best way of interpreting the evidence from all the studies so far, is to suggest that it appears to be the extent to which the social/communication process is interrupted which is important, and that severity is only one of the factors that will have an impact in this process.

2.9   Social support

Social support is emerging as a further important factor in predicting

successful outcome (Baker 1992; Browne et al 1985). Blakeney et al (1990)

reported that the adjustment of children after severe burns injury is positively

influenced by a supportive family environment, and others have suggested

that those who report themselves as able to cope effectively, often live within

a small supportive community where they are well known (Partridge 1994).

However Moss (1997) points out that social support may have many different

components, from practical problem solving to emotional support. Different

aspects of support may be important for different individuals or for the same

individual at different stages in the illness.

Although this is an area where more work needs to be done, it seems

reasonable to conclude that social support is most effective where it most

closely matches the needs of the individual, and that this is therefore an

important issue for clinicians planning effective rehabilitation. It is also worth

noting that the benefits of social support are recognised not only by health

professionals, but also by the target population themselves. The growth of

self-help and lay-led voluntary groups and the numbers initiating contact as

these groups become better known is an important indicator of its perceived

value. Figure 2 illustrates the numbers of self-referred adults contacting the

charity Changing Faces during the first five years. Self-referred adults

continue to contact the charity particularly in response to publicity in the media

and are mirrored by similar figures for parents of children with a facial

disfigurement and health professionals asking for guidance in the long-term

support of their patients.

Figure 2. Number of adults self-referring to a lay-led voluntary organisation

offering help in managing facial disfigurement. First five years.
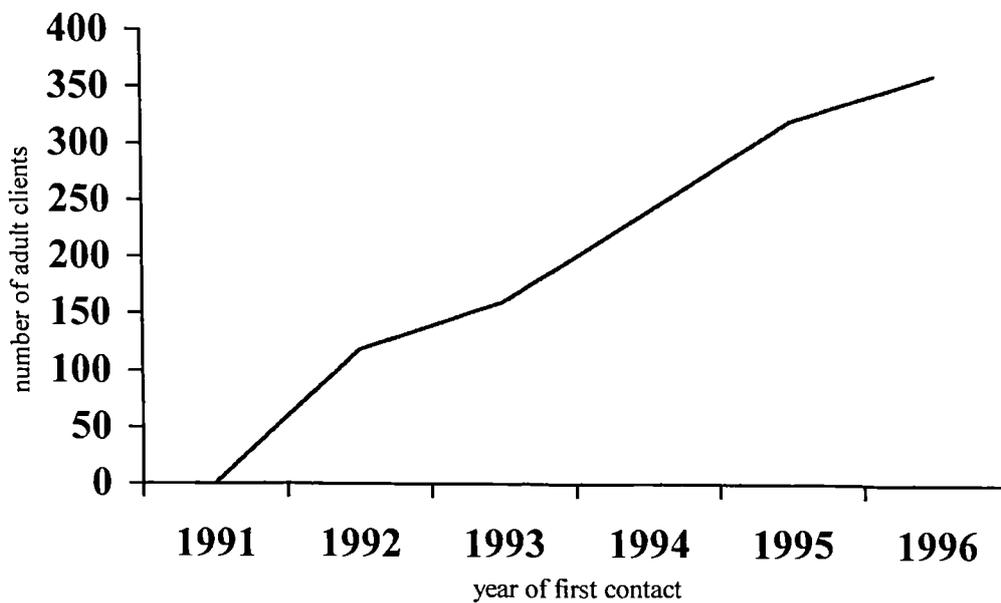
2.10 The social model of disability

One final area must be considered before considering the ways in which

psychological intervention can be effective in this population. Ethical

concerns have been expressed about how appropriate it is to put the

responsibility for successful social interaction on the individual who is visibly

different, whilst the problem can be rightly be conceptualised as that of a

society which puts increasing emphasis on appearance. Social models of

disability would stress the role of the non-disfigured majority in changing *their*

behaviour to accommodate those who do not necessarily fit a standard or

norm. Historically this has been an issue for psychologists, for example, in the

use of behavioural techniques to 'modify' homosexual behaviour (McConaghy

1976). This is a major issue in disability research and anyone working with

people who have a disfigurement needs to be quite clear about their

objectives. Perhaps the strongest argument for individual change is the high

social anxiety in a significant percentage of this population; many people feel

unable to leave their homes at all. Given this level of distress, it is hard to

maintain the ethical argument for doing nothing. It can also be argued that the

two approaches are not incompatible, and it is through the ability of people

who have an unusual appearance to succeed in social situations, that there

will be an eventual shift towards increased tolerance from a population that

currently discriminates against them.

2.11   Managing the problems of facial disfigurement

Reviewing the impact of surgery on psychological functioning is not within the

scope of this chapter, but it is worth noting that physical solutions to

disfigurement, including surgery, prosthetics and cosmetic camouflage have

received very little attention, with some notable exceptions, (e.g.: Carr and

Harris 1992; Klassen et al 1996.) One of the difficulties is the lack of appropriate instruments with which to measure psychological status and change. Carr (1997) suggests that for this reason, research studies so far supply us with only very basic information about both physical and psychological methods of intervention. He suggests that a little more is known about the effectiveness of psychological intervention than surgical intervention, but that there are now enough well validated instruments for exploration of these different methods of treatment to take place and that progress in the management of disfigurement will depend on a far more rigorous approach to the measurement of outcome in the future.

2.11i Social skills training

Despite these methodological problems, it is worth looking at the small amount of work that has been reported so far. In terms of reviewing the effectiveness of psychological interventions, the area of social skills is a logical starting point. Since good social skills have been linked with good outcome and poor social skills with poorer outcome, social skills training can be seen as a procedure worth investigating. The earliest study in a relevant population is that of Fiegenbaum et al (1971), who report a positive outcome with a small sample of patients recovering from head and neck cancer. Their programme consisted of client generated problem situations covering not only disfigurement related issues, but also problems with speech and eating difficulties. Training in effective coping strategies led to significant reduction in

social anxiety, and improvement in social skill. However, despite the positive outcome, this kind of intervention has not been widely taken up; the small group size and waiting list rather than alternative treatment control group, together with the practical problems of running groups and the general shortage of psychologists working with this population may go some way towards explaining this. A further problem, is that although defined as a social skills training exercise, the problem focused strategies being used here use effective social skills to achieve a coping response, but appear to go beyond the basic social skills model. Social skills training provides the general strategies for managing social situations, but the development of specific problem orientated cognitive and behavioural coping responses is arguably a more focused approach which fits more comfortably within a coping skills framework. Good social skills may well be a necessary but not a sufficient coping tool; certainly, it is not possible to assess the impact of social skills training per se from this study. Moss (1997) has suggested that this may be a problem in other social skills research, and that more work is need to 'unpack' the various effective components involved.

A more recent study has been carried out by Robinson et al (1996b) working within Changing Faces. Here, a two day social skills interaction training programme was developed and tested with a larger sample of 65 individuals with facial disfigurements from a variety of causes, who self referred to the charity. Results demonstrated that social anxiety fell significantly after the workshop and the group continued to show gains at six months post intervention, suggesting that skills learned during the intervention were

applied and practised in day to day situations. Again, this study raises

questions. In particular, the lack of a control group means that it is difficult to

address criticisms that it was simply the opportunity to meet other people with

a disfigurement that was effective, social support rather than social skills

being the important factor. However, the increasing fall in social anxiety over

time supports the argument for an explanation in terms of acquisition of skill.

Nevertheless, the problem-focused exercises used in this study go beyond the

traditional social skills model; like the Fiegenbaum study, perhaps this too can

be best described in terms of coping skills.

2.11ii The 'coping skills' approach

Other studies report the outcome of working with individuals; Bradbury (1996)

has used Lazarus's (1993) coping skills model within a counselling setting, for

both children and adults, and reports positive outcome in terms of self esteem

and development of positive coping strategies.

The problem with proposing a coping skills model for interpreting and

promoting research into facial disfigurement, lies in the wide gap between

empirical research and clinical practice. Despite the apparent attractiveness of

coping as a concept, the complexity of interactive models often makes them

difficult to test in applied settings. The temptation has been to identify those

parts of the model which appear to have particular relevance for a given

population, and in doing so, lose sight of the holistic nature of the original

concept (see Somerfield 1997 for a full review). However, Somerfield

suggests a much more simple, pragmatic strategy of studying coping as an

applied problem, concerned with identifying the optimal ways of managing the

specific problems facing a certain population. The essence of this

microanalytic strategy depends on using more complex conceptual models as

heuristic devices to help the investigator to focus on common stressors.

These must be clearly defined, occur with high frequency causing distress to a

large percentage of the target population, and be potentially responsive to

testable interventions.

In considering the facially disfigured population, it can be can seen that it fits

these parameters very neatly; there is a body of research, described earlier,

which has consistently identified both highly specific and frequently reported

problems in the area of social interaction. These problems consistently cause

distress, commonly in the form of social anxiety and avoidance, and there are

effective, testable, psychological interventions that can address them. It is

therefore proposed that this kind of applied coping model, highly problem

specific, provides a conceptual framework within which all of the relevant work

on intervention so far can be categorised. It also provides a simple, workable

model for the future design and testing of appropriate therapeutic intervention.

Partridge et al (1997) used this model in setting up and evaluating the first

Disfigurement Guidance Unit. Individual programmes were developed for

patients which increased non-avoidant cognitive and behavioural strategies

for managing social situations. Statistical significance on a series of

standardised measures was supported by evidence of clear clinical benefits with patients reporting substantial changes in lifestyle.

In facilitating the development of these coping strategies, Cognitive Behaviour Therapy (CBT) has emerged as a particularly useful therapeutic approach. In addition to the study above, evidence of the benefits of CBT in treating disorders of body image have been reported (Cash and Hicks 1990; Freedman 1990; Rosen et al 1995; Veale et al 1996). Papadopoulos et al (1999) report a controlled study of the effectiveness of CBT in the treatment of Vitiligo. Improved self-esteem, quality of life and body image were recorded after eight sessions with the therapist, and maintained at five months follow up. In developing a self-help information series for Changing Faces, a social cognition model was used to help the individual understand the general problems of disfigurement in a social context and to identify inaccurate beliefs, whilst a coping model was used to devise new coping behaviours. For example, the booklet "Everybody's staring at me!" (Clarke 1997c) explains the role of the face in communication, and gives a rationale for why people who have an unusual appearance will be stared at. It then goes on to offer a section where different strategies for dealing with staring can be generated and tested. The aim of the booklet is therefore to challenge any unhelpful cognitive beliefs – people are staring at me because they are repelled and horrified by my appearance - and substitute more helpful beliefs - that people are looking at me because they are curious -, and then to provide the individual with a range of appropriate responses. An evaluation of the information series has demonstrated that both individuals with a

disfigurement, and health professionals find the approach easy to understand and to apply (Clarke 1997c).

2.12 Problems with intervention studies

Carr is justified in his suggestion that intervention studies need to employ a much more rigorous methodology (Carr 1997). Studies are generally vague about the underlying model being tested or ascribe the techniques being used to one model where another might be more appropriate. Sample size is usually small, and whilst the self selected or volunteer status of many of the experimental groups is acknowledged, it is very easy to lose sight of the important implications in generalising outcome to a wider population. Like much clinical work, the use of a randomised controlled trial is not always feasible, and where control groups have been included in studies, these have been waiting list control groups rather than comparison of alternative procedures. The impact of studies using alternative cohort methodologies, although effective in influencing clinical practice with individuals and in pointing the way for future research studies, are likely to have little impact in generating changes of provision for this population in health care settings. However, it is clear that researchers in this field are well aware of these limitations. Carr and Harris (1994) have been particularly influential in recognising the need for adequate measurement tools and for developing and refining a scale with good psychometric qualities validated on an appropriate population. Partridge et al (1997) have recognised the need to look at

alternative models of health care in setting up and evaluating the Disfigurement Support Unit. The recent establishment of the Centre for Appearance and Disfigurement Research at the University of the West of England is evidence of an increasing commitment to high quality research in this area.

In summary then, it is clear that whilst we are beginning to know more about the problems of facial disfigurement, we know far less about its management. Taken individually, all the studies reviewed can be criticised, but the sum of the evidence that they provide collectively suggests that psychology has a role in the management of facial disfigurement and that further research is justified, provided it is grounded in sound methodological procedures. Future studies need to compare different kinds of intervention, their outcome in different populations, how different kinds of intervention e.g.: physical and psychological might be combined into a package of long term care, issues concerning timing of intervention, and appropriate models of health care delivery.

2.13   The Changing Faces 'Package'

Whilst Somerfield's model has been suggested as a means of providing a unifying model for the intervention studies reviewed above, it has also been useful in generating a framework for offering direct help to people who self refer to Changing Faces. Working from within the context of a lay-led

voluntary organisation provides a unique opportunity to assess the kinds of help/intervention that are appropriate for a self referred, and therefore highly motivated population. Unlike the health service, there is no necessity for medical screening before referral; indeed we have argued elsewhere that screening is inappropriate; since the probability of being singled out for comment at some point is so high, everyone with a facial disfigurement should be offered the opportunity to develop their coping skills (Clarke 1997a; Robinson et al 1996a).

One of the challenges of working in any multidisciplinary setting, and one that is highlighted in the voluntary sector where staff may come from a variety of professional backgrounds, or be volunteers, relatives or individuals from the target population itself, is to find a framework that gives a coherent and consistent focus for intervention. This framework must be informed by research and incorporate best practice, whilst valuing the role, skills and experience of everyone working within it.

Figure 3. illustrates the framework that has been developed at Changing Faces. This is not a model, in the sense that it relates the different components with each other and as such provides a basis for testing alternative clinical interventions, but simply a framework or schema within which the Changing Faces approach to managing disfigurement can be summarised. It also helps to provide boundaries for the charity; long-term psychotherapy and provision of an emergency service are two examples that

are specifically excluded from the work of the charity, and therefore excluded

from this framework

- Figure 3. The Changing Faces strategy for support. SCARED and REACH OUT are acronyms which facilitate recall of strategies for re-evaluating social situations and initiating appropriate responses

What do we do?

- Acknowledge legitimacy of feelings and concerns, including anger, loss and bereavement
- Introduce clients and families to other people with disfigurement and their families
- provide social support

**FEELINGS
EMOTIONS**

**SELF
ESTEEM**

**THOUGHTS
BELIEFS**

**ACTIONS
BEHAVIOURS**

What do we do?

Introduction   to SCARED and
REACH OUT

- Provide information about disfigurement

- Identify/challenge faulty beliefs ("I'm the only one...")

- Evaluate beliefs by identifying cognitive errors (eg: exaggeration ("my whole life is ruined")

- Define rational counter-arguments and rehearse ("my skills and experience are more important to employers than my face")

- Expose to appropriate role-models and images (CF staff and clients, video, children's books)

What do we do?

- Assess and teach social skills, (eg: initiating a conversation)

- Devise strategies (verbal and non verbal) for managing difficult situations (eg: coping with staring)

- Modelling and behavioural rehearsal of coping strategies(eg: answering questions about appearance)

- Hypothesis testing in graded situations, exposure and practice

- Revision:
  TARGET
  TOOLS
  TROUBLESHOOT
  TEST

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Clients are seen in an environment where the concern with appearance is clearly the focus and, as such, a legitimate concern. The presence of both disfigured and non-disfigured staff can be seen as increasing the perceived validity of the organisation, whilst reducing the sense of stigmatisation for those attending. Assessment at first interview records the specific problems that the client is experiencing and their frequency, together with the coping strategies that they use. The Hospital Anxiety and Depression Scale, (Zigmond and Snaith 1983) the Derriford Scale- short form (Carr and Harris 1994), and the PANAS scales (Watson et al 1988) are used to provide standardised baseline data, and are re-administered at the end of therapy. Individual clients have individual objectives, but the overall aim of the charity is to promote positive self-esteem by working with clients to examine their feelings, beliefs and behaviour, and to explore alternatives where necessary. This is offered as part of a group workshop, in a series of one to one sessions, or increasingly through the use of written and video resources.

2.14   The focus of intervention

The first focus of intervention can be summarised under the heading 'feelings and emotions'. A forum is provided in which the client is able to acknowledge feelings of bereavement including anger and grief for lost looks. This is an important opportunity for some people, whether or not recently disfigured;

grieving can equally focus on looks that one never had if born with a congenital disorder. In providing this kind of support, the contribution of other individuals who have undergone a similar experience can be very helpful. New parents may find it reassuring to discuss their feelings at the birth of a disfigured child with others who have shared the experience. Children, who are very often the only child at their school to have a disfigurement, report relief at the opportunity to meet others like them, both to share the experience for example of bullying, but also, and more importantly to share coping strategies. Clients may visit the centre and meet staff informally or call in to read resources before embarking on a more formal series of sessions or workshops. Changing Faces tries to be reactive in matching the kind of support offered to client need. There is no point in offering a problem-focused coping skills programme to a client who is newly disfigured, shocked and looking simply for support from someone who has shared their experience. Many clients re-establish contact months or years after a first approach, often in response to the trigger of a media report or significant life event, or following receipt of a newsletter, with a request to take up the chance of attending a workshop or series of one to one sessions.

Challenging beliefs about disfigurement is the second important focus of intervention at Changing Faces. Commonly held beliefs include the belief that surgery offers the only solution to the problem. Clients may spend years looking for alternative procedures, surgeons, clinics and even countries in pursuit of 'magic solutions.' The ill informed and inaccurate information portrayed in magazines and on television add to client expectation and

contribute to the disappointment when procedures fail to match expectations. A second common belief concerns life chances; that the disfigured person must expect to limit their ambitions in terms of job, relationships etc. The opportunity to meet other people who act as positive role models, or to observe them on video, can be very helpful.

Freedman (1990) gives an excellent review of cognitive behaviour therapy (CBT) in the treatment of body image disorders, and the same kinds of techniques have been developed for use with disfigurement. Understanding the process of communication failure is a first step in interventions that aim to help the individual to cope. Identifying the reactions of others as *uncertain* rather than *hostile* allows people to develop strategies for taking the initiative and putting people at their ease. Faulty or unhelpful beliefs are often concerned with the perception of others. Examples include employment: 'no-one will be prepared to employ someone who is visibly different'. This can be challenged with 'my qualifications and experience are the things that will influence my employer the most'. Similarly, there may be a strong belief that intimate relationships will be impossible, 'no-one is going to want a relationship with someone who looks like me' can be challenged with the alternative statement 'close relationships are based on personality and not on face values'. Cognitive errors can be monitored and tested experimentally, for example, the belief that 'everyone will stare at me' (exaggeration), can be challenged by recording the percentage of intrusive stares versus non-staring behaviour, as a homework task. CBT is particularly useful for those individuals with a relatively unnoticeable disfigurement, where poor self-

esteem is related more closely to negative expectations, or subjective beliefs about appearance, than to repeated objective experience of negative events.

The third focus of intervention with this population is directly on behaviour, and problem focused coping skills. As a first step, social skills are assessed, and where necessary a social skills package focusing on body language, posture, eye contact etc. is implemented. Conversation skills are often weak and perceived to be weak by this population, and training is offered in participating in and initiating conversation. Particular emphasis is put on dealing with questions and comments about appearance, with alternative responses being generated and tested. There is a strong focus on self-monitoring and record keeping, with graded practice of target situations. The REACH OUT model (figure 4, Partridge 1998) is used to provide a 'tool box' of eight principles or 'tools' which the individual uses to shape his/her behaviour. Encoded as an acronym, REACH OUT, to assist recall, these can be illustrated either face to face, on video or in written form, and used as the basis for tackling general problem situations, eg: using public transport, walking into a crowded room, or for problems specific to the individual. Behavioural rehearsal with the therapist is followed by graded practice in the target situation.

Figure 4. The REACH OUT model.

R   REASSURANCE   O   OVER THERE

E   EFFORT   U   UNDERSTANDING

A   ASSERTIVENESS   T   TRY AGAIN!

C   COURAGE

H   HUMOUR

('Over there' is a distraction strategy involving the development of skills for changing the subject, focusing the attention away from the individual with a disfigurement and on to the questioner, other member of the group, environment etc.).

Individuals may be involved in any or all of these activities during contact with Changing Faces, but at any given time, intervention can always be described within this framework. This ensures that a number of different forms of support e.g.: provision of information, social support and more specific psychological intervention are always provided within a focused and integrated package. Anything that cannot be located within the framework, e.g.: advice about medical/surgical solutions is not offered.   Evaluating the package as a whole is difficult, but each element can be monitored separately. The effectiveness of the workshop programme has been reported (Robinson et al 1996b), and preliminary assessment of the information series demonstrates it to be easy to understand, very helpful and effective in achieving behaviour change (Clarke

1997b). A controlled trial is planned. The effectiveness of one to one sessions

is currently being studied via a pre and post-test design using standardised

measures, with the aim of producing data on a substantial cohort in due

course. In addition, qualitative data about the service is provided by routine

questionnaire follow-up of all clients, within six to twelve months of first

contact. This is very positive, and stresses in particular the value of the

organisation in legitimising individual concerns, and providing practical

strategies for coping.

2.15   The role of volunteers

Whilst psychological intervention is provided only by those with professional

training, there is a clear emphasis on the role of the ex-patient or volunteer in

achieving the overall aims of improved self esteem and social confidence for

those who make contact. Indeed, it can be argued that the validity of a coping

model is strengthened by the active demonstration of a group selected from

the target population itself. The determination to help others by becoming

involved in the organisation has emerged as such an important recurring trend

in those clients who do well, that it is now included as an outcome measure.

Locating these offers of help into the organisation in an appropriate way has

proved challenging, and this framework has proved helpful in defining the

volunteer role.   Whilst this particular aspect of intervention can perhaps be

seen as unique to the voluntary organisation, the importance of social support

as a factor predicting good outcome in this area and indeed in many other

areas of health psychology, suggests that psychologists working in more

traditional settings, for example pain management clinics, could look more

closely at how patients themselves can become an important resource,

particularly in generating and modelling problem-focused coping strategies.

2.16 Conclusions

The problems of facial disfigurement are becoming more widely understood

as research in the medical setting becomes integrated with psychological

studies that provide an empirical basis for understanding the issues reported.

The conceptual shift away from categorising populations by means of medical

diagnosis towards the investigation of facial disfigurement independent of

cause has helped in the understanding of those difficulties that consistently

occur in the area of social interaction. Perhaps the most encouraging findings

so far are those that suggest the importance of behaviour in predicting

successful outcome in social situations. From the clinician's point of view, this

is invaluable in planning intervention either for an individual client, or for a

group in a specialist setting. It is also important in focusing attention on the

problems as *psychosocial* i.e.: concerned with the everyday experience of the

disfigured population in social settings, rather than *pathological* i.e.;

concerned with individual difficulty in adapting to situations that cause few

problems for the majority. This vital difference has enormous implications for

the provision of care. The development of psychosocial support on the basis

of screening the population at risk, which is the strategy employed in referring

patients to the Disfigurement Guidance Unit, may be less appropriate than offering an appointment to everyone routinely; since everyone who is subject to intrusions such as staring or comments can benefit from learning how to manage them, this can logically be seen as part of routine care. This is an important message for health professionals and fund holders. The commonly held beliefs that disfigurement is "only minor" and that "there is nothing that can be done about it" are no longer tenable.

Although very little work on intervention has been reported, there is clear evidence that significant gains can be made, particularly in the reduction of social anxiety and avoidance. This small body of work relies mainly on self-referred populations, and therefore reflects the outcome of a motivated sub group. Further research urgently needs to address those individual differences that predict the success of therapeutic intervention. In particular, we need to know more about ethnic issues and educational level, together with the important features of social support. Social skills training has proved to be effective, but increasingly, in group, one to one settings and in the provision of self help literature, a specific problem focused coping skills model has proved to be more comprehensive. However other therapeutic models need investigating; given the problems faced by children who have a disfigurement and the value of family support, a systems model, where any problems are investigated within the conceptual framework of how the family is organised (Jones 1993) would seem to have obvious benefits in approaching work with families. Most importantly, a rigorous methodological

approach is needed if any of this work is to have an impact on health care provision.

This chapter has also considered the role of the lay-led voluntary organisation. Whilst traditionally one of offering support and information, Changing Faces has moved beyond this to offer direct help to individuals through groups and individual sessions. In providing this direct help, a problem focused coping skills model has been used to generate a framework which includes a role both for skilled health professionals, and for people without professional training who are drawn from the client group. In proposing the utility of this framework for providing a service to people who have a disfigurement, it is also suggested that this integrated approach is of value in other health care settings, particularly where a coping skills model is being used to promote behaviour change.

Finally, it can be seen that the package of care provided by Changing Faces can have implications for how health psychologists might work in other health care settings. Patient-led or lay-led organisations have traditionally supported the work of health professionals. At Changing Faces the roles are reversed. Here the psychologist works to bring a knowledge of sound psychological principles including knowledge of the relevant literature, measurement and evaluation techniques to support and structure a process that is essentially developed by the patient population itself. This is a similar role to that of psychologists working with self-management of illness e.g.: Barlow et al (1998) who have developed an evaluation process for a self-management of

arthritis programme set up by another voluntary organisation, Arthritis Care.

Moving away from traditional health-care settings and facilitating the ideas

and resources represented by the patient population itself is an exciting

opportunity for health psychologists.

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CHAPTER THREE. THE DESIGN OF AN

INFORMATION RESOURCE FOR PEOPLE WITH

FACIAL DISFIGUREMENT: A CASE REPORT.

3.0 Introduction

The aim of this section of the thesis is to present a case study from the area of

facial disfigurement. Writing a case study is often part of a postgraduate

training for many practitioner disciplines. However, for psychologists who are

essentially problem solvers working in the scientist practitioner tradition, the

task itself can be seen as a problem solving exercise and is worth examining

in more detail. Reading other case studies from theses available in the

University library, consulting practitioner reports in journals such as *Clinical*

Psychology and Psychotherapy, in preparation for this part of the thesis was a

revealing exercise. It was clear that most of those writing were highly

effective practitioners, but what was less clear was how they used the clinical

setting to reflect upon and develop their own skills.

This section therefore briefly reviews the tradition and function of the case study in clinical psychology, and then considers the criteria which need to be satisfied in order to produce a 'useful' case study. Finally, a case is presented which tries to satisfy these criteria.

3.1   The practice of clinical psychology

Clinical psychology, as defined by Powell and Lindsay (1994) is " the scientific approach to the investigation, treatment and management of psychological problems." Many practising clinical psychologists and certainly health psychologists would include the *prevention* of psychological problems within this definition. Thus clinical psychologists work in an empirical way, formulating problems by using the information they gain about their clients to generate hypotheses about the causes and maintaining aspects of symptoms and behaviour. These are then tested via appropriate clinical interventions. Successful outcome can be measured not only in terms of whether or not the client has resolved the problem, but whether or not the therapist understands the process of change. Indeed, in terms of developing as a clinician, it can be less satisfying to have a client who makes good progress when there are a number of explanations as to why this might have happened, than it is to have a client whose symptoms remain but where there is good understanding of why this should be.

3.2   Problem solving in clinical settings

In a clinical consultation, both the client and therapist are trying to understand a problem, and it is equally as important that the therapist understands how he/she is reasoning as it is to understand the reasoning process of the client. There is an important difference between the process of *inductive reasoning* in which information is collected with no a priori assumptions, evidence and data being used to generate a hypothesis about the cause and maintenance of symptoms and a conclusion and treatment plan formulated, and the *hypothetico deductive* form of reasoning where a hypothesis is generated early on with evidence and data collection being framed within this context (Newell and Simon 1972). Recognising that most psychologists work in this way is important because as Wallsten (1978) suggests, in practice, there is a clear bias towards seeking supporting information for a hypothesis rather than evidence that refutes it. The more efficient and arguably more scientific approach is to look for evidence that refutes a hypothesis or hypotheses early on and which therefore considerably shortens the decision making process. Wallsten (1978) has discussed the way in which this can lead to delay in diagnosis in medical settings, but it can also be helpful to recognise how this potential bias can influence a psychological assessment.

For example, in working in the area of disfigurement, an awareness of this bias in the assessment process has proved helpful. Referral letters from medical practitioners are often based on the incorrect assumption that severity

of psychological distress is linked with severity of disfigurement. Clients may therefore arrive with an inappropriate 'label' that they are 'neurotic' or unreasonably distressed given the minor nature of disfigurement, or conversely, at risk of problems purely because their disfigurement is severe. The practice of seeing a client for assessment before reading a referral letter can be helpful in achieving a genuinely unbiased baseline. A further source of bias arises in the work of any 'specialist' medical or psychological practitioner who by definition is so familiar with a particular pattern of symptoms or problems in a specific condition that it can be easy to assume problems or ways of coping that are not there. In working specifically with disfigurement, psychologists have to be aware of their own bias towards seeking evidence about common concerns such as staring, comments and questions and overlooking something unique to this client or related to some quite different concern. Given that clients may quite commonly be blaming their appearance for lack of success in a number of areas of their life, it is vitally important that the psychologist can identify these errors in thinking and is able to challenge these assumptions where appropriate. Keeping an open mind, not automatically accepting a psychological diagnosis from a medical practitioner, generating as many explanations of a problem as possible, looking for refuting evidence rather than supporting evidence, are strategies that help to reduce bias and focus attention on the important issues in the initial assessment of an individual client. This then provides a sound basis for the beginnings of therapy.

3.3 The function of the case study

Understanding the process of problem solving is also helpful in presenting case studies. In the search for increased understanding of human problems, and particularly in medical settings, the case study has historically been extremely important. Indeed the tradition of reporting individual cases in detail lies at the heart of our knowledge about medicine and clinical psychology (Barlow and Hersen, 1984; Porter 1997), but is currently undervalued and unpopular in terms of published literature. The well conducted randomised controlled trial clearly has no equal in terms of what it can tell us both about the effectiveness and ability to generalise from any given treatment, but the case history or series of case histories often generates the ideas and frames the content for a later group study. Salkovskis (1995) describes this process in which intervention is first refined and explored in a single well structured or series of case studies. It is intriguing to look at why it has become such an unpopular way of transferring information. Perhaps few case studies are published because they do not achieve their objective. Where they are recorded, and this is frequently as coursework for a programme of training, they can be criticised as a rather bland account of a successful therapeutic intervention, usually with an individual client. Whilst demonstrating how well the student has understood and can apply different psychological models, they often follow the pattern of looking for confirming evidence for an early hypothesis and fail to show the psychologist working reflexively or considering other alternatives. This is followed by a 'textbook' intervention and almost inevitably, the outcome for the client is wonderful; learning points if addressed

at all appear as an unconvincing addendum. The purpose of the writer is to show that they can 'cure' their client, whereas the purpose of the study should be to show that they understand the therapeutic process.

3.4 Meeting the criteria for a 'good' case study

A good case study is therefore a report that extends knowledge about the causes, maintaining factors or treatment of a condition, or refines and develops a model of working. Where practitioners focuses on their own knowledge, clear learning points should be discussed rather than left implicit ie: left for the reader to deduce from the fact that the result has been successful. If intended for publication, these learning points should be even more explicit since the purpose of the exercise is to add to the general knowledge pool. Ironically, it may be a therapeutic intervention that has failed in terms of outcome for the client that has most to tell us as practising clinicians, yet it is very rare to read this kind of report. Indeed, we behave in precisely the biased way that Wallsten has suggested; we attempt to add support for our methods of working and our credibility as competent clinicians (hypotheses) by reporting only confirming evidence (successful outcome). Not only is this fundamentally 'unscientific', but ultimately this is probably the principle reason that case studies are unfashionable; we are only interested in publishing something that has 'worked'.

This section of the thesis therefore presents something of a dilemma. It is tempting to present an account of a client with a serious facial dog bite treated using a cognitive behavioural approach over six uncomplicated sessions. The outcome data would be successful statistically - dramatic falls in social anxiety and avoidance measured on standardised scales, clinically- return to work and resumption of social activities, and even personally - hearing her ring into a radio phone-in to tell them about her marvellous therapist. We could therefore conclude that cognitive behavioural therapy was a successful way of managing social anxiety after acquired disfigurement. This very good outcome would be a very good example of a dull case study because there is nothing particularly controversial or challenging about the findings; the results are very much what we might expect, and as such, there is very little that we can learn from it.

It is therefore proposed that this section describe a piece of work which presented a different kind of challenge, and in which case study is defined rather more broadly in terms of tackling a problem in an organisation rather than with an individual. The problem was to design and write an information resource for Changing Faces which met the needs of the client population. Psychologists are often involved in providing information in hospital settings and evaluating outcome on the basis of this information. However this area is dominated by Ley's (1988) cognitive model, and looking for evidence for the utility of other models, deciding what information was needed, testing and rejecting a hypothesis with one format of the information, and finally developing a new format which was successful, was a process in which there

were many opportunities for individual learning. In the process of this work a
new 'active participant' model of information provision has been generated
which may provide a useful framework for similar work in other settings.

3.5 Developing an information resource for a facially disfigured population

The problem solving approach to providing of an information resource for a
voluntary organisation has been very similar to that used when working with
an individual client. Figure 5 illustrates an adaptation of the Newell and Simon
model to the current task. The first step was to understand the problem, ie: to
consider why patients might want information, and from the organisation's
point of view, why this was a problem that needed addressing. Step two was
to break down the problem into units. This was essentially a data gathering
exercise with no a priori assumptions: essentially, what does the client want to
know and why? Step three consisted of evaluating past experience via an
investigation of the relevant literature and psychological models concerned
with providing 'medical' information, and a review of patient literature already
available. This allowed the development of a new model of information
provision which shaped the form and content of information to be produced.
Information was then developed in two forms to test the effectiveness of the
proposed model and evaluated by piloting it with a small sample. After
relevant changes, evaluation concluded by collecting data from a larger

sample. The model was then used to develop a wide range of different

information resources generated by the charity.

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Figure 5: Applying a problem solving approach to the development of an information resource

Understand the problem and develop representation

Break problem up into units

Derive and apply heuristics

Appraise success of heuristics

Appraise acceptability of solution

Finish and verify solution.

Prior experience

Understand the problem

Why is information needed?

What kind of information do people want?

What do they want it for?

How will they use it?

What information already exists?

Which psychological models have utility in information provision?

Devise information

Test hypotheses about effectiveness with pilot group.

Revise information in line with results

Evaluate with larger sample

Apply final model to all new information

3.6 Why do people want information about their condition?

The request for information is a consistent and long-standing finding in research into patient satisfaction with diagnosis and treatment, in studies of quality of life during rehabilitation, and throughout the health psychology literature. (Cartwright 1964, 1967; Gibbs et al 1990; Ley 1982, 1988, 1998; Morris 1990.)   Clients and patients want to be adequately and honestly informed at each stage of treatment, even where information is unpalatable e.g.: diagnosis of cancer (Kalish and Reynolds 1976; Levy 1983; Ley and Llewellyn, 1995.) Given the length of time that these issues have been studied, it is interesting that the percentage of patients who are dissatisfied with the information that they have been given has remained relatively constant over a twenty year period. Ley (1988) carried out a meta-analysis of twenty-one studies carried out between 1961 and 1985 on hospital patients and found a mean dissatisfaction level of 41%. There was no association between date of survey and percentage of patients dissatisfied. Interestingly, Hall and Dornan (1988) in a meta-analysis of one hundred and seven studies, found that satisfaction with provision of psychosocial information is consistently ranked lowest.

However, balanced against this desire for information, patients

sometimes complain of being overwhelmed by factual information at

certain points in the treatment course - for example, at diagnosis, and of

feeling bewildered and unable to take all of it in. Information given orally

at any stage may not be remembered accurately, the patient may lack

the appropriate framework for asking questions, and information may be

poorly understood. (Adamson et al 1988; Carstairs 1970; Mayou et al

1976). Ley (1988) in particular, has been instrumental in investigating

these cognitive aspects of information provision, in which the objective

of a consultation is the transfer of the knowledge base of the health

professional to the patient. Ley emphasises the need to maximise

understanding and recall. Structuring the order as well as the content,

stressing important parts of the communication, avoidance of jargon and

simple sentence construction in written communications, have all been

demonstrated to assist understanding and recall. This has been very

effective where non-compliance with treatment has been unintentional

(see Ley 1988 for a full review). The same problems are reported by

relatives and carers, even if present during consultation, who may

remain uninformed or misinformed, and therefore unable to offer the

optimum level of appropriate support both during treatment and when

the patient goes home. Given the evidence of the importance of social

support in health outcomes generally, they can be seen as an untapped

or wasted resource.

The implicit and exciting message in the request for information is the increasing awareness by the patient of his/her own potential role in the management of the condition. Whilst health psychologists in particular are concerned with behavioural control in conditions such as diabetes and hypertension, pain management, there is an increasing awareness amongst the general public that health is dependant on behaviour: that diet, exercise, control of alcohol and smoking have an enormous potential for avoiding illness. If they do become ill, people want to know as much as they can, not only in order to give informed consent, but also to become active in managing change. Self-management programmes, particularly of long term or chronic conditions. e.g.: arthritis, set up and run by patients themselves, have moved the traditional support function of lay-led organisations into symptom management and control (Barlow 1998, Lorig et al 1999).

Whilst health professionals recognise that patients need information to manage their working and social lives, they have been slower to recognise this role of the individual in actively managing the condition. Despite the evidence that an informed and knowledgeable patient can expect a better outcome (Coulter 1997, 1999; Fallowfield, et al 1990; Schulman 1979), patients can still be viewed with suspicion if they ask for a second opinion, read professional literature, access information via the Internet or even take notes in the consultation. There remains a problem in providing the kind of information the patients are asking for,

which facilitates rather than challenges the working arrangement between health professional and patient.

Like many lay-led organisations, Changing Faces recognised the request of its client base for information and, therefore, the need to provide it. The challenge was to understand what kind of information was needed, what function it would serve, what model should be used to develop it, and then to produce it in a form that was easily understood and demonstrated to be effective. It was also important that it should be acceptable to health professionals who were an important source of referral to the charity.

3.7   What kind of information do people want?

The first step in planning any psychological intervention is to try to understand the nature of the problem as clearly as possible. With an individual, the first assessment may often take more than one session, and will involve the collection of data. In trying to define the information needs of a facially disfigured population, the first step was therefore to define the kind of information that the population was requesting.

It is interesting to note that this first stage, whilst a very simple and basic first step for a psychologist, is regularly missing in many attempts to provide information and goes some way to explaining why much

information is unhelpful. Lorig et al (1999) who have pioneered the first

successful self management programmes for chronic disease in the

USA stress the vital step of analysing need by first asking the patient

about his/her needs in individual interview or via focus groups.

However, because health information is so often written by health

professionals for a specific target group, it most commonly addresses

what the clinician thinks the patient ought to know rather than what they

actually are asking for. Coulter et al (1999) reviewed a sample of

materials produced by 128 organisations, both voluntary organisations

and health service departments, in which only very few consulted the

target population before hand. Consulting the target group is one of

their four key recommendations for good practice.

At Changing Faces, this analysis was achieved by retrospective

sampling of the database of contacts over a five year period (since the

charity had been set up), and classifying them into categories. Figure 6

summarises the results of this exercise for the resulting 1500 adults

with a facial disfigurement and 600 family groups with a disfigured child

member. This illustration indicates the information need, focus of

concern, action by Changing Faces, and intended outcome of any

intervention. From this exercise it could be seen that requests for

information from Changing Faces fall into two broad but distinct

categories. (A minority of requests, 17%, were inappropriate, asking for

addresses for cosmetic surgery, requests for funding etc.) The first set

(31%) can be broadly grouped together as *factual* or *procedural*

questions. These range from questions about possible diagnosis - have I got skin cancer? - the likely progress of the condition - will my scars get better? - to advice about appropriate treatment - is my birthmark treatable using lasers?

The second, and larger category of information that was requested (52%) could be categorised as about advice about *support* and *coping*. This ranged from questions about using the health service effectively - how can I get my General Practitioner (GP) to refer me to a specialist?- to coping with the everyday problems that result from the condition - how can I go out, when everyone stares at me? With children there was a major emphasis on coping at school, both preparing a child to manage the school environment and coping with unsuccessful school experiences such as teachers' low expectations of performance and severe bullying. This question - *'what can I do?'* was another key area identified by patients as missing from most of the materials reviewed in the Coulter study.

The most obvious point to make about these data, is that it is the minority of clients with a facial disfigurement who are asking about medical information; most are asking about how they themselves can manage their condition. This review of the information needs of the disfigured population suggests that the needs are, therefore, twofold. The challenge for Changing Faces was to find away of addressing both of these needs in the provision of information about disfigurement.

Having obtained this data and classified it, the next step of this process

was to review the existing information for this client group and to

consider the psychological models that might be helpful in suggesting

how information might be designed to address the need identified.

Figure 6 CLASSIFICATION OF INFORMATION NEEDS

	INFORMATION	

| FACTUAL /MEDICAL
eg:
what is dermabrasion?

(31%) | **FOCUS?** | COPING/SUPPORT
eg:
 how can I prepare my
child for school?
(52%) |

| TREATMENT
DECISIONS | **FUNCTION?** | SELF MANAGEMENT
COPING
SELF ESTEEM |

| FACILITATION
 • clarify
 • frame
 •organise
 • specify
 • question | **CHANGING FACES**
ACTION | MODIFICATION AND
CHANGE
  • beliefs (self
    esteem, self
    efficacy)
  • behaviour (non
    avoidant coping
    skills) |

| FOCUSED
INFORMED
EMPOWERED.

INSTRUMENTAL IN
DECISIONS | **OUTCOME** | PROBLEM
MANAGEMENT

NON AVOIDANT
COPING |

ACTIVE PARTICIPANT

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3.8 Existing information: the medical model

Previous literature searches of the academic databases had revealed a

very small amount of research on disfigurement spread across mostly

medical rather than psychology journals. (See chapter 2 of this thesis for

a review). It was, therefore, not surprising to find that there was very

little information produced for patients' use. Most of that obtained was

written by health professionals and produced by voluntary organisations,

pharmaceutical companies or (rarely) hospital units. These few

examples shared common characteristics that limited their value.

Perhaps the worst practical omission was the date, so that the reader

was not able to make a judgement about the how up-to-date or

otherwise the information was.

Without exception, literature employed a medical model, which was

largely descriptive, defined terms and procedures, and tended to

encourage the passive receptive role of the patient. Causes of disease

took precedence. Illustrations, where present, were of simplified

anatomy, eg: of the mouth and throat area. Common investigations and

treatments were described, eg: chemotherapy and radiotherapy with a

description of common side effects such as hair loss, vomiting. It was

encouraging to see a management or coping model being used for

some common side effects of treatment for head and neck cancer, eg:

advice about food preparation and dry mouth, managing a

tracheostomy. However, there was no evidence of any attempt to

extend the coping model to the management of behaviour or the use of

psychological strategies; coping in this context could best be defined as the self management of medical procedures. Psychological issues such as altered body image, changes in mood, beliefs or behaviour routinely appeared at the back of the booklet, and the only reference to psychological management was in the form of contact with a GP or recommendation of non-directive counselling.

The major problem with information that used this medical model was that it appeared that no assessment had been made about how the patient could use it. This conclusion was suggested by factors such as the redundancy of information. For example, information about prevention is only of use to a population at risk of a disease rather than a population that already has it. Recognising that the needs of patient as opposed to a medical population were essentially different had not been acknowledged in terms of *the function* of information produced. This was interesting because patients' level of understanding had been considered; there was a clear difference in complexity between this kind of information and that produced for a medical audience. Thus there was evidence that language had been modified in line with readability formulae eg: short words and sentences (Flesch 1948). There was therefore a clear inconsistency with recognition that health professionals and patients represented two different populations with respect to their ability to understand information, but not in terms of how they might want to use information.

Even a fairly basic analysis of existing information therefore supported

the claims being made by the clients who contacted the charity that

there was either no information available or that it was not very helpful.

It was clear that no attempt had been made to move beyond a medical

model, and where a psychological approach to providing information

had been considered, this had only been in terms of a *cognitive*

approach eg: to do with understanding and recall of information and not

in terms of a *coping approach* ie: to do with managing the condition.

Evidence from other conditions such as depression, shows a similar

lack of attempt to provide a therapeutic intervention in written form. Any

book shop provides an array of titles classified in the self-help category,

but there is little research evidence of their efficacy. An exception is the

work of Scogin and colleagues, (Scogin et al 1989, 1990) who evaluated

the use of cognitive and behavioural therapies delivered in booklet form

for older people with mild and moderate depression. This intervention

was helpful when compared with a waiting list control, and clinically

significant change was maintained at two-year follow-up. It is surprising,

given how cost effective this approach is, and how popular with the

target group, that there is not more interest in delivering therapeutic

strategies in written format. Roth and Fonagy (1996) in their exhaustive

review of psychotherapy research, report only the two studies outlined

above.

3.9 Psychological models

Whilst there are some familiar psychological models that are used in provision of medical information, eg: cognitive models, behavioural modelling, there are others that appear to have potential but have not yet been widely explored. Of these, coping and social cognition models appeared to the most relevant in this client group.

3.9i Cognitive models

Ley's cognitive model is perhaps the most well known model in this field. Ley's original investigation of the relationship between understanding and compliance has been further redeveloped to consider the effects of information provision on outcome (see Ogdon (1996) for review). However, the model was developed to examine the presentation of medical information, and assumes an underlying medical model in the transfer of knowledge from the expert (health professional) to the layman (patient). The idea that the health professional is not necessarily the best source of information nor necessarily a reliable source of information has arisen as a result of other later investigation (Marteau and Johnston 1990). This is widely supported in the area of

disfigurement where the general practitioner, usually the first point of contact for the patient, is not a specialist; he may not be in a position to offer accurate information. The British Association of Dermatologists report that 47% of skin cases referred by GPs to a Dermatologist have been incorrectly diagnosed (Russell Jones 1996).

The amount of research generated by these cognitive models is enormous, but this research proved of limited value in trying to set out to provide a new resource. Whilst it was clear that any information produced needed to be readable and understandable, this was a necessary but not a sufficient model on which to base the generating of new resources. Indeed it was surprising to see how dominant these models are in the area of information provision, given that they only address the style rather than the substance of information offered. It was clear that other models would need to be examined in order to relate content to function.

3.9ii   Behavioural modelling

Although a long standing, well researched and recognised psychological technique for producing behaviour change (Bandura et al 1963), there was surprisingly little evidence of behavioural modelling in health education or health promotion according to academic sources. This may not, however, be an accurate reflection of how modelling is used in

clinical practice, since there was good evidence that this was a

commonly used model when health information leaflets were reviewed.

Booklets commonly used cartoons or drawings of children or toys to

introduce ideas such as medical procedures, staying in hospital,

wearing bandages etc. This "Teddy goes to Hospital" approach looked

initially appealing, but parents reported little interest from children;

understandably, Teddy having to keep his bandages on was not a

particularly interesting storyline.

Lansdown (1996) reviews some of the techniques used with children

and parents at Great Ormond Street Hospital in London. Some of these

are particularly interesting in that they use the patients' own experiences

to create a personal log. For example, a diary can include significant

milestones in treatment, visitors, souvenirs etc. This is a very

accessible way for a child to measure progress, or to simply mark the

passage of time in a positive way. It would be interesting to know

whether these logs can be used as a library resource so that other

children/patients can use them as a model. Lansdown also reports the

use of illustrative video and handbooks that introduce a number of

different approaches for health professionals who work with children

who have cancer. This is an example of behavioural modelling providing

the basis of peer education through the use of a variety of modern

media.

Eiser (1997) has recorded the gap between theory and practice particularly with regard to health education in children. Whilst this phenomenon is common in health settings, the evidence is more commonly suggestive of a delay in implementing research findings in clinical settings. Reviewing the work being done on communicating with children in hospital suggests that there is some innovative work being done in the clinical setting that is not always reported in the academic literature. Eiser is, therefore, correct in identifying the gap between theory and practice, but should perhaps stress that this is not a unidirectional problem. It is clear both from the review of Lansdown's work, and from reviewing the very simple leaflets produced ,for example, by hospital departments that clinical tools have been developed which are based on sound psychological principles, in particular behavioural modelling, but that evaluation of these tools tends to be either informal or unpublished. This is disappointing because of the difficulty in evaluating the effectiveness of this kind of approach, but not surprising, given the rigour with which academic journals assess submitted work, the need for large samples, control groups etc, and the difficulty in obtaining research funding in clinical settings.

Behavioural modelling was less common in literature for adults except in terms of pictures. Again it was difficult to know whether the model had been used deliberately or whether pictures had simply been used to break up text. Typical pictures would be of someone wearing a prosthesis whilst shopping, or swimming with a tracheostomy. In

literature produced by support groups there was much greater tacit

acknowledgement of the therapeutic value of modelling with readers

letters of the "How I overcame tragedy" type. These commonly included

psychological strategies eg: take one day at a time, challenge unhelpful

beliefs etc.

Behavioural modelling therefore seemed to be a useful model; the lack

of academic support in health education literature was redressed

somewhat by evidence of its efficacy in other areas of psychology. Even

though parents suggested that information using behavioural modelling

was often not very interesting for children, this could equally be the

specific story content rather than the modelling approach; the fact that it

was used as the informal basis of much of the information for children

suggested that it could be a useful device.

3.9iii Social cognitions

Although there was no academic evidence of attempts to link social

cognition theories to practice in the provision of information, there was

some acknowledgement of social cognitions in the very small amount of

literature produced for clients. Unfortunately, this was not always

consistent and demonstrated a confusion of ideas: thus an information

leaflet for teenagers about acne stressed the importance of looking

beyond stereotypes in making judgements about appearance, but included cartoons of spots/pimples wearing eye-patches to stress the fact that they were the 'bad guys'.

Like all cognition theories, social cognition theories view the individual as a rational processor of information; they can be criticised for ignoring the dimensions of emotion and feeling. The particular attraction of these models with a disfigured population, however, was the emphasis on the internal representations of individuals about their social world. Thus social cognition models attempt to understand the individual in terms of the relationship between himself and others around him. 'How other people perceive me', 'What other people think about me', 'Other people are horrified by my appearance', 'How can I influence other people to see the real me?', are just a few of the common themes in the belief structure of many people who have a disfigurement, and indeed support the pattern of behavioural avoidance. (It might be argued that the central concepts of 'self' and 'self-esteem' or 'how I perceive myself' can only be understood in a social context; it is only by trying to understand ourselves in terms of the belief systems of other people, and by making comparisons with other people, that the concept of the individual makes any sense). Further exploration of these models suggested that the Health Action Process Approach (Schwartzer 1992) might be helpful in understanding the information needs of the population. The focus on both a decision making/motivational stage and an action/maintenance stage in health related behaviour suggested parallels in terms of the

factual/medical component and action/coping component described in figure 6.

3.9iv Coping models

Coping models have been considered in Chapter 2, and their utility in practical clinical settings discussed. Moos and Schaefer (1984) described a three stage model of coping, comprising cognitive appraisal, adaptive tasks and coping skills. Coping skills were themselves categorised into three groups: appraisal-focused coping, problem-focused coping and emotion-focused coping. Problem-focused coping skills have been found to be a particularly useful way of understanding the evidence of effective intervention in both group and individual sessions with this client population. It was therefore predicted that a problem-focused approach would be an practical and effective way of designing written information with this group.

There remained problems with interpreting "problem-focused". Learning how to apply camouflage make-up could be described as a problem focused coping skill, but in what sense could it be described as psychological? Similarly, using skin ointments regularly is also a problem focused coping skill; evidently, there is a psychological component to all coping given that it involves assessment, decision making and action, but the over inclusiveness of this term threatened to make it unworkable. A theory is only useful if it allows the rejection of

some alternatives, and to be useful for the current purpose, there had to be a way of ruling out medical treatments.

The frustration of health psychologists working within the field of coping has been widely reported (see Chapter 2). Coping models sound very plausible and intuitive, but in practice they can be over complex or the practitioner must adapt the model for it to be useful. For the purposes of this task, a coping model appeared to have good utility provided the definition of a problem focused coping skill could be narrowed to a psychological one. This was eventually done by reference to work with individual clients, and their use of avoidant and non-avoidant coping strategies. In individual and group sessions, the focus was never on solving the problem by removing the disfigurement, but on reducing its importance both to the client and in social settings by promoting other elements of the clients beliefs and behaviour. Problem focused coping could therefore be defined either as cognitive strategies that altered the individuals' concept of themselves, or as behavioural strategies which encouraged the individual to remain in the social situation and manage rather than avoid any problems. (Withdrawal from the situation is seen as a strategy of last resort). Using this definition, it was possible to reject the use of camouflage make-up and medication because both aimed to remove or disguise the disfigurement (avoidant strategies) rather than to develop psychological strategies for managing it (non-avoidant strategies).

4.0   Generating a new model of information provision

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The logical next step appeared to be the development of a new

framework (figure 7), which took account of the needs of clients, was

grounded in psychological research, but which emphasised both the

function (WHY? and HOW?) and the content (WHAT?) in providing

information that allowed the client to become an active participant in

decision making and in achieving change. This framework combines

elements of the different psychological models outlined above and

connects them all together in a hexagonal format. Cognitive and coping

factors can be linked; thus information that is basically factual - eg: to do

with tests and procedures can be presented within a coping framework.

Rather than present a list of facts, a list of questions can be presented

which individuals use to facilitate what they want to know. This has the

added advantage that the information they obtain is always up to date,

and is not invalidated by individual variation between units/health

professionals. Similarly, social cognitions can be linked with coping

skills; understanding the role of the face in communication and the likely

explanation of intrusions such as staring provide a basis on which to

develop a behavioural response. Finally modelling is incorporated into

the framework by introducing examples that are used as the basis for

developing an individual plan of action. The aim of the model is to facilitate the self-management of the condition (disfigurement) through using information to move from a passive recipient role to an active participant role.

Figure 7.

Facilitating the 'Active' role of the client: a model for the provision of information

Cognitive models understanding and recall		Social cognitions 'self' in the social world
CLIENT Passive recipient	INFORMATION	CLIENT active participant
Behavioural modelling		Problem focused coping skills
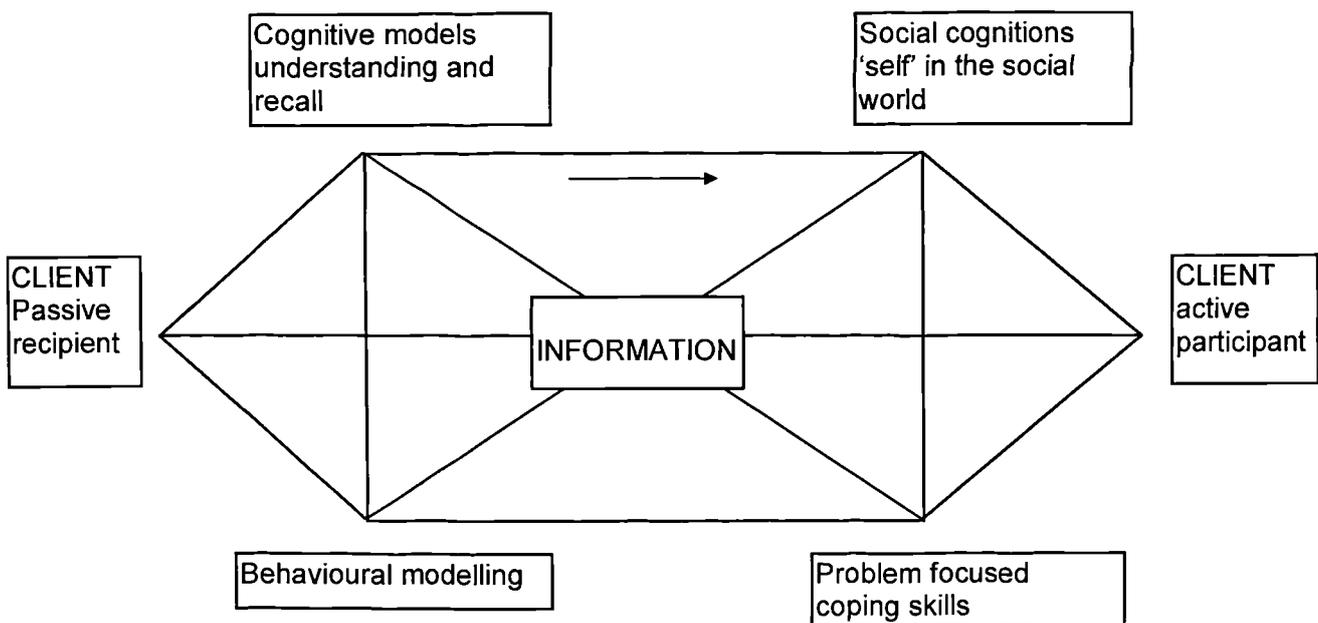
4.1 Testing the model

Once this model had been clearly outlined, it could be tested by developing information based on it. At the same time, it was important to recognise that confirming evidence for the model was not enough on its own to validate it. As discussed earlier, far more can be learned by refuting a hypothesis than by accepting it. If this model was going to be the best one to use, then information presented using a different model was likely to be less effective and less well received.

Informal canvassing of Changing Faces adult specialists indicated that clients with facial cancer comprised a significant proportion of contacts to the charity, and that they reported a paucity of relevant information from hospitals and other lay-led organisations. A booklet about facial cancer was therefore identified as a priority. Two forms of a booklet about facial cancer were prepared. The first presented basic factual information following a traditional medical model. Common forms of facial cancer were described, investigations and treatment described, side effects, types of prosthesis etc. were all included and the booklet edited using the Flesch formula to ensure easy understanding and recall. No attempt was made to describe coping strategies, to explain the social role of the face or to provide examples from everyday experience. This draft was sent to a small number of clients and health professionals for comment. Comments were polite but the general feeling was that the booklet felt very 'medical' and that the most useful

sections were those that described changes in appearance because this was information ' that could not be got elsewhere'.

The second draft was based on the new model (*When Cancer affects the way you look*, see appendix). Rather than a 'medical' introduction, the booklet opens with a 'psychological' introduction about the face. All medical information was kept to a minimum by referencing to other existing resources. Instead of presenting a list of medical facts, a list of potential questions was drawn up so that people could generate a personalised information base by discussion with their own medical team (page 4). Rather than providing information, the aim was to facilitate information gathering by the individual. Coping with physical problems such as pain, eating and drinking is included to promote the active participant role before extending the coping concept into the social arena. Finally examples are given which model potential problems and coping strategies before introducing an interactive section in which the individual can identify some likely difficulties (eg: answer the question "what happened to your face?") and generate some responses (page 19). The aim throughout is to stress the active managing role of the individual.

4.2   Evaluation of the information booklet

Again, the cancer booklet was reviewed by a small group of clients and health professionals. Results were much more positive from both groups. It was interesting that in terms of hard medical information this second booklet contained far less, but from particularly the clients' point of view it was rated much more favourably. After some minor revisions, this booklet was printed and distributed to clients and health professionals. Other booklets using the same format for different conditions were also introduced. A simple questionnaire was included to provide continuous monitoring of all these resources. The results of this were again very positive. Data from the first 70 clients indicated that the booklets are very easy to understand (87%), helpful (73%), and effective in that in that they stimulated the individual to try out some of the strategies suggested (69%). Both health professionals and patients commented that they had been unable to find information of this kind anywhere else. Asking health professionals for their evaluation of the information was done to ensure that they were happy with the contents and would recommend it to their patients; in fact they reported that the booklet facilitated their own individual work with patients. This outcome was unexpected.

eg: from head and neck nurse specialists:

"A very practical approach for encouraging people to prepare responses in advance and to be better prepared for difficult tasks. I feel that these are situations that I can work through with patients, particularly those who do not take so readily to reading literature or peer support through self help groups."

"The examples given in the Cancer booklet are very helpful. By allowing patients to read the booklet first, we are able to focus on the main issues and do so in a positive way"

The active participant model for providing information to this population was therefore assessed as being effective both in terms of meeting the factual/medical and support/coping needs of the client population, being acceptable to health professionals and in promoting the active self management approach to the problems of facial disfigurement. Continued monitoring of the resources (ten more titles have now been added) demonstrates that the booklets are consistently highly rated by clients and health professionals. Sales to health service departments indicate an increasing demand for these resources. The model has also been used to design a resource pack for burns units which consists of six separate booklets for adult and child burn patients, teens, teachers and health professionals. This has been commissioned by a pharmaceutical company on the basis of both client and health professional demand for Changing Faces information, and is currently being distributed throughout Europe and the USA. The model has been particularly adaptable in producing information for children. *'Show*

Time!' (see appendix) appears superficially to be a very different kind of information resource, but it uses the model to promote coping in social situations, to challenge beliefs about disfigurement and to provide a model of an effective strategy for children. This is proving to be a particularly highly rated and effective resource.

4.3   Summary

The development of an information resource for people who have a facial disfigurement has been successfully achieved. The original objectives, that the information should meet the needs of the clients, be based on psychological principles, be easily understood and effective in promoting change, and that additionally, it should be accepted by health professionals, have all been met. In one sense this is therefore a successful piece of work.

In terms of professional development it has also been successful. This work has involved the review of existing information for people with a facial disfigurement and the research background to provision of health information in general, and has generated a new model of information provision which promotes the active management of the condition.

One of the most interesting aspects of this work was the lack of utility of existing psychological models in practice. This is an issue that is extensively discussed in professional settings and the frustration of trying to find a model which would facilitate the solution of the problem has been experienced at first hand. However, the development of psychology relies upon the constant testing and rejecting of models and the development of new ideas; trying to develop a solution to a problem without recourse to any theoretical framework is not an option in applied psychological settings. This new model combines the important dimensions of others and has been demonstrated to be useful in producing the cancer booklet. The utility of the model is also demonstrated by its application to other conditions; thus it has been possible to use it to generate a whole series of information resources without constantly returning to the problem afresh. This is a practical demonstration of the value of working within the scientist/practitioner problem solving tradition.

It is always useful to review work by asking questions about how it might have been done differently. In this case, it might have been helpful to consider other models of behaviour change. But here, as in clinical practice so often, there were time constraints that prevented the kind of review that might be carried out in an academic setting. The same limitations prevented the comparison of the two versions of information in a more controlled way with a bigger sample. However, the preparation of information in a traditional (and indeed preferred format in

terms of how other people at Changing Faces initially perceived the task) in order to *reject* the preferred hypothesis was a very effective strategy in defining the final format of Changing Faces information. It would have been quicker and easier to use the new model from the outset, but the positive evaluation of the final form of the information is much more convincing given the poor evaluation of the information in its alternative form.

In summary, this was a piece of work that had a satisfactory outcome in terms of solving the original problem for the organisation. However, it is presented here, not because of that positive outcome but because it illustrates an understanding of how that positive outcome has been achieved, and suggests a new approach to similar problems in other settings. In this sense, it is proposed that it meets the criterion of a useful case study.

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CHAPTER FOUR, SECTION ONE.

RESOURCING AND TRAINING HEAD AND NECK CANCER NURSE SPECIALISTS TO DELIVER A SOCIAL REHABILITATION PROGRAMME TO PATIENTS.

5.0 Abstract

5.1 Aims of this research

The aims of this research are:

- To investigate the training needs of specialist nurses working with patients who have disfiguring conditions.

- To design and evaluate a training resource which meets the need identified

- To test the effectiveness of this resource when used by nurses, with their patients

5.2 Background to this research

As the psychosocial impact of disfiguring illness and disease becomes more widely recognised and understood, there are increasing issues

about who can provide this kind of input. Whilst nurses have been identified as the health professionals who are often the most appropriate to fulfil this role, there is less evidence that they feel confident in their skills to provide it. The volume of requests from health professionals, particularly nurses, to Changing Faces, suggested both an acknowledgement of the importance of providing psychosocial support to this population, together with a perceived lack of skill in this area.

5.3 Design/Method, Study One

This study used a cross-section design. Two groups of nurses working either in burns or in head and neck cancer were surveyed by questionnaire.

5.4 Results, Study One

Both the burns group and head and neck group rated their skills in the social rehabilitation of their patient group as significantly lower than their skills in physical rehabilitation.

5.5 Design/Method, Study Two

Using a multiple baseline design, a pilot intervention consisting of a specifically focused resource pack and one-day training course was delivered to eight head and neck cancer nurses.

5.6 Results, Study Two:

Post intervention, only the targeted skills (those concerned with social rehabilitation) were rated as significantly improved.

5.7 Design/Method Study Three

The final study builds on the results of the first two. Using a multiple baseline design, this study examined the way that the social rehabilitation approach was implemented by nurses in the clinical setting and passed on to patients.

5.8 Results, Study Three

Results indicated that nurses were able to use the social rehabilitation approach with patients, that patients found the approach helpful, and that standardised measures demonstrated change on only the areas specifically targeted.

5.9 Conclusions

These findings suggest that although nurses do not feel as skilled in delivering psychosocial support to patients as they do in delivering more traditional aspects of physical nursing care, they can very easily take on this role given simple training and access to appropriate resources. There is a measurable transfer of skill from nurse to patient in clinical settings.

THE PSYCHOSOCIAL IMPACT OF HEAD AND

NECK CANCER

6.0   Introduction

6.1   The challenge of evaluating multidisciplinary research

The preparation for any piece of research begins with a review of the

literature and the published work that has so far been done in the area.

This provides a baseline of knowledge, or the shared set of verified and

tested beliefs that underpin practice in that area. An important part of

establishing this baseline is the critical analysis of the means by which

this knowledge has been acquired, or how well designed the research is

on which this evidence is based. Although this statement is self-evident,

it is highlighted in the review of a large body of work when the variation

in quality of research studies becomes really apparent.

In addition to research quality, a further source of variance is evident in

the work that has been done in head and neck cancer. Like many areas

of medicine, there is multidisciplinary investigation of outcomes,

including psychosocial outcomes, evident in the number and range of

journals reporting aspects of this disease. It has become clear that

there is a marked difference between carrying out research within a

circumscribed area in psychology, in which models are defined and

refined within a reasonably finite framework, and carrying out research in a multidisciplinary field where it may be much harder to develop a coherent picture of how different studies relate to each other. This is not simply an issue of research quality, although this is often important, but of understanding that the conceptual approach of someone with a nursing background is very different from someone with a surgical, psychological or medical background. Marteau and Johnston (1990) discuss the health professional as a source of variance in health related outcomes, but they focus principally on the health professional in the clinical setting. However, this potential source of variance is also evident in academic settings, in the interpretation and design of research. Different professionals may use the same, or they may use quite different models to understand psychological processes, or indeed they may use what to purports to be the same model in completely different ways. A simple example in the head and neck cancer field has been the preference for the term 'altered body image' within the nursing literature, whilst the medical and psychological literature more commonly discusses 'altered appearance' or 'disfigurement' to describe an alteration in physical appearance. It is clear from reading the papers that the researchers are probably talking about the same thing, that is, an objective alteration in appearance rather than a distorted cognitive perception, but are dealing with this by using what are in fact quite different conceptual ideas. This issue is made even more muddled by the paucity of reliable instruments for measuring either of them. Body image, which psychologists use as a cognitive rather than a physical

concept, has been extensively explored within the field of eating

disorders and valid instruments developed for its measurement (Garner

and Garfinkel 1979). The application of this idea of distorted self

perception has its origin in the field of neurology (Schilder 1950) and

early psychoanalysis (Fisher and Cleveland 1968) and may perhaps be

a useful one in studying visual neglect or phantom limb pain, and in

psychiatric conditions such as eating disorders (Rosen 1990) and body

dysmorphic disorder (Veale et al 1996). However, the application in

general surgical settings is to be proven rather than assumed; review of

the literature has produced many reports which discuss the importance

of altered body image, but none in which the concept has been

objectively measured using appropriate scales (Price 1980, 1998).

Particularly in the British nursing press, a patient may be automatically

assumed to have an altered body image following any procedure that

results in a change of appearance, an assumption that is not justified.

The American nursing literature acknowledges the complexity of these

issues; Scott et al (1980) suggest an interesting model for body image

reintegration following head and neck surgery which takes account of

both physical and cognitive processes. At this level, the concept may be

a useful one, and certainly this approach supports the experience that in

clinical practice, it is often the fact that body image in the true sense of

perception of self, remains unaltered or lags behind objective change,

which results in problems of adjustment. Most discussions of head and

neck cancer written from a nursing perspective would discuss the range

of psychosocial issues under, however, the concept has been found to

be so variable as to be unhelpful, and where relevant, studies from the nursing press will therefore be grouped with others under the heading 'psychosocial issues'.

A second source of variance in multidisciplinary research is found in differentiating studies where psychological factors are considered either within a psychosocial or within a psychiatric framework. This is a dilemma that is common in the study of physical disease; conceptually, the argument is concerned with the extent to which psychological change is a 'normal' and expected consequence of a change in health status, or can be classified as an illness within the Diagnostic and Statistical Manual of Mental Disorders (DSM1V) classification (American Psychiatric Association, 1994). Whilst the same instruments may be used to measure outcome eg: Hospital Anxiety and Depression Scale, (Zigmond and Snaith 1983; Johnston and Weinman 1995), the implications in terms of how clinicians attempt to understand response to illness and in particular how they attempt to manage it, may be quite different.

Thus, whilst the core knowledge base in any research area can be seen to be modified by the beliefs and experience of the health professional reporting the research, it is suggested that this is of much greater significance in multidisciplinary research, where backgrounds may be more diverse. It may be that psychology is particularly vulnerable to this source of variance because of the assumed 'lay' understanding of

psychological evidence which contrasts with the perceived expertise required in the interpretation of anatomical, biochemical or radiological evidence (Tunstall et al 1982).

One way around these problems is to develop a multidisciplinary concept in which sources of health professional variance are, by definition, minimised. An example is the concept of quality of life, which has generated an enormous amount of research across many conditions (Jenkinson and McGee 1997). Typically, quality of life scales include measures of both physical and psychological outcomes, but the approach has its own difficulties, ranging from problems of definition to validation on different populations, weighting of different criteria, and questions of self versus health professional assessment. Quality of life has nevertheless become a very popular outcome measure within the field of cancer research, and with the development of well validated scales, an increasing number of studies have used this approach to study outcome after head and neck surgery.

This review therefore presents a considerable challenge. It has been necessary not only to assess the methodological aspects of the studies reported, but also to assess their conceptual base and sophistication, and to consider the professional background of the authors. Particular emphasis is put on the quality of the measuring tools being used, particularly where psychosocial issues are related to outcome. The aim has been to weigh each study and to create a cohesive picture of how

each of the different approaches has contributed to the understanding of the main issues. To achieve these aims, studies have been grouped under headings and described largely chronologically within each group.

Since it is helpful to consider the psychosocial aspects of any condition with a basic understanding of the medical and surgical aspects of that condition, the medical aspects of head and neck cancer will first be described.

6.2 Aetiology, prevalence and treatment of head and neck cancer.

Cancer of the head and neck is a collection of conditions, comprising all cancers of the upper aerodigestive tract, including cancer affecting the larynx, pharynx, mouth and nose. Cancers affecting the eye and the brain are categorised separately, although resection of the neoplasm often involves loss of an eye. Within the UK, approximately 6,500 new cases are diagnosed each year, but these numbers are increasing: the incidence of intra-oral cancer alone has increased by 21.9% over the last twenty years (Nally 1992; Johnson et al 1993). Although a relatively rare disease, (5% of new neoplasms, most dentists/GPs will see 3-4 cases over a lifetime), the combined morbidity of head and neck cancers has been estimated as greater than that for malignant

melanoma and cervical carcinoma combined (Edwards 1997). Although

there have been some limited campaigns aimed at early detection

(Desmond et al 1993), there has clearly been nothing like the interest

from health promotion campaigns and in early detection compared with

the former two conditions.

Although typically, those affected are aged over 50, there is some

evidence of an increase in prevalence in younger populations. Whilst

tobacco causes the greatest incidence of mouth cancers, its effects are

potentiated by the heavy use of alcohol (Buglass 1995); alcohol and

tobacco are implicated in the aetiology of some 90% of cases. The

increase in consumption of both alcohol and tobacco in younger age

groups is therefore of significance for future morbidity, with the increase

in smoking amongst young women of particular concern, since the ratio

of men to women affected has already fallen from 5:1 to 2:1 in the past

decade (Nally, 1992; Johnson et al 1993).

80% of head and neck carcinomas are squamous cell carcinoma.

Depending on the primary site, early symptoms range from hoarseness

(cancer of the larynx) to soreness of the mouth or throat. Major

treatment is via surgery and/or radiotherapy, with chemotherapy used

less frequently. Few randomised controlled trials mean that treatment is

based usually on case series, and the trade-off between quantity and

quality of life is a recurring theme in the literature where for example

surgery produces better survival after cancer of larynx, whilst

radiotherapy produces better speech (Maas 1991).

Smaller cancers and those on the lip and larynx have a better prognosis

than those in other sites. Half of those patients treated survive for five

years (the worst five-year survival rate of all cancers), with about one in

six going on to develop another cancer (Haughey et al 1992).

It is hard to give a sense of the impact of this disease through these

statistics. Radiotherapy and chemotherapy are discussed so routinely

that the impact of simple preparatory procedures can often be

overlooked. A common first step in treating cancer of the jaw is to

remove all the teeth to prevent later complications with infection; access

to neoplasm at the root of the tongue may be by splitting the chin and

opening the jaw 'like a book'. These 'simple' procedures can be

experienced as profoundly upsetting by the patient but their impact

easily overlooked in the context of major surgery for a life-threatening

condition (Diamond 1999).

6.3   Organisation of treatment

Because of the variety of sites and types of cancer within the category,

treatment may vary more than in other conditions. Referral from either

GP or dentist may be to a general, maxillo-facial, plastic or ear nose and

throat surgeon. A consultant oncologist and radiologist may also be involved within the multidisciplinary field that can also include a speech and swallowing therapist, dietician, prosthodontist, prosthetic technician, and specialist nurses. (The range of potential specialists involved in patient care was highlighted in the current study: in order to inform those of consultant level with whom eight head and neck cancer nurses would be working, forty-eight separate information letters were sent out). The centralisation of services within a regional specialist unit may or may not have been achieved. Where it has, the advantage of co-ordination of care may be out-weighed in the patient's eyes by the need to travel further for appointments and follow-up. Not surprisingly, the need for better organisation and co-ordination of care both within and between different providers and sectors, was identified as a key finding in Edwards' (1997) report on patient, family and professional perspectives of head and neck cancer care.

Within this multidisciplinary team, psychosocial provision is rare although there may occasionally be access to a counsellor. Specialist nurses are ideally placed to provide this input, and although their role has not yet been clearly defined (McGurk 1997), some have set up informal support groups with the support of other members of the team. Again, the need for psychosocial support to patients and relatives was highlighted by Edwards (op cit).

6.4 An overview of the clinical impact of the disease and treatment

The impact of a diagnosis of cancer is enormous; the immediate threat to life followed by the trauma of medical investigation, uncertainty about treatment issues and outcome all add together to make this a profoundly disrupting experience. There can also be an immediate effect on the individual's personal support systems. Because cancer remains one of western society's great taboos, people experience embarrassment about telling family, friends, and employers. Thus at a time of maximum need, social support networks may break down (Diamond 1999).

For the patient with cancer of the head and neck, the site of the disease can be expected to have an additional impact. The face is an important determinant of our internalised sense of who we are (Cash and Pruzinsky 1990). Adapting to any disfiguring condition, even where change is very minor, can be a very long process, often described as one of bereavement, with a clear focus on grieving for lost looks (Partridge 1990). The face is also the focus of physical attractiveness, which in turn is an important determinant of our expectations about how other people will judge us. First impressions are important in our image conscious society and adapting to disfigurement even when minor can be profoundly difficult (Lansdown et al 1997). First encounters are particularly stressful, staring and intrusions are commonplace, and social avoidance can rapidly develop as the simplest means of survival

(Bull and Rumsey 1988). Since physical attractiveness reinforces the sexual stereotype (Bar-Tal and Saxe 1976), patients may feel either less feminine or less masculine and the expectation of no longer being sexually desirable is a major concern. Simple barriers to sexual activity such as altered facial sensation and the ability to kiss a partner can cause enormous distress and yet have received very little attention in terms of investigating psychosocial sequelae and/or support (Siston et al 1997).

Facial expression also underpins social interaction. We all look at faces when we are speaking and listening, developing a complicated signalling procedure that depends on eye contact, smiling and gesture (Argyle 1972). The potential for breakdown in communication when the face is disfigured is reviewed fully in chapter two, and is of major significance for this population for whom surgery can result in radical change (Edwards 1997), and be associated with anxiety and embarrassment about being looked at .

Communication can also be mechanically disrupted. The very process of speech articulation is clearly dependent on structures in the head and neck region. Laryngectomy and removal of the vocal chords will remove the ability to speak permanently, future 'speech' being achieved through a variety of alternative mechanical means. Tracheostomy, which may be temporary or permanent, will facilitate breathing through a stoma in the neck, but prevent normal voice production via the vocal chords. (It

also prevents the isolation of the diaphragm and therefore the ability to lift heavy objects, a side effect that seems almost unrelated to the original disease process but which can have a huge impact where it leads to loss of employment). Cancer and the treatment for invasive disease can therefore have a major impact on what the voice sounds like or whether the individual can speak at all, with psychological factors playing an important part in whether the individual re-establishes communication through oesophageal or other prosthetic speech mechanisms (Natvig, 1983; Stam et al 1991).

Similar problems occur with swallowing. Ingestion of food, chewing, swallowing and salivation are frequently affected, with profound implications for ensuring optimum nutrition, but also impacting dramatically on the social aspects of eating. Patients can be embarrassed about the difficulties of drooling or spilling food, using special utensils or straws. The interruption of what is an important social activity might be expected to impact on self-esteem; indeed the inability to express personality through speech and the social exclusion from activities such as having a drink or a meal with friends can have as great an impact on self-image as objective change in physical appearance (Diamond 1999).

Other effects of head and neck cancer include reduced shoulder motility plus the various side effects of altered diet and pain control, such as weight loss and constipation.

6.5   Psychological aspects of head and neck cancer

Section 6.4 gives an overview of the impact of head and neck cancer. It is also deliberately written in a way that suggests something of the ease with which what is a *potential* area for concern becomes a *recognised* clinical problem. Thus: 'faces play a central role in communication, therefore a change in appearance following cancer causes communication difficulties'. 'Sexual stereotypes are maintained by physical attractiveness, therefore women who have had facial surgery are likely to have sexual problems'. Psychologists can see the error in this reasoning, and hopefully these statements appear to be grossly unsupported; however, these errors of logical deduction are not unusual either in nursing journals or book chapters, and it is particularly common where information has been 'simplified' and in the process distorted in patient information intended for a lay audience.

The *evidence* for the psychological impact of head and neck cancer is reviewed below, and classified into three main categories: the first of these groups include studies which are essentially exploratory and descriptive, which can be loosely pulled together under the heading 'psychosocial issues'. A second group of studies is discussed under the heading 'quality of life', and a final group of studies are considered under the heading of coping models and management strategies.

6.6 Psychosocial problems in head and neck cancer.

Like many areas within medicine, the identification of psychological problems related to a specific medical condition are identified first as case reports and are then developed as survey studies which are measuring a variety of outcomes. The quality of the information that they provide depends on the background and experience of the researcher, research design, the use of quantitative versus qualitative data, and the reliability of any measuring scales employed. In addition, many studies are simply descriptive with no attempt made to explain or interpret the findings. One of the first studies which fits within this category is that of West (1977), who frames her work as a study of social adaptation. 152 patients were followed up retrospectively, by means of questionnaire and semistructured interview. Data was analysed into simple categories and reported as percentages of the total cohort. Thus, 60% of patients were working post-operatively compared with 79% pre-operatively. 4% gave their reasons for not returning to work as disfigurement related. The author concluded that this sample was remarkably well adapted socially, and suggested that the older age range together with the 'relief' at having survived cancer might be mitigating factors. This is a very simple study both conceptually and in execution. Methodologically, there is much that can be criticised, not least the use of non-standardised research tools in a retrospective design. However, this study is superior to most in that West (op cit)

attempts to interpret some of the findings and suggest future directions for research.

Until March 1984, 291 references to rehabilitation after head and neck cancer were reported in the literature, of which only 117 were research studies, and of these, 8 were concerned with psychosocial issues (Pruyn et al 1986). Concerns highlighted in these papers include patient isolation because of speech difficulties, anxiety and loss of self esteem (David and Barrit 1982). Other psychosocial difficulties reported include swallowing and chewing together with the inability to express emotions where speech is affected (Dhillon et al 1982; Shedd et al 1980). Psychological constructs such as 'self-esteem' or 'social isolation' are deduced from patient self-report rather than measured, and selected in a relatively ad hoc way.

Pruhn et al (op cit) reviewed all these early studies on rehabilitation in 1986 and the quality of this early work is clear in their summary. They conclude that there is great variability in reported results of rehabilitation, with hardly any information about the factors that predict successful outcome, and in particular, the successful acquisition of oesophageal speech after laryngectomy. They conclude that methodological problems are the central source of this ignorance with the preponderance of retrospective studies distorting the findings, both because of sampling error and subjective judgement. The picture is very much one of a research area in its infancy, with a small number of

researchers from different backgrounds effectively duplicating each others work, publishing in a range of journals, and using too many different *ad hoc* concepts and ideas for further research to be planned in a cohesive and constructive way.

One very interesting omission in this review is the failure to refer to the work of Dropkin and colleagues (Dropkin1983; Scott et al 1980) published in the nursing press. Given the quality of this work, it is an important omission. Dropkin makes the first attempt to measure or produce a method of scaling of both dysfunction and disfigurement, by asking physicians and nurses to rate portraits of various surgical procedures according to the level of dysfunction and disfigurement that result. Thus, for the first time, it is possible to consider psychological distress in relation to the severity of the condition. Dropkin and colleagues also use very clear outcome measures such as delay in ward socialisation and participation in self care behaviour, such that it is very easy to understand the practical implications of measures such as lowered self-esteem. They report that the more severe the structural or functional loss, the slower the recovery, and the greater the resulting social isolation. Depression is worse, and self-esteem and sense of worthlessness marked in this group. However, this severe group included people who had undergone very radical procedures. They included orbital exenteration with radical maxillectomy resulting in loss of an eye, and segmental mandibulectomy combined with radical neck dissection, anterior partial mandibulectomy and nasal amputation.

Whilst it is clear that these are exceptionally disfiguring procedures, they also have an immense impact on function. This is important, since this is one of the only reports in the entire disfigurement literature that establishes a link between the severity of the condition and psychological distress. Gamba et al (1992) similarly report higher psychological distress in patients more severely disfigured; indeed 18% of their sample felt that the disadvantages of therapy outweighed the advantages of overcoming the disease. It is interesting that this relationship between severity and distress, leading to this 'trade off' between disfigurement and treatment for some patients, is highlighted in the head and neck literature and not elsewhere in the literature on disfigurement. It is hard to reject the idea that, in fact, dysfunction and disfigurement are so confounded in such major surgery, that it is very difficult to determine the extent to which either independently predicts outcome. It would be very useful to have some indication of how severely disfigured the patients rated themselves in these samples; it might well be that it is the cognitive appraisal of appearance that has the closer relationship with distress, or that, as other studies suggest, social support has a mediating role in the impact of disfigurement. Certainly Baker (1992) suggests that degree of facial disfigurement does not predict distress, and that it is perceived social support together with the extent of dysfunction, which correlate most closely with outcome. Feber (1999), a clinical nurse specialist, suggests that a good working understanding of the ways that these factors combine is in terms of the 'impact of the disease on the individual'. In other words, how well can

this person adapt to the changes caused by treatment for head and neck cancer, given their lifestyle and the extent of their social support. Effectively, this is a shift within the nursing discipline away from an 'altered body image' explanation of outcome to a 'quality of life' explanation.

Breitbart and Holland (1988) working within the psychiatric department of the Sloan-Kettering Oncology Centre, provide the next important review paper, partly because they include reports from a much wider selection of journals and therefore include work from a wider variety of health professionals. Although entitled 'Psychosocial Aspects of Head and Neck Cancer', this paper is reported within a psychiatric framework, with the identification of psychiatric symptoms linked with psychiatric management and illustrated through the use of case histories. Theirs is also the first paper to point out the important contribution of premorbid psychological traits in predicting outcome. In particular, the evidence linking heavy alcohol use and smoking with neoplasms of the aerodigestive tract suggests that alcoholics are disproportionately represented within this patient group. This in turn has as an impact on psychiatric disorder in the post-operative population, since depression and suicide are higher in the alcoholic population than in other groups. Farberow et al (1971) endorse this finding. They studied suicide in cancer patients over an eight-year period, and reported that three sites accounted for 50% of the total; lung, larynx and tongue. Henderson et al (1997) make the same point; although relatively few cancer patients

commit suicide, this is a population at greatly increased risk. The most common psychiatric disorder among cancer patients generally is a reactive anxiety usually combined with depression. Much of the research has been done with breast cancer patients, where it is estimated that 25-30 per cent of patients experience anxiety and depression, at some stage, which is serious enough to need treatment (Carlsson et al 1994; Edwards 1997). Particular vulnerable stages have been identified including diagnosis, discharge and recurrence (Bushkin, 1995). There are several other studies reporting increased psychiatric symptomatology in the head and neck population, or discussing psychosocial implications in terms of altered lifestyle (Davies et al 1986; Languis et al 1993; Wells 1998; Park 1999). Many of these duplicate each other and add little to the summary above. Those that are worth noting include Straus (1989), a maxillofacial surgeon. In discussing psychosocial issues, he identifies lack of compliance with treatment as potentially a positive trait in patients who are trying to take responsibility and manage their own condition. This contrasts with the usual approach to lack of compliance, where it is seen more in terms of a problem in ensuring good outcome; modification of smoking and drinking present considerable challenges for rehabilitation in this group (McDonagh et al 1996). It is encouraging both to see an acknowledgement of the patient as an active manager of his condition, and also the potential role of coping strategies emerging at this early stage from a surgical rather than psychological paper.

Rapaport et al (1993) produced a key study in which they looked at the change in outcomes for this patient population over time. Although they used only a small clinical sample (n=55), their findings are very significant. They report that whilst medical problems decrease with time following surgery, psychosocial problems increase. They suggest that patients lack the appropriate coping skills to manage the profound change that they have experienced and that this pattern might be prevented with better clinical input. This is a finding that has also been found in the long term follow up of patients who have had severe burns (Wallace and Lees 1988), a population which shares many characteristics with the head and neck population, notably severe disfigurement and dysfunction. This finding, that whilst medical problems may resolve, psychosocial problems remain and may get worse with time is significant for several reasons. In the first instance, it stimulates the ethical arguments about the morality of procedures which have this devastating impact, and in doing so supports a more comprehensive approach to the study of outcomes – the quality of life model. It also provides support to those researchers working within a coping skills framework, who are attempting to discover not only those factors which predict successful coping, but who are beginning to develop models for clinical intervention.

One small subset of studies must be considered before considering quality of life issues. The area of sexual functioning has been of interest to clinicians, perhaps because of the relationship between physical

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attractiveness and sexuality. Curtis and Zlotolow (1980) assert that the impact of facial disfigurement on sexuality exceeds that associated with mastectomy and colostomy, although this is based on clinical opinion rather than research. Despite considerable controversy about the nature and extent of sexual difficulties in cancer patients generally, and almost no data at all on head and neck patients, sexual dysfunction is commonly reported as a long term problem for this group (Metcalfe et al 1985). Monga et al (1997) provide the most thorough investigation of these issues in a descriptive self-report survey of 55 patients. Using standardised questionnaires, they found that whilst the majority of their sample experienced problems in sexual functioning, there was no correlation with disfigurement. This challenges Gamba et al (1992) who report worse sexual difficulties with severe disfigurement. Once again, the confounding of disfigurement with dysfunction makes these results hard to interpret, together with the difference in the methodology being used. Gamba et al used an oral interview technique, where Monga et al used standardised questionnaires. Siston et al (1997) similarly investigated a sample of 36 people using standardised measuring tools. They reported that the majority of their sample had significant sexual difficulties, dry mouth, in particular, being reported as a persistent barrier to sexual enjoyment. The experience of prostheses and medical equipment such as tracheotomy tubes is experienced as having a marked impact on perceived attractiveness, particularly for women (Ulbrecht 1986), and Shell (1995) notes that fatigue is a contributing factor to loss of sexual responsiveness across many different cancers.

It is clear that this is an area that needs more investigation, but the findings so far can be summarised by saying that there is strong clinical belief and good anecdotal evidence that this group may have long term problems with sexual functioning. However, the only good research evidence is concerned with men, and the intuitive and often reported relationship with severe disfigurement has not been substantiated. Nevertheless, this is an area which clinicians perceive to be extremely important, and where there is a real lack of appropriate help and support (Feber 1999).

In summarising the psychosocial aspects of head and neck cancer, the following conclusions can be drawn. There is a small literature, which is essentially descriptive in nature, which outlines the problems that patients experience. These papers are often reported under the heading of psychosocial aspects of the condition, and depending, usually on the background of the author, focus either on the day to day problems that these patients encounter, or describe their concerns in terms of psychiatric symptomatology. Although there is variation in the use of psychological concepts and little use of standardised measurement tools, there are still some consistent findings which cannot be dismissed. Taken as body of work, they confirm that cancer of the head and neck may have a major impact on the individual, particularly where dysfunction and disfigurement are marked, and that psychosocial problems may persist and get worse over time even where medical problems resolve. Patients represent a high-risk group for

severe psychiatric illness especially given the high incidence of premorbid conditions such as alcoholism, which increase the probability of severe depression, anxiety and potentially suicide post-operatively. Good long term outcome is associated with minor severity of the condition, although these findings may perhaps be better interpreted in terms of understanding the cognitive appraisal of the disease given the level of social support that people have available. The most encouraging thing about these findings is the stimulus to the debate about alternative or additional forms of clinical management.

6.7   Quality of life studies.

The value of using a quality of life framework for investigating long term impact of medical conditions lies in the intrinsic acknowledgement of the patient as a person with life roles beyond those of a sick patient. The model includes the basic premise that the value of a procedure will be determined not only in terms of the impact on the course and progress of the disease, but in terms of the effect on the individual. As such, medical issues such as side effects of drugs are important, but social issues such as ability to continue with employment also become key indicators of the value of a procedure. It is not difficult to see that this model provides not only a comprehensive picture of outcome within conditions, but also has the potential for comparing across conditions.

Thus hip replacements might be compared with coronary artery bypass surgery in terms of the value to the individual/society. It is clear from reviewing this literature and noting how studies have been funded, that this is an approach that is attractive to health economists (Bowling, 1995).

The definition of quality of life has proved challenging. Cella and Tulsky (1990) have developed a definition that has been widely adopted. "Quality of life refers to patients' appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal". The World Health Organisation Quality of Life Group defined quality of life as "An individual's perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (WHO 1997). Whilst this definition seems comprehensive, others have suggested that quality of life is simply 'what the patient says it is' (O'Boyle et al 1993). As the model has been developed, issues such as religious beliefs have been added to it, and a large number of researchers have been involved in devising and validating quality of life measuring scales. Self-report has become a contentious issue, with some suggestion that a large part of the literature on quality of life is redundant because it is based on health professional assessment of what is essentially an individual issue. Self-report is, today, considered vital if the measure is to have any meaning. As scales have become more and more precisely validated on specific populations, other

researchers have stressed the artificiality of imposing set categories on questionnaires, and the need for people to generate their own categories (O'Boyle et al 1993). Despite all these difficulties, the quality of life literature has grown enormous, and within the field of head and neck cancer, has produced perhaps the most useful approach to understanding the disease process and measuring outcome.

Not surprisingly, the earliest of the papers using the quality of life approach can be criticised for all the reasons outlined above. Lack of a good definition of the term is the most consistent omission, and once again in this early literature, retrospective sampling of a small clinical cohort is the most common research design. Studies use a wide variety of dimensions of quality of life, ranging from physical issues such as eating and speech difficulty, to patient mood, sexual functioning, social status and occupational functioning, with many studies including an overall evaluation of the quality of life e.g.: perceiving life as worth living, still enjoying the things they used to enjoy (Gotay and Moore 1992). Early studies report very similar findings to those reported previously in this review in terms of impact on social and psychological functioning. Thus Morton et al (1984) found 60% of their sample to have problems of psychological adjustment whilst 40% were clinically depressed. Dhillon et al (1982) carried out the first self-report study with a sample of patients contacted retrospectively; 43% of those having had severe disfiguring surgery had become total social recluses. Lansky et al (1989) found the same outcome as Rapaport et al (1993) in their sample of 35

patients, where 5 years after surgery, patients could eat only soft food and 20% had severe communication difficulties. Matthias et al (1988) conclude that social support makes the most significant contribution towards good quality of life in the long term, and suggest that support groups are a potential way of maximising this post-operatively. Drettner and Ahlbom (1983) used a quality of life framework in a controlled study where they compared 52 patients with 104 age-matched controls. Differentiating between patients with a good or bad prognosis allowed them to study the differences between the groups. They found that those who had a good prognosis reported a better quality of life than those in the control group, despite the fact that many of them still had eating difficulties. Drettner et al (op cit) conclude that patients who have had a life threatening illness may value their activities more. This is intriguing and encouraging, since it suggests that despite the severe impairment post operatively, head and neck patients may be capable of good quality of life post operatively.

One valuable reason for using quality of life measures in these early studies was the ability to compare different treatment modalities. Thus, three studies compared radiation with surgery, all finding an advantage for radiation in terms of better speech production, earlier return to work and generally better overall function (Harwood et al 1983; Karim et al 1987; Morton et al 1984). Van Knippenberg and de Haes (1988) and Donovan et al (1989) reviewed quality of life studies in cancer research generally; there was increasing recognition that this was a vital outcome

measure, and one that should be included in the majority of clinical trials. However, of the seventeen existing scales available, none met all the criteria for an adequate research tool.

Similarly, whilst recognising the advantages of this multidisciplinary approach to measurement of outcomes, and in particular the ability to compare different treatment regimens more comprehensively, Gotay and Moore (1992) concluded that both the consistent and explicit use of quality of life definitions was vital for future studies of head and neck cancer. The use of standardised measuring scales was also proposed, together with agreement that self-report would give more valid information than clinician assessment. For some studies it was not clear who had completed the scales; proxy completion by relatives was especially common, and on some occasions, patient report had been rejected in favour of clinician ratings, on the basis that these were more accurate.

From the mid 1990s, there was a tremendous international interest in quality of life in medicine generally, and in particular the demonstration that reliable definition and measurement was possible. Morton (1995) reports that in 1993 alone, there were over 1200 papers published which contained the term quality of life in the title or abstract. Of these, 250 were related to cancer, 18 of them to head and neck cancer. Only two of these studies were prospective in design however, and by 1995 there were only 8 studies that had monitored quality of life changes over

time. An increasing number of researchers were engaged in trying to develop adequate research tools. In the USA, Dropkin et al (1983, 1992) had developed a method of scaling dysfunction and disfigurement that allowed comparison of outcomes between differing severity of conditions. Baker (1992) had developed a functional status scale for measuring quality of life in head and neck patients. This provided a good basis for comparing different groups in cross sectional studies, but did not included standardisation for comparisons over time. List et al (1996), at the University of Washington, developed the 'Functional Assessment of Cancer Therapy – Head and Neck Scale', a self-report scale which has proved to be a useful clinical tool, adding to the information gained by standard clinical assessment. Morton and Witterick (1995), in New Zealand, produced a standardised scale for measurement of quality of life in head and neck cancer, consisting of a combined (thirty-item) general health questionnaire and life satisfaction scale, which was sensitive to change. Although comparatively short, this questionnaire lacks some important quality of life domains, notably those relating to occupational status, spiritual life and sexual dysfunction. Finally, a large-scale research study run by the European Organisation for Research and Treatment of Cancer set out to develop quality of life scales for a variety of cancers . This EORTC scale consists of a (thirty item) general scale common to all cancers, with separate add on modules for each different disease subgroup. (Thirty-seven items for head and neck module). Standardisation on different populations in Europe is nearing completion and the scale is available in

several different European languages. This instrument has become the instrument of choice for researchers working in Europe (Bjordal and Kaasa, 1992; Bjordal et el 1994).

Using the EORTC scales, Bjordal and colleagues have produced some of the most convincing studies of head and neck cancer so far published in the literature. Bjordal et al (1995a) compared 204 long-term surviving head and neck patients with a matched control group. They noted reduced quality of life in the experimental group and suggest that clinicians need to be aware of continuing psychosocial morbidity in the 'cured 'group. This is one of the first papers to suggest the potential for psychological interventions to make an impact on quality of life and that this patient group is one that would potentially benefit from this kind of support. In a second paper (Bjordal et al 1995b) patient rated quality of life scores were compared with physician ratings. Patients consistently rated their quality of life as lower than that rated by the clinicians. This study once again stresses the importance of self-report. Bjordal et al (1995b) again stress the need for interventions which attempt to improve patients' coping strategies and meet their rehabilitation needs. Finally, in a paper examining outcome between 7 and 11 years after treatment, Bjordal and Kaasa (1995) report considerable psychological distress on both the GHQ and the EORTC questionnaire. Again they suggest that psychological distress should be treated, ideally in the form of teaching coping strategies which might impact on quality of life. These are very informative studies, using well-validated research tools,

but again there is a retrospective sampling technique, with associated problems of subjective bias.

Morton (1995) carried out a prospective study of 201 patients followed up for two years. Morton is particularly interested in a global or life satisfaction index developed from a range of quality of life measures. Using a questionnaire that he and his team had been refining since 1988 (Morton and Witterick 1995), he reported that life satisfaction improved significantly with time after successful treatment for head and neck cancer. Principle determinants of life satisfaction appeared to be speech difficulty and pain, although it was not clear that all important parameters had been measured, disfigurement, in particular, being a frustrating omission.

These studies using a quality of life approach to studying outcome after head and neck surgery can therefore be seen to share many of the problems of those studies reported within the more general framework of psychosocial outcomes. Small numbers of patients, usually sampled retrospectively in non-experimental designs have none the less produced supporting evidence for the major impact of treatment for head and neck cancer. The importance of this approach lies in the multidisciplinary nature of the concept itself; psychological and social factors are weighed alongside more traditional surgical outcomes. The other major advantage that his approach has brought has been the development of measuring tools. From a point twenty years ago when

psychological concepts were measured in an ad hoc way in this field, there are now a number of well-validated research tools that can be used to describe the population. Few longitudinal studies have been reported so far, and those that have been done follow the natural progression of outcomes rather than evaluate the effectiveness of particular interventions. However this work has led to an exciting stage in the field where having outlined the problems, and developed appropriate research tools, the next logical step is the development of appropriate clinical intervention programmes.

6.8   'Coping' research

One important group of research studies which merit evaluation before describing the current research study, are the small group of studies that can be understood within a 'coping' framework. The difference between these and earlier studies grouped under the psychosocial heading is that they have an a priori model within which they attempt to describe psychological issues and how patients manage these issues. Some studies then go on to suggest or investigate potential intervention strategies within this coping framework. For this reason, it is worth considering them as a separate group, although they do not appear as any kind of separate group in the literature itself, and like other categories of research, they differ from each other in the way that they apply a common model.

'Coping' theories have generated much work in clinical and health psychology, and in particular on cancer. Johnson et al (1997) investigated the effects of nursing care guided by self-regulation theory on coping with radiation therapy. By preparing patients carefully pre treatment, less disruption to life activities was found both during and after treatment. Although this is a study of breast and prostate patients, this is a well designed and controlled study which has a clear practical application in the suggestions for the way in which nurses can prepare patients for radiation therapy for a variety of different cancers. Studies using coping models in head and neck cancer are in general far less well designed and have much more limited value. An exception is the work of Dropkin.

Dropkin (1989) discusses rehabilitation after surgery in the context of Lazarus's cognitive transactional theory of stress. Dropkin proposes that a patient will respond to the stress of surgery by trying to identify and develop an appropriate coping response. Together with colleagues, Dropkin has developed the Stress-Coping model (Scott, Oberst and Dropkin 1980) which has allowed them to explore the process of rehabilitation and to predict those aspects of behaviour which facilitate good outcome. This has been translated into a very practical care plan with specific objectives defined for each post-operative day. For example, early socialisation is identified as a predictor of good long-term outcome, therefore patients are encouraged to leave their rooms and use the whole ward during early ambulation. Immediate post-operative

care includes early confrontation of the facial disfigurement by looking in the mirror. Although attempted avoidance may be common, this is vigorously challenged, and patients are also encouraged to take part in self-care, for example helping with dressings, from the earliest possible stage. Dropkin (op cit) suggests that post-operative day five is an important watershed, with patients who are still having difficulty in taking part in their care more likely to have long term problems. By day seven, very active clinical intervention from an experienced nurse is indicated for those patients who still have problems in the area of socialisation and early ambulation. This intervention takes the form of challenging unhelpful beliefs and emphasising the importance of surgery; essentially, a cognitive intervention aimed at encouraging the patient to develop a behavioural response. This is the first study to introduce the idea of 'coping' into the literature, and it is an extremely effective piece of applied research, using psychological theory to generate and test very practical outcomes. However, there is clearly scope to develop more creative and innovative forms of intervention as Dropkin herself points out. The application of this model is also confined to inpatient care, and providing more input during rehabilitation in the community is an obvious next step. Breitbart and Holland (1988) summarise the goals of rehabilitation in terms of reintegration into social and work settings. They stress the importance of a rehabilitation programme that starts early, preferably pre-operatively, and includes strategies such as those outlined above to ensure that the potential for healthy psychosocial recovery is maximised. Together with the research on quality of life in

head and neck cancer, those papers using a coping model to underpin

their work consistently stress the need for patients to be offered some

kind of support following surgery. Dropkin (op cit) stands out in

specifying the very practical ways that support can be offered. Other

papers are much more vague about the kinds of intervention that might

be helpful, commonly recommending counselling with no description of

the specific aims or content, or rely on case history format to describe

the management of one case (Kunkel et al 1995). A number of papers

present evidence framed within the concept of coping, but use the

construct simply to indicate some attempt at management of symptoms,

rather than examining outcome on the basis of an underlying theory of

coping, ie: in the technical or psychological sense. For example, Harris

et al (1985) report the positive effect of group therapy for post-operative

patients. Group therapy in this context indicates weekly support

meetings, and although positive outcome is reported, this is not

measured objectively. Llewellyn et al (1999) evaluated the use of group

therapy with metastatic cancer patients and found that the impact of the

group was limited. Although there are no reports of similar studies with

head and neck patients, there is some anecdotal evidence that the

unstructured emotionally focused group approach is not helpful (McGurk

1997). With so little evidence, it is impossible to draw firm conclusions,

but there appears to be more evidence for a practical skills based

approach to rehabilitation rather than a non-directive exploratory or

emotion focused approach. However, there are problems in the

application of this skills based approach. It is interesting to note that

whilst 'coping strategies' can seem very easy to generate in some areas

of rehabilitation, there appears to be a real problem when considering

psychosocial issues. Wilson et al (1991) used a coping model to

investigate dietary management after head and neck cancer. They

reported that patients and their spouses developed a range of strategies

such as boiling rather than baking or frying foods so that they achieved

a softer texture. Professional advice included specific recipes and

advice on how to blend food or cook food for longer. This kind of

practical approach to psychosocial issues is virtually unexplored in the

head and neck field. The paper from Koster and Bergsma (1990) is a

good example. They produce a review in which they use Cohen and

Lazarus's coping model to interpret the problems reported generally in

the head and neck cancer literature. They identify coping as a process,

in which the cognitive interpretation of a stressor predicts the emotional

cognitive and behavioural response. They then assess the extent to

which this approach is helpful in classifying the particular problems that

patients experience, at each stage of their diagnosis and treatment.

Whilst Koster and Bergsma (op cit) conclude that it is useful to interpret

the literature using this model, it is difficult to see why, without the

development of the approach into some kind of practical application.

The post hoc application of a theory to any body of work is of little use

unless it is being used to justify some future study or predict the value of

a particular intervention. Similarly, Langius et al (1994) used both a

prospective and a retrospective sample of 42 patients in a study of

functional status following surgery. Patients completed the sickness

impact profile as a measure of functional status and the sense of coherence scale as a measure of coping. Results on the SIC showed a wide range of scores suggesting the importance of individual approach to any rehabilitation plan. Those patients with a stronger sense of coherence on the SOC were functioning more successfully at a psychosocial level. The problem with this study is that coping is defined as a generalised index or personal quality rather than as a response to a given stressor. As with much research on coping, there is the tautological problem of findings that tell us little more than people who are good copers cope better with head and neck cancer than people who are poor copers. In terms of head and neck cancer, research is still at the stage identified by Folkman et al (1997), of needing to turn coping theory into an intervention. For the kind of practical approach that is implicit in the recommendations of Bjordal and colleagues, it is necessary to look at work done with other groups who face major life change as a result of severe injury. King and Kennedy (1999) report the benefits of coping effectiveness training in a prospective controlled trial of patients with spinal cord injury. This is a psychological study which uses a coping model both to analyse and understand the patient response, and then goes on to use the model to develop an intervention package which generates and refines specific coping strategies. Given that psychologists working with other patient groups King and Kennedy (op cit) with spinal cord injury, Chesney and Folkman (1994) with HIV, dieticians (Wilson et al 1991) and nurses (Dropkin et al 1980) working with head and neck cancer, have all used a coping framework to

generate practical coping strategies which can be tested and taught to

patients, it is frustrating that these ideas have not yet been extended to

the psychosocial aspects of this condition.

The only exception to this rule can be found in a paper from

Fiegenbaum (1981). Working with head and neck cancer patients,

Fiegenbaum developed a practical programme, within a social skills

model, for teaching patients how to manage the day to day problems

caused by their facial disfigurement. Although a very small sample (17

in total) this study included a waiting list control group. The programme

consisted of client generated problem situations covering not only

disfigurement related issues, but also problems with speech and eating

difficulties. Training in effective coping strategies led to significant

reduction in social anxiety and improvement in social skill. Patients were

followed up for two years, and standardised questionnaire results

indicated that they continued to be more confidant in managing social

contacts, had less social anxiety and were more self confident. This

study has all the problems of a small sample size, but has been

important in influencing other research studies. Robinson et al (1996)

designed a similar programme to be delivered to people who had

disfigurement from a variety of different causes and found similar

positive outcomes after an intervention of only two days. What is

surprising, is that there has been no further development of this kind

within the head and neck cancer field. Given the number of papers that

have suggested the importance of coping strategies, and of teaching

effective management strategies to patients, it is striking that this paper has become almost totally overlooked. Its publication in the rehabilitation press rather than in the head and neck journals may be part of the reason, or it might be that the specialist practitioner who is charged with the responsibility for delivering a rehabilitation programme is usually a nurse rather than a psychologist, and lacks the skills needed to design and implement this kind of approach. This paper raises very important questions about delivery; it is clear that for any intervention to succeed, it should be designed it such a way that it is accessible to those health professionals who are the most likely to be able to deliver it. Providing a model for psychologists to use is not a practical approach in a setting where psychologists are rarely available to see the client group.

In summarising the work on coping in head and neck cancer, the conclusions must be that there is good evidence from the nursing literature that applied coping models can be used to design effective rehabilitation programmes, although so far this work has focused on the immediate aftercare of patients in hospital. Psychological studies have been disappointing in their failure to extend a coping analysis of psychosocial issues to an intervention package with the exception of one paper. Nevertheless, the work being done with other patient groups together with work carried out with other disfiguring conditions supports the development of an applied coping or problem focused skills

approach with this group as the basis of longer term rehabilitation.

Issues of delivery, in particular, the identification of health professionals able to undertake rehabilitation with head and neck patients, are clearly central to the type of intervention designed.

6.9   Patient and family perspectives on head and neck cancer.

There is a small, further collection of studies which can be included together, and which are concerned with patient and family perspectives on head and neck cancer (Mathieson et al 1992; Mah and Johnston 1993; Harrison et al 1995; Watt-Watson and Graydon, 1995; Bottomley et al 1997; Mesters et al 1997). These include research papers together with studies based on focus groups or discussion with patient organisations. Their conclusions can be summarised by reference to the recent study by Edwards (1997), published by the Kings Fund. Her study was based on focus groups at different hospital sites, and produced some consistent findings, which both support and add to those discussed earlier in this review. Quality of life was extremely important to patients and they stressed that head and neck cancer has a major impact on both patients and their families. Information was perceived to be either lacking or inadequate, and an examination of the various information leaflets produced by patient organisations corroborates this fact. The recently published directory of cancer related information produced by the Macmillan Cancer Relief Fund has

one published leaflet about throat cancer, and no section for head and neck cancer. This contrasts sharply with the information available for breast and prostate cancer. There is only one research study specifically examining patients information needs in head and neck cancer, and this, in line with the general findings in health psychology, suggests that better informed patients have a better outcome in terms of psychosocial adjustment (Kreitler et al 1995). However there is some suggestion from this study that better informed patients worry more: thus there is a very clear need for further investigation of the information needs of this group.

Some of the most striking findings of Edward's study were concerned with deceptively simple issues, such as kindness and patience from medical staff, and someone available to really listen to their concerns and advise. This suggests that counselling might have a role, and many of the patients in this study were aware that counselling has become an important part of rehabilitation after conditions such as breast cancer. Many people wished that it had been offered and felt that they were unable to ask unless it was offered. Some felt that counsellors would not understand unless they had undergone a similar experience, suggesting that there might be a role for group interventions. Long term support from an informed professional has been highlighted as important in other studies. Parsons (1997) reported that patients often discovered that they knew more about the management of a tracheostomy or other aspect of their condition than their GP or district

nurse. The opportunity to access very practical help such as how to get

hold of portable suction equipment was not available. Feber (1997) has

shown that facilitating the skills of health professionals in the community

by providing training for district nurses and inviting them to meet

patients before discharge can considerably facilitate rehabilitation.

6.10 Summary of psychosocial issues in head and neck cancer

The reported research into the long-term aspects of head and neck

cancer is clearly very variable both in aims, conceptual basis of

investigation and in quality. Dividing the papers into the groups above:

psychosocial aspects of the condition, quality of life issues, studies

based on a coping framework and the patient/family perspective is

hopefully a successful *post hoc* strategy aimed at organising a range of

material. In some senses it is an artificial categorisation since all these

studies could be grouped under the simple heading of psychosocial

issues in head and neck cancer. However, this grouping demonstrates

more clearly the different approaches to the problem, and the different

ways that people working in different health professions have identified

and recorded the problems that patients experience. The shortcomings

of many of the research studies have been described, but it is important

to remember that these are not unusual in a new field where reports are

essentially describing a clinical cohort retrospectively, rather than setting

up a prospective controlled investigation. Having taken note of all these

issues, it is still possible to come to some disturbing conclusions. Taken together, the findings suggest that patients undergoing surgery for head and neck cancer commonly experience major long term changes in their quality of life. Dysfunction and disfigurement lead to psychosocial problems and an increased psychiatric morbidity in the group as a whole. One of the most striking things about this population is the role of social factors in maintaining the problem. Thus, disfigurement is a problem because of the reaction of other people; going out is embarrassing, people stare and comment etc. Communication difficulties are by definition a problem in terms of their social function, but it is interesting to note that eating difficulties too have a strong social component; eating is a problem because it is embarrassing to drool or to use a child's cup. Those who have the best outcome appear to be those with good social support, and who develop effective coping skills. Finally, studies at the service level suggest a wide variation in how this group is managed, with the absence of appropriate rehabilitation and support identified as a major concern.

6.11 The goals of effective psychosocial rehabilitation

In rehabilitating this group, the aims should, therefore, be the facilitation of both social support and the ability to manage the problems that the group encounter, with awareness that this needs to be delivered in a way that people find empowering, relevant and non-threatening. These are the aims encapsulated in the term social rehabilitation. There is a

clear need for information produced in a way that supports these objectives, and promotes the role of the individual as active participant in the management of their long term condition.

Service issues need also to be considered. How is any rehabilitation programme to be delivered? Designing an effective intervention has no purpose if there is no one interested or available to carry it out. Similarly, facilities vary from region to region; what can be offered in one setting, for example, where patients live near enough to travel, might be inappropriate in another where people live at some distance from the centre. Clearly the design of an intervention for this group is a major challenge, however, the clear evidence of need makes the challenge justified. A further positive reason for undertaking this work at this point is the existence of measuring scales with which to measure outcome. Without these scales, the value of designing an intervention would be debatable, since it would be very difficult to demonstrate its value. Tackling the problems of social rehabilitation in head and neck cancer by designing an appropriate intervention package is a compelling next step in the progression of understanding and meeting the needs of this population. The following sections therefore describe the design, development and method of evaluating a social rehabilitation programme for head and neck cancer patients.

CHAPTER FOUR, SECTION TWO. THE DESIGN, DEVELOPMENT AND EVALUATION OF A SOCIAL REHABILITATION PROGRAMME FOR PATIENTS FOLLOWING TREATMENT FOR HEAD AND NECK CANCER.

7.0   The development of the social rehabilitation programme

The goals and definition of the social rehabilitation programme have been summarised in section one, and are, in essence, the development of a coping effectiveness training programme which focuses on the area of psychosocial issues. This needed to be designed in such a way that it was flexible and could also be delivered by a health professional currently in post. Since social support is identified as such a strong factor in facilitating good outcome, and relatives are required to undertake a key role in rehabilitation, a programme that involved relatives where possible was also assessed to be ideal. In reviewing the rehabilitation work that has already been undertaken in head and neck cancer, together with the successful outcome of the programmes designed by Changing Faces to manage pan-disfigurement, it

was clear that there were successful models on which a more detailed programme might build. A programme designed to promote coping was indicated both by the conclusions of the research studies in head and neck cancer and by the success of coping effectiveness training in other long term conditions. This built on the work of Dropkin (1983), extending inpatient self-care and early socialisation, to similar targeted activities in the outpatient setting. Early involvement in self-care, managing dressings, socialisation on the ward, managing dietary needs, all contributed to an ethos of self-management and independence which are the precursors to effective long-term coping.

Psychosocial rehabilitation effectively begins at this point; for example; carrying out dressings provides a one to one setting in which coping strategies can be discussed. Clarke (1998) proposes that all patients with a facial disfigurement should rehearse an answer to the question "what happened to your face?" before leaving hospital, and that the dressing procedure provides the ideal opportunity to rehearse alternatives. Similarly, early ambulation on the ward facilitates social encounters and is an opportunity to practise basic social skills such as the maintenance of eye contact and good posture. Understanding social difficulties in terms of social embarrassment allowed the design of a rehabilitation programme that used techniques of coping skills and graded exposure which have been successfully employed in the general management of social phobia.

Fiegenbaum's (1981) model of generating problem focused coping strategies in a group setting proved successful, and an intervention using this problem focused approach to move along a continuum, was a logical progression that could be designed as an intervention for delivery either in group or individual sessions: for example, from the management of altered dietary requirements to the management of eating in public.

Changing Faces has developed an intervention package aimed at managing the problems of facial disfigurement. However, many of these techniques have potential in the management of related issues of social embarrassment. For example, the strategies developed to take the initiative in social encounters have been found at a clinical level to be equally effective both for managing altered appearance and managing an altered voice. Learning how to deal with staring triggered by unusual appearance is the same in principle as learning to deal with staring triggered by any eye-catching behaviour. The application of the Changing Faces approach to managing staring was therefore thought to be helpful in managing issues such as dribbling or spilling food. The Changing Faces programme developed to help parents manage children with a facial disfigurement included proxy responses which the parent s model to their child. With the head and neck population the involvement of relatives and carers in generating appropriate responses and coping strategies had potential for facilitating social support as the relative identifies and becomes skilled in their own supporting role. In designing this social rehabilitation programme, the process was, therefore, one of

identifying the problem issues, and then pulling together and adapting a number of successful coping strategies evaluated both on head and neck cancer patients and on people with other forms of facial disfigurement.

However, before designing the programme, it was important to identify those health professionals who might be interested and able to use it. The programme was then designed with the training and skills of this group in mind, together with flexible alternative formats for different models of service delivery. The most obvious group to target in the development of this project was head and neck cancer nurse specialists.

7.1 The role of the head and neck cancer nurse specialist in social rehabilitation

It was clear both from the literature review and from requests for information to Changing Faces, that nurses were interested in these long-term issues of quality of life after treatment. These contacts support Price (1998, 1990) who has suggested not only that psychological aspects of altered body image are important in a range of conditions, but that nurses are in a particularly strong position – indeed may be the only health professionals - in a position to provide relevant patient support. However, there are important questions about how well trained nurses feel to manage the concerns of those with

disfiguring conditions. In addition to the evidence provided simply by the numbers contacting Changing Faces, an evaluation of the resources produced by the charity suggested that nurses were concerned about their skills in this area. Although written information and video had been designed for use by patients, they were also very popular with health professionals, particularly nurses, who were using them both to work directly with patients and to inform their clinical practice (Clarke 1999b). In 1997, when this work on head and neck cancer commenced, there were 76 nurses on the Changing Faces database who were specifically involved in working with head and neck cancer patients. Of these, 24 were employed as clinical nurse specialists, operating as independent practitioners. These are senior roles (grade H), which means that the incumbents have achieved at least charge nurse status. Many are graduates, and a master's degree is encouraged at this senior level. All have undertaken postgraduate training in their fields. This is usually in the form of a supplementary ENB course in maxillofacial, ENT or plastic surgery nursing. Reflecting the relatively new development of the specialist nurse role in head and neck cancer, the British Association of Head and Neck Cancer Nurses was established and had its first meeting in 1997 at the Fourth National Head and Neck Oncology Conference, in Nottingham. The conference indicated that nurses employed in this specialist role were keen to fully define it, and the potential for social rehabilitation using the Changing Faces approach was outlined in a keynote paper at that conference (Clarke 1997). The concept and rationale of social rehabilitation was received very enthusiastically, and many nurses present

added their names to the Changing Faces database, offering to take part in

the development and evaluation of the programme. Most of these nurses had

responsibility for continuity of care, attending outpatient clinics and managing

the impact of the initial diagnosis, preparing patients for surgery with a strong

emphasis on providing information, liaising with ward staff and providing

outreach or continuing care post discharge. Psychological aspects of the

condition were identified with the specialist nurse role, yet there appeared to

be a mismatch between role expectation and the perceived ability to meet it.

On the basis of this informal feedback generated by the conference, a study

was designed to discover whether or not nurses on the Changing Faces

database perceived their skills in psychosocial rehabilitation as less good

than their skills in fulfilling the more traditional aspects of physical nursing

care. (This study is the first of three studies which comprise the research

section of this thesis, and is fully reported in Chapter Four, section three).

The results of this study supported the hypothesis that nurses working in both

head and neck cancer (and in burns care) identified themselves as less

proficient in providing social rehabilitation to their patients than in providing

the more traditional parts of physical rehabilitation. This finding challenged

reports by Price (1990) which suggest that nurses can provide this kind of

input, and also identified specific issues such as coping with social situations,

which could be incorporated into the social rehabilitation training programme.

It also helped to frame the structure of the programme. It was clearly

necessary to provide not only specific resources and training, but also an

introduction to the rationale and background of coping strategies, social skills

training and problem focused coping skills, as well as an introduction to

delivery techniques such as behavioural modelling, role play and graded

practice. A preliminary outline of the social rehabilitation programme was

devised, as follows.

7.2   Structure of the social rehabilitation programme

A training manual (Clarke 1999c) was developed with the aim of

informing and resourcing the health professional using it.   The

programme was designed in four main parts:

Part One consists of a review of the evidence from recent studies of

the psychosocial problems of head and neck cancer patients and the

challenges for successful rehabilitation. This section of the resource

pack is essentially a summary of information about the psychosocial

aspects of the condition, and an introduction to the nurse's role in

management. The problem-solving skills approach is described,

together with those opportunities to carry out the intervention whilst

completing nursing tasks. For example, teaching the patient how to

assist in dressings introduces the ideas of self-management in the

immediate post-operative period. This one to one setting can also be used to discuss the importance of developing basic conversational strategies e.g.: answering questions about appearance. The goal is to encourage early socialisation and to have a satisfactory answer to the question "what happened to your face?" by the time that the patient is discharged. Thus this first part of the resource pack is concerned with presenting the issues and the principles of rehabilitation, together with an outline of methods of delivery; a simple information resource.

Part Two extends this approach to practical intervention, concentrating on the nurses role in the outpatient setting, and consists of a manual or 'how to do it' section. A six-session group-training programme for outpatients and relatives is set out. Based on the problems summarised in the literature on head and neck cancer, these sessions teach basic social skills and problem-focused strategies using group exercises, role-play and discussion. Patients and relatives may work as pairs so that relatives can learn more about the common difficulties of rehabilitation and specific strategies for support. Training is backed by specially developed patient literature (see chapter three) and video which is designed to be used in the training sessions but can also be used independently, for example, at home. This part of the resource pack is therefore concerned with providing a very detailed model of how social rehabilitation can be delivered. It can be used verbatim or used as an information resource for nurses to pick out those aspects of

rehabilitation that are most relevant to their patient group e.g.: the section on managing altered speech is not necessarily relevant to everyone. The information contained here can also be used in one to one settings to support people who have concerns about social embarrassment as a result of their condition and who dislike the group setting.

Part Three consists of graded exercises, which guide patients through common social situations and allow them to apply the skills that they have learned to everyday situations, for example using public transport, queuing in a shop and buying a small item. The acronym TTTT Task, Tools, Troubleshoot and Test was developed to provide a framework in which the individual focuses on a specific task, reviews the various skills (tools) which will be needed to execute it, considers all the potential barriers to success (troubleshoot) and revises alternatives, before testing in the appropriate setting.

Part Four provides an evaluation process, introducing the idea of measurement of outcomes with the appropriate rating scales, together with the identification of those patients for whom further help in the form of specialist referral is required. Additional resources for managing sexual difficulties are also included. Finally, contact addresses for other lay-led organisations are listed, together with a list of academic references.

In its entirety, the pack provides the resources to do any of the following:

- Use the programme as a simple information source for nurses and their patients.

- Set up a six-session group-training programme with patients and their carers using the session guides and exercises provided, to guide the process of psychosocial rehabilitation.

- Select from the session guides to provide a shorter training programme.

- Use some of the exercises or resources within the context of a more traditional support group.

- Use some or all of the exercises in one-to-one settings instead of in groups.

- Use the additional resources (booklets and videos) as a patient library.

- Identify those patients in need of specialist referral

The resource pack, together with supplementary material, is included in the

appendix, but the list of contents is reproduced in figure eight to give a

clearer indication of the detail of each section.

Figure Eight: Table of contents of the Changing Faces Social Rehabilitation after Head and Neck Cancer Resource Pack

PART ONE: FACING UP TO CHANGE – THE CHALLENGE OF SOCIAL REHABILITATION

7.3 Design of the evaluation for the Social Rehabilitation Resource Pack

Having designed the resource pack, this was sent to two head and neck nurses for feedback. Changes were essentially concerned with the correct use of terminology, and a request for a section on the management of sexual issues, which was then included. Both nurses were excited by the pack and had immediately begun to use it with their patient group. Before offering the resource pack widely to nurses working in the field, an evaluation process was designed. This stage represented a critical step in the development of this project. Although it would have been relatively easy to evaluate the usefulness of the pack by running a series of workshops led by the author, this would have produced no information about whether or not nurses could use these resources. However evaluating the use of the pack in situ was a much bigger and more cumbersome project with much potential to fail. Nevertheless, it was decided that the simple evaluation of the pack by the author was little more than a replication of the Changing Faces approach with a specific client group and would be far less useful than trying to demonstrate both the effectiveness of social rehabilitation for the patient group, and to demonstrate that nurses can deliver it. This evaluation was therefore planned as two further studies, which built on the results of the earlier exploration of nurses' skills.

This project therefore consisted of three separate studies:

Study one: Social rehabilitation after disfiguring injury or disease: an investigation of the perceived skills set of specialist nurses.

This study comprises a comparison of nurses' perceptions of their skill in providing social rehabilitation and physical rehabilitation, for two disfiguring conditions. It was hypothesised that nurses would rate their skills in social rehabilitation as less good as their skills in physical rehabilitation.

Study two: Social rehabilitation after Head and Neck Cancer: the evaluation of a resource/training programme for nurses

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This second study builds on the findings from the first, in an investigation of whether nurses perceived their skills deficit as improved if trained and resourced to use a social rehabilitation training programme. It was hypothesised that nurses would be able to learn these skills and would therefore perceive themselves to be more skilled in managing social rehabilitation with patients.

Study three: Social Rehabilitation after Head and Neck Cancer:

evaluating the delivery of coping skills training by nurses to patients

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The final study builds on the results of the first two, in an investigation of whether nurses could use the social rehabilitation approach and resources with their patient group, and whether any gains could be measured in terms of better outcome for patients. It was hypothesised that nurses could use this approach with their patients, and that patients would report the approach to be helpful. It was also hypothesised that there would be gains only on those issues directly targeted by the programme, i.e.: social issues, and not on other health measures. The impact of change on self reported quality of life was also measured.

7.4   Practical constraints

7.4i   Funding   A grant of £6000 was obtained from Marks and Spencer plc, which allowed some direct expenses of the project to be covered. This included administration costs such as postage and photocopying, the production of a small number of resource packs and some travel expenses, provision of patient booklets and video. No salary

costs were available. Funding therefore limited the number of nurses who could be recruited to the study. The issue of whether or not nurses would have to time to be involved in the study was an important one. Limiting the amount of data collection to a manageable amount was an essential component of the study design given that nurses would also be running the programme with patients. This meant that instead of one nurse working with a large group of patients, several nurses would need to collect data from a small number of patients. This had the advantage of allowing comparison between how the approach worked in different settings. A maximum of ten nurses was considered feasible. Access to local facilities was known to be variable, and it was clear that some nurses would need support to carry out simple administrative tasks such as photocopying or typing up letters to patients invited to support groups. The project depended on keeping costs for the health service to a minimum, and relied heavily on the generosity and good will of those involved; this included running support groups on days off and having to take annual leave to attend training, even though expenses were paid.

7.4ii Ethical issues and consents

The design of this project raised practical problems which although anticipated in advance, became in practice, exceptionally difficult and time consuming. Had the aim of the study been the simple evaluation of

the social rehabilitation resource pack, then this could have been carried out by the author on one site. However, this would not have added much to earlier studies. In order to be of long term benefit, then it was important to show that nurses could be effective in using these resources, and it was in getting permission for several nurses in different sites to work with patients that the problems arose. Ironically, had the pack simply been made available for use without any attempt at evaluation, there would have been no checks or controls on its impact or effectiveness.

The protocol for the study (see appendix, volume 2), was passed by the ethical committee of City University without any difficulties. Consent from Consultants involved in care of the patients recruited into the study was then sought. The nine nurses who eventually attended training worked with a total of 48 consultants. This is an interesting demonstration of how complicated service delivery in this speciality has become. All these consultants were contacted, and 13 eventually replied (27%). All other consultants required repeat contacts, and signed consent before submission of the project to ethical committees. The Multicentred Research Ethics Committee (MREC) requires submission of all projects which are being run in four or more NHS regions. A submission to the MREC was delayed because of the number of applications to that committee and therefore forwarded to another centre leading to a delay of three weeks. The project was deferred whilst changes were made to the patients' information sheet, proposed statistical procedure and research

protocol. The entire application procedure was repeated (three days were allowed to do this in order to get the papers to the next meeting one fortnight in advance!) and approved on the basis that separate application be made to all the Local Research Ethics Committees (LRECs) involved. There was no centralised record of where these were. Although the approval of the MREC should have led to a standardised application to the LRECs, this process was undergoing review at the time of application, and all LRECs required a different format. Numbers of copies of all documentation to be sent to the LREC ranged from two to fifteen. All patient information sheets and consent forms had to be submitted on the relevant hospital notepaper. One LREC required the patient information sheet to be altered in direct contradiction to the changes required by the MREC. Meeting the demands of the ethical committees delayed this project for nine months. A similar application by the charity six months earlier, for a simple audit of patient need in different clinics in London and Bristol, was delayed for seven months. This cost the charity one third of the final research grant in salaries for the period when the research assistants were waiting for approval, and limited the amount of data that could be collected by the same proportion. Although costs for the current project were less of an issue, the challenge of keeping up the momentum with nurses who wanted to get started was considerable. Two were lost from the project because of the delay. It is concluded that the current procedure of gaining ethical approval for research in this country is at best cumbersome, and at worst scandalous. The costs in terms of lost opportunities, compromises in research design and wasted financial

resources are currently quite unacceptable. The threat to patients of a system which invites abuse because it is so inefficient is perhaps the worst aspect of all. These issues will be reported back to the MREC.

7.5   Procedure:

Once ethical permission had been granted, the project could proceed. Each study is presented separately in the following section, with research design, sampling procedure and size, and method discussed for each one.   A short discussion of the findings of each is presented, prior to a final section discussing the outcome of the project as a whole.

CHAPTER FOUR, SECTION THREE.

STUDY ONE. SOCIAL REHABILITATION AFTER DISFIGURING INJURY OR DISEASE: AN INVESTIGATION OF THE PERCEIVED SKILLS SET OF SPECIALIST NURSES.

8.0   Method

Design: A simple survey using a self-report questionnaire tested the hypothesis that nurses in two specialities, burns and head and neck cancer, would rate themselves less skilled in providing social rehabilitation than in traditional physical rehabilitation for their specific patient group.

Subjects: Subjects were identified from the database compiled by the charity Changing Faces over a five year period. 70 nurses working in specialist head and neck cancer units were sent a questionnaire by post, and 43 were returned (62%), which is a good rate of responding for a postal questionnaire. Data from nurses working in burns was accessed in

a slightly different way. 27 burns units were contacted, and the manager asked to photocopy the questionnaire for all their staff. 11 units (41%) responded to this request and 40 questionnaires were returned. In using two different sampling techniques any bias in the sample of nurses that had contacted the charity directly (because they felt particularly unskilled in this area) was acknowledged.

Materials and method: Figure 9 illustrates the questionnaire used. Items designed to measure social aspects of rehabilitation were based on the problems identified from the research literature and those encountered most frequently in clinical settings e.g.: coping with staring, dealing with comments and questions. These were kept constant for both the burns and cancer questionnaire. Items concerned with physical rehabilitation varied according to whether it was sent to burns or head and neck nurses. They included both general items e.g.: managing pain, and items common to the specific condition e.g.: managing a tracheostomy (cancer) managing pressure garments (burns). In order to check the face validity of the items chosen, they were recorded on cards, and a panel of judges (three clinical staff working at Changing Faces) asked to sort them according into physical versus social categories. Inter rater reliability was 100% and all items therefore allocated to either the social or the physical subscale on this basis. One item, communication strategies, intended as a social item, was interpreted as a physical item by raters considering cancer, because of the earlier questions about tracheostomy and speech impairment. This item was therefore included

in the physical subscale for the cancer study. Similarly, the scarring item

on the burns questionnaire, intended as a social item, was interpreted as

a physical item because of the earlier question about pressure garments.

Again, this was included in the physical subscale for analysis. Each item

was scored by the nurses on a four point scale from 1 (need more

training), 2 (adequate), 3 (good) to 4 (very good).

Figure 9. Nurses skills questionnaire

How would you rate your skills in advising patients about the following?

	need more training	adequate	good	very good
pain relief				
coping with the change in their appearance				
coping with others staring				
dealing with comments and questions from others				
management of a tracheostomy *				
communication strategies (talking to other people)				
managing the impact of the cancer diagnosis*				
managing the impact of altered speech (if relevant)*				
taking the initiative in social situations				
choice and preparation of food*				
strategies for eating out				
resuming social activities with family and friends				
developing confidence in social situations, e.g.: public transport, supermarket, large groups of people				
changes in close relationships e.g.: sex life				
resuming everyday activities, e.g.: housework				
preparing to return to work				
changing smoking, drinking habits				

*these items were substituted for the burns survey, with:

management and use of pressure garments, impact of injury on close family and friends, management of symptoms of post traumatic stress disorder: e.g.: nightmares, flashbacks, fear, coping with worries and questions about surgery, managing physical disabilities, coping with prolonged hospitalisation.

(Social rehabilitation items indicated in italics)

8.1 Analysis: Questionnaire responses were analysed using SPSS for Windows, version 9.0. All questionnaires showing a response bias (ticking the same category for all items) were discarded, leaving 40 questionnaires from head and neck nurses and 39 questionnaires from burns nurses.

8.2   Results: sample one: Head and neck nurses

Table 1. shows the mean scores by item. The pattern of the data, with lower scores for those items identified *a priori* as social rehabilitation compared with those items identified as physical rehabilitation is as expected. This supports the hypothesis that nurses feel better trained and able to deal with the practical aspects of patient care in their speciality such as managing a tracheostomy, than they do in preparing a patient to deal with issues of social intrusion such as staring, comments and questions.

Table 1:   Mean scores for each item on Head and Neck
Questionnaire

	MEAN	STANDARD DEVIATION
PAIN	2.5750	.9306
CHANGE IN APPEARANCE	2.5750	.9306
STARING	2.1250	.8469
COMMENTS	1.9750	.9165
TRACHEOSTOMY	3.5500	.6775
COMMUNICATION	2.5750	1.0099
CANCER DIAGNOSIS	2.5250	.9334
SPEECH IMPAIRMENT	2.1500	1.0513
TAKING INITIATIVE	1.7000	.8228
FOOD PREP.	2.5200	.8165
EAT OUT	1.6000	.7442
SOCIAL ACTIVITIES	1.7500	.8086
SOCIAL SITUATIONS	1.6000	.8102
SEX	1.3000	.5639
HOUSEWORK	1.8500	.6622
RETURN TO WORK	1.8000	.7232
SMOKING AND DRINKING	2.1750	.9306

(n=40)

The data was then reduced to form two separate subscales, physical and

social, calculated as a mean value for each nurse across each set of

items, determined on the basis of face/content validity, as above.

Although a principal components analysis of the skills questionnaire had

been intended in order to determine the ways in which item was related to

others in the subscale, the eventual data set proved too small for this

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technique to be used reliably. (Usual ratio of subjects to items for principal components analysis is 4, and in this study, the ratio reached only 2.3). The reliability of the subscales was therefore calculated by means of Cronbach's Alpha, which gives a measure of internal consistency based on the average inter-item correlation of items in each scale. Scores should be above 0 .8. A score of 0.9034 for the social scale, and 0.8025 for the physical scale therefore demonstrated that each had good internal consistency.

The calculation of inter-item correlations also allowed the identification of any 'rogue' items which were not significantly related to any others in the subscale. Tables 2 and 3 illustrate the correlation matrix for each scale. The social scale appears to be a unitary scale, with all items correlating highly with each other. The physical scale is multifactorial, consisting of clusters of related items e.g.: those concerned with eating versus those concerned with speech production. This is not an unexpected finding given the wide physical impact of the condition, and since no items appeared unrelated to any others on the scale, none was eliminated from further analysis.

Table 2 Inter-item correlation coefficients for social subscale items

	Change appear	staring	comment	initiative	Eat out	Social acts	Social sits	sex
Change appear	1.000							
staring	.7133	1.00						
comment	.5468	.6824	1.00					
initiative	.5495	.6145	.7016	1.00				
Eat out	.3352	.4719	.4721	.5109	1.00			
Social acts	.3181	.4212	.4052	.3469	.5965	1.00		
Social sits	.5003	.6950	.7759	.6232	.6634	.5479	1.00	
sex	.4147	.5530	.5094	.5306	.7210	.3937	.6623	1.0

Table 3 Inter-item correlation coefficients for physical subscale items

	pain	trache	Comm strats	diagno sis	Sp.imp	food	work	h.work	Smo.dr
pain	1.00								
trache	.2583	1.00							
Comm strats	.1848	.5378	1.00						
diagno sis	.2635	.1804	.4876	1.00					
Sp.imp	-.0580	.4212	.5929	.3097	1.00				
food	.3013	.1136	.1221	.4031	.2047	1.00			
work	.0610	-.0341	.3370	.4654	.3103	.3128	1.00		
h.work	.2268	.0743	.4390	.4626	.2542	.5291	.7389	1.00	
Smo.dr	.2953	.0061	.2449	.5705	.2346	.4491	.3962	.3766	1.00

Mean scores calculated for each subscale were compared using a t-test

for related samples. The mean score on the social rehabilitation items

1.72, (SD.61) is significantly lower than the mean score on physical

rehabilitation 2.139, (SD .55), (t= -8.062, df 39, p> 0.000, two tailed).

These results support the hypothesis that this sample of head and neck

nurse specialists rate their skills in dealing with social aspects of

rehabilitation as significantly weaker than their skills in physical aspects of

rehabilitation.

8.3   Results: Sample two: Burns nurses

Design and Sample (see above)

Although the focus of this research is head and neck cancer, replicating

the findings with a second group of specialist nurses working with another

disfiguring condition was undertaken out of interest and to add weight to

any findings. The relatively small sample size and use of a simple survey

design with a non-standardised questionnaire make the design of the

study weak, but the replication with a separate sample of nurses helps to

overcome this weakness. This is important since the findings form the

basis for the development of the resources themselves and the method of delivery.

Materials: The questionnaire used with the head and neck nurse specialists was adapted for burns nurses. Social rehabilitation factors were left the same, but items relating to specific burn care management (e.g.: managing the use of pressure garments) were substituted for those cancer specific items. Again, face validity of items was established via inter-rater agreement before allocation into separate subscales. Sixteen items were included in total (see figure 9).

Questionnaires were examined for response bias and one discarded (n= 39). Table 4 shows the mean scores by item. The pattern of the data, with lower scores for those items identified *a priori* as social rehabilitation compared with those identified as physical rehabilitation fits the pattern observed in the head and neck cancer sample. It can be seen that nurses report their skills in preparing patients for condition specific tasks such as wearing of pressure garments, as much better than their skills in facilitating early socialization.

Table 4: Mean scores for each item on burns questionnaire

	MEAN	STANDARD DEVIATION
PAIN	2.9487	.7930
CHANGED APPEARANCE	2.2308	.7767
STARING	1.8205	.7905
COMMENTS	2.3590	.8732
PRESSURE GARMENTS	2.8718	.9228
SCARRING	2.2308	.8099
IMPACT ON FAMILY	2.41	.8801
PTSD	2.0513	1.0500
WORRIES	2.9744	.8425
PHYSICAL DISEASE	2.6410	.8107
SOCIAL ACTIVITIES	2.2564	.7511
SOCIAL SITUATIONS	1.8718	.8329
SEX	1.7436	.7853
HOUSEWORK	2.6154	.7475
WORK	2.3846	.7114
SMOKING/DRINKING	2.7179	.7591
HOSPITAL	2.8205	.6437
TAKING INITIATIVE	1.8205	.8231

(n = 39)

As in the previous sample, the data was then reduced to form two separate subscales, physical and social, calculated as a mean value for each nurse across each set of items, determined on the basis of face/content validity. The reliability of the subscales was again calculated by means of Cronbach's Alpha. A score of 0.8143 for the social scale, and 0.8012 for the physical scale demonstrated that each had good internal consistency.

Inter item correlations were calculated as before to determine any rogue

items which could be omitted from further analysis. Tables 5 and 6 give

the correlation matrices for each subscale.

Table 5. Inter item correlation matrix for social subscale (burns)

	Ch.app	staring	commts	initiative	Soc. acts	Soc.sits	sex
Ch.app	1.00						
staring	.6265	1.00					
commts	.4955	.8152	1.00				
initiative	.1488	.2728	.2751	1.00			
Soc. acts	.0312	.0796	.0967	.7149	1.00		
Soc.sits	.1690	.4438	.1735	.6565	.6850	1.00	
sex	.2290	.3478	.2913	.7005	.5159	.6634	1.00

Table 6. Inter item correlation matrix for physical subscale (burns)

	pain	Ps.gar	scar	impact	PTSD	wor	Phys.d	work	h.wk
pain	1.00								
Ps.gar	.1706	1.00							
scar	.0599	.3928	1.00						
impact	.1063	.2609	.7128	1.00					
PTSD	.2245	.0613	.4809	.5461	1.00				
wor	.2343	.3680	.3174.	.2630	.0908	1.00			
Phys.d	.1753	.1831	.2898	.3225	.2695	.1403	1.00		
work	.0359	.3577	.3900	.2457	.3604	.6316	.3370	1.00	
h.wk	-.0785	.2700	.4548	.5262	.3946	.5689	.2873	.6814	1.00

As with the two subscales identified for the head and neck nurse study, the social subscale is a unitary scale with high inter-item correlation. Again the physical subscale is multifactorial with different groups of items reflecting concern with different aspects of physical care. No rogue scores were identified and all items of both subscales included for subsequent analysis.

Comparison of mean scores on the social and physical subscales was achieved using a t-test for related samples. The mean score on the social rehabilitation items 2.01, (SD.55) is significantly lower than the mean score on physical rehabilitation 2.58, (SD.49) (t= -7.19, df 38, p> 0.001, two tailed). The same finding, that nurses consider themselves less skilled in dealing with the social and psychological aspects of rehabilitation than the physical aspects of rehabilitation, has therefore been found in two independent samples of nurses working with two different disfiguring conditions, burns and head and neck cancer.

8.4   Discussion

There are some difficulties with this study, which should be noted before any conclusions are drawn. The main difficulties lie with the scale itself and the relatively small sample size. Because the sample is small, it has not been possible to 'unpack' the subscales and investigate the different

components, particularly of the physical scales. One interesting observation is the fact that skills around pain management seem to be quite a separate factor from others tested here, and this is worth separate investigation. Criticism might also be made of the response format of the scale. Although the four response categories are all intended to indicate some level of skill, from poor to very good, producing interval data, some post hoc discussion of the study has suggested that the data could also be treated as ordinal: the nurses are either competent or they are not, in which case a different statistical analysis might be more appropriate. However, investigation of other standardised scales, in particular the European Organisation for Research and Treatment of Cancer (EORTC) scales used in the later studies here, suggests that they can equally be criticised on similar grounds. It is an important point however, and one which can be addressed if the scale is used in further studies with other groups of nurses, such as dermatology nurses. However, given these criticisms, the study has still obtained some very interesting findings on which to base the further studies in this sequence.

This study has demonstrated that nurses working with people who have disfiguring conditions feel less able to address the social and psychological aspects of rehabilitation than those concerned with physical rehabilitation. Although this may seem self-evident, these findings are important for several reasons. In the first instance, they challenge other reports that nurses are competent to provide this kind of intervention, and

that they are therefore the health professional in the best position to provide support as the patient prepares to resume their social role. This study suggests that although nurses recognise the issues as important, and identify themselves as having a responsibility in providing this kind of support, they do not necessarily identify themselves as having the skills to provide it. If they are, indeed, the health professional in the best position to provide psychosocial support to the patient population, then they need further training. This finding is strengthened by being reproduced in two separate groups of nurses; those working with burn injuries and those working with head and neck cancer.

The use of two separate groups sampled in different ways allows the rejection of the hypothesis that the head and neck nurses on the database were likely to have contacted Changing Faces initially because they recognised that their skills were poor. The burns data was collected from nurses approached by the charity rather than the other way round, and the replication of findings suggests that the identification of poor skills is a real phenomenon rather than an artefact of the experimental design. It is clear from this study that if nurses are to take on the responsibility of managing the psychosocial rehabilitation of patients, that some kind of training/resource should be offered. Changing Faces has successfully set up and run a study day for nurses working in different disfiguring conditions, and the evaluation of this training has been very positive. It is clear that if training is offered, nurses will take it up. It has also been interesting to see the widespread use being made of Changing Faces

resources with patients. The Changing Faces video, REACH OUT which illustrates a number of successful strategies for managing social situations has proved a particularly important resource. Nurses have bought the video and used it with patients to illustrate coping strategies, and have reported that this is a service that they would not have felt able to undertake without the provision of the resource and some minimal training.

These findings therefore suggest that the development of a training and resource programme for nurses working in head and neck cancer would be a logical way of providing nurses with those skills needed to provide psychosocial rehabilitation to patients. This hypothesis was examined in study two.

STUDY TWO: SOCIAL REHABILITATION AFTER HEAD AND NECK CANCER: THE EVALUATION OF A RESOURCE/TRAINING PROGRAMME FOR NURSES

9.0   Introduction

Having established empirically (study one) that the observed need for extra training in the management of disfigurement was supported in two independent groups of nurses, the next step was to consider how this deficit could be addressed.

It was clear that a): an appropriate intervention was needed which would directly target those skills identified by nurses as needing more input, and which would facilitate the delivery of coping effectiveness training with patients, and that b): a simple way of measuring any impact of this intervention was required.

9.1   Design:

A controlled design was used, comparing a pilot experimental group of head and neck nurse specialists with a control group of head and neck

nurse specialists selected from the Changing Faces database. Data from the experimental group was collected within a multiple baseline format. This allowed the prediction that only those skills directly targeted by the intervention should improve, and provided additional evidence that any change was due to the intervention rather than to day to day experience.

9.2 Sample:

Ten nurses were selected randomly from he British Association of Head and Neck Nurses, each of whom had indicated their interest in taking part in this study at the inaugural meeting of the group. All nurses had therefore undertaken a recognised post-graduate training in head and neck cancer, and were currently employed as head and neck cancer nurse specialists. The control group of similar nurses comprised those nurses who had already taken part in study one and for whom data was therefore available for pre-post test comparison.

9.3 Measurement

A semi-structured interview was designed in order to get quantitative and simple qualitative information about the resources and training from the experimental group (see appendix, volume 2). The head and neck questionnaire (study one) was administered to nurses pre and post

intervention. In order to gain data from a control group, and to provide

details of the re-test reliability, the questionnaire was sent to all those who

had originally completed it (N=40), one year later. 18 questionnaires

(45%) were returned.

9.4 Procedure

Invitations to a training day were sent to ten nurses, nine of whom

accepted. Eight nurses attended on the day. After completing the head

and neck questionnaire, training was provided in the principles of

providing social rehabilitation to head and neck patients, based on the

areas identified as problematic in the original survey (study one). Issues

included managing the impact of disfigurement, e.g.: dealing with staring

comments and questions, but also applying the same principles to social

activities, managing eating in public, managing the impact of altered

speech etc., using the resources and programmes developed in the

manual. Methods of delivery, including modelling and role play were

introduced. Examples drawn from the nurses' own practice were

discussed and the resources used to plan sample rehabilitation

programmes. Training was supported by providing the Social

Rehabilitation Resource Manual (see appendix, volume 2, and

description in Chapter Four part two), to each nurse. They then undertook

to implement the programme in their own practice, subject to appropriate

ethical committee approval, and to collect data from participants in order

to evaluate the impact of this model with this patient group. One nurse subsequently withdrew from the study due to other commitments.

Seven nurses were followed up at three months after attending training. This delay was to allow them to fully read and digest the resources that they had been given and to decide how they could use them in their clinical practice. They were then assessed by semi-structured interview and readministration of the head and neck questionnaire.

9.5   Results

9.5i   Standardisation of the head and neck questionnaire

The reliability of the head and neck questionnaire was calculated by comparing scores generated by the control group at time one and time two, one year later. Pearson correlation coefficients were calculated for each item at time one and time two. All items that did not correlate with each other significantly were eliminated, leaving ten items from the original seventeen. Although the very small size of the control group (N=18) means that more items are eliminated than might happen with the same statistical procedure using a larger sample, it was decided that the loss of the less robust items was justified in increasing the reliability of the questionnaire for use in a multiple baseline design for the experimental group. Table 7 shows the ten items remaining, together with their correlation coefficients and statistical significance. Not surprisingly, the more ambiguous items such as the items referring to housework or return

to work which are less specific than items such as staring, are the ones

that are subject to more variability in response. The remaining items show

a relatively low but, nonetheless, significant correlation, and can therefore

be used to measure change in the experimental group.

Using the classification process developed in study one, it is possible to

group these remaining items under the heading 'social' rehabilitation or

physical' rehabilitation; five items are classified under each.

Table 7:   Significant Paired Samples Correlations for Head and Neck
questionnaire on control group, at time one and time two (one year later)

		N	Correlation	Sig.
Pair 1	PAIN1&PAIN2	18	.753	.000*
Pair 2	CH.APP1&CH.APP2	18	.689	.002*
Pair 3	STARING1&STARING2	18	.639	.002*
Pair 4	COMMENTS1&COMMENTS2	18	.468	.050*
Pair 5	TRACHE1&TRACHE2	18	.900	.000*
Pair 6	COMMUNICATION 1&2	18	.421	.082
Pair 8	SP.IMP1&SP.IMP2	18	.530	.024*
Pair 9	INITIATIVE1&INITIATIVE2	18	.530	.024*
Pair 13	SOCIAL SITS 1&2	18	.626	.005*
Pair 17	SMOKE/DRINK 1 & 2	18	.472	.048*

* INDICATES SIGNIFICANT CORRELATION BETWEEN TIME ONE AND
TIMETWO

Using these ten items as robust variables, it is possible to predict that

only those five items classified as social rehabilitation will show a change

after training, and that this change will be observed only in the

experimental and not in the control group.

9.5ii Results: impact of training and resourcing head and neck nurse specialists

Mean questionnaire scores for the experimental group pre and post training were compared item by item using the Wilcoxon test. Table 8 shows that all the social items, i.e.: those items directly targeted during training and in the resource pack show a significant improvement. There is no consistent change in the non-targeted items although there is an improvement in perception of skills in advising patients about smoking and drinking habits which nears significance.

Table 8
Mean scores on the ten most robust variables, pre and post training

VARIABLE	Z SCORE	Asymp sig 2-tailed
PAIN	-.577	.564
TRACHEOSTOMY	-1.414	.157
COMMUNICATION	-1.414	.157
SPEECH IMPAIRMENT	-.816	.414
SMOKING/DRINKING	-1.807	.071
CHANGED APPEARANCE	-2.000	.046
STARING	-2.121	.034
COMMENTS	-2.121	.034
TAKING THE INITATIVE	-1.890	.059
SOCIAL SITUATIONS	-2.271	.023

This finding can be displayed most clearly in graphic form as the comparison of differences in mean scores pre and post training compared

with difference in mean scores of the control group at time one and time

two, see figure 10.

Figure 10. Differences in mean scores on head and neck questionnaire (ten items) for the experimental group (graph one) and the control group (graph two).

Graph one: Experimental group

Rehabilitation variables

Graph two   Control group

Rehabilitation variables
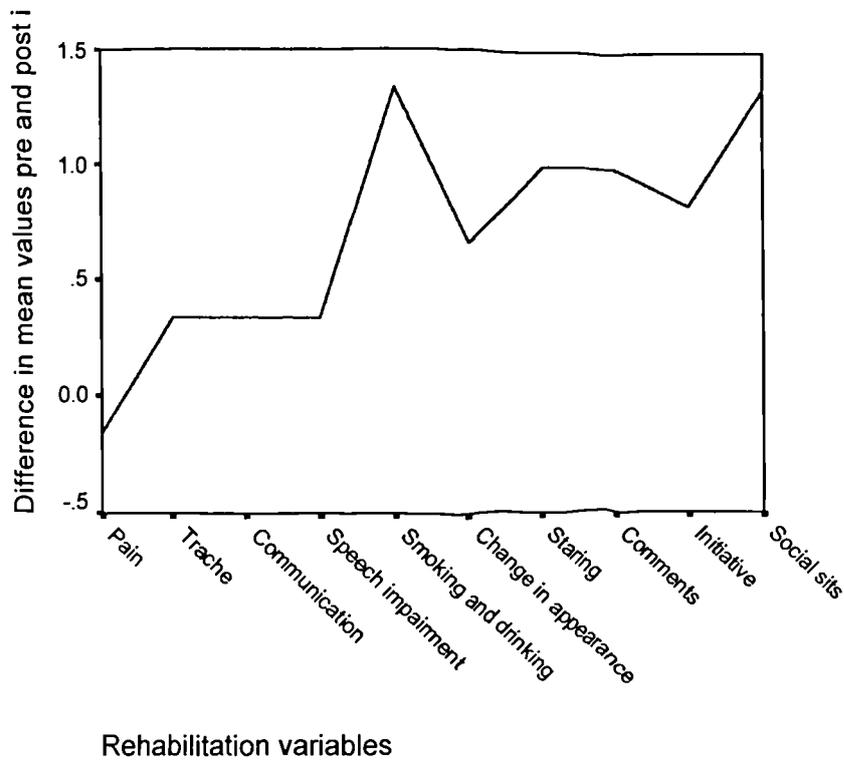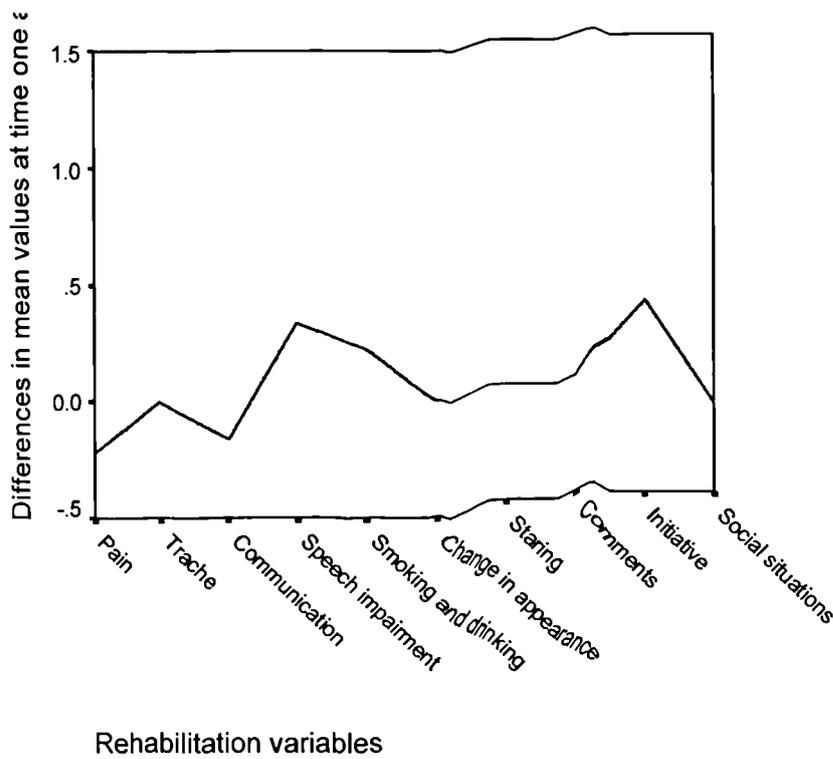
It is clear from this analysis, that there is significant statistical difference between nurses perceived skill in social rehabilitation pre and post training in social rehabilitation techniques, and that there is no corresponding increase in perceived skill over time in the control group. It might be expected that after one year of working with patients, nurses perceptions of their skills would have improved, but the lack of change in the control group suggests that the changes seen in the experimental group are indeed due to an intervention and not simply to changes over time. This explanation is similarly supported by the lack of change in those items that were not targeted by the intervention.

It is equally interesting and important to understand what these findings mean in terms of clinical practice. Hevey and McGee (1998) have discussed the value of anchoring statistical measures to other health outcomes as a means of learning more about the clinical significance of statistical change. They advocate the routine reporting of effect size alongside traditional p values. The effect size statistic is commonly used as a means of estimating the responsiveness of clinical instruments to change, and it is therefore a useful additional statistic in reporting the significance of change on a questionnaire which has not been widely used. The effect size statistic was therefore calculated for the mean score on the five social rehabilitation items of the head and Neck questionnaire using the standardised response mean (SRM) formula developed by Liang et al (1990), and interpreted using Cohen's (1977) criteria. The

resulting score of 4.41 indicates a large effect size (see Cohen 1977), which suggests significant clinical change.

9.6 Results of semi-structured questionnaire

Finally, quantitative and qualitative data was collected from the nurses who had taken part in the study, using a semi-structured questionnaire (see appendix, volume 2) divided into three parts:

- Ease of use

- Relevance to the head and neck cancer population

- Impact on nurses skills

Table 9 illustrates the data on ease of use:

Table 9. Overall, how do you rate this resource pack on the following criteria?

Please tick in appropriate box

	poor	average	good	excellent
Readability			50%	50%
Ease of understanding			50%	50%
Informativeness			33%	66%
Ease of use			33%	66%
Comprehensiveness			33%	66%
Practical usefulness			33%	66%

All nurses rated the resource pack as either good or excellent on all five measures of ease of use. Individual comments stressed the ease of

access and practical ideas. 83% rated the coping skills model as very

helpful with this population, and 100% thought that the inclusion of

relatives in the exercise was very helpful. There were no suggestions

that any of the material was redundant, and some useful suggestions

were made for additions such as more information about sexuality and

some advice about relaxation particularly for those individuals who had

previously controlled high anxiety through smoking and/or drinking.

When asked to pick out any parts of the pack that were particularly

helpful, comments were very specific, but wide-ranging. Thus one nurse

had found the information about managing disfigurement in the workplace

particularly helpful, whilst another mentioned the handouts about

sexuality. The very practical nature of the examples was a recurring

theme, and the ability to section information into small manageable

amounts, particularly through individual booklets was found beneficial.

These results highlight the individual differences in different patients,

nurses and individual settings and are particularly encouraging since it is

clear that the nurses were able to use the resources according to their

own particular need.

The questions relating to skill set are clearly important, since the purpose

of the project is not only to provide good working resources, but to

change nurses perceptions so that they feel able to tackle issues that

they did not feel competent to tackle before. In this regard, it is important

that all the nurses had used the resources. 66% reported that the pack

had added to their skill set very much, and had increased the variety of

ideas and strategies that they could use to help patients manage

particular problems. 33% felt that the pack had achieved this quite a lot.

The same proportions felt that the pack enabled them to *deliver*

rehabilitation strategies effectively and had increased their confidence

about dealing with social rehabilitation issues. All nurses reported that the

resources had encouraged them to include relatives more in

rehabilitation, and had influenced the timing of intervention, since they

had become much more aware of patients long term needs. Finally, all

nurses valued the pack as an information resource for patients and for

themselves and 83% had used it both to run support group sessions and

to work with patients on an individual basis. All of them thought that the

resource pack and training should be made widely available. In terms of

general comments, the nurses were very clear that the pack contained

material that was not available elsewhere and which was very useful. The

following two examples encapsulate the main themes:

Example one

> *This is an extremely useful tool and has been needed for a long
> time; the subject has not been addressed so comprehensively and
> practically before and I feel it will help the self confidence of health
> professionals to deal with this "difficult" personal issue.*
> *Allows patients to feel more confidence in the team and to ask
> questions they may have wanted to ask. Also essentially, this is
> also extremely useful to train other health professionals in all units,
> increasing awareness.*

> _Having read literature on cancer survivorship and the rehabilitation_
> _needs of the head and neck cancer population for my degree_
> _course, I have found this pack to be immensely valuable and an_
> _innovative piece of work. The areas I believe are particularly_
> _useful are those dealing with speech and eating and drinking_
> _which have a huge impact on the QOL of our patients, more so_
> _than facial disfigurement. The pack has stimulated me to_
> _introduce a rehabilitation programme at my unit._

In summary then, all nurses reported that the pack had increased their
basic skill set and had increased the number of ideas and strategies that
they could use with patients. Specific examples of problem situations and
how to manage them were singled out as particularly helpful, and all
nurses reported that their confidence in tackling social rehabilitation
issues had increased. All nurses had been able to use the pack to
support their work with patients in two or more ways, and all thought that
it should be made available to other nurses working in head and neck
cancer.

All forms of assessment therefore support the effectiveness of the social
rehabilitation training and resource pack in improving nurses perceptions
of their skills in managing the psychosocial issues faced by their patients.

9.7   Discussion

This study is concerned with an intervention to address the perceived
lack of skill reported by head and neck nurses in dealing with the social

rehabilitation of their patients. It has been shown that a simple one day training course introducing a coping effectiveness model, backed up with a substantial resource pack, is highly effective in meeting the needs of a group of head and neck cancer nurse specialists. A possible problem in interpreting this data is the potential ceiling effect on the items intended to measure skill in physical rehabilitation. It could be argued that because nurses rated their skills in this area as better than in social rehabilitation at the outset, there is less room for change as a result of the intervention. However, this interpretation is unlikely, partly because most nurses did not score themselves at the full extent of the scale, leaving room for improvement, and also because the qualitative information obtained on semistructured interview is unequivocal about the value of the intervention. Both quantitative and qualitative measures demonstrate significant change in both skill and confidence in dealing with these issues.

A further finding, which is important to record, is that nurses did indeed use the resources that were provided. The delay in obtaining ethical consent for the third and final study, investigating the transfer of skills from the nurses to their patients, meant that there were many months in which the nurses could have put this work aside. However they all reported that they were using the resources, indeed the regular requests for further booklets etc. were evidence that the resources were being used. One of the problems of the delay in carrying out the final study was the perception that the resources were so self evidently useful that the

exercise was pointless! There was also increasing interest from other nurses who had heard about the study or had been in the control group and were keen to have the resources themselves. However it was vital to demonstrate that patients themselves made positive gains; it is very likely that nurses who felt very enthusiastic about having something to offer their patient group at last, would be biased towards believing that the intervention they were offering was effective, and data from the patient group themselves is the only way of addressing this issue.

A final point should be raised before describing the third and final study in this series. This second study raises questions about the role of lay-led groups in health professional training. The study clearly demonstrates that lay-led groups are in a unique position to identify trends in need through their monitoring of both client and health professional requests for support. That these groups can provide an effective evidence based intervention for patients has been demonstrated previously (Clarke 1999a). This study shows that they can additionally provide an effective intervention for health professionals. The particular strength of the lay-led model lies in its focus on identifying issues directly from the patient group; the emphasis is not on what health professionals identify as important but what the patient identifies as important. Using this model to first identify where the gaps in skill lie before designing a training intervention and set of resources to meet those needs is an extension of this approach which has had clear benefits in this study. Medical schools and schools of nursing are increasingly approaching the voluntary sector to provide input

on training so that students can tap into the patients' experience early in

their training. The evidence shown in this study suggests that lay-led or

voluntary organisations can have an equally important part to play in the

ongoing training of qualified health professionals.

STUDY THREE: SOCIAL REHABILITATION AFTER HEAD AND NECK CANCER: EVALUATING THE DELIVERY OF COPING SKILLS TRAINING BY NURSES TO PATIENTS

10.0 Introduction

Having established that head and neck nurse specialists identify deficit in their level of skill for managing social rehabilitation in their patient group (study one), but that this skill shortage can be met by training and resources (study two), the last part of this investigation relates to the patient group itself. It is important to demonstrate that patients benefit from the social rehabilitation programme as delivered by the nurses. The following study is ongoing. Because of the problems in ensuring ethical consent for the study and because of the natural lag in setting up the study in different units, data collection has been slow. However, the first sets of data from two different units are available and have been analysed in order to provide an early indication of how successful the approach has been so far and, therefore, to allow planning about how to take it ahead. This data is presented in this section. The early results are extremely encouraging and on the strength of the results so far, the

charity has secured funding to publish the resource pack and to develop

training courses to accompany it. The success of the project has led to a

considerable demand from other head and neck nurse specialists, and

the charity is keen to respond to this as quickly as it can. Changing Faces

has also negotiated a contract with a health service authority to develop a

similar programme for health professionals working with burn injuries on

the basis of the results so far. This section is therefore a preliminary

report, and a fuller report will be prepared for publication once the full

data set has been completed. Whilst the numbers in the sample are not

large enough to do a detailed breakdown by demographic variables, the

results are detailed enough to answer the central questions posed in the

study; ie: whether nurses can pass on the skills that they have learned to

their patients, and whether improved outcome for patients can be

measured.

10.1   Design of the study.

The essential research question in this study is a familiar one: does the

intervention being assessed have a measurable impact on the target

population? It is therefore necessary to carefully define the population, to

be clear as to the nature of the intervention, to standardise the outcome

measures and to design the whole project to eliminate the effects of type I

and II errors.

In considering the study design, the randomised-controlled trial would generally be the ideal way of satisfying many of the demands above. As with much applied clinical research however, this is often a standard that is difficult to achieve in a first study, not least because of issues of cost. As a first attempt to establish whether a new kind of intervention is likely to be successful, a simple pre-post test study is an acceptable beginning, provided that the limitations of the design are understood at the outset and interpretation of results is done with these constraints clearly in mind. The logic of this pilot approach is simple: if there is no measurable impact of the intervention at this preliminary level, then the cost and effort of a full scale randomised study are avoided.

Two other issues militate against the use of a randomised-controlled trial in this study. Perhaps the most important of these are the ethical considerations involved in withholding treatment based on patient need (Owens, Slade and Fielding 1997). Its trustees particularly commit Changing Faces to providing a service to patients, and withholding information which informal feedback has shown to beneficial is a particular problem. For this study, patient information in booklet form was included as part of the programme, and providing a control group would have meant withholding this information at least for a period of time. Many studies overcome this problem by setting up a waiting list control group, which receives the intervention after the experimental group has completed the study. Again, this was considered, but head and neck

cancer patients are a particularly difficult group to manage in this way. All patients were potentially terminally ill, and even a wait of three months was judged to be unethical given their likely poor quality of life and limited life expectancy. The same considerations ruled out a repeated measures design, where follow up at six months or one year could not sensibly be included in the study design. The simple pre-post test design was therefore selected, but measures were included which would allow each patient to operate as their own control by providing multiple baseline data.

Selecting this research design is also important in taking account of issues regarding regression to the mean. Regression towards the mean was first reported by Galton (1886), in his measurement of the heights of children compared with their parents. His finding, that the mean height of children of tall or short parents, is more closely related to the mean height of the general population rather than to the parental height, demonstrates the tendency for any repeated measure to regress back to the mean value of the relevant population. The common impact of this phenomenon in psychological research is the apparent effect of an intervention where, in fact, the change in measurement is purely a statistical effect caused by the initial selection process.

The selection of a multiple baseline design, ie: the repeated measurement of a series of variables, only some of which are targeted by the experimental intervention, is one way of overcoming this problem. Regression to the mean can be expected to occur across all variables

equally. This design, therefore, allows the prediction that where only the

outcomes specifically targeted in the intervention show change in the

post-test, this is likely to be due to the experimental intervention and not

to this type of statistical error. By including several different measures of

the independent variable, additional weight can be given to any positive

findings. In this study, as with the evaluation of the nurses themselves

(study two), all the outcomes relating to social rehabilitation and only

these would be expected to change, with physical aspects of

rehabilitation remaining constant.

10.2i Nurse researchers

Seven clinical nurse specialists currently employed as practitioners in

NHS hospitals agreed to take part in the study. All had post graduate

qualifications in addition to their basic nursing registration and all were

employed at grade H. Participating hospitals were:

Cookridge Hospital, Leeds

Torbay Hospital, Devon

Queens Medical Centre, Nottingham

Mount Vernon Hospital, Bucks

Radcliffe Infirmary, Oxford

Southmead Hospital, Bristol

Royal Victoria Hospital, East Grinstead

(Data presented in this preliminary study is from Leeds and Bristol study sites)

10.2ii Patient population

All post-operative head and neck cancer patients with whom the head and neck nurse specialists were currently offering care were considered potential recruits to the study. Candidates were all adults over 18 years of age who were capable of informed consent, i.e.: did not have any cognitive deficits, and who spoke English. No medical/surgical exclusion criteria were used, and no limits put on length of time since surgery. Since the programme was designed to be flexible and meet the needs of patients with a range of dysfunction/disfigurement, it was considered important that no pre-selection of patients should take place at this stage. Any degree of dysfunction or disfigurement or both was therefore acceptable in this study. Pre-selection of candidates implies some sort of screening procedure by the nurses, which was considered unacceptable and counterproductive for a programme which is aiming to offer potential benefits for all head and neck cancer patients.

All nurses were asked to recruit up to 10 patients into the study. All patients were given an information sheet to read (see appendix) together with an advice leaflet about medical research published by the Medical ethics society. All patients were then asked to sign consent forms (see appendix). No pressure was placed on patients to participate in the

study, and all patients were reassured that there would be no implications for their medical care. Those patients who wanted access to information, or to attend support groups without completing questionnaires for the study were treated equally with those who agreed to complete the study questionnaires. Of the 20 patients approached by two nurses for this preliminary report, 16 agreed to take part. (The remaining four reported positively on the information provided, but did not want to complete the questionnaires).

10.3 Measurement

In order to satisfy the demands of a multiple baseline study, a series of measures were used, both to provide a cross validation of impact on social outcomes, and to provide a baseline of data on general health and quality of life outcomes.

10.3i Standardised self- assessment scales

Hospital Anxiety and Depression (HAD) scale (Zigmond and Snaith 1983)

This self-assessment scale was initially constructed using data collected from outpatients attending general medical clinics. Thus it is standardised on a hospital rather then normal population and therefore of particular benefit for assessing clinical groups. It is made up of 14 items;

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each rated on a 4-point scale. As well as being quick and easy to administer and score, it has been found to be both reliable and valid both for indicating levels of anxiety and depression in the hospital population and for evaluating change over time. The HADs is routinely used both clinically and for research purposes at Changing Faces, and has been particularly useful for measuring changes in anxiety pre and post intervention. Scores from 0-7 on either the anxiety or depression sub-scale fall within the normal range, scores from 8 – 11 are borderline, and 12+ indicate the clinical range.

European Organization for Research and Treatment of Cancer (EORTC) Quality of Life scale: QLQ-C30 (Aaronson, Ahmedzai, Bergman, et al (1993)

The EORTC QLQ is an integrated system for assessing the quality of life of cancer patients, which allows comparison between different cancers and across different treatments internationally. This 30 item self report scale consists of five functional scales, three symptom scales, a global quality of life scale and six single items. All of the scales and single item measures are scored on categorical scales, most of them with four categories. The scale scores are then linearly transformed to 0-100 scores, with a high scale score representing a high response level; thus a high functional scale score indicates a high (healthy) level of functioning, whilst a high symptom scale score indicates a high level of

symptomatology. Good reliability and validity have been reported for this scale. The scale was used to provide baseline data in this study, against which the predicted changes in the social outcome data could be interpreted.

European Organization for Research and Treatment of Cancer (EORTC) Quality of Life scale: Head and Neck module QLQ-HN35 (Bjordal, Ahlner-Elmquist, Tolleson, Jensen, Razavi, Maher and Kaasa 1994)

This self-assessment questionnaire is designed to be used in quality of life assessments before during and after surgery. Developed by the EORTC group, it comprises a 35 item quality of life scale which is used in conjunction with the EORTC QLQ-C30 (see above). The scale consists of seven multi-item scales, including speech, social eating and social contact which are of particular interest in this study, together with a further 11 single item scales. Scoring is consistent with the QLQ-C30. Both tests are undergoing exhaustive trials to develop reliable norms and good psychometric indices, and are being standardised on different populations across Europe. Although comparatively new, these scales are becoming the clear scales of choice in carrying out work in this field, although there is less data on their responsiveness to change than on their validity in measuring symptoms in descriptive studies.

Derriford scales – short form (Carr and Harris 1994)

The Derriford Appearance Scale was developed to look at subjective

adjustment to abnormalities of appearance defined by Moss et al as "The

resultant emotional distress and behavioural dysfunction arising from the

individual and social consequences of having a different appearance".

(Moss et al, 1998). Patients rate social situations associated with

appearance on a low to high scale depending on how well the situation

applies to them.

The score range of the scale is between 0 and 85. A score of 47

represents the mean with a standard deviation of 11. High scores

represent high responsivity, i.e.: the higher the score the more the

distress. Although the scale is not yet in the public domain, it is

increasingly used in studies of disfigurement and is included routinely in

studies run from the Centre for Appearance and Disfigurement Research

(CADR). It is also included as part of the baseline assessment carried

out with the clinical population at Changing Faces.

Social Situations Questionnaire (SSQ) (Trower, Bryant and Argyle, 1974,1978)

The social situation questionnaire (SSQ) provides self-ratings of both the

frequency and difficulty of performing social activities, scored on a five

point scale. It is suitable for both normal and clinical populations, and is

sensitive to change, although no published norms are available. As a routine screening questionnaire at Changing Faces, it has been found to be easy to complete and to have high face validity for those patients attending clinical sessions. Since it is easy to use, it was included in the study to provide further evidence for the predicted changes in social functioning.

Head and Neck skills questionnaire (Clarke 1999c)

The scale used in study 2 for comparison of nurses skills pre and post training was modified for a patient sample in order to give comparable data pre and post intervention (see appendix).

10.3ii Qualitative data

Patients were also asked to complete a brief questionnaire to provide qualitative data. This questionnaire examined their views of the intervention, whether or not it was helpful and in what way, and whether or not they had been able to use any of the coping skills in their day to day life (see appendix, volume 2).

10.3iii Scaling of dysfunction and disfigurement

Since measures of disfigurement and dysfunction are notoriously missing from most research in this area, an attempt to quantify these factors was achieved by using the scaling measures developed by Dropkin et al (1983). These scales have been standardised by using different groups of health professionals to rate the degree of disfigurement and dysfunction of standard surgical procedures. Each scale is scored from 0 - 9, 9 indicating the maximum and 0 indicating no impairment. The scales measure different dimensions of surgery; thus the relative dysfunction of aphonia following a complete laryngectomy is ranked as far more severe than the disfigurement caused by the resulting tracheostomy. Good rater agreement was achieved in the development of these scales and their use in this study was included to provide an objective measure of both dysfunction and disfigurement which could be compared with the relative levels of distress on each of the psychological scales. Nurses were provided with the scales, and asked to score each patient from 0-9 on each measure using Dropkin's criteria.

10.3iv Demographic measures

Details of age, sex, socio-economic status, ethnicity and medical and surgical history with regard to head and neck cancer were also taken. Pre and post morbid measures of smoking and drinking were also included (see appendix for full questionnaire).

10.3v Power analysis

In order to determine the probability of obtaining positive findings with this sample of patients, a power analysis was carried out using one of the outcome measures. The HADs was selected, following statistical advice, because this test had the best standardisation data available. Given a sample size of 100, there was a 90% chance of detecting a change of 1.9 in the HADs sub-test scores, using a t-test with a 0.05 two-sided significance level.

(Clearly, this analysis is of particular importance given the small sample of patients being reported on here, and will be discussed in the results section).

10.4 Procedure

Unlike most studies, where the intervention with patients needs to be explicitly described and adhered to, the purpose of this programme was to allow the nurses to be flexible in the way that they presented the social rehabilitation skills programme for patients. All nurses had attended the same training day and had been given exactly the same resources to use. Written information for patients was also standardised, but the way in which nurses worked with their patients was not. Some were keen to set up support groups, whilst others favoured working with individuals or couples in one to one settings. Data as to the mode of delivery of the programme was therefore collected, together with number of sessions, but the specific format of the intervention was left for the nurse to decide. Whilst this means that patients might all receive something slightly different from each other, this is considered a major strength rather than a weakness of the programme.

Figure 11 gives details of two of the sessions devised by one of the nurses, in the format presented to her patient group. This nurse also established a regular newsletter for all her patients in line with the section in the resource pack suggesting how this could be achieved, and the support group sessions were advertised here as well as offered directly to particular patients. In order to introduce each topic within the framework of learning new (coping) skills a particular specialist has been invited to come along and introduce the session, which then goes on to include the

psychosocial aspect of each issue. Thus for eating difficulties, the

dietician introduces the idea of choice and preparation of food, but then

the psychosocial dimension of eating with other people is considered.

This is in essence the social rehabilitation part of the package, and the

aspect of rehabilitation that is typically absent for this population.

Similarly, in session three, the same model is used with the introduction

to the group of a speech therapist. The focus of this session moves from

a discussion of the management of a tracheostomy and alternative forms

of artificial speech to the psychosocial aspects of altered speech and how

these can be managed. All the specific practical examples and exercises

are those provided by the resource programme.

Figure 11

Facial Friends Support Group, for patients and families coping with cancer of the head and neck

Improving your confidence

This session will be about coping with looking and sounding different. Everybody feels self conscious about changes in their appearance or speech. Many people feel that they lose their confidence after head and neck cancer treatment. We will discuss how to cope with this and feel more confident about going out and meeting people. For example, we will discuss how to cope with going to shops, the pub, a party and so on, what to do if people stare or ask awkward questions. Yes, you can learn how to deal with these things confidently! We will learn from each other and offer moral support, so if you are someone who has overcome these problems, please come along with your hints and tips. Partners/friends are also welcome – you can learn how to help.

Dealing with eating problems

Nearly everyone experiences eating problems at some time after head and neck cancer treatment. This session will deal with how to cope with these problems. Everything from what sort of meals to cook, recipe ideas, taste problems, coughing and spluttering problems, dribbling, how to cope with food going cold whilst you struggle to eat it. We will also learn how to cope with eating out in restaurants, friends' houses etc. Partners and friends will benefit from this session too. Meet other people with the same problems, get some moral support and learn from each others ideas. Bring along all your own ideas and questions. Julie Batty, Senior Dietician at Cookridge Hospital will be there to give expert advice.

This particular nurse therefore chose to run a support group that met together on five occasions. There were ten members of the group, of whom three brought along a relative/partner. The format of each session is closely based on the format suggested in the resource pack.

The nurses also formed themselves into an informal network as the study progressed, advising each other about how the process and content of the intervention. Where one nurse had found the inclusion of one aspect of the rehabilitation programme to be particularly helpful, this rapidly became incorporated into the programmes in other settings. For example, the inclusion of another member of the multidisciplinary team in the delivery of support sessions worked so successfully that this model was repeated in other settings. This growth and change within the experimental setting is typical of 'action research' where each step in an intervention becomes refined by the earlier work. Again, this development and networking between researchers was considered one of the strengths of the project.

All patient participants were asked to complete the questionnaire pack prior to the first meeting as a group, and again one month after the last session as part of routine outpatient follow up.

10.5 Analysis

The Statistical Package for the Social Sciences was used for the analysis of all quantitative data. Non parametric tests of significance were used

because of the problems of satisfying the distribution requirements for parametric tests.   Wilcoxon tests were used for comparison of mean scores and McNemar's test to compare changes in response categories from low to high on relevant variables. Effect sizes were calculated using the standardised response mean (SRM) formula developed by Liang et al (1990), and interpreted using Cohen's (1977) criteria. Qualitative data were interpreted using content analysis.

10.6   Results

10.6i Sociodemographic characteristics of the study sample

Sixteen patients took part in this preliminary study, 10 from Cookridge Hospital in Leeds and 6 from Southmead Hospital, Bristol. All were post operative head and neck cancer patients currently receiving outreach support from the head and neck nurse specialist and all met the inclusion criteria determined for the study.   All attended support group sessions, eight on their own and eight with a partner.

Table 10. summarises the demographic details of the patient group.

It can be seen that although this is a small sample, it is characteristic of this patient group as described in the research literature, and reviewed earlier. Figures 12 and 13 illustrate the premorbid smoking and drinking history of the sample. Not surprisingly, given their eventual diagnosis, over 50% of the group were heavy smokers although 30% of the group had never

smoked. Significantly, all reported that they had stopped smoking following

surgery. Figure 13 reports figures for drinking history. It can be seen that

this sample does not report a significantly high level of drinking and that the

pattern is unchanged following surgery. Whilst there is a strong

relationship between smoking and drinking in the aetiology of the disease,

this sample demonstrates the clinical observation that many patients have

no history of substance misuse, although it is important to note that this

data is self reported, and not, therefore, validated by objective assessment

such as blood tests.

Table 10.   Sociodemographic characteristics of the study sample

Mean Age(SD), range	60.5(8.6) range 43-76
Sex male/female	8/8
Socio-economic status	
Professional	1
Managerial/technical	2
Skilled non-manual	4
Skilled manual	4
Partly skilled	3
Unskilled	1
Retired/working	11/5
Ethnicity (white)	16
Living alone/with partner	4/12

Figure 12 Premorbid smoking history

PREMORBID SMOKING/ CIGARETTES PER DAY
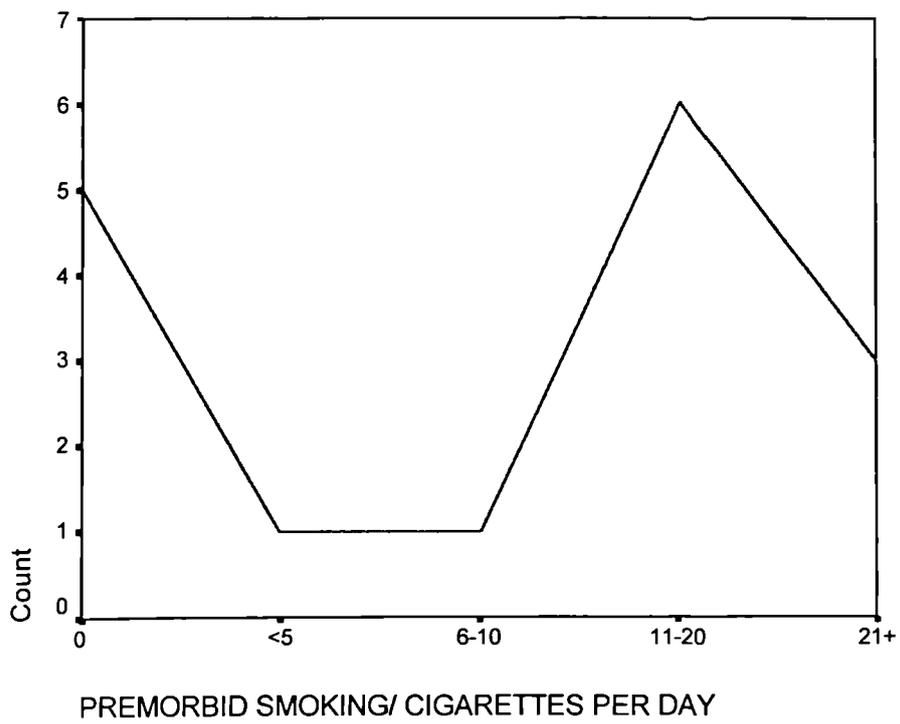
Figure 13 Premorbid and postmorbid drinking history

PREMORBID DRINKING HISTORY, UNITS PER DAY

POST OPERATIVE DRINKING, UNITS PER DAY
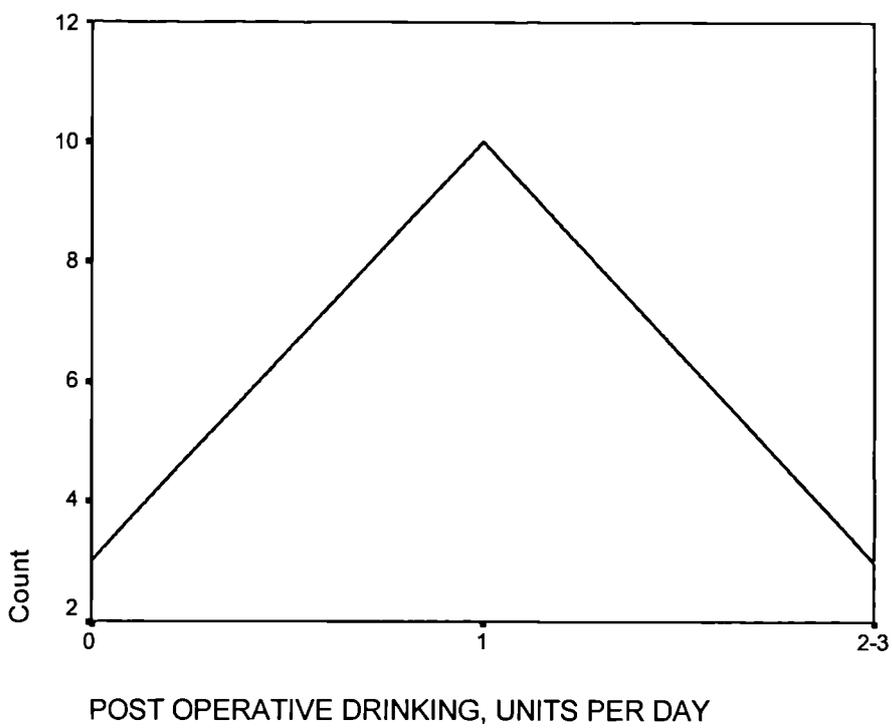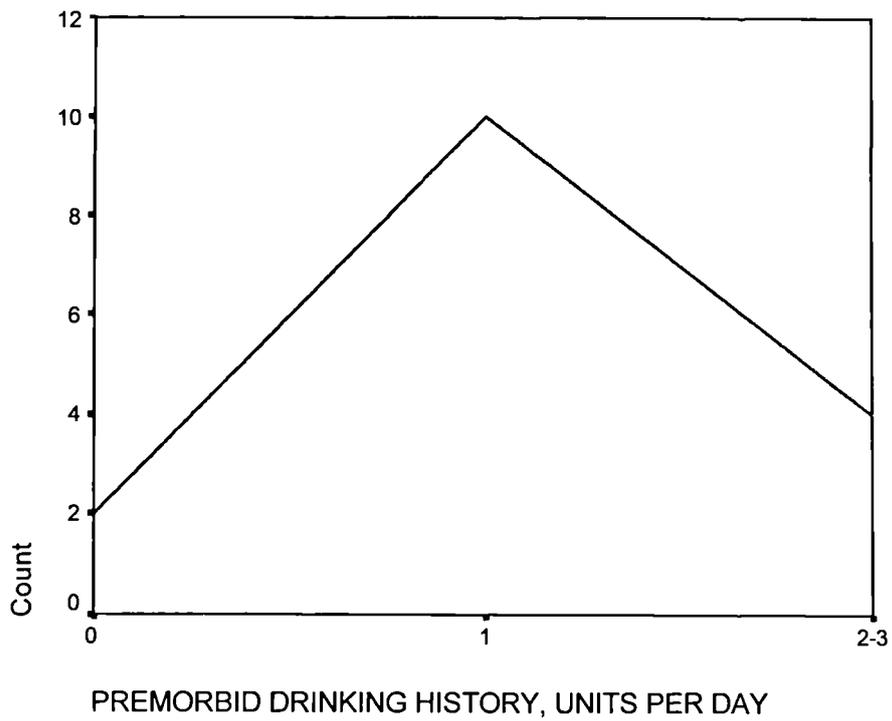
10.6ii Diagnosis and treatment history

Table 11   gives details of the diagnoses and treatment history for this

sample. The survival figures are interesting in that they indicate that

patients survive and remain in contact with Outpatient services and that

they are able to make use of rehabilitation input long after the initial

recovery period.

Table 11 Diagnosis and Treatment

Diagnosis	
Oral cavity	8
Pharynx	0
Larynx	8
Surgical stage	
I	3
II	3
III	2
IV	4
(missing)	4
Treatment	
Surgery	4
Surgery plus radiotherapy	12
Length of time since treatment	
less than 6 months ago	2
6 to 12 months ago	4
1 to 3 years ago	9
more than 3 years ago	1

10.6iii Dysfunction and disfigurement

Data on dysfunction and disfigurement were considered particularly

important in the context of this study, and distribution on objective scales

produced interesting results. All patients were assessed by the head and

neck nurse specialist in line with Dropkin's scoring criteria. All were classified as having level three dysfunction or above, with the distribution skewed towards the severe end due to the high proportion of laryngectomy patients in the sample. Disfigurement was more normally distributed with two patients scoring at the maximum end of the continuum, but 4 having no noticeable disfigurement. The majority of patients fall within the moderate category. Thus, even within this small sample, the data support the finding that dysfunction is a bigger problem for more people than disfigurement in head and neck cancer. They also pose an interesting challenge for the rehabilitation programme, since the resources have been developed as an extension of the model used for people who are disfigured. The inclusion of such a high proportion of people whose principal concerns are more to do with altered speech and eating problems is potentially a much better test of the resources and training than a sample where disfigurement is the principle issue. The significant correlation (r= 0.686, p= 0.003) between dysfunction in this sample and scores on the social eating subscale of the QLQ-HN35 is additional evidence of the large proportion of the sample who have eating related difficulties.

Figure 14   Frequency data for dysfunction and disfigurement using
Dropkin's criteria (0 = minimum, 9= maximum deficit.)

DYSFUNCN

DISFIGUREMENT
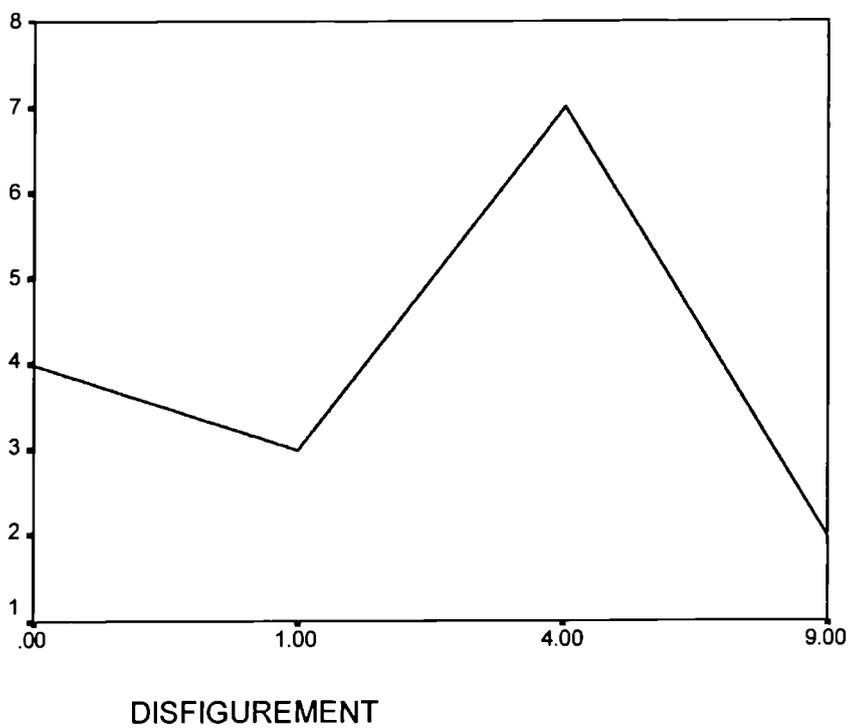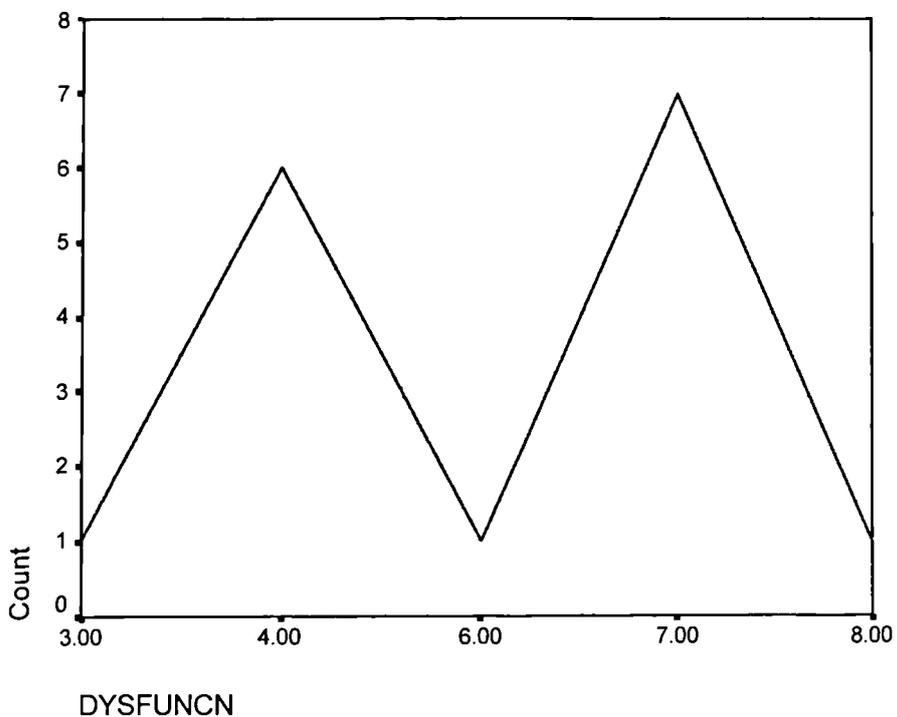
Subjective assessment of dysfunction was achieved by self-report using the EORTC QLQ-C30 and QLQ-HN35 scales. Scores were transformed using a linear transformation, in accordance with the scoring instructions given by the EORTC study group. These scores were then interpreted using high/low categories (cut off point 50) in line with Bjordal and Kaasa (1995). These results together with mean scale scores are given in table 12. Scores on the functional scales are very interesting. 44% of the sample rate their social functioning as low and 37% rate role functioning as low, despite the fact that only 25% of the sample report their physical functioning to be low, and there is only a relatively low rate of reported symptoms on the symptom scales. The most interesting finding, in the light of this low level of reported symptoms, is that 44% of the sample rate their overall quality of life as low.

Scores on the specific head and neck module, the EORTC QLQ-HN35 are given in table 13. It can be seen that the over half of the sample report a high level of difficulty with loss of sensation (smell and taste) social eating and sexuality. Symptoms affecting the oral cavity and airways, such as dry mouth, sticky saliva and coughing are also marked. Social contact is not a significant problem for most of the sample, despite the low score on the social functioning scale of the EORTC-C30, suggesting that it the majority of problems for this group relate to social eating rather than contact per se.

Table 12.
Patient reported functioning and symptoms as measured at baseline by EORTC QLQ-C30 (High score = high level of symptoms, and high level of functioning)

EORTCQLQ-C30 functioning scales	Mean scores	Response category	N
Physical functioning	73.3(24.8)	High	12
		Low	4
Role functioning	67.6(33)	High	9
		Low	7
Social functioning	66.5(30.9)	High	8
		Low	6
Cognitive functioning	88.4(20)	High	14
		Low	2
Emotional functioning	76.1(22)	High	12
		Low	4
Global Health status/QoL	61.37(26.5)	High	9
		Low	7
EORTC QLQ-C30 symptom scales			
Pain	20.8(30)	High	4
		Low	12
Fatigue	32.9(25.9)	High	3
		Low	13
Emesis	11.5(21.9)	High	2
		Low	14
Dyspnoea	22.8(34.3)	High	3
		Low	13
Insomnia	15.5(16.4)	High	0
		Low	16
Appetite loss	28(34.2)	High	3
		Low	13
Constipation	6.1(17.9)	High	1
		Low	15
Diarrhoea	13.5(28)	High	1
		Low	15
Financial difficulties	26(40.7)	High	4
		Low	12

Table 13
Patient self-reported functioning and symptoms at baseline, as measured
by EORTC QLQ-HN35 High scores indicate high level of symptoms

EORTC QLQ-HN35 symptom scales	Mean score (SD)	Response category	
Pain	19.1(22.5)	High	3
		Low	13
Swallowing	29(28.5)	High	3
		Low	13
Senses	51(38.6)	High	9
		Low	7
Speech	36.5(31.4)	High	5
		Low	11
Social eating	48.6(32.3)	High	8
		Low	8
Social contact	24.1(30.1)	High	3
		Low	13
Sexuality	51.8(40.9)	High	10
		Low	6
Teeth	24.9(41.2)	High	4
		Low	12
Open mouth	21.7(31.3)	High	3
		Low	13
Dry mouth	43.5(37.9)	High	5
		Low	11
Sticky saliva	49.7(37.9)	High	7
		Low	9
Coughing	51.8(34.3)	High	7
		Low	9
Feeling ill	18.6(29.6)	High	2
		Low	12
Use of pain killers		High	8
		Low	8
Nutritional supplements		High	3
		Low	13
Feeding tube		High	2
		Low	12
Weight loss		High	3
		Low	13
Weight gain		High	6
		Low	10

10.6iv Anxiety and Depression

Scores on the HADs are displayed in table 14. Using the standardised scoring criteria, mean scores for both anxiety and depression fell within the normal range. However, the range of scores was wide, with 4 patients falling into the clinical case category for anxiety, and 2 for depression. Correlation between scores on the HADs and on other tests administered pre intervention produced some interesting findings. Scores on the anxiety subscale showed a positive correlation with scores on the physical functioning subscale of the adapted head and neck questionnaire

($r = -0.581$, $p =0.01$), indicating that the more skilled people felt about dealing with the physical aspects of their condition, the less anxious they felt. There were also significant correlations between the anxiety scale of the HADs and two of the subscales of the QLQ-C30; emotional role functioning ($r =-0.511$, $p =0.04$) and cognitive functioning ($r = -0.757$, $p=.001$). These scores demonstrate that the anxiety subscale and the EF subscale are effectively measuring the same dimension of emotion/anxiety, and that high levels of anxiety are associated with low cognitive function.

A similar analysis of scores on the HADs depression subscale revealed high scores to be correlated with several subscales of the QLQ-C30. High levels of depression were related to high fatigue ($r = 0.829$, $p = 0.000$), and to lower perceived physical functioning($r =-0.804$, $p=0.000$), role functioning ($r = -0.820$, $p=.000$), social functioning ($r =-0.793$, $p =0.000$)

and global quality of life (r =0.744, p =0.001). All of these relationships are consistent with previous findings in the research literature.

Table 14. Mean scores on the HADs scales pre intervention

	N	Minimum	Maximum	Mean	Standard deviation
Anxiety	16	0	16	6.43	4.66
Depression	16	1.00	12	4.87	3.48

10.6v Standardised measures of social functioning

The Derriford Appearance Scales.

The range of the scale is between 0 and 85, with a score of 47 representing the mean with a standard deviation of 11. The higher the score the more distressed the person is about their appearance. Scores in this sample ranged between 22 and 85 with a mean of 42.75, SD 18.43. Collectively, patients' scores on the Derriford scale fell within the normal range indicating that generally, they were not reporting high levels of social anxiety. However, maximum scores indicated that some patients were reporting severe problems with social encounters. Higher scores on the Derriford scale (that is patients high on social anxiety) were

significantly related to high levels of depression (r=0.556, p=0.02) as measured on the HADs.

The Social situations questionnaire (SSQ)

Like the Derriford scales, scores on the SSQ had a wide range. Scores ranged from 6 – 111, mean 37.2, SD 32.1. There was no correlation between the SSQ and any of the scores on other measures, except with other measures of social functioning (see below, table 15).

Table 15. Pearson Correlation coefficients between the Derriford Appearance Scales. SSQ, EORTC HN35 Social Eating and Social Contact Subscale, and Modified Nurses Skills Scale.

	Derriford	SSQ	Social function	QLQHN35 SO	QLQHN35 SC
Derriford		.521 **p=.02**	-.546 **p=.016**	.806 **p=.004**	.802 **p=.000**
SSQ	.521 **p=.02**		-.653 **p=.002**	.468 p=.068	.622 **p= .010**
Social function	-.546 **p=.016**	-.653 **p=.002**		-.416 p=.10	-.672 **p= .004**
QLQHN35 SO	.676 **p=.004**	.468 p=.068	-.416 p=.10		.476 p= .063
QLQHN35 SC	.802 **p=.000**	.622 **p=.010**	-.672 **p= .004**	.476 p= .063	

(significant p values in bold)

Table 15 gives the correlation between the different standardised measures of social function, the social function subscale of the modified nurses skills questionnaire and the social subscales of the EORTC-HN35. Correlation between the different scales measuring social functioning was high, suggesting that all these scales are useful in measuring aspects of

the concept. The social function score obtained using the adapted Nurses' Skills Questionnaire correlated significantly with the Derriford Scale, the Social Situations Questionnaire and the Social Situations Subscale of the QLQ HN35. Since the scale was designed to focus on social contact, the correlation with the SC scale on the QLQ-HN35 is further evidence of its validity, since the SC scale comprises 5 items measuring social contact. The SO scale of the QLQ-HN35 measures social eating, and although there is a weak correlation with most of the scales used, it is only the Derriford Scale which shows a correlation with this and all other measures of social performance. It is clear from this evidence that the Derriford Scale is the most comprehensive in summarising the collective social deficit within this sample. Unlike study 2, where nurses rated their skills in managing the physical aspects of rehabilitation as better than their skills in managing social aspects of rehabilitation, this sample of patients reported no significant differences in their management of the two different areas. Mean scores suggest that they rated their skills as adequate in both areas (Mean score for physical function = 2.88 (SD=0.76), mean score for social function = 2.66 (SD=0 .88).

10.6vi Summary of sample characteristics.

In summary, this sample of head and neck patients can be considered typical of the wider group. They are elderly, most of them retired with a mixed history of heavy smoking. Assessed years rather than months after surgery, they report their quality of life as low, with symptoms affecting the

oral cavities and airways. Half the sample are laryngectomy patients with accompanying speech and eating difficulties and for this group, as with others, dysfunction appears to be the major focus of concern rather than disfigurement. There are marked social difficulties, although these relate more closely to the problems of public behaviour rather than simply to appearance, and, in particular, social eating stands out as a problem for the group. The area of sexual function is also a major concern in line with clinical opinion about the head and neck population, and this is interesting given the equivocal findings in research studies. Whilst it would be more useful to have a larger sample of patients, there is nothing about this group which appears to make them an unusual or unrepresentative sample with whom to evaluate the social rehabilitation resource pack. The only disappointing feature of the group is that the length of time since surgery suggests that they may have adapted more to their dysfunction and learned how to manage any problems to some extent. It is therefore arguable that they are less likely to show considerable gains following the intervention. However, because of this, any improvement may be more convincing than it would be with a group who have been through surgery more recently.

11.0   Post intervention results

Following the social rehabilitation programme, it was hypothesised that

scores on measures of social functioning would be improved, but that

measures of physical functioning would remain unchanged.

Table 16. Patient reported functioning and symptoms as measured pre and post intervention by EORTC QLQ-C30 (High score = high level of symptoms, and high level of functioning)

EORTCQLQ-C30 Functioning scales	Mean scores(pre)	Mean scores (post)	Response category	N pre	N post	P value
Physical functioning	73.3(24.8)	74.1(26.8)	High	12	12	0.46
			Low	4	4	
Role functioning	67.6(33)	71.68(34.28)	High	9	12	0.57
			Low	7	4	
Social functioning	66.5(30.9)	76.81(23.61)	High	10	10	0.44
			Low	6	6	
Cognitive functioning	88.4(20)	80.75(17.55)	High	14	13	0.70
			Low	2	3	
Emotional functioning	76.1(22)	72.68(26.4)	High	12	13	0.68
			Low	4	3	
Global Health status QOL	61.37(26.5)	69.0(16.05)	High	9	15*	0.13
			Low	7	1	
EORTC QLQ-C30 s Symptom scales						
Pain	20.8(30)	19.81(28.0)	High	4	3	0.88
			Low	12	13	
Fatigue	32.9(25.9)	35.81(27.96)	High	3	4	0.47
			Low	13	12	
Emesis	11.5(21.9)	10.37(20.83)	High	2	2	0.78
			Low	14	14	
Dyspnoea	22.8(34.3)	19.88(31.48)	High	3	3	0.28
			Low	13	13	
Insomnia	15.5(16.4)	27.93(29.4)	High	0	0	0.03
			Low	16	16	
Appetite loss	28(34.2)	21.75(28.89)	High	3	2	0.41
			Low	13	14	
Constipation	6.1(17.9)	4.12(11.27)	High	1	1	0.70
			Low	15	16	
Diarrhoea	13.5(28)	6.25(2.50)	High	1	0	0.10
			Low	15	15	
Financial difficulties	26(40.7)	22.75(31.39)	High	4	3	0.38
			Low	12	13	

*significant shift in response category (p = 0.01)

11.1   EORTC-C30 and EORTC-HN35

On the EORTC C30 (table 16), there were no significant changes on any of the symptom scales, in line with a priori predictions, and the very small improvements on the functioning scales were also non-significant. Effect size statistics were calculated for social functioning and the global quality of life subscale.   For social functioning, an effect size of 0.24 suggested a minor effect, whilst an effect size of 0.52 suggested a moderate degree of change on the quality of life scale. This suggestion of clinical significance was further explored by reclassifying respondents into high versus low categories post intervention. There were no significant changes on any of the scales except on the quality of life scale, where six of the seven individuals whose scores placed them in the low category, moved into the high category post intervention.   These scores on the EORTC C30 are therefore in line with the experimental prediction that there would be no change in self reported physical status, but there is some suggestion that both social functioning and overall quality of life has improved.

Results on the EORTC HN35 allow further exploration of the impact of the intervention on social compared with physical variables (table 17). Wilcoxon tests for related samples demonstrated significant changes on only the three target variables: speech difficulties, (p= 0.018), social contact (p= 0.05) and social eating (p= 0.008) in line with experimental predictions. These are highly significant results given the small sample

size. On the remaining 15 scales, scores are unimproved with some

symptoms, eg: dry mouth getting worse. Effect size statistics for these

scales were calculated and demonstrated a moderate effect size for

social contact (0.47) and a large effect size for both speech difficulties

(0.71) and social eating (0.90).

The results on the EORTC HN35 are therefore exactly in line with

experimental predictions; the observed changes in scale scores are

significant both statistically, and in terms of impact on the clinical

population. These changes are plotted for comparison against other

physical baseline measures in figure 15.

Table 17.

Patient reported functioning and symptoms post intervention, as measured by EORTC QLQ-HN35. High scores indicate high level of symptoms.

| EORTC QLQ-HN35 Symptom scales	Mean score (SD) pre-test	Mean score (SD) post-test	Response category (score 50+)	Pre-test	Post-test	P value
Pain	19.1(22.5)	18.18(23.9)	High	3	2	0.72
			Low	13	14	
Swallowing	29(28.5)	27(27.5)	High	3	3	0.36
			Low	13	13	
Senses	51(38.6)	49.5(37.5)	High	9	10	0.67
			Low	7	6	
Speech	36.5(31.4)	23.93(27.8)	High	5	3	0.02
			Low	11	13	
Social eating	48.6(32.3)	32.56(31.6)	High	8	4	0.01
			Low	8	12	
Social contact	24.1(30.1)	14.06(22.5)	High	3	1	0.05
			Low	13	15	
Sexuality	51.8(40.9)	42.5(45.6)	High	10	10	0.10
			Low	6	6	
Teeth	24.9(41.2)	20.75(36.1)	High	4	3	0.58
			Low	12	13	
Open mouth	21.7(31.3)	18.81(31.8)	High	3	3	0.75
			Low	13	13	
Dry mouth	43.5(37.9)	49.68(34.3)	High	5	8	0.56
			Low	11	8	
Sticky saliva	49.7(37.9)	48.75(39.1)	High	7	8	0.83
			Low	9	10	
Coughing	51.8(34.3)	43.37(26.3)	High	7	6	0.12
			Low	9	10	
Feeling ill	18.6(29.6)	10.31(15.7)	High	2	0	0.16
			Low	12	16	
Use of pain killers			High	8	8	
			Low	8	8	
Nutritional supplements			High	3	3	
			Low	13	13	
Feeding tube			High	2	2	
			Low	12	12	
Weight loss			High	3	3	
			Low	13	13	
Weight gain			High	6	6	
			Low	10	10	
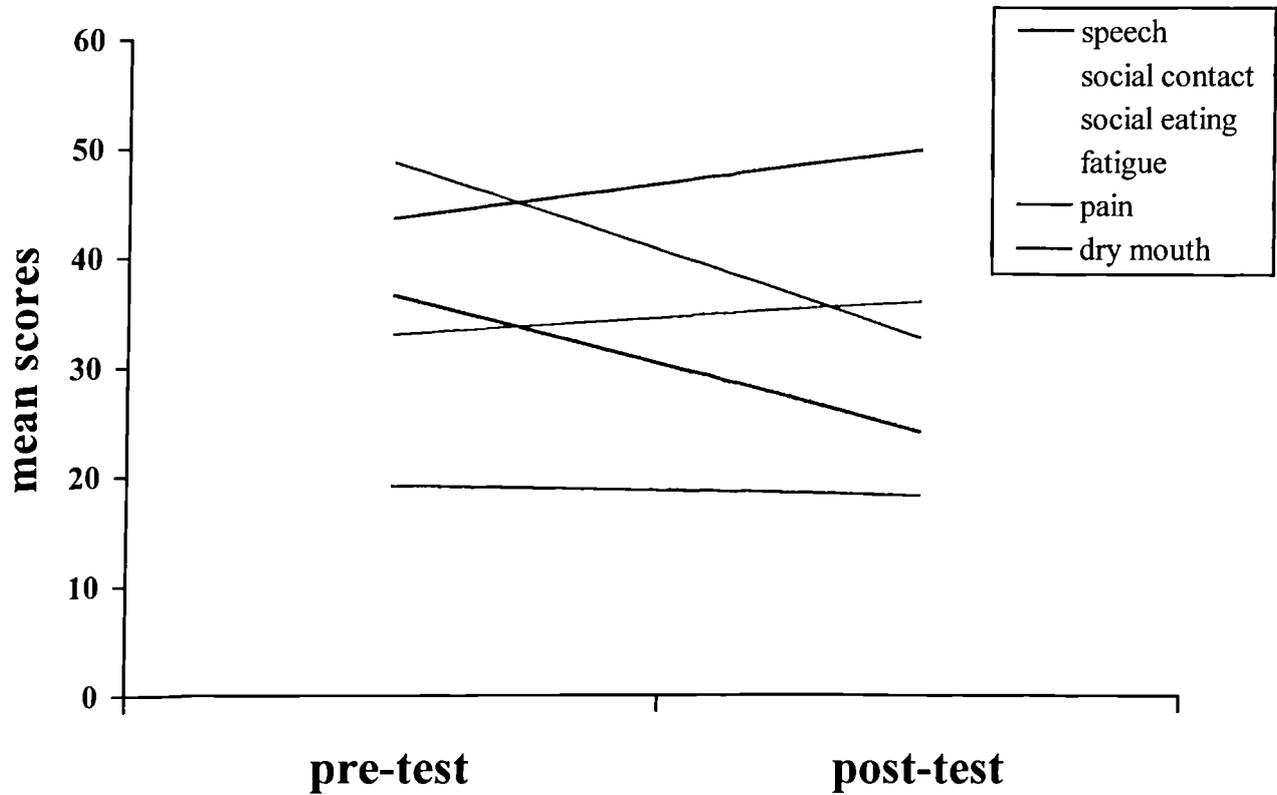
Figure 15. Pre and post test differences in mean score for EORTC C30
and HN35 social functioning scales and reported physical symptoms.
(High score = high level of functioning and high reported symptoms).

11.2 Standardised measures of social functioning

Scores on the standardised measures of social functioning, the Derriford Scales and the SSQ were analysed similarly, table 18. Results are in line with the results on the EORTC scales. Both the Derriford Scale and the SSQ show significant changes in the predicted direction with evidence of fewer problems with social functioning. Effect size scores demonstrate that the degree of change is likely to have significant impact on the respondent.

Table 18. Pre and post-test mean scores on the Derriford scales and SSQ

	Pre-test mean score	Post-test mean score	Significance level	Effect size
Derriford	42.75 (SD=18.4)	35.62 (SD=16.2)	P= 0.008	0.71
SSQ	37.25 (SD=32.1)	26.37 (SD=26.9)	P= 0.05	0.61

Results on the adapted nurses' skills questionnaire were analysed to see whether scores matched the prediction that only the social function subscale and not the physical function subscale would show an improvement. Scores are given in table 19.

Table 19. Pre and post-test mean scores on the physical function and
social function subscale of the nurses skills questionnaire

	Pre-test mean score	Post-test mean score	Significance level	Effect size
Social function	2.88	3.16	P=.03	0.59
Physical function	2.68	3.05	P=0.08	0.47

Whilst scores on both scales have improved, only the social function

scale has achieved significance; however, both scales have a moderate

effect size. This unexpected result can be explained by the inclusion in

the physical function scale of questions relating to speech difficulties.

Since this is an area which has been targeted by the intervention and has

shown a significant improvement as measured on other scales, this is

likely to account for the change on this scale in the absence of change on

any of the other physical measures.

11.3 The Hospital Anxiety and Depression Scale

The final set of results to be considered is the scores on the HADs. Post

intervention, mean scores on both anxiety and depression had fallen, with

one less clinical case in each category (see table 20).

Table 20 Comparison of mean scores on the HADs scales, pre and post intervention

	N	Minimum	Maximum	Mean	Standard deviation	P value
Anxiety pre	16	0	16	6.43	4.66	
Anxiety post	16	0	17	5.50	5.26	0.08
Depression pre	16	1.00	12	4.87	3.48	
Depression post	16	0	13	4.0	3.52	0.06

Despite the fact that the sample size is much smaller than that suggested by the power analysis, comparison of mean scores using the Wilcoxon test for two related samples indicated a trend to significance for both anxiety and depression. However, the effect size statistics gave a moderate effect size for the falls in both anxiety (0.47) and depression (0.39). These findings suggest that there is a meaningful clinical change in response which is likely to be significant if evaluated on a larger sample, and lend some support to the hypothesis that improved functioning in social situations is associated with lower anxiety and depression, as reported in earlier studies.

The fact that significant findings, in line with predictions, have been obtained on a series of measures with such a small sample of patients, is very encouraging.

11.4 Analysis of semistructured questionnaire

Each participant in this study completed a semi-structured questionnaire (see appendix, volume 2) together with the standardised measures reported above. This included open-ended questions asking for comments on the social rehabilitation programme. Results were subjected to content analysis.

56% of respondents rated the written information that they had been given as very easy to understand, and 37% as easy. (Numbers adding up to less than 100 reflect patients who did not answer the question). No respondents rated the information either difficult or very difficult. 56% considered it to be very helpful and 32% helpful. No respondents rated it unhelpful. When asked in what way the information had been helpful, respondents were able to be quite specific about the practical strategies that they had learned, as in the examples below:

> *How to get on with people*
> *Most of it because it reminds you to think for yourself and take your time*
> *How to manage the difficult part about communications and about eating*
> *How to get out of difficult situations – good tips on numerous things*
> *Generally, the information gave me some new ideas*

When asked *how effective* the information had been in helping the individual manage any problems that they were experiencing, 50% rated

it very helpful and 37% quite helpful. When asked again how the

information helped, the answers given were again quite specific, as

below:

It made me less self-conscious
Very useful in situations where you don't feel the need to
explain – to virtual strangers for instance
Most of it because it reminds you to think for yourself and
take your time
It gave me new angles and ideas to work on
Suggestions for eating out and being in company – how to
explain your situation
It helps you realise you are not alone and your problems are
the same for other people with the same condition
Helped me to control my feelings

There were no negative comments about the information prepared for the

programme, and the feedback above gives a clear indication that the

content has been understood, and found to be useful. This is particularly

encouraging given the length of time since surgery for this sample, since

it clearly challenges the perception that people work out all these coping

strategies and ideas for themselves.

Questions about the support group setting were equally revealing. 75%

of patients rated the support group sessions as very helpful, and 12% as

quite helpful. None rated them as unhelpful. The rate of attendance is a

good measure of the perceived value given to the sessions, and it is

interesting that in this sample of patients, who have considerable practical

difficulties, 50% attended all the sessions, 31% missed only one session,

and 18% missed 2 sessions. When asked in what way the sessions were helpful, the content of the replies had a very clear theme of support from other people, understanding that the problem was one shared by other people, together with comments about the practical value of speaking to other people. It was interesting that only one person commented on the opportunity to speak with health professionals or experts who were also attending the group sessions.

> *They helped me to understand other peoples problems*
> *The sessions have made me more confidant mixing with groups of people, speaking aloud which I now find less embarrassing*
> *If the subject did not apply to me, it was useful to hear how other people coped*
> *Its good to talk to others with similar problems*
> *realising you're not on your own*
> *Knowing that other people had the same problems*
> *Listening to other people and comparing our problems with theirs*
> *Because you can relate your own problems with others instead of bottling them up*
> *It helped a great deal being able to talk to people who have the same problems as I do*
> *Finding how other people coped*
> *Talking to people with the same condition and some experts helps to understand and accept the problems you may or may not have*
> *To give self confidence*

Although it is important that people report the intervention as helpful and the resources as easy to understand, the most important question is whether or not people used the coping strategies in their day to day lives. When asked this question, 12% said that they had used many of the ideas in the programme, and 50% said that they had used some of them.

When asked which of the skills they had used, respondents listed specific

examples from the programme:

Body language
Humour always helps
Instead of dismissing people as ignorant, I've taken my time
and we've managed to get along
Mixing with other people as much as possible
Trying to do more for my self and not relying on other
people to do it
When eating out, taking an extra plate and having a little of
everyone's food
Trying to become more self reliant

Of the 25% who had not used any of the ideas, their comments confirmed

that they had already been using the coping strategies described in the

programme, or that they were not relevant; this is clearly accurate for

some of the skills, for example the management of altered speech where

this has not been affected. These figures are very encouraging in that a

large percentage of the sample are actively using the skills that they have

learned, and even those who claim that they have not learned anything

new, are validating the approach in their existing use of the same ideas.

The final questions asked the respondents directly about the value of

including advice about managing social situations. 56% stated that they

thought this kind of intervention was very helpful and 37% helpful. No

respondents thought it unhelpful. 50% thought that it was very helpful to

include relatives in the sessions and 37% thought it helpful. One

respondent thought the inclusion of relatives was unhelpful, and it is

interesting that this was one of the patients who lived alone.

A section of the questionnaire was left blank for patients to add any extra

comments, all of which summarised or repeated the support for the

programme outlined above. Perhaps the most useful of these was the

example given below:

> *It was without doubt an excellent idea to hold this support group. It*
> *seemed more helpful for recent victims. My problems first arose*
> *three years ago and I would have found greater benefits from*
> *these meetings had they occurred much earlier*

The qualitative data therefore adds supporting evidence to the findings of

the quantitative measures, with patients reporting that the programme

was very helpful. The most important aspect of this feedback is the fact

that the programme is clearly being delivered in the form that it was

prepared and delivered to the nurses, and that patients find it useful and

are able to use the skills that they learn in their day to day life. The

experimental aims of the project have therefore been fulfilled.

11.5 Discussion

The first and most important point to make about these findings is that

they relate to a preliminary study carried out on the data from the first two

centres to finish data collection. Once the full data set has been obtained, it will be possible to repeat the analysis of the findings and to establish whether some of the inconclusive findings, such as the changes on the HADs scales, become clearer. At this later stage, it will also become possible to break the sample into smaller groups to study the effects for example, of receiving written information only versus taking part in a support group. It will also be very useful to look for any differences in outcome depending on how long after surgery patients take part in the programme. Looking for these sorts of relationships in a sample of this size is likely to result in inconclusive or even inaccurate findings. Analysis of a larger sample will also allow the use of more sophisticated parametric tests of significance. For example, analysis of variance will allow the impact of factors such as age and social class, length of time since surgery and other demographic variables to be assessed as a stepwise function to discover their individual contribution to the impact of the intervention.

Having noted these limitations, it is clear that this small sample has produced data which is exactly in line with predictions, and which is therefore worth discussing in some detail. Although the sample size is small, the calculation of effect sizes and the inclusion of qualitative data considerably ameliorate the associated problems, indeed some researchers would suggest that there is little to be gained from simply increasing sample size, since this also increases the chances of producing type 1 errors (Hevey and McGee 1998). Some researchers

have called for the banishing of p values from the journals of the APA, but a balance between different kinds of analysis, as carried out in this study, would appear to offer a more informative way forward.

The first thing of note about this sample is that it appears to be typical of the patient population as a whole. In addition to the demographic characteristics of the group noted earlier, the important thing to note is the level of difficulty experienced several years after surgery (mode = 1 to 3 years). The EORTC scales give a detailed picture of this group. They are clearly not a group who are suffering severe pain, but they have chronic problems with respect to the simple functions of everyday life, in particular eating and communication. Although the functioning scales of the EORTC-C30 place only a small proportion of the group in the low category, i.e.: low level of functioning, it is extremely interesting that the majority of respondents rated their overall quality of life as low at baseline assessment. This suggests that the impact of physical functioning on quality life is less significant than other factors such as social function or support.

The measurement of dysfunction and disfigurement using the Dropkin scale has proved very satisfactory in this study; the scale was easy to use, and has produced several interesting findings. The first of these is that there is no evidence of a link between disfigurement and distress. Although this finding is becoming more and more common in research studies, there has always been concern that disfigurement is not

measured objectively (see chapter two). However, this study used a standardised measure and still found no evidence to link the two. This is, therefore, additional support for the explanation that distress in disfigurement is mediated by other factors such as age, level of social support, and good social skills. Level of dysfunction, however, did produce a relationship with social functioning as measured by the Derriford scales and depression on the HADs. These findings fit very closely with the clinical observations of those working in the field, that it is the practical difficulties of everyday tasks that cause the distress in the head and neck population. These findings are also interesting in that depression rather than anxiety is related to dysfunction. Social anxiety is far more commonly associated with disfigurement than depression in previous studies (Robinson et al 1996; Williams et al 2000), so once again there is evidence to confirm the clinical belief that that this is a group who are less concerned about their appearance than about the limitations in their everyday life. This is clearly a finding that is influenced by the characteristics of the sample, not least age and diagnosis, and it will be very interesting to study it more closely when the data set is complete.

The correlation in scores on the various measures of social functioning is confirming evidence of the validity of the scales. The only measure that is out of line with the others is the social functioning scale of the EORTC-C30. One explanation for this is the nature of the questions being asked on this scale. The EORTC C30 is designed for use across all cancers

rather than head and neck and the questions relating to social functioning are therefore much more general than those on both the EORTC HN35 and the detailed psychological questionnaires. It is particularly interesting that the Derriford Scale picks up issues relating not only to social *contact* as it was designed to do, and as evidenced by the correlation with the social contact scale on the EORTC HN35, but it also picks up issues relating to eating in public, as evidenced by the correlation with the relevant scale of the EORTC HN35. The Derriford Scale was described as a potentially useful scale in chapter two of this thesis, and these findings support its value in research with the head and neck cancer group. Although the mean scores for the study sample fall within the normal range, there is tremendous variability in functioning with a wide range in scores and standard deviation. This is not surprising given the variation in dysfunction and disfigurement within the group. Those falling at the top of the range on any of the social functioning scales are clearly reporting many difficulties in resuming social activities.

The Nurses' Skills Questionnaire has produced a different pattern in the patient sample from that observed in the nursing group, with patients failing to draw a distinction between their skills in managing social versus physical rehabilitation. There are a number of possible explanations for this. Optimistic bias about health judgements may be a factor, with patients reporting themselves as coping better with situations than objective observers might report. However if so, then this should influence scores on other self-report scales. A more likely explanation

may be that people report that their skills are good because they are unaware that there are different skills that they could be using. Nurses are likely to be more aware that psychosocial intervention can lead to better outcomes, and aware of their lack of training in providing it.

Assessing the impact of the intervention is extremely encouraging. The first important thing to note is that the nurses were able to deliver the package successfully. Both nurses in this preliminary report chose to set up support groups, although nurses elsewhere have used the resources primarily with patients on an individual basis. Although each modified the package to suit their differing service needs, the essential model of teaching coping effectiveness and practical strategies has been used as is evident in the qualitative data collected from patients. This data also testifies to the fact that patients find the approach easy to understand and helpful. Given the mean length of time since surgery it is particularly encouraging that this sample of patients found the approach helpful, since it might have been predicted that they had already learned coping strategies on a trial and error basis. Whilst some comments testify to this, a large percentage of the sample reported that they had altered their behaviour as a result of the intervention. Similarly, the fact that this approach was successful with a group of people for whom speech and eating difficulties predominated, demonstrates the fact that it can be extended beyond disfigurement to other problems of social embarrassment. The 100% response from patients that this kind of rehabilitation programme is useful, is further evidence not only that the

intervention was helpful, but that patients are willing to take responsibility for managing their own rehabilitation if given guidance and training in the skills that can help them. The inclusion of relatives in the support group was also rated positively, and in future studies, questionnaires for relatives should be included to discover whether this is a mutual benefit and in what way. Certainly it was noticeable that all those patients who were living with a partner chose to bring that partner with them to the support group when invited.

The results of the quantitative data analysis are equally encouraging, in that they are exactly in line with a priori predictions with all the target variables, and only these, showing statistical improvement. The specific targets of this approach are the areas that produce social embarrassment, i.e.: social contact, management of altered speech and social eating. These are exactly the scales that show significant change on the EORTC scales. Interestingly, although sexuality is included within the resource pack, it is suggested as an intervention to be managed on a one to one basis, and because this first study includes only those attending support groups, none of the patients received any direct input in this area. The absence of any significant change on this subscale is, therefore, additional evidence that successful outcome is only obtained as a result of the intervention on specific issues. Non-targeted problems and general level of symptom severity show no significant change. Explanations that patients report better outcomes only as part of an attention placebo or 'feel good' factor are very hard to sustain given the

evidence that fatigue, dry mouth and other areas of functioning actually get worse. Although it will be essential to try to extend this study to include a control group as this research continues, the evidence obtained by using the patient as their own control in comparing physical with social changes in this multiple baseline study has produced very clear results.

The significant changes on EORTC subscales are further validated by changes on the independent measures of social functioning. The Derriford Scale, SSQ and Modified Nurses' Skills Questionnaire all show corresponding improvement in mean scores. Use of effect size statistics has been helpful in trying to estimate the impact of this statistical change in clinical terms, and has confirmed that this intervention is one that is likely to have meaningful impact in terms of day to day function. In fact, the qualitative data from patients is even better evidence on this point, but gathering the separate strands of evidence in these different ways all helps in the analysis of what statistical change really means in terms of clinical effect.

Scores on the HADs scales show only a trend towards significance, and these results will be examined more closely in the larger sample. Lack of change is most easily understood in terms of small sample size and the variation in the scores at baseline. Although some patients scored very highly, mean levels of anxiety and depression were within the normal, non-clinical range, and therefore less likely to show dramatic improvement. However, levels of anxiety and depression have previously

been reported to be high in the head and neck population as a whole, even when measured many months or years after surgery. In this sample, the correlation of anxiety with perceived skill in managing the physical aspects of rehabilitation is the most interesting outcome, and suggests that rehabilitation programmes for these patients should emphasise the teaching of coping skills, for example with relation to managing tracheostomy, dietary requirements and use of prostheses. There is clearly scope for extending the strategy used by the nurses in this study, where a group setting was used to discuss the physical management of eating problems and then extended to include the social aspects of these problems. This strategy works well for the other major problems in the population; notably disfigurement, where management of a prosthesis can be discussed with relation to staring, comments and questions relating to appearance, and speech management related to social embarrassment about sounding unusual or indistinct.

Evidence that this intervention has had an impact on quality of life, although exciting, needs to be treated with some caution. Quality of life/global health status, as measured on the EORTC C30 is an aggregate score obtained by combining the mean responses on two questions with a seven point scale, which then undergoes linear transformation to give scores between 0 and 100. The question referring to health status asks for scoring based on the last few weeks, whilst that for quality of life is based on the last year. There are therefore problems in interpreting exactly the time frame to which the aggregate score relates, and with

looking for test – retest changes; it is likely, in fact, that the scale underestimates the extent of recent change. Similarly, the classification of scores into high and low categories is relatively arbitrary, based on a cut – off point half way along the scale, rather than anchored to objective measures of functioning. For these reasons, there were no a priori predictions that quality of life post intervention would be improved. Nevertheless, the finding that a significantly large proportion of patients move from the low to high quality of life classification following intervention is one that is entirely consistent with the other changes recorded, and suggests that social rehabilitation training may well increase perceived quality of life through facilitating better social interaction. This is not only a finding that will become clearer with increased sample size, but is an area that could be studied in future studies using some of the other quality of life instruments that are available.

In summary, study three has successfully demonstrated that nurses, who are trained and resourced appropriately, are very effective in delivering practical coping skills training in social rehabilitation to head and neck cancer patients. Clear gains have been measured on the areas that cause the greatest problems of social embarrassment for this group, i.e.: speech changes, social contact and eating in public. Early results suggest that facilitating this social functioning has an impact on quality of life. Patients rate the intervention to be easy to understand and very helpful, and report making changes in their behaviour with successful outcomes.

Although there are obvious limitations with this study, notably the size of the sample and the simple pre-post test multiple baseline design, the evidence obtained provides a very good basis on which to build further research, training and resource development.

CHAPTER FOUR, SECTION FOUR:

RESOURCING AND TRAINING HEAD AND NECK CANCER NURSE SPECIALISTS TO DELIVER A SOCIAL REHABILITATION PROGRAMME TO PATIENTS: SUMMARY AND CONCLUSIONS.

The major aims of this research programme have been achieved. It has been demonstrated that despite being identified as the health professional charged with delivering psychosocial input to patients with disfiguring conditions (Price 1990, 1998), nurses perceive their skills as deficient in this area when compared with their skills in the more traditional, physical aspects of rehabilitation. This is a robust finding, first identified by analysis of contacts to a lay-led organisation, and demonstrated empirically in two separate populations of nurses, one working with burn patients and the other with head and neck cancer patients.

Following a review of the literature and informed by direct clinical work with patients following head and neck surgery, the psychosocial problems encountered by patients were re-interpreted as problems of social embarrassment, and an intervention designed to overcome them. This

was then developed into a set of resources and training package for nurses, who were trained in the approach.

In the second study of this series, an evaluation of the impact of training demonstrated that nurses who had taken part in it and who had been given the resources were using them in their clinical practice and described them very positively. Comparison with an untrained control group of nurses demonstrated significant gains in perceived skill at managing psychosocial issues with patients, and enthusiastic use of the approach on a day to day basis.

In the final study of the series, nurses were asked to evaluate the impact on patients who underwent psychosocial rehabilitation delivered as part of long-term follow up. Results both of standardised questionnaires and qualitative feedback from patients illustrated gains in exactly the areas targeted by the intervention. Social functioning in all three targeted areas, altered speech, eating in public and social contact were significantly improved whilst all other baseline measures remained constant. A corresponding improvement in quality of life was recorded.

It can therefore be concluded that it is possible to design an appropriate coping skills training programme of the kind envisaged by Bjordal et al (1995), which has an impact on quality of life for this very severely impaired patient group. As discussed earlier, Fiegenbaum et al (1981) reported similar findings thirty years ago, but this package did not receive

much attention and has not been further explored. It is hard to explain why this should be, given the increasing number of papers describing the very low quality if life that patients in this group describe. There are two possible explanations for this. One of these is that this is an area that has not yet received any attention from psychologists unlike other conditions such as spinal injury (King and Kennedy 1999). Designing a coping package and running a group are part of the skills set of a clinical psychologist, but are not necessarily within the skill set of the nurses who are in the position to deliver them; this has been highlighted by this research in study one. Designing a package which from the outset, has been prepared in a format for nurses to use, will hopefully mean that there is far more interest in taking this work ahead from a group who are in the best position to do so. The approach is also facilitated by being written up in the form of a manual; all the patient information is standardised, sessions set out very simply, and all material photocopyable to facilitate ease of use.

There are clearly shortcomings in this work despite the fact that the experimental objectives have been achieved. The characteristics of the patient group, i.e.: the fact that many are terminally ill and have a very short prognosis made the design of the research very difficult. It was inappropriate to plan either a control group or a repeated measures design, although post hoc, given the length of time that the research sample had survived following surgery, both of these could have been

employed. It can be argued that the multiple baseline design is particularly well suited to these kind of research limitations, and certainly the results of his first study are clear enough to allow the research to proceed to a more rigorous design with a patient group such as those with burns injures, where these particular constraints do not apply.

Finally, it is important to note that his work has been achieved within a non-health service setting. Chapter Two includes discussion of the role of a lay-led organisation in focusing on the psychosocial issues of health problems, particularly in long term or chronic conditions where biomedical solutions have no further impact on the condition. There is a clear role for clinical, counselling and health psychologists in these kind of settings, where the close relationship with the client group can act to maximise the resource represented by the patient group itself, whilst keeping clear controls over the aims and process of any intervention.

Without doubt, the final points of this discussion should acknowledge the enthusiasm and commitment of the nurses who took part in this research. A small amount of funding obtained from Marks and Spencer plc was enough to pay the expenses for nurses attending a training day and supply the resources free of charge. Nevertheless, at least two of the nurses had to take annual leave in order to attend. Some support groups took place at weekends during the nurse's free time, and all of the nurses were required to spend their own time in data collection. There is clearly a great deal of work to be done in ensuring that the psychosocial aspects

of medical and surgical conditions receive the attention that they deserve, and are properly funded, particularly given the evidence as in this research, that simple cost effective interventions can have a positive impact on social functioning and quality of life.

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