ORAL DISEASE IN DEPENDENT ADULT PATIENTS: EXTENT OF THE PROBLEM AND THE NEED FOR STAFF TRAINING

by

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FRONTISPIECE

Perhaps I simply need to explain that if special care dentistry is about humanity then dental public health is about equality. It is about identifying those people whose oral health is most compromised and taking action to make it better. It is to bring them in from the periphery and put them at the centre; to bring them up from the lowest level and put them at the top. For those who are neither seen nor heard it is to see them and be heard on their behalf.

J Sinclair-Cohen, 1999

For John, Caroline and Neil

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Last, but not least, my patients.

PREFACE

This thesis has been compiled from January 1999 to January 2000, under the guidance of Professor Jeremy Bagg.

The text and the personally authored studies represent original work carried out by the author. Where studies have been performed in collaboration with others, this is made clear in the text and on the authorship of the published papers. These studies have not been submitted in any form to any other university, but two of the publications cited describe work previously submitted to the University of Glasgow in fulfilment of the degree of MSc (Med Sci) conferred in 1996.

DECLARATION

This thesis is the original work of the author

....

M. Petrina Sweeney

January 2000

SUMMARY

The data reported in this thesis provide a description of the extent of oral disease among three groups of adults with special needs, namely the elderly, those with advanced cancer and patients suffering from psychiatric illness. In all three groups, the prevalence of oral disease is high, but when the provision of oral care is examined, it is clear that there is widespread unmet treatment need. This results in reduced quality of life and creates the potential for development of systemic disease such as aspiration pneumonia.

The responsibility of providing oral care for dependent patients usually falls to medical and nursing staff. The literature discussed in this thesis illustrates that there are many barriers to the provision of such care by health care workers other than dental personnel. Mouth care is typically given a low priority in relation to other nursing tasks and is often undertaken by the most junior staff. One of the underlying problems is a widespread lack of knowledge of oral disease and practical mouth care procedures among health care workers. Studies have identified that this probably stems from a lack of training at both undergraduate and postgraduate levels. The final chapter of this thesis describes the development of multi-media training materials, produced by dental personnel for other groups of carers, particularly medical and nursing staff, to provide essential information on detection and prevention of oral disease. External evaluation of these training aids has proved their potential value in this context.

The conclusion to be drawn from all the material presented in this thesis is the need for a much greater level of interdisciplinary working, both in relation to staff training and in the provision of mouth care for dependent patients. It is only when such interactions take place that there will be a significant oral health gain for those unable to care for themselves.

CHAPTER 1

ORAL CARE FOR THE SPECIAL NEEDS ADULT PATIENT: A MULTIDISCIPLINARY PROBLEM

1.1 INTRODUCTION

The term 'special needs' dentistry has arisen in recent years to describe the provision of dental care for adults with physical or mental health problems, which complicate their clinical management or reduce access to care. The term has not been clearly defined on an international basis and means different things to different people. In the United States of America, the discipline of 'oral medicine' plays a large part in the management of medically compromised patients. In the United Kingdom more of the active care of such patients occurs within the community dental service, in which many of the Senior Dental Officer posts have been dedicated to the care of 'special needs' patients, both paediatric and adult.

Within the United Kingdom, 'special needs dentistry' is not yet a recognised speciality. However, efforts are being made to rectify this situation and one of the surgical colleges is planning a diploma in special needs dentistry, which will provide a training and career pathway for those working in this area. In one London teaching hospital a Consultant in Special Needs Dentistry has been appointed and the same institution also has a Professor of Special Needs Dentistry.

Thus, 'special needs dentistry' has become something of a 'catch all' term. There are, however, a number of professional associations which are dedicated to the issues of 'special needs dentistry'. As these are potentially relevant foci for those involved in the development of 'special needs dentistry' as a discipline, they will be described briefly in the ensuing sections.

1.2 PROFESSIONAL ORGANISATIONS

1.2.1 The International Association for Disability and Oral Health

The International Association for Disability and Oral Health (http://www.iadh.org/) was formerly the International Association of Dentistry for the Handicapped, and is still known as the IADH. The Association serves as a focus for national academies, associations, societies and federations as well as for individuals striving to improve access to, and the quality of, oral health for people with disabilities. The IADH traces its roots to the first International Congress of Dentistry for Handicapped People in Atlantic City, USA, in 1971. The Association was officially formed at the Third International Congress in Stockholm in 1976. Since that time a major activity of the Association has been the biennial congresses held in a variety of international locations. The Association exists to:

- Improve and develop international communications by acting as a forum for the exchange of information in the area of oral health care for people who are disabled in some way, intellectually, physically, medically, sensorily or socially.
- Represent these activities at national and international organisations like the Federation Dentaire Internationale (FDI) and the World Health Organisation (WHO).
- Initiate, support and advance the teaching of oral health care for people with disabilities in all the health disciplines.
- Encourage research and scholarship in oral health care for people with disabilities.
- Raise the awareness of related health professionals of the need for oral health professionals to be involved in the overall care of those with disabilities.

1.2.2 The Academy of Dentistry for Persons with Disabilities (ADPD)

The Academy of Dentistry for Persons with Disabilities is an American organisation, which provides technical and moral support for clinicians and facilitates networking among caring, involved peers. Its activities are stated as follows:

- The Annual National Conference on Special Care Issues in Dentistry provides a forum for friendships, as well as for the exchange of ideas. It also helps to assure members that they are practising within the accepted standards of care for dental patients with special needs.
- The ADPD is a group of involved professionals. If a member has a difficult case or needs advice on any topic related to dental care for patients with disabilities, he or she can call a free-phone number and an experienced colleague will provide a personal consultation. This is a unique service of the ADPD.
- The ADPD advocates on behalf of both patients with special needs and clinicians who serve them. Advocacy issues include access to care, adequate pre-doctoral education, and fair and reasonable compensation for services. In this regard, ADPD benefits from its association with the Federation of Special Care Organisations in Dentistry (http://www.bgsm.edu/dentistry/foscod/). Joint advocacy allows a more forceful voice when intervening on behalf of the special needs of the groups served by the Federation.
- The *Special Care in Dentistry* journal is published six times a year and is the only journal dedicated to the special concerns of dentistry for people with special needs.

- The ADPD newsletter, *Interface*, provides timely information on current and future events within the field and the organisation.
- Membership of the ADPD also provides entitlement to membership of the International Association of Dentistry for the Handicapped (see above).

1.2.3 British Society for Disability and Oral Health (BSDH)

This UK-based society (http://www.bsdh.org.uk/) is affiliated to the International Association for Disability and Oral Health and has over 600 members. In response to pressure from its membership and to a precedent set by the International Association, the former title of 'British Society of Dentistry for the Handicapped' was formally changed to 'British Society for Disability and Oral Health' in December 1998. It had been felt by people with impairment, carers and the dental team, that the old title was stigmatising and did not accurately reflect the client group for whom oral care was being provided.

The stated objectives of the society are as follows:

- To improve, preserve and protect the oral health of people of all ages with disabilities.
- To undertake study and research into the provision of dental care for people with disabilities and to publish the useful results thereof.
- To develop undergraduate and postgraduate teaching in the subject.

It achieves these objectives through a range of activities. The society holds two scientific meetings each year, a winter meeting in London and a spring meeting at various locations

throughout the UK. Meeting programmes cover a wide range of topics, behavioural and social as well as clinical. The proceedings of the society are published annually and, as well as reporting on the scientific meetings, include articles and items of information relevant to special care dentistry. The Society welcomes contact from disabled people or their carers who have experienced difficulty in obtaining dental care. A register is kept of the specific areas of interest of members, which can be used to put clients in touch with appropriate dental services.

The Society has also produced a series of guidelines covering:

- Oral health care for long stay patients and residents.
- Oral care for people with a physical disability.
- Oral care for people with a learning disability.
- Sedation and day case general anaesthesia for people with special needs.
- Oral health care for people with mental health problems.
- The oral management of oncology patients requiring radiotherapy: chemotherapy: bone marrow transplantation.

1.3 THE NEED FOR MULTIDISCIPLINARY WORKING

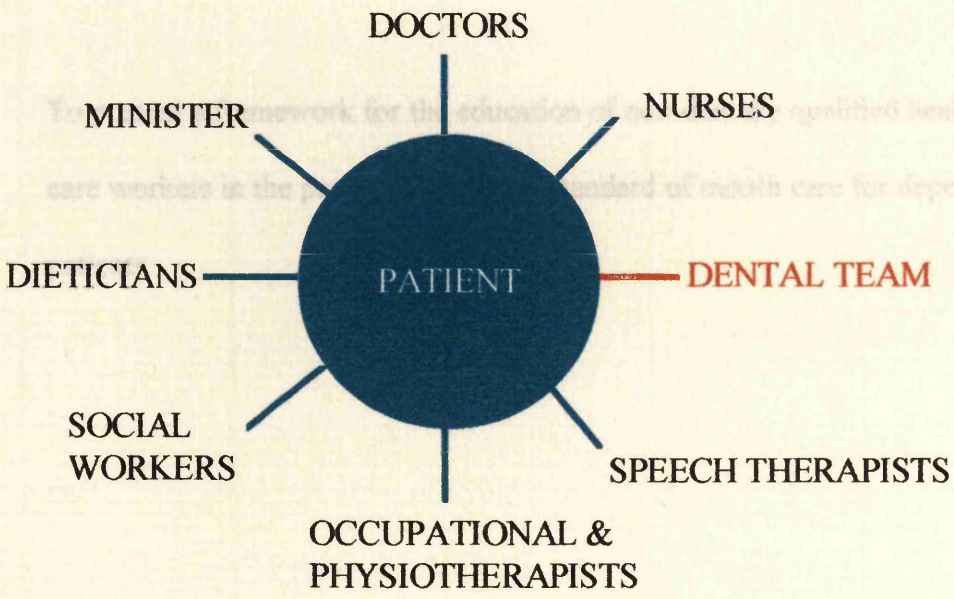
Providing care for patients with 'special needs' is often very demanding but can also be extremely rewarding. Maintenance of a high standard of oral hygiene is important for all groups of patients with special needs. Some patients may be able to undertake all or part of their own oral care, but a large number will need help to enable them to achieve a

standard of care which will lessen the need for operative intervention. It is well documented, however, that unrecognised and untreated oral disease is widespread among this category of patient, both in hospital and in those being cared for at home or in other environments, as will be discussed at length in this thesis. An appropriate Oral Health Standard (Scottish Office Department of Health, 1995) can be defined as: 'a standard of health of the oral and related tissues without active disease which enables the individual to eat, speak and socialise without discomfort or embarrassment and contributes to general well-being'. Results of research, however, show that this criterion is not being satisfied for a large number of elderly, systemically ill and related categories of patient. Relevant data will be presented in this thesis.

Nursing, medical and other healthcare staff have the potential to play a critical role in the provision of oral care for these patients and multi-disciplinary team work must be encouraged (Ettinger and Manderson, 1975; Hoad-Reddick,1985). Although active dental treatment can be provided only by the dental team, daily oral care can be provided by a variety of carers as long as suitable training has been given. Such training is essential, since Ettinger (1997) reports that most caregivers have never been shown how to care for another person's oral health. Regular examination of the mouths of these patients is also an important task, which tends to fall to doctors, nurses and other caregivers. Unfortunately, as detailed in Chapter 5, the training on oral and dental disease provided for doctors and nurses is often inadequate. As a result, painful and distressing conditions of the oral cavity are often misdiagnosed or missed entirely in this vulnerable group of patients.

If this situation is to be avoided, multidisciplinary teamwork and multidisciplinary education must be encouraged, so that all aspects of patient care can be considered. Communication between all those involved in the care of 'special needs' patients is essential, with all disciplines recognising the role each other has to play (Figure 1). It is self-evident that multidisciplinary team working will function most effectively when the various members of the team understand and respect each other's ideas and perspectives (World Health Organisation, 1990). In simple terms, a team is a group of individuals with a common purpose working together. Each individual will have a particular expertise and training, and will be responsible for making individual decisions within his area of responsibility. The common purpose will be understood by the individual members coming together to share knowledge and information and out of this discussion there will emerge plans for future action. Communication is the thread that runs through teamwork, bringing all the pieces together into a coherent whole (Cummings, 1998). Only a committed level of interdisciplinary interaction will ensure improvement in the oral health of 'special needs' adult patients.

Figure 1 A selection of the various groups of personnel involved in the multidisciplinary care of adult special needs patients



1.4 AIMS OF THESIS

The authored papers presented in this thesis (Appendix IV) represent the culmination of 12 years of clinical work and clinical research undertaken in the provision of oral care for dependent adult patients, in particular the elderly, those with advanced cancer and patients with psychiatric illness. The two aims of the thesis are as follows:

1. To present data highlighting the extent of oral disease among three groups of adult special needs patients.

2. To present a framework for the education of non-dentally qualified health care workers in the provision of a high standard of mouth care for dependent patients.

CHAPTER 2

ORAL DISEASE AND ITS MANAGEMENT IN THE ELDERLY

2.1 INTRODUCTION

Ageing is a very broad issue, affecting cells, physiological systems, provision of clinical care, society, economics and ethics. Ageing has become an important issue because of dramatic changes in life expectancy. For example, only one in six Britons born 150 years ago reached 75 years of age, whereas two thirds of those born today will do so (Greengross *et al*, 1997). At the present time, people over 60 constitute a fifth of the British population, but will be a third by 2030 (Greengross *et al*, 1997). The fastest growing section of the British population are those over 80 years old and the structure of the population is changing to one in which older people will outnumber children, a situation for which society is not yet properly prepared (Greengross *et al*, 1997).

The aim of science and medicine is not so much to lengthen life as to reduce the number of years that people spend diseased or disabled. At present, those aged 60 in Britain must expect to spend about a quarter of their remaining years with some disability (Khaw, 1997). In the USA, more than five million people over the age of 65 have limitation with at least one activity of daily living, for example bathing and dressing and with one instrumental activity of daily living, for example shopping, cooking or taking medication (Leon & Lai, 1990). However, healthy ageing is clearly possible and those who are rich, well educated, do not smoke and are physically active are experiencing what has been described as a 'compression of morbidity', enjoying their extra years of life in good health (Greengross *et al*, 1997). Provision of appropriate oral health care should be seen as part of this whole process. The following sections will outline the oral health problems experienced by the elderly, consider their implications for general health and examine the

delivery of oral care for the elderly.

2.2 ORAL DISEASE IN THE ELDERLY

There have been many studies of oral disease in the elderly, but careful interpretation is necessary. It is important to realise that there is a large degree of heterogeneity among persons aged 65 years and over (Nelson & Dannefer, 1991). The elderly represent a complex combination and expression of individual genetic predispositions, lifestyles, social situations and environments, all of which affect their health, including oral health. Thus, a chronologic definition of the ageing population is not particularly useful in dentistry and a functional definition has emerged that categorises the ageing population into three distinct groups based on ability to seek services (Ettinger & Beck, 1984):

- Functionally independent older adults.
- Frail older adults.
- Functionally dependent older adults.

Not surprisingly, the poorest oral health and the greatest need for treatment and oral care support is seen in the latter two groups. In particular, oral health of the institutionalised elderly gives great cause for concern and will be described separately (Section 2.3).

Another problem in relation to all aspects of health care among the elderly is the observation by Stoller (1982) that many older persons view illnesses as the 'inevitable consequences of ageing', and therefore expect to be less healthy, less active and to feel ill.

As a result they do not seek out health care. These sentiments are particularly prevalent in less affluent socio-economic groups, among whom there is a much higher incidence of both chronic and acute disease (Syme & Berkman, 1976). Thus many elderly patients will not seek professional dental help for either routine care or for potentially significant and sinister lesions such as mouth ulcers, which they view as part of the normal ageing process.

2.2.1 Edentulousness

The number and percentage of edentulous older adults has declined consistently over the last 30 years (Anonymous, 1999). Recently, data from the WHO Global Oral Data Bank for non-institutionalised European adults aged 65-74 years for the period 1986-96 have been published (Bourgeois, Nihtila & Mersel, 1998). They showed that the proportion of 65-74 year olds who were edentulous varied from 12.8% to 69.6%, depending on the country, indicating clear disparities across Europe (Bourgeois, Nihtila & Mersel, 1998). Many factors are implicated in the reduction in edentulousness. There have been changing attitudes towards oral health and dentistry among the general population, and these have been influenced to some degree by technologic advances in restorative dentistry. Fluoride has also had an impact. In addition, the attitude of dentists has changed from one of extractions and replacement with complete dentures to one of restoration and maintenance of teeth, together with prevention and restoration of function and aesthetics (Ettinger, 1993).

2.2.2 Periodontal disease

Increasing age has been established as one of the risk factors for periodontal disease (Grossi *et al*, 1994 & 1995). However, it is not clear whether this risk is related to intrinsic changes resulting from ageing or is the consequence of earlier pathology that has been untreated over a period of time. Cross-sectional population-based surveys demonstrate a close association between increasing age and increased prevalence and severity of periodontal disease (Kamen, 1997). In the USA, a large amount of information pertaining to periodontal epidemiology has been made available from large population-based surveys conducted for the American government. Trends emerging from two such studies were analysed by Douglass and colleagues in 1983. One significant trend was an increase in the number of people without periodontal disease and a second trend was towards decreased edentulism in all age cohorts. The authors concluded that this decline in edentulism and increase in number of teeth per person might contribute to greater risk of advanced periodontal disease problems in the later decades of life.

In combination, the results of a number of surveys (Beck *et al*, 1990; Burt, Ismail & Eklund, 1985; Haffajee *et al* 1991; Hunt *et al*, 1985; Ismail *et al*, 1990; Ship & Wolff, 1988) suggest:

- A continuing decline in edentulism.
- A strong association between loss of attachment and increasing age.
- Severe attachment loss restricted to a relatively small portion of the population.

- A strong association between increased recession and increasing age.
- A high prevalence of gingival inflammation (as manifested by bleeding) among all age groups.

Another factor to consider in relation to periodontal disease among the elderly is the impact of medical risk factors and of medication. Many older patients have chronic diseases and whilst these may not directly affect the periodontal tissues, they may have indirect effects. For example, patients with rheumatoid arthritis may have difficulty maintaining oral hygiene through inability to hold a toothbrush or manipulate other tooth cleaning aids such as floss. Diabetes mellitus is another common disease of the elderly that has important implications for periodontal care (American Academy of Periodontology, 1996).

Drugs prescribed for the over 65 year old age group account for nearly one third of all drugs prescribed in the USA (Paunovich, Sadowsky & Carter, 1997). Direct effect of medications on gingival tissues is manifested most commonly as gingival enlargement. This reaction is associated primarily with anti-convulsants, immunosuppressants (cyclosporin) and calcium channel blocking agents. Phenytoin is associated with the highest rate, occurring in approximately 50% of patients and the severity appears to be related to dose, plasma levels and duration of therapy (Dongari, McDonnell & Langlais, 1993). Calcium channel blocking agents are especially relevant to the elderly, since they are used for a wide variety of cardiovascular disorders including hypertension, arrhythmias, angina and coronary artery spasm. The greatest prevalence of gingival

overgrowth in this class of medication is associated with nifedipine (20-40% of patients) and diltiazem (20%) (Fattore *et al*, 1991).

2.2.3 Dental caries

In many industrialised societies, recent years have seen a decreased caries rate in children and an increasing caries rate in the ageing population. Indeed, it has been shown that the incidence of caries in a population aged 65 and older is greater than in a population of 14 year olds living in a nonfluoridated area (Hand, Hunt & Beck, 1988; Klein *et al*, 1985). In the elderly, one study showed that untreated caries was most commonly found on the crowns of the teeth (25%), although a substantial number (18%) also had root caries (Heft & Gilbert, 1991). One longitudinal study of caries in older adults has found that over three years, caries developed on an average of 2.4 coronal surfaces and 1.1 root surfaces per person per year (Hand, Hunt & Beck, 1988). For the elderly who are functionally frail and unable to manage oral hygiene measures independently, the rates are much higher (Weyant *et al*, 1993).

Existing data suggest that caries is present in more than 95% of the elderly population (Ettinger, 1997). Those at highest risk are the mentally confused and physically frail, most of whom are homebound or institutionalised. It is inappropriate merely to place restorations for such patients without helping them to improve their diet and / or oral hygiene measures. Fluoride use may help to re-mineralise early lesions, agents such as chlorhexidine can reduce the number of acidogenic bacteria and sugar substitutes may reduce the acidogenic environment (Clark, Morgan & MacEntee, 1991). However, one

of the major problems is the education of the older adult population and, more particularly, the education and motivation of the carers of functionally dependent older adults to perform oral hygiene measures regularly. This issue is covered in more detail in later sections of this thesis.

2.2.4 Oral mucosal lesions

Oral mucosal lesions are common in the elderly, but many of these are expressions of oral manifestations of systemic disease, poor nutritional status, side-effects of drugs and oral infections, rather than age changes in the mucosa *per se*.

Denture stomatitis

Denture wearing is one of the more common factors associated with oral mucosal changes in the elderly (Budtz-Jørgensen *et al*, 1996; MacEntee, Glick & Stolar, 1998; Schou, Wight & Cumming 1987). Denture-induced changes include mucosal inflammation, such as diffuse and granular denture stomatitis, atrophic changes and denture-associated hyperplasia. There is a strong relationship between denture stomatitis and the presence of *Candida albicans* (Cross, 1998). Dentures that are worn continuously and not cleaned adequately become covered in denture plaque, that contains a wide variety of microorganisms, including *C. albicans* (Cross, 1998). It is the production of inflammatory mediators by these organisms that is responsible for denture stomatitis.

The reported prevalence of denture stomatitis depends on the population examined and the diagnostic criteria used (MacEntee, 1985). As a result, the prevalence of denture stomatitis quoted in the literature varies widely from 9% to 97% (Budtz-Jörgensen, Stenderup & Grabowski, 1975; Manderson & Ettinger, 1975; Smith & Sheiham, 1979; MacEntee, 1985). In studies using randomised samples, designed to be representative of the elderly population as a whole, the prevalence of denture stomatitis ranges from 16.3% to 65% (Love, Goska & Mixson, 1967; Budtz-Jörgensen, Stenderup & Grabowski, 1975; Smith & Sheiham, 1979; Mikkonen *et al*, 1984; Ambjörnsen, 1985; Hand & Whitehill, 1986).

Angular cheilitis

Denture stomatitis has a frequent association with angular cheilitis, which is present in 33-82.6% of patients with denture stomatitis (Chick, 1962; Cawson 1965; Mäkilä, 1969; Ritchie *et al*, 1969; Davenport, 1970; Russotto, 1980; Bergendal & Isacsson, 1983). Although *Candida*-associated denture stomatitis has been proposed as an important aetiological factor of angular cheilitis (Cawson, 1963; Nairn, 1975; Rose, 1968), the condition is also found in dentate, non denture-wearing patients (Öhman *et al*, 1986). It is generally accepted that angular cheilitis has a multifactorial aetiology (Davenport, 1970) which includes nutritional deficiencies, such as iron deficiency anaemia (Rose, 1968; Mäkilä, 1969; Burton & Thomson, 1972; Murphy & Bissada, 1979), vitamin B12 deficiency (Mäkilä, 1969) or folic acid deficiency (Rose, 1971). Shuttleworth and Gibbs (1960) and Cawson (1963) emphasised the aetiological importance of microbial infection, particularly with *C. albicans,* which is frequently present in angular cheilitis lesions.

MacFarlane and Helnarska (1976) and Dahlén *et al* (1982) pointed out the association of organisms other than yeasts, namely *Staphylococcus aureus* and β– haemolytic streptococci. The roles of *S. aureus* and *C. albicans* in angular cheilitis are not clear, although Cawson (1963) and Nairn (1975) found that lesions heal rapidly after antifungal therapy. Furthermore, they suggested that topical application of antifungals to the angles of the mouth is unnecessary if denture stomatitis is adequately treated. Prior to this, Lyon and Chick (1957) had already stated that angular cheilitis resolved when the associated denture sore mouth was successfully treated. Some workers (Ritchie & Fletcher, 1973) have reported the association of angular cheilitis with poorly designed or faulty dentures, in particular a loss of the vertical dimension. However, other studies (Cawson, 1963; Turrell, 1968; Öhman *et al*, 1986) suggest that neither loss of the vertical dimension nor the condition of the dentures seem to be significant factors in the aetiology of angular cheilitis.

Staphylococcal mucositis

Bacterial infections of the oral mucosa are far less common than both fungal and viral infections. *Staphylococcus aureus* has already been mentioned in relation to angular cheilitis (MacFarlane & Helnarska, 1976). Recently, the author and colleagues have described a form of intra-oral mucositis caused by *S. aureus* in elderly patients who are completely dependent, receiving nasogastric or PEG tube feeding and whose mouths have become dry through mouth breathing and lack of oral care (Bagg *et al*, 1995). Thick, hard mucous crusts develop on the oral mucosa (Figure 2.1), which can be removed with a moistened gauze, often with resultant bleeding.

Staphylococcal mucositis can be prevented by maintenance of impeccable oral hygiene through regular oral lavage, which is also the most important element of treatment. Flucloxacillin can also be considered in the management following culture and sensitivity testing.

Figure 2.1 Two patients with staphylococcal mucositis. The crusted material poses a major risk factor for aspiration pneumonia in the elderly.

Denture-associated hyperplasia

Resorption of the alveolar ridges results in a gradual deterioration in the fit of dentures over time. The response of the oral soft tissues to this low-grade irritation is denture-induced hyperplasia (Watson & MacDonald, 1982). This occurs most commonly at the periphery of complete dentures, especially in the mandible, where support and retention are poorer and the rate of resorption is four times greater than in the maxilla. There may be associated ulceration and keratosis.

Drug-associated changes in the oral mucosa

Many of the chronic systemic diseases associated with old age are treated with drugs, which may have an adverse effect on the oral mucosa. These have been reviewed recently (Paunovich, Sadowsky & Carter, 1997). Examples would include xerostomia caused by antidepressants, lichenoid reactions caused by non-steroidal anti-inflammatory agents and oral ulceration caused by nicorandil (Agbo-Godeau *et al*, 1998).

Oral cancer

As for most cancers, the incidence of oral cancer is higher among older adults, with an average age at diagnosis of over 60 years (Salisbury, 1997). It should therefore be thought of as a disease of older adults. However, in addition to ageing, there are other well-recognised risk factors for oral cancer, the most significant of which are tobacco and alcohol use. In men, a long history of smoking increases the risk of oral cancer by seven times and in women the increased risk is 12 times (American Cancer Society, 1996). Alcohol consumption is also a risk for oral cancer, although most oral cancers are found

in individuals who use both alcohol and tobacco, for whom the risk is compounded beyond what either produces individually. A large case-control study showed that the risk of oropharyngeal cancer increased more than 35 times in individuals who consumed two or more packs of cigarettes and more than four alcoholic drinks per day (Blot *et al*, 1988). Early detection of oral cancer in the elderly is, therefore, a very important part of the duties of all health care workers. This is particularly important because of the asymptomatic nature of early oral cancer. Dentists and other health care professionals who examine the mouth should focus on the following:

- Patients with known risk factors predisposing them to oral cancer.
- Sites in the mouth where oral cancer is most likely to occur.
- Clinical appearance of areas of keratosis and, more importantly, erythroplakia.

Appropriate management of oral cancer requires a multidisciplinary approach and staff education is a major issue (see Chapter 5). Dentists should be involved at all stages of oral cancer care, including initial diagnosis and referral, prevention and treatment of sequelae from surgery and radiotherapy, and prosthetic rehabilitation of the oral cavity and other selected facial structures.

2.3 ORAL HEALTH OF INSTITUTIONALISED ELDERLY

It has been widely stated that institutionalised elderly people have poorer oral health than those living at home (Steele *et al*, 1998). The number of people over sixty-five years of age in the United Kingdom is rising annually and will continue to do so. As the proportion of elderly people in society increases, the number of private residential establishments catering for their needs is also increasing and there has been a marked change in the pattern of residential care for this group. Before the early 1980's most of this care was provided by local authority run social services or charitable / church - funded institutions, but with the onset of 'care in the community' there was a marked swing to private residential care, with many of the local authority homes closing down (Hoad-Reddick, 1992). Although these private nursing homes were obliged to register with a central agency - the Registered Nursing Home Association - they were not obliged to provide regular dental / oral care for their residents.

Many surveys of the elderly have highlighted oral problems (Figure 2.2) (Ritchie 1973; Grabowski & Bertram, 1975; Fiske, Dans & Watson, 1990; Sweeney *et al*, 1995). Particular problems relating to elderly residents in long stay care were found to be dirty dentures, lost dentures and high levels of oral pathology (Gerrish *et al*, 1971; Manderson & Ettinger, 1975; Hoad-Reddick, 1985). National data from the United States show that more people than ever before are retaining some natural dentition and among those with teeth, the number of teeth is rising (Weyant *et al* 1993). Other studies show a high caries incidence among older institutionalised adults, with both coronal and root caries common (Weyant *et al*, 1993). In fact, Chauncey and co-workers (1978) reported that the dental

caries incidence among adult veterans was higher than the rate commonly found in children when the number of surfaces at risk are considered.

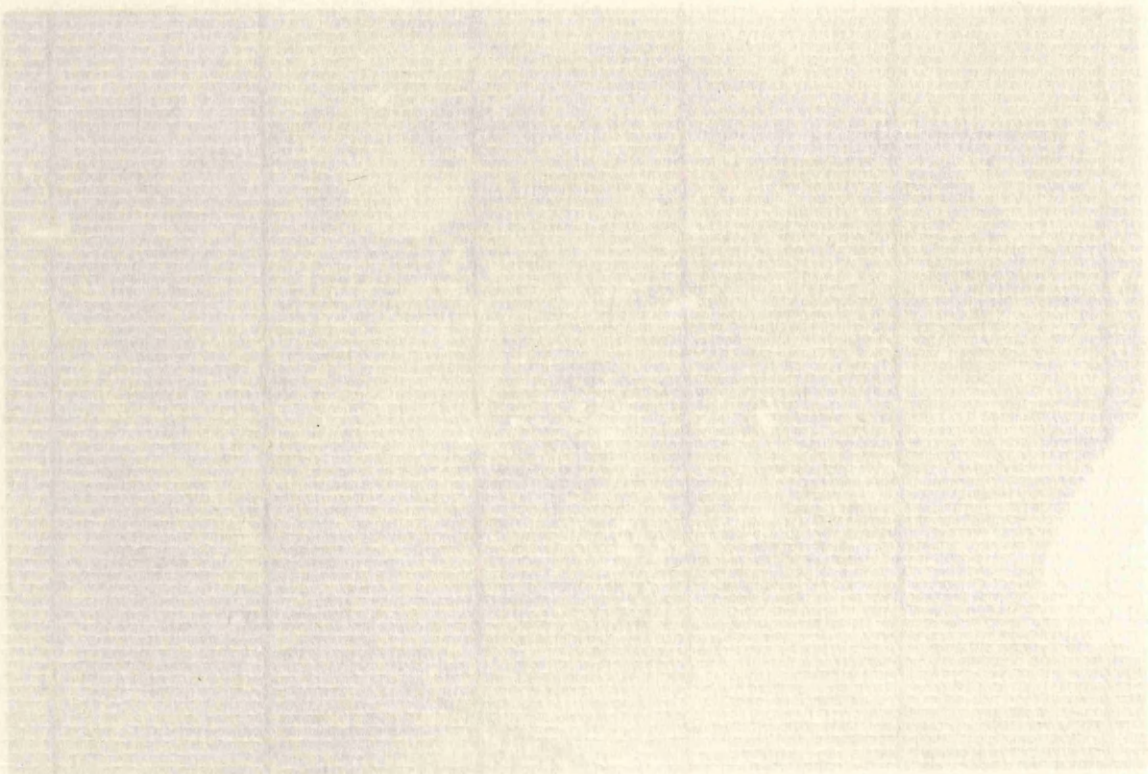


Figure 2.2 Extensive oral pathology in the oral cavity of an elderly patient referred to the author from a long-stay ward in a hospital for care of the elderly.

The presence of chronic debilitating diseases is always higher in a population of elderly people residing in institutions than it is in the population at large (Manderson & Ettinger, 1975). In one study it was found that 83% of the patients interviewed had medical conditions or were taking medications which would put them at risk for general anaesthesia, minor oral surgery (including exodontia) or would, due to physical disabilities such as arthritis, disseminated multiple sclerosis, Parkinson's disease or cerebrovascular disease, hinder routine treatment (Manderson & Ettinger 1975). The presence of a physical disability also affects the patients' ability to manage their own oral care.

Despite much evidence showing that dental health of the institutionalised elderly is poor and that there is a great need for treatment, which would benefit the elderly and improve their quality of life, provision of dental care for this group tends to be poor. Dental care is often not provided at all because administrators, patients and their families fail to recognise that patients continue to need dental attention even though they are chronically ill or aged, and thus facilities and personnel for providing dental services tend to be inadequate (Simons, Kidd & Beighton, 1999).

Simons, Kidd and Beighton (1999) further reported that managers and deputy managers indicated that there was no systematic approach to arranging dental care. Dental care was sought only when acute problems such as pain or a broken denture presented. Furthermore, dental assessments were not carried out routinely on admission and there were no care plans that included oral care. Hoad-Reddick (1992) showed clearly that

there is little investigation of dental status when people enter residential accommodation, dentures are not routinely named and dentists make few regular, routine visits to elderly people's homes.

Obviously there is much room for improvement in the provision of dental services for long-term care adult patients, a group who would benefit from simple preventive measures such as daily oral hygiene, either self- or care-worker assisted, and from regular oral assessment.

2.4 ASSOCIATIONS BETWEEN ORAL DISEASE AND SYSTEMIC DISEASE IN THE ELDERLY

2.4.1 Oral health, diet and nutrition

The mouth is an integral part of the gastro-intestinal system and disease of the dental tissues is abundant and in many cases irreversible. The sequelae of dental disease, such as tooth loss and impaired masticatory function are cumulative over a lifetime and may have a limiting effect on dietary intakes. The diet may also have a major impact on the condition of the dental tissues, dietary sugars being instrumental in dental caries and acid-rich foods implicated in tooth wear (Steele *et al*, 1998).

If a person is unable to chew and swallow nutritious foods because of missing or painful teeth, then his or her medical health will deteriorate (Loesche *et al*, 1995). Regular oral and dental check-ups and intervention could improve the quality of life for the elderly by

keeping them free from infection, allowing them to be comfortable and to enjoy mastication and consequently nourishment (Manderson & Ettinger, 1975).

There is a definite relationship between the condition of the mouth and a person's ability to eat a range of foods (Steele *et al*, 1998). It also follows that if oral intake is limited in any way then the intake of certain nutrients must also be limited, which could in turn impact further on the status of the teeth and supporting structures. Steele *et al* (1998) found that a significant number of elderly institutionalised patients were unable to eat certain foods such as nuts, raw carrots, steak, lettuce and toast, because of the condition of their teeth. There was little difference found in the level of nutrient intake between the dentate and the edentate elements of the institutionalised patients (Steele *et al*, 1998). This perhaps reflects the nature of the food provided within the institution, which may be tailored to the masticatory capacity of the edentate element of the sample without making allowance for the presence of some residents with teeth who might be capable of managing a more varied diet. However, data relating to the chewing problems with individual items and the daily nutrient intakes related to dental status suggest that being edentate, having fewer natural teeth and having fewer pairs of occluding natural teeth affected the types and quantities of food and nutrients consumed (Steele *et al*, 1998). Analysis of nutrient intake showed that edentate people had lower mean intakes of protein, intrinsic and milk sugars, non-starch polysaccharides (fibre), calcium, non-haem iron, niacin and vitamin C than dentate people. In dentate people, the number of natural teeth was also related to the nutrient intake, with those having 21 teeth or more showing higher mean intakes than those with 20 teeth or less (Steele *et al*, 1998).

The relationship between dental status and blood and plasma levels of haematological and biochemical analytes was also explored, to examine whether the relationship demonstrated between foods consumed, nutrient intakes and dental condition was related to haematological and biochemical markers of nutritional status (Steele *et al*, 1998). For both mean haemoglobin and plasma iron levels, the difference between edentulous and dentate patients was found to be non-significant. Dentate patients with a dry mouth did, however, exhibit significantly reduced mean haemoglobin levels. There was also a highly significant association between edentulism and plasma ascorbate (vitamin C) levels with the edentulous level being significantly lower than the dentate. The group reported similar findings for 25-hydroxy vitamin D (25-OHD) and plasma retinol (vitamin A) but not for plasma -tocopherol (vitaminE) , riboflavin, thiamin or plasma calcium and phosphate (Steele *et al*, 1998).

Steele *et al* (1998) also looked at the relationship between diet and dental disease and found significant differences between institutionalised and free-living elderly patients with respect to the frequency of sugar intake. The institutionalised sample consumed a wide range of foods high in sugar content, including confectionery and table sugar, and exhibited more decayed tooth surfaces and greater accumulations of plaque. Overall Steele *et al* (1998) concluded that being edentate or having fewer pairs of teeth could affect what older people were able to eat easily, or at all and this had a definite impact on nutritional status.

In the USA, the 1976-1980 National Health and Nutrition Examination Survey (NHANES) survey revealed that low-income, non-institutionalised elderly had inadequate dietary intakes of vitamin B6, folate and zinc. Zinc deficiency can lead to a loss of taste, which can result in decrease in dietary intake, or an excessive use of salt (Marshall & Saunders, 1990). According to Konis (1991) many dietary deficiencies in the elderly can be observed as oral lesions or abnormalities. In a Scottish study of 37 geriatric patients, those with mucosal pathology had significantly lower serum iron concentrations ($p=0.02$) (Sweeney *et al*, 1994). However serum or plasma concentrations of zinc, copper, selenium, vitamin A and vitamin E were not significantly different between those with oral disease and those with healthy mouths (Sweeney *et al*, 1994).

Deficiencies of B complex vitamins can show up in the soft tissues, for example, niacin deficiencies (pellagra) affect the tongue and other oral soft tissue and can cause the tongue to swell and press against the teeth (Konis, 1991). Most of the B vitamins, with the exception of B12, are not stored in the body to any great degree and therefore regular daily intake is important for maintenance of oral as well as overall health. Calcium deficiency in the elderly may result in osteoporosis and may be exacerbated by vitamin D deficiency. Vitamin C deficiency has notable consequences for the oral tissue (Rubinoff, Latner & Pasut, 1989). It is required for many metabolic processes and it appears to enhance the development of intracellular ground substance in bone, dentine and other connective tissue. Deficiency in this vitamin can cause oedematous interdental and gingival tissue, which can lead to ulceration and bleeding. If left untreated this can cause

the loosening of the teeth and marked halitosis that is characteristic of scurvy.

Oral health makes eating enjoyable as well as possible and can greatly improve the quality of life for the older individual. It is important, therefore, that elderly patients are screened regularly to ensure that difficulties arising from poor dentition, ill-fitting dentures, swallowing problems or any other symptom that makes eating uncomfortable, can be treated rapidly to avoid nutritional deficiency.

2.4.2 Systemic infection from an oral source

The oral microflora is increasingly recognised as a source of systemic infections in the elderly. As the colonisation resistance of the oral mucosa changes with age and general ill health (Bagg, 1990), exogenous micro-organisms such as aerobic Gram negative bacilli (Sedgley & Samaranayake, 1994) and *Staphylococcus aureus* (Jackson *et al*, 1999) become more prevalent in the oral flora. These organisms, together with members of the normal oral flora, are implicated particularly in aspiration pneumonia.

Pneumonia is the fourth overall leading cause of death and is the leading infectious cause of death in the elderly (Chan & Welsh, 1998). The majority of cases of bacterial pneumonia are acquired from the microaspiration of colonised oropharyngeal flora (Chan & Welsh, 1998). The elderly may be at increased risk of such aspiration from a depressed level of consciousness, oropharyngeal dysynchrony, or alterations in deglutition due to stroke, senile dementia, medications or Parkinson's Disease (Chan & Welsh, 1998; Lee-Chiong & Matthay, 1996). Normal oropharyngeal flora, composed of a mixture of

aerobic and anaerobic bacteria, may account for a significant number of cases of pneumonia (Hill & Sanders, 1991). It has been estimated that the overall incidence of anaerobic lung infection caused by aspiration of oral flora may be as high as 33% (Bartlett, 1987; Hill & Sanders, 1991).

There are now a significant number of studies which are demonstrating an association between poor oral health and respiratory tract infection in the elderly (Mojon *et al*, 1997; Limeback, 1998). The importance of this issue is graphically illustrated in Figure 2.1, which shows friable crusts, heavily infected with *Staphylococcus aureus*, on the palate in two patients with staphylococcal mucositis (Bagg *et al*, 1995). Another recent study has suggested a relationship between dental disease and cerebrovascular accident in the elderly (Loesche *et al*, 1998). As it becomes increasingly clear that poor oral health can have a significant deleterious effect on the general health of the elderly, the need to improve mouth care for this section of the population becomes ever more pressing.

2.5 PROVISION OF ORAL HEALTH CARE FOR THE ELDERLY

2.5.1 Introduction

It is clear from the preceding sections that there is a high level of need for dental services among the elderly, particularly the institutionalised, and that there are many problems related to the provision of this care. These include attitudes to dental treatment and perceived need for such treatment by both patients and carers, difficulty of access for the patients and paucity of training in oral health and disease throughout the healthcare team.

2.5.2 Clinical techniques

It is important to realise that when providing treatment for elderly patients, standard techniques may need to be modified or adapted. The presence of systemic illnesses such as Parkinson's Disease, stroke disease or Alzheimer's Disease may make dental treatment more difficult. These patients often have a problem with communication, taking longer to understand and respond to simple commands, they may have a short attention span and they may have an impaired swallowing reflex leaving them vulnerable to pulmonary inhalation. Also, conditions such as rheumatoid arthritis may render the patient less mobile and will affect manual dexterity. Particular tolerance, patience, reassurance, compassion and understanding are required for any treatment and it is important that patients are not pushed beyond their limits. Non-verbal communication - touch, gesture and facial expression- are important, as is an understanding that the patient may not be able to recline fully in the dental chair, or even sit in a dental chair.

Simple preventive interventions are recommended, such as the daily use of fluoride gels to prevent or limit both root and coronal caries and the daily removal and cleaning of dentures (complete and partial) to reduce the prevalence of fungal infections in this group. Regular daily toothbrushing is essential for the dentate elderly. Those with impaired ability may find it easier or preferable to use a brush with a modified handle to aid their grip, or an electric toothbrush. One study showed that an electric toothbrush was superior to a manual brush for removing supragingival plaque among nursing home residents when oral care was provided by a carer (Day, Martin & Chin, 1998). This does, of course, have serious cost implications for the nursing home.

Regular inspection of all prostheses for comfort, fit and ease of use should also take place. Prosthetic treatment in this group can be difficult for a variety of reasons. As previously stated, certain medical conditions, for example dementia and stroke disease, can make the wearing of a denture difficult. Presence of resorbed or flabby ridges also poses problems with comfort and retention as do both xerostomia (a side effect of many drugs) and drooling and pooling of saliva associated with Parkinson's disease. It is important to remember that many older people experience great difficulty when presented with new dentures and that it is often preferable to repair or adapt existing dentures, where possible, for further use.

Overall, when planning dental treatment for elderly patients it is important to consider the individual requirements of the patient and to be realistic about the amount of treatment that is possible and acceptable to the individual.

2.5.3 Access and utilisation of service

Dental attendance patterns of the elderly are poor. In England and Wales there is a very low uptake of NHS dental care among people more than 75 years of age. Of this age group, only 30% registered with a general dental practitioner in 1992 compared with 61% of all adults (Annual Report of the Dental Practice Board 1991-2, Eastbourne Dental Practice Board, August 1992). When only frail and functionally dependent elderly people who find it difficult to go out unaided are considered, it is suggested that this figure drops to 7 - 14% (Annual Report of the Dental Practice Board 1991-2, Eastbourne Dental Practice Board, August 1992). A study by Lester, Ashley & Gibbons (1998)

confirmed that the dental attendance pattern of frail and functionally dependent elderly is very low, with only 25% of the study population having attended a dentist in the previous two years. This figure was lower still in the older groups, the edentulous and in those in residential homes.

Barriers to care have been investigated and found to include mobility, cost of treatment, perceived need and lack of dental knowledge of carers (Lester, Ashley & Gibbons, 1998). Lack of understanding and fear of dental problems have also been shown to be important factors that prevent elderly patients from seeking treatment. Problems with hearing and eyesight, medical problems which tend to be more common with advancing age, such as angina, incontinence, impaired respiration or side-effects from prescribed drugs may also make it more difficult for an elderly patient to contemplate dental treatment. Many carers state that they have difficulty in arranging transport to and from dental premises and experience problems in providing an escort to attend with the patient. Easy access to the dental surgery is important for those elderly patients living in the community, therefore the dental premises should be situated close to public transport routes, have adequate parking facilities and provide wheelchair access by ramp (Hoad-Reddick, 1995). Problems for many elderly people could be overcome if domiciliary care were more readily available and Hoad-Reddick (1995) showed that many elderly, especially the very old, would prefer this. Carers' attitudes are very important when discussing barriers to care for this patient group. Older carers and those who were unpaid perceived insurmountable barriers. Carers who had received dental treatment themselves in the previous year were more likely to perceive a benefit (Hoad-Reddick 1995).

Those elderly least likely to seek care are the very old and those in long-term care but they are as entitled to good oral health as people in the community. Admission to residential care, whether temporary or permanent, should not mitigate against the maintenance of a resident's oral health. However certain groups in residential care, particularly the elderly, have poor oral health and inadequate or restricted access to dental services (BSDH Guidelines, 1997). Facilities and personnel for providing dental services tend to be inadequate, because the managers of the residential care establishments fail to recognise a need for this type of continuing care and often ignore it until emergency care is required (Simons, Kidd & Beighton, 1999). One study looking at the dental status of an institutionalised elderly population found that 71% of those studied required prosthodontic treatment, such as occlusal adjustments, relining or replacing dentures (Manderson & Ettinger, 1975). Eleven per cent of these people required removal of retained roots or hyperplastic tissue before the prosthodontic treatment could be carried out. A further small group required both periodontal and restorative treatment (Manderson & Ettinger, 1975). Thus, the need for dental intervention was high.

In order to deliver adequate oral health care to individuals in need of care, the concept of access must be addressed. Perchansky and Thomas (1981) define access as 'the fit between clients and the system', which is reliant on availability, accessibility, accommodation, affordability and acceptability. If any component of the concept of access is not addressed for either the patient or the service-provider then barriers to the receipt of care can arise (Matear, 1998). Finch *et al* (1998) found that both cost and

anxiety were the two main barriers to an adult seeking dental care. However, within the elderly population these barriers would appear to be less important. For a geriatric population the main barriers may be the perceived need for dental care and the perceived importance of dental care (Kiyak, 1989). These barriers highlight the importance of educating all healthcare workers in the holistic care of the elderly population as well as the need for an integrated approach to total health care including oral health care (Matear, 1998).

2.5.4 Oral health promotion

Health promotion is any combination of educational, organisational, economic and environmental supports for behaviours conducive to health (Green & Lewis, 1986). In an ageing population, oral health promotion is generally focused on the prevention of caries, periodontal disease and oral cancer (Erickson, 1997). The prevalence of these diseases among the elderly has been discussed earlier. Preventive dentistry has been very successful within younger populations and has resulted in a higher proportion of adults entering old age with standing teeth. It is important that oral health promotion is not neglected for older adults and that it is applied broadly enough to include diseases such as oral cancer. In a survey of preventive programmes for older adults, deBaat and colleagues have highlighted the need for instruction and demonstration, together with reinforcement and systematic evaluation (deBaat, Kalk & Schuil, 1993). They also suggested that programmes should be appropriately adapted for the ability of the individual or population for whom they are designed. Oral health promotion among the elderly has been an area of active research within the USA and has been reviewed by Gift

(1992). The dental profession should be seen to take the lead in provision of up to date and appropriate oral health promotion for the elderly. This may include training in these issues for other groups of carers, an important role for the dental team, which will be discussed in the next section and in Chapter 5 of this thesis.

2.5.5 Staff training

As previously stated, many more people are now living into old age and many more of these elderly are retaining some natural teeth. This will inevitably have a significant impact on the field of dentistry as more elderly patients utilise healthcare institutions or seek care in non-institutionalised settings such as the home, community-based clinics or private practice (Matear, 1998).

Oral health closely correlates with general health and for that reason alone should be carefully looked after in all patients, but particularly the elderly. One report stated that in a recent study of elders admitted to hospital, 70% were found to have dental infection, 95% had periodontal disease and 75% had difficulty chewing (Thompson, 1999). The level of dental and mouthcare knowledge amongst different grades of nurse is inadequate (Rak & Warren, 1990) and yet oral care for the institutionalised elderly is generally provided by nursing aides who, by their own admission, have received little formal training in mouthcare. One study states that only 41% of nursing aides reported attendance at a dental in-service programme in their nursing facility during the previous year (Chalmers *et al*, 1996). Other authors relate that oral care issues receive little attention in most nursing school curriculae and that within nursing organisations, oral

health care is not standardised and is often neglected (Arvidson-Bufano, Blank & Yellowitz 1996; Benson, Maibusch & Zimmer, 1980; Hunt, 1987). This lack of training in oral issues is not just restricted to nurses, as figures presented in Chapter 5 of this thesis show that there is little training in oral disease, prevention and mouthcare within both the undergraduate and postgraduate medical curriculae throughout Great Britain.

Elderly people who are functionally dependent because of physical frailty, mental confusion or dementia are at the highest risk for dental and oral disease because of their inability to maintain oral hygiene independently. Unless caregivers or significant others are trained and motivated, maintenance of oral health is not possible and disease is inevitable (Ettinger, 1997). Although the dental team gain a thorough knowledge of oral anatomy and pathology, oral disease and prevention during their undergraduate years, it is important to stress the need for continuing post-graduate education. If they are to treat elderly patients appropriately, members of the dental team must be knowledgeable not only about dental materials and procedures but also about the psychosocial aspects of ageing, systemic diseases, pharmacological issues, environmental and other mental health issues that confront the older individual (Saunders, 1997). The importance of continuing medical education for all members of the healthcare team cannot be overstated and this issue will be dealt with more fully in Chapter 5. It is also important to note that fundamental changes in attitude towards the issues of oral health and disease are required throughout the health care system if the problems described above are to be dealt with effectively. Such a change can only be achieved by the development of a comprehensive oral health care programme which would alert carers to the importance of regular oral

hygiene and provide them with the necessary skills and resources to take appropriate action (Eadie & Schou, 1992).

2.5.6 Advocacy

Advocacy is defined as ' The process of interceding, defending and pleading the cause of another'. In relation to health care for older adults, advocacy is important because this patient group is very vulnerable and the rights and needs of the elderly patient can easily be neglected. Hospital in-patients, in particular, have little or no access to ordinary advice and information services, therefore it is necessary to take such a service to them and to act as a link to other services. Attitudes towards older people with mental health problems tend to be devaluing and condescending. Hence they need independent 'allies ' to offer autonomy and dignity. This subject will be discussed more fully in Chapter 4, since it is of particular relevance to those with psychiatric illness.

The principles of advocacy state that any person, whatever the nature of their disability, has the right to:

- Be treated in a dignified manner and valued as equals.
- Be consulted about their needs and influence plans being made to meet those needs.
- Be neither over-protected nor under-protected.
- Avoid being segregated from the rest of the community in work, education,

recreation or where they live.

Sinclair-Cohen (1999) perhaps puts this all into context when he describes a patient with grand mal epilepsy resident in a psychogeriatric hospital on the outskirts of Jerusalem: 'We notice him straight away as he is lying with his mouth wide open. As we approach we both fall silent at what we see. His mouth is covered in plaque and his upper premolars are almost completely buried by gingival hyperplasia. His body is arched back with his eyes looking heavenwards, his hands *main accoucheur* almost as if he is begging..... *"Brush his teeth?"* challenged a nurse..... *"Why should we?"'*

Why should we? We should because the issue here is not teeth, it is humanity. These patients should have their teeth brushed for the same reason that they have their hair brushed, to give them the dignity of being treated like human beings.

2.6 RELEVANT AUTHORED PAPERS

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CHAPTER 3

ORAL DISEASE AND ITS MANAGEMENT IN PATIENTS WITH ADVANCED CANCER

3.1 DEFINITION OF PALLIATIVE CARE

Care of patients for whom there is no effective curative treatment, or who are considered to be in a terminal condition, has always been part of the duties of doctors, nurses and other healthcare workers. Until recently it was not regarded as a speciality, either for the medical or nursing professions, but was carried out on an 'ad hoc' basis. As a result of this, many patients received inadequate care and their families inadequate advice and support. It was only as recently as 1987 that palliative medicine was recognised as a medical speciality (World Health Organisation, 1990).

Although the hospice has been a recognised institution for the care of dying and incurable patients outwith their own homes since medieval times, it was only in the mid 1970's, after the publicity associated with Cicely Saunders' work in the hospice movement, that the need for palliative care was widely recognised and hospices and other palliative care units increased in number throughout the United Kingdom, Northern Europe and the United States (Stoddard, 1979). Of the modern hospice concept, Dr. Cicely Saunders says, 'This is indeed a place of meeting. Physical and spiritual, doing and accepting, giving and receiving, all have to be brought together... The dying need the community, its help and fellowship...The community needs the dying to make it think of eternal issues and to make it listen...We are debtors to those who can make us learn such things as to be gentle and to approach others with true attention and respect'.

It was only in 1987 that an attempt to define palliative care was made. Palliative care, as described by the World Health Organisation (1990) is: '*The active total care of patients*

whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families'.

'Palliative care affirms life and regards dying as a normal process.....neither hastens nor postpones death.....provides relief from pain and other distressing symptoms .....integrates the psychological and the spiritual aspects of care.....offers a support system to help patients live as actively as possible until death.....offers a support system to help the family cope during the patient's illness and in their own bereavement'.

Fletcher, in 1960, stated: 'The classical deathbed scene, with its loving partings and solemn last words, is practically a thing of the past; in its stead is a sedated, comatose, betubed object, manipulated and subconscious, if not subhuman' (Stoddard, 1979). Hopefully, with the advent of hospice care, this sort of political and coldly clinical health care has become a thing of the past. Death must simply become the discrete but dignified exit of a peaceful person from a helpful society. A death without pain or suffering, and ultimately without fear. Rezendes, in 1976, was perhaps optimistic, though certainly taking a step in the right direction, with his view that: 'In the course of the next decade, the Hospice programme will no longer be innovative, but will be folded right into the existing healthcare system. Everybody in the health field will be sensitive to, and knowledgeable about, the care of terminally ill patients and their families' (Stoddard, 1979).

3.2 HOSPICES AND HOME CARE - THE ROLE OF MACMILLAN NURSES AND DISTRICT NURSES

According to the Oxford English Dictionary, 'Hospice (ho'spis)' is defined as 'A house of rest and entertainment for pilgrims, travellers or strangers....for the destitute or the sick'. The term was described in a petition by the citizens of London to Henry VIII in 1538 as '...For the ayde and comforte of the poore, sykke, blynde, aged and impotent persones...whereyn they may be lodged, cherysshed and refreshed'.

Palliative care can be applied outwith the hospice. Some patients may be more suitably treated at home, in accordance with their own or their families' wishes. For others, a hospice may be more appropriate because of home circumstances or in view of the specialist nature of the treatment required.

Specialised units dedicated to palliative care may be:

- A ward within a general hospital.
- A free-standing unit within a hospital complex.
- A free-standing unit geographically separate from any other hospital (a hospice) (Doyle, 1998).

Many people are involved in palliative care - medical and nursing staff, physiotherapists, speech therapists, occupational therapists, dentists, dieticians and other support staff who should all be trained in the care of these patients. Teamwork is essential, with all team members having a role to play. Palliative care will only be successful if all members of the

team recognise that everyone has a different skill and that in different situations different skills may be required, therefore communication and co-operation are essential (Cummings, 1998; Lowe & Herranen, 1981; Bennet & Corcoran, 1994). Hospice work must begin with the question, 'what does this patient need?'. Patient and family wishes must be respected, even if this goes against the recommendation of the care team. When dealing with patient care at home and trying to balance the wishes of the patient and family against the aim of the staff to attain perfect care, compromise is often necessary. Comfort, respect and dignity for the patient are of paramount importance. There is no place for professional competition and certainly not for suspicion, criticism or defensive distancing.

In the home setting, some members of the team may be called on more than others, for example the homecare or Macmillan nurse, the district nurse and the Marie Curie nurse. Macmillan nurses are funded by a national charity called Macmillan Cancer Relief (http://www.macmillan.org.uk) which supports people with cancer and their families by providing specialist information, treatment and advice. Macmillan's aim is to ensure that everyone has access to the best information, treatment and care, which will make people's lives easier and reduce unnecessary levels of fear. The first Macmillan nurses were established in 1975 and by the end of 1997 there were 1600 Macmillan nurses working throughout the UK. They aim to help patients and their families from the moment cancer is diagnosed. These nurses can give advice about treatments and are experts in controlling pain and other symptoms. They spend time with patients and their families, helping them accept and cope with the many emotional and practical problems they may

face and also help to guide them through the often overwhelming amount of information they receive during their illness. Many Macmillan nurses are based in the community, helping people to remain in their homes, whilst others support patients in hospital. They work as part of a team with other nurses, doctors and a variety of other health professionals to ensure that treatment and care for patients, from hospital to home, is continuous.

A vital part of a Macmillan nurse's job is to share knowledge and skills with students, other nurses and doctors. In doing this, they help to raise the level of skill and knowledge of cancer care throughout the health service. In fact, in the author's experience, it is often the Macmillan nurse who is responsible, in the first instance, for requesting dental advice for a patient with oral problems.

District or Community nurses are employed by the National Health Service and are accountable to senior managers in that service, but may either be attached to a medical practice or work in a designated geographical area. These nurses have a wide variety of duties. They are not specifically trained in palliative care but they are expected to carry out all aspects of such care. They give comprehensive care to the patient in their own home including general nursing care, dressings, routine injections, catheter care and oral care. In relation to the latter, the level of training is often inadequate (see Chapter 5). The community nurse may also be called on to deliver dietary advice, offer emotional support and order essential nursing equipment and aids. Liaison with specialist palliative care nurses and other healthcare professionals such as community physiotherapists,

occupational therapists and community dentists is another important aspect of the work of a community nurse.

Marie Curie nurses (http://www.mariecurie.org.uk), who may be registered general nurses, enrolled nurses or even nursing auxiliaries, provide a unique practical nursing service across the UK to cancer patients who choose be nursed in their own homes. Referrals are usually made via the District nurse or by the patient's medical practitioner. These nurses give nursing care throughout the day or night, free of charge, and give those looking after patients at home the opportunity to take a break from caring in order to rest, go shopping or simply get a good night's sleep.

3.3 ORAL DISEASE IN PATIENTS WITH ADVANCED CANCER

3.3.1 Introduction

From the few published studies to date, it is clear that patients suffering from advanced cancer at any primary site frequently present with symptoms and signs of oral disease (Pople & Oliver, 1986; Clarke *et al*, 1987; de Conno *et al*, 1989; Jobbins *et al*, 1992b; Aldred *et al*, 1991; Sweeney *et al*, 1998). The extent of the need for oral and dental care among cancer patients is frequently underestimated and there has been a reported failure by many hospice administrators to appreciate the problem (Gordon, Berkey & Call, 1985). However, in the United Kingdom, physicians and nurses working in palliative medicine are leading the way in providing high quality mouth care for those with serious illness. Nevertheless, there remains an important need for training, as highlighted by a

recent paper examining the provision of mouth care by nursing staff for cancer patients in Scotland (Sweeney *et al*, 1996). Patients may not complain spontaneously of what they believe to be inevitable discomfort in their mouths, or they may be physically or mentally unable to do so. It is important, therefore, that such patients are specifically questioned about mouth problems and that their mouths are examined regularly to reveal signs of treatable oral pathology. The terminally ill need, by definition, palliative and not necessarily curative care (see Section 3.1). Any therapeutic measures used should, therefore, relieve distressing symptoms and, if possible, delay progression of the disease process, but should not worsen the prognosis.

Many hospice units across the United Kingdom do not have the services of a dentist / dental team. Dental emergencies are dealt with as and when they arise, but experience has shown that for administrative and practical reasons, it is often difficult to arrange for emergency dental care. All too often, however, oral problems are overlooked due to lack of knowledge and lack of skilled personnel. This is perhaps not surprising, as attitudes to dentistry, particularly in the United Kingdom, are such that patients, their relatives and the hospice staff are likely to have a fear or dislike of dentistry and display an almost antagonistic misunderstanding of the necessity for dental care. They certainly do not recognise the dentist as an important member of a multidisciplinary team involved in care of the dying. The author's personal experiences support this statement, having many times been asked why a dying person should be 'bothered' by a dentist. A close relationship between the dental team, the hospice and the Macmillan team is desirable, as oral problems frequently manifest themselves as a result of a patient's weakened

condition, side-effects of drug therapy or treatment such as radiotherapy, chemotherapy or surgery. In addition, those with oral cancer may need specialised oral care provided under the supervision of professionally qualified staff. There is an obvious need for close liaison between the disciplines of dentistry and medicine, particularly palliative medicine, and there is also a need for adequate training in oral care for all members of the palliative care team. This issue is dealt with more fully in Chapter 5.

If regular dental care, including emergency treatment, is to become widely available, formal arrangements with Community Health authorities, or funding for outside provision, has to be considered. It is not within the powers of any of the team members already providing care to organise further services. The ethic within which palliative care operates needs to be an ethic of action, an ethic that mobilises and links governments, institutions, programmes, services, persons and resources, to form a tissue of effective bonds of compassion, a vision that no one is a stranger to us among those who anguish and suffer as they face loss and death (Roy & MacDonald, 1998).

The predominant oral problems experienced by those with advanced cancer and aspects of their management will be described in the ensuing sections.

3.3.2 Oral dryness (xerostomia)

Oral dryness is one of the most upsetting and common symptoms affecting patients with terminal cancer (Clarke *et al*, 1987; Gordon, Berkey & Call, 1985; Jobbins *et al*, 1992b). In one study, 77% of 197 terminally ill cancer patients complained of xerostomia (Jobbins

et al, 1992b). In addition to the distressing nature of this problem for the patients, the lack of saliva also predisposes to other types of oral pathology, for example candidosis. There are many general causes of xerostomia, several of which are relevant to the terminally ill, but drug therapies are probably the most important (de Conno *et al*, 1989). Many of the drugs used in palliative medicine, for example opioids, phenothiazines and anti-depressants reduce salivary flow (Sreebny & Schwarz, 1997). Permanent damage to salivary glands occurs in patients given local radiotherapy for treatment of tumours of the oral cavity or the oropharynx (de Conno *et al*, 1989). The effects of xerostomia on patients' symptoms are varied. They may complain of a burning mouth (de Conno *et al*, 1989). Soreness of the mouth may also result from mucosal infections secondary to xerostomia, for example candidosis (Pople & Oliver, 1986; Clarke *et al*, 1987; Finlay, 1986; Jobbins *et al*, 1992b) or staphylococcal mucositis (Bagg *et al*, 1995). The absence of the protective effect of saliva on the oral mucosa is an important factor in facilitating spread of these infections and of permitting colonisation by exogenous bacteria (Jobbins *et al*, 1992c). The loss of lubrication makes chewing and swallowing difficult and painful, contributing to anorexia. In denture wearers, retention of their prostheses becomes problematic. Alteration in taste discrimination is another feature of xerostomia which can affect appetite. Dry mouth may also seriously affect speech, leading to further discomfort, difficulty in communication and subsequent frustration and embarrassment for patients, relatives and carers (de Conno *et al*, 1989). Finally, in addition to protecting the oral mucosa, saliva plays an important role in preventing loss of tooth substance by both direct and antimicrobial activity and by buffering (Gibson & Beeley, 1994).

Therefore it is not surprising that dental caries and dental erosion may become problematic in terminally ill patients with xerostomia.

Xerostomia (dry mouth) is defined as the subjective feeling of oral dryness (Sreebny & Valdini, 1987; Fox *et al*, 1985; Crocket, 1993; Fox, Busch & Baum, 1987). The principal causes of xerostomia include drug treatments, dehydration states and salivary gland disease such as Sjögren's syndrome or previous radiotherapy to the head and neck region. Most frequently it is induced by drugs that inhibit the flow of saliva. Sreebny and Schwartz (1986) listed 315 medications that had been documented as inducing varying degrees of xerostomia. The anti-cholinergic drugs are, by definition, bound to cause a degree of xerostomia, but xerostomia is also a side-effect of drugs in other categories, for example some antidepressants, antihistamines, antihypertensives, sedatives, hypnotics and diuretics. Irradiation of the head and neck damages both the salivary acini and the vascular supply to some extent, depending on the dose (Sreebny *et al*, 1992). Xerostomia can occur within a short period and may be irreversible, particularly if bilateral exposure of the glands is unavoidable. Since the serous cells are more sensitive to radiation than are the mucus-secreting cells, the residual secretion after irradiation tends to be reduced in amount and is more viscous (Sreebny *et al*, 1992).

3.3.3 Oral candidosis

About 40% of healthy adults harbour yeasts in their mouths as commensals, with no evidence of mucosal disease (Arendorf & Walker, 1979). *Candida albicans* is one of many candidal species found in the oral cavity and this organism is responsible for most

oral candidal infections (Samaranayake & Lamey, 1988). A minority of infections are caused by at least 12 other species including *C.glabrata*, *C.tropicalis*, *C.parapsilosis* and *C.krusei* (Samaranayake & Lamey, 1988). *Candida* species are notorious opportunistic pathogens. Both general factors, such as diabetes mellitus, and local predisposing factors, for example poor denture hygiene, are important in the pathogenesis of oral candidal infections. Debilitated patients, such as those receiving antibiotic, steroid or cytotoxic therapy, are particularly susceptible to oral candidosis. Xerostomia, from whatever cause, is a further important predisposing factor.

High levels of candidal carriage have been reported among the terminally ill (Pople & Oliver, 1986; Clarke *et al*, 1987; Finlay, 1986; Jobbins *et al*, 1992b; Jobbins *et al*, 1992c) with correspondingly high levels of mucosal disease.

Clinical Features

Oral candidosis can be classified into three clinical types: pseudomembranous, erythematous and hyperplastic (Wray & Bagg, 1998). Apart from these three types, there are a number of related conditions in which oral yeasts are implicated. These include angular cheilitis, in which there may also be a staphylococcal element, and median rhomboid glossitis which is now believed to be a low-grade chronic candidal infection.

- **Pseudomembranous candidosis (Thrush)**

Pseudomembranous candidosis presents clinically as a thick white coating (pseudomembrane) on the affected mucosa which can be rubbed off to reveal a granular,

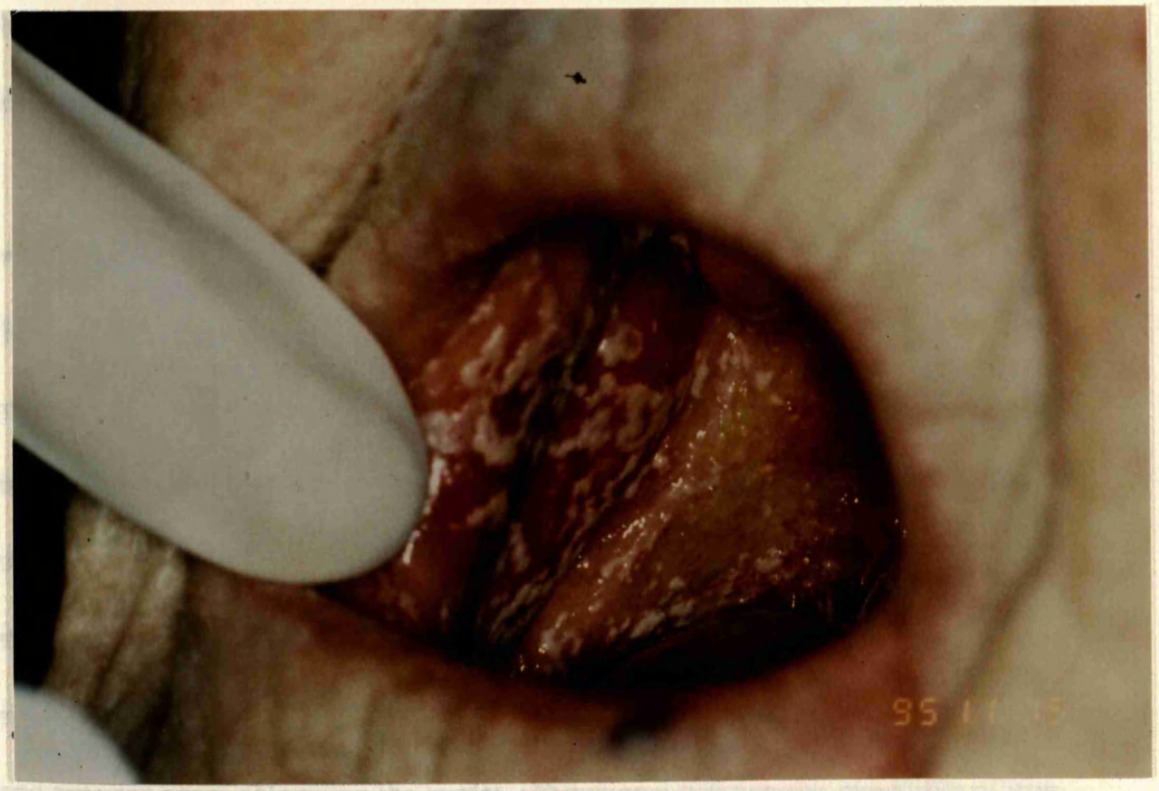
erythematous base (Figure 3.1). Lesions may occur on any mucosal surface of the mouth and can vary from isolated patches to large confluent areas.

- **Erythematous candidosis**

Intra-oral candidal infection frequently causes erythema of oral mucosa in addition to, or instead of, white patches. Denture stomatitis is the commonest form of erythematous candidosis. The characteristic picture is of an area of erythema and oedema corresponding exactly to the fitting surface of the upper denture. Poor denture hygiene, continuous wearing of dentures and tobacco smoking are thought to be contributory factors, as is a high carbohydrate diet which favours candidal growth.

Erythematous candidosis, not necessarily associated with denture wearing, may also occur (most commonly on the dorsum of the tongue) following the use of broad-spectrum antibiotics, or in patients undergoing prolonged corticosteroid therapy. More recently, erythematous candidosis has been described as a feature of HIV infection.

Figure 3.1 Pseudomembranous candidosis (oral thrush) in an elderly patient with advanced malignancy.



- **Hyperplastic candidosis (Candidal leukoplakia)**

This presents as persistent white patches on the oral mucosa which are clinically indistinguishable from leukoplakia. These plaques are firmly adherent, unlike those of thrush. In some cases there are areas of erythema within the plaque, producing a speckled leukoplakia. Typical sites are the buccal mucosa just within the commissures, or the dorsum of the tongue. The lesions are often bilateral. Long-standing angular cheilitis and denture stomatitis may be associated. In many patients there is a long history of tobacco smoking and denture wearing. Diagnosis depends on biopsy. The lesion is premalignant, with epithelial dysplasia seen in 50% of cases.

- **Angular cheilitis**

This is frequently associated with intra-oral candidosis, particularly with denture stomatitis. It may be a mixed infection with *Staphylococcus aureus* or less frequently beta-haemolytic streptococci (MacFarlane & Helnarska, 1976). Clinically, angular cheilitis may affect one or both angles of the mouth and presents as painful, cracked, erythematous fissures at the corners of the mouth. It can occur in dentate patients, edentulous or partially dentate patients and is the result of organisms from the oral cavity and anterior nares colonising the angles. Nutritional deficiencies, especially of iron, folate and vitamin B12, are recognised predisposing factors.

3.3.4 Oral viral infections

Herpes simplex virus (HSV) is the commonest cause of viral infection of the oral mucosa. Like all herpes viruses, following resolution of the primary infection HSV establishes latent infections. Intermittent, asymptomatic shedding into the oral cavity may occur in health (Kameyama *et al*, 1988) as may secondary (reactivation) infections, typically in the form of herpes labialis. However, among immunocompromised hosts reactivations may be atypical, often intraoral, and severe (Figure 3.2). Such reactivations have been described in up to 65% of patients with leukaemia (Barrett, 1986; Barrett, 1987), although others describe a much lower incidence (Dreizen *et al*, 1982). Another group showed that HSV culture was positive in 85% of patients with chemotherapy-induced stomatitis (Rand, Kramer & Johnson, 1982). It is likely that the incidence of HSV infections among the immunocompromised is underestimated, because of the wide range of possible clinical presentations (Barrett, 1986; Barrett, 1987). Laboratory diagnosis by culture or rapid antigen detection (Bagg *et al*, 1989) is therefore essential for confirmation of the clinical diagnosis. Treatment is with antiviral agents such as aciclovir or penciclovir. Limited data are available on either asymptomatic shedding of HSV or on oral mucosal infection with this virus in patients with terminal cancer (Sweeney *et al*, 1998), but in the author's experience atypical HSV reactivations are a relatively common cause of acute, painful oral ulceration in the palliative care setting.

Figure 3.2 An atypical intra-oral reactivation of herpes simplex virus in an elderly lady with advanced breast cancer. The diagnosis was confirmed by viral culture and the lesions responded well to systemic aciclovir.

3.3.5 Cytotoxic drugs and stomatitis

Cancer patients are liable to suffer from specific oral adverse effects of the treatment for their malignant disease. These effects are due to direct toxic damage to the tissues of the mouth. Some anti-cancer drugs, for example 5 fluorouracil, methotrexate and vinblastine, are especially liable to result in stomatitis, and it is important to minimise damage by trying to avoid concomitant treatment with drugs of other classes which may result in xerostomia or have other adverse interactive effects.

Inhibition of stomatitis is important for a number of reasons, the most obvious of which is prevention of pain and thus improvement in quality of life. In addition, it may help to maintain compliance with treatment regimes, thus permitting higher chemotherapy dose intensity and improving the likelihood of treatment success (Nguyen, 1992). Severe ulceration of the oral cavity can limit nutritional intake, hinder proper oral hygiene, increase the risk of local and systemic infection and cause serious pain and bleeding. Appropriate management is, therefore, essential (Childers *et al*, 1993). Chemotherapy - associated stomatitis may, in fortunate patients, be mild. On the other hand it may be so severe as to be life-threatening, thus requiring cessation of chemotherapy. Damage to the oral mucosa is a result of impaired cell division and disruption of the normal replacement of superficial epithelium by basal layers. Mucosal damage is generally dose-related, with increased risk of mucosal toxicity accompanying high dose induction therapy, escalating dosage patterns, continuous infusion (versus bolus doses) and combination chemotherapy/radiotherapy treatments.

Oral mucositis starts with erythema and oedema then progresses to painful ulcerations. Ulceration is most prominent on non-keratinised tissue including the floor of the mouth, buccal mucosae and soft palate. Loss of epithelium as a protective barrier may result in local infections and provide a portal of entry for micro-organisms into the systemic circulation. This may result in life-threatening septicaemia in patients who are immunosuppressed (Landsaat *et al*, 1995). The incidence of oral infections is also influenced by antibiotic use during prolonged neutropenia which alters the flora of the mouth and creates a favourable environment for fungal super-infections. Bleeding of the gingivae may also occur, especially in the presence of thrombocytopenia. Other serious complications of oral mucositis include pain, haemorrhage, airway obstruction and nutritional deficiencies. The pain that accompanies oral mucositis is considered a major problem for the cancer patient and often requires continuous intravenous infusion as well as bolus doses of analgesia (Zerbe *et al*, 1992).

3.3.6 Alteration in taste sensation

Changes in taste sensation may be of three types. There may be a reduction (hypogeusia), distortion (dysgeusia) or absence (ageusia) of normal taste sensation. Between 25% and 50% of cancer patients are reported to experience taste disturbances (Twycross & Lack, 1986). As noted earlier, xerostomia may contribute to taste disturbances. However, zinc deficiency has been linked with abnormalities in taste sensation (Cohen, Schechter & Henkin, 1973) and it is of interest that zinc levels may be reduced in patients with malignant disease (Davies, Musa & Dormandy, 1986). Drugs

administered to treat cancer patients may also alter taste sensation (Willoughby, 1983). From personal experience, the author has found that alteration in taste perception or complete loss of taste sensation often proves to be one of the most troublesome symptoms for cancer patients. At a time when they are being actively encouraged to eat and drink as much as possible, to help regain lost weight and strength, they complain that all foodstuffs taste and feel like pulped cardboard. Eating should be a pleasurable activity but it rapidly becomes a chore when the sense of taste is lost.

3.4 MANAGEMENT OF ORAL DISEASE AMONG THE TERMINALLY ILL

3.4.1 Routine mouth care

The importance of routine mouthcare for terminally ill patients cannot be over-stressed. Good, regular oral hygiene is fundamental to the well-being of cancer patients. Lesions of the oral cavity are often painful and unpleasant and can impact greatly on the quality of life of patients with advanced cancer, interfering with both physical and psychological function. If the sore mouth interferes with the patient's ability to eat, then malnutrition, anorexia and cachexia may result (Ventafridda *et al*, 1998). The mouth also plays a vital role in communication, the pleasures associated with eating and drinking and even kissing. If the mouth is too painful to allow the patient to anticipate and enjoy food, too dirty and offensive to allow close contact with family and friends, then psychological distress and social isolation are inevitable.

Oral hygiene procedures need not be difficult or time-consuming but must be carried out regularly if the patient is to benefit. This is an area where family involvement should be encouraged if the patient so desires. Regular oral hygiene will allow the lips and the oral mucosa to be kept clean and moist by removing plaque and débris. It will help to prevent oral infection such as gingivitis, halitosis and also the development of tooth decay. For patients who wear complete or partial dentures, regular cleaning and moistening of the oral mucosa may allow the dentures to be worn at least while friends are visiting, thus reducing the degree of social embarrassment. Most importantly, regular oral hygiene will help to maintain a clean, healthy oral environment which is comfortable and functional.

3.4.2 Management of xerostomia

The management of xerostomia in patients with advanced cancer has been reviewed recently (Davies, 1997). The first element is to take a clear history and remove, if possible, any extraneous causes of oral dryness. Changes to regimens of drugs whose side-effects include xerostomia may sometimes be possible. Patients who are dentate should receive preventive advice (eg use of fluoride mouthwash) and dietary advice, as well as treatment of any caries present.

Relieving the symptoms of oral mucosal dryness is very difficult and, as yet, no single satisfactory method has emerged. At present two approaches are used, either stimulation of additional salivary secretion or use of salivary substitutes. Gustatory and masticatory stimulation, achieved by sucking sugar-free sweets or chewing sugar-free gum, can increase saliva flow but only in the short-term. The increased salivation only lasts for as

long as the stimulus is present. In addition, terminally ill patients are often in such a weakened state that the effort needed to physically chew or suck may be too great. Use of the parasympathomimetic drug pilocarpine can help patients with severe xerostomia by increasing saliva production both in the long and short term (Greenspan & Daniels, 1990). Many patients find that frequent sips of water or water sprayed from a pump dispenser are the most effective and best tolerated ways of dealing with their problem. However, several saliva substitutes are now commercially available, some fluoridated, both in spray and lozenge form. These, and the other treatment options already mentioned, will now be discussed more fully.

3.4.2.1 *Pharmaceutical agents used in the treatment of xerostomia*

Pilocarpine has been used the most extensively. Pilocarpine is an alkaloid, first isolated from South American plants of the genus Pilocarpus in the 19th century. It functions primarily as a muscarinic-cholinergic agonist and has potent effects on both smooth muscle and exocrine tissue, for example salivary and sweat glands (Fox *et al*, 1986). It has been used to combat xerostomia appearing as a side-effect of drug treatment, for example antihypertensives and tricyclic antidepressants (Prutting, 1965; Ferguson *et al*, 1991). The main side-effect of pilocarpine is sweating.

Within the field of palliative care, a recently published paper described a crossover study comparing a mucin-based artificial saliva (Saliva Orthana®) with pilocarpine hydrochloride (Salagen®) in the management of xerostomia in patients with advanced cancer (Davies *et al*, 1998). Whilst the pilocarpine proved more effective than the

artificial saliva, as judged by mean change in visual analogue scores for xerostomia, the former was associated with more side-effects, though these were generally mild (Davies *et al*, 1998). More patients wished to continue with the pilocarpine after the study, but overall 50% preferred the artificial saliva and 50% preferred the pilocarpine (Davies *et al*, 1998).

3.4.2.2 *Saliva stimulants and substitutes*

- **Saliva stimulants**

A range of agents has been suggested for stimulation of salivary flow. Citric acid was one of the earliest preparations to be recommended (Watanube & Dawes, 1988). It has been used in the form of sweets and chewing gum but, in view of the potential adverse effects on the dental hard tissues, its use has been supplanted by newer agents such as chewing gums and lozenges. These have not been examined among patients receiving palliative care but have had valuable effectiveness among trials in other groups, for example these with Sjögren's Syndrome (Aagard *et al*, 1992; s'Gravenmade & Vissink, 1993).

- **Saliva substitutes**

A clear-cut distinction cannot always be drawn between salivary stimulants and salivary substitutes. For example, mucin-containing lozenges function in both capacities. There are currently no ideal saliva substitutes. Their effects are of limited duration and they may have unpleasant tastes or textures. Most preparations available at present are based either on carboxymethylcellulose (CMC) or mucin (Levine *et al*, 1987). CMC imparts

lubrication and viscosity and the preparations usually contain sorbitol or xylitol to act as a sweetener and provide surface activity. However, they tend to be very viscous. As a result, animal mucins have been employed to produce substitutes with a viscosity and surface tension similar to that of human saliva. A number of clinical trials have compared the effectiveness of these two types of saliva substitutes (Visch *et al*, 1986) and, in general, the mucin-containing preparations are preferred by patients.

Within the palliative care setting, a recently reported double-blind, single-phase, placebo-controlled trial examined the effectiveness of the mucin-containing oral spray Saliva Orthana® for relief of xerostomia in hospice patients (Sweeney *et al*, 1997). There were no significant differences between those on the active spray and those using a mucin-free placebo for any of the symptoms recorded, but the majority of patients in both treatment groups wished to continue using a mouth spray at the end of the trial period (Sweeney *et al*, 1997). The value of an oral spray in relieving xerostomia had been reported previously from a double-blind, placebo-controlled trial of chlorhexidine oral spray in terminally ill cancer patients (Jobbins *et al*, 1992a), despite the fact that the chlorhexidine provided little benefit in relation to reduction of oral infection.

When one considers the complexity of natural saliva it is perhaps not surprising that none of the currently available saliva substitutes are ideal. However, great advances are being made in our understanding of salivary biochemistry (Beeley, 1993). The genes that code for some of the bioactive proteins in saliva are now being cloned and there is no reason why they should not be produced in due course (Gibson & Beeley, 1994). In the next few

years it is likely that completely new preparations will be available which have increased bioactivity. The use of lactoperoxidase-containing toothpaste (van Steenberghe *et al*, 1994) and a saliva substitute based on polyglycerylmethacrylate, lactoperoxidase and glucose oxidase (Oral Balance®) (Regelink, *et al*, 1998) in those with radiation-induced xerostomia, as reported recently, are good examples of this new generation of saliva substitutes.

3.4.3 Treatment of oral candidosis

Treatment of intra-oral candidal infections involves both non-specific and specific measures. In respect of non-specific measures, it is particularly important that denture wearers remove their prostheses overnight and soak them in a suitable cleansing solution, since the fitting surface of the denture is the main reservoir for *Candida* species (Arendorf & Walker, 1979).

Specific antifungal treatment may be provided either topically or systemically. The main topical treatments are nystatin and amphotericin B, neither of which is absorbed systemically. Nystatin is available in the form of oral suspension, pastilles, cream and ointment. Duration of therapy is based on clinical response and should be continued for at least two weeks after clinical resolution. Amphotericin B is also available as lozenges or as an ointment. Miconazole oral gel is particularly useful for the management of angular cheilitis, which often has a mixed aetiology (fungal and bacterial), as it has activity against Gram positive cocci as well as yeasts.

Three drugs are available for systemic treatment of oral candidosis. Ketoconazole is available in a number of oral and topical forms. The oral form is well absorbed but should be used with caution owing to recognised side-effects, notably liver toxicity. Fluconazole, a newer triazole antifungal agent, is available in both oral and parenteral forms and has a broad spectrum of action. It is useful in mucosal and cutaneous forms of candidosis and is well tolerated, but some resistant strains of *Candida albicans* are emerging following long term treatment, particularly among AIDS patients (Warnock, 1992; Cartledge, Midgley & Gazzard, 1997). Itraconazole, another triazole antifungal drug, is available in oral capsule form and has a broader spectrum of action. It is useful for deep forms of oral candidosis and is well tolerated. The newer cyclodextrin solution of itraconazole (Blatchford, 1990) has shown potential in the treatment of oropharyngeal candidosis among immunocompromised patients (Graybill *et al*, 1998). It has a dual topical and systemic action and may prove of value in hospice patients in due course, although in the author's experience many patients experience gastrointestinal disturbances as a result of osmotic effects of the cyclodextrin.

The problem of azole resistance is of potential relevance to palliative medicine, since many cancer patients receive repeated courses of antifungal medication. It is known that the oral cavity of patients with advanced cancer contains a relatively high proportion of non-*albicans Candida* species (Jobbins *et al*, 1992c). These species, such as *Candida glabrata* and *Candida krusei*, are inherently less sensitive to azole antifungals. In a recent study of oral yeast carriage in 30 patients receiving palliative care, 35 strains were

collected from a total of 25 (83%) of those sampled (Ball *et al*, 1998). Twenty of these isolates were non-*albicans* yeasts, of which 11 were *C. glabrata*, the latter demonstrating significantly higher MIC's for fluconazole than the isolates of *C. albicans* (Ball *et al*, 1998). A further interesting development has been the description of the new human pathogenic yeast, *Candida dubliniensis* (Sullivan *et al*, 1995). This organism appears to be an emerging pathogen which is only relatively rarely encountered in the normal oral flora of immunocompetent individuals, but is enriched selectively in the oral cavities of immunocompromised patients, especially those undergoing antifungal therapy (Coleman *et al*, 1997; Sullivan & Coleman, 1998). Its prevalence among those receiving palliative care is unknown and is currently being investigated by the author and colleagues.

3.5 PROBLEMS OF RESEARCH AMONG THE TERMINALLY ILL

As the speciality of palliative medicine has developed, research has tended to take a back seat. Indeed there is a view that scientifically rigorous clinical research is incompatible with the basic tenets of palliative care and the emotive accusation of experimenting on the dying has been an ever present deterrent to some. In palliative care, the issues of the primacy of the individual and whole person care versus the 'greatest happiness of the greatest number' are brought sharply into focus (Anonymous, 1979). The physician's obligation to keep the interests of his patient as paramount is a fundamental precept of medical practice and is given great emphasis in palliative care. However, the physician has another obligation, which is to promote the acquisition of scientific knowledge (Doyle, 1998). These obligations constitute a real conflict and raise difficult ethical dilemmas. Many people believe that it is impossible to carry out useful, accurate clinical

research within the palliative care setting. Controlled clinical trials are required and the usual guidelines and ethical principles must apply (Declaration of Helsinki, 1975). However, many of the patients are elderly and frail, and they may have a number of physical, emotional and spiritual problems. As a result of the supportive care they are receiving, either within the hospice or from the home care team, they may feel obliged to agree to participation in a research project. This is a difficult situation for the research staff and since 'informed voluntary consent' is required from all participants in a clinical trial, it is perhaps good practice to involve a family member at this stage, together with a member of the nursing staff involved in daily care of the patient (Hill, 1963).

Confusion is a problem seen in many patients and when this is obvious and severe the patients must not be considered for inclusion in a research project. However, confusion may be mild or variable, so it is extremely important that the patient and the patient's relatives are able to understand what is required. Despite careful exclusion criteria and a careful selection process, there may be times when the patient is too weak, too unwell or too confused as a result of medication to continue with a trial into which they have been enrolled. A proportion of those enrolled will also die. This frequently results in large dropout rates, requiring recruitment of a very large cohort of patients if a meaningful result is to be obtained. The value of multicentre trials is self-evident. Unfortunately this can lead to problems such as lack of research experience in the other teams, lack of control of data and perhaps too many variables being introduced (Calman & Hanks, 1998).

As well as these practical difficulties related to the patients, there can also be problems with the attitudes of staff and other carers, many of whom feel that any research among the terminally ill is morally wrong. In many teams there will be members who are totally opposed to research involving vulnerable patients and it is these staff who can influence the outcome of ongoing clinical trials in their area. Indeed, the author has personal experience of this type of attitude, having been involved in conducting a clinical trial which suffered due to the lackadaisical and unhelpful attitude of certain staff members. One commentator, articulating many concerns about research in terminally ill patients, states: 'To research at all into the needs and experiences of this client group could be said to be an affront to the dignity of those people who are terminally ill and an expression of profound disrespect for the emotional and physical state of such patients.' (Cassell, 1991). This author goes on to say, 'One wonders whether they (research questions) should ever be asked by the living to the dying.' In rebuttal to this article, a group of physicians engaged in palliative care research state: 'We disagree with this distinction. The terminally ill are living. Furthermore, the suggestion that others have the right to deprive them of making their own decisions regarding whether they wish to participate in clinical research is paternalistic, demeaning, and disrespectful. The frailty of the very ill does not preclude autonomous decision-making, participating in society, giving to others or finding purpose and meaning. The personhood, integrity and sanctity of all individuals must be equally respected.' (Mount *et al*, 1995).

It is probably true that because of the difficulties encountered in carrying out research within this group, most advances in palliative care must be projected from clinical trials in other classes of patients. It is also important to remember that research can also be based on observation, taking into account the disease suffered, the treatment given, the course of the disease and reaching a reasoned conclusion.

3.6 RELEVANT AUTHORED PAPERS

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CHAPTER 4

ORAL DISEASE AND ITS MANAGEMENT IN PATIENTS WITH PSYCHIATRIC ILLNESS

4.1 INTRODUCTION

The term mental illness is used to describe clinically recognisable patterns of disturbed thought and behaviour, causing acute or chronic problems and personal distress or distress to others (World Health Organisation, 1993). Mental illness is not a single condition, nor do mentally ill people form a 'homogenous group' of the sick in society. Mental illness is a continuum, ranging from minor distress to severe disorders of mind and behaviour, such as dementia and schizophrenia (Thompson, 1993). Mental illness may also be related to misuse of alcohol or other substances (Bradizza, Stasiewicz & Carey KB, 1998). A detailed description of each form of psychiatric disorder is outwith the scope of this thesis and the interested reader is referred to a standard textbook (Stoudemire, 1998).

In the United Kingdom, one in seven people will have a diagnosable mental disorder at any one time, the commonest disorders being anxiety and depression (Department of Health, 1997). Identifying these people in the population can be difficult, as they are not institutionalised and may not be in contact with any form of primary health care agency.

Institutionalised care for people with mental health problems can be provided by psychiatric hospitals, district general hospitals, psychogeriatric units, secure units which house mentally disordered offenders, and prisons (Griffiths *et al*, 1997). Only a small proportion of patients require admission to hospital for specialised care, though in the USA it is estimated that schizophrenic patients occupy approximately one quarter of all hospital beds (Friedlander & Liberman, 1991). Such patients generally

fall into the three categories of continuing care (including psychogeriatric) for:

- Patients who are unlikely to regain their independence.
- Patients admitted for assessment and short-term therapy (released to care in the community).
- Patients with acute problems requiring intensive psychiatric care.

A further change has been the shift to a greater emphasis on care in the community. Until recently, patients suffering from a severe mental disorder were admitted to psychiatric wards for life, but due to the increased emphasis on community care, the number of long-stay mental patients has declined (World Health Organisation, 1985).

4.2 ORAL HEALTH AND MENTAL ILLNESS

The oral health of patients with mental illness has not been widely studied, but is reported to be poor (Rudolph & Chitke, 1993; Hede, 1995a and 1995b; Angelillo *et al*, 1995; Velasco *et al*, 1997; Thomas *et al*, 1996; Stiefel *et al*, 1990).Many patients in this group suffer from self-neglect - a symptom of their illness (Clark, 1992). However, there is no part of the body that suffers more from such neglect than the mouth.

In order to highlight the extent and nature of oral disease among patients receiving treatment for mental illness, the following sections contain data from the author's own clinical practice in a large psychiatric hospital. The figures have been derived by reviewing the case notes of 114 consecutive patients receiving dental treatment in 1999.

4.2.1 Psychogeriatric / dementia patients

A summary of the figures relating to the psychogeriatric patients and those with dementia is shown in Table 4.1. The raw data are provided in Appendix I (Table 4.1A).

Very little has been published about this particular group of patients. In fact, as a group, psychogeriatric and demented patients are often excluded from specific studies due to the difficulties encountered when carrying out even a simple examination and also because of the unreliability of the verbal responses obtained, if any. In the present study, 70% of the dentate patients had root and/or coronal caries, 79% demonstrated xerostomia and 63% had some form of mucosal pathology. Both oral hygiene and periodontal health were very poor for most of those examined. Hede (1995b) looked at 278 psychiatric patients admitted to a regional Danish hospital with respect to the number of teeth present, DMF, gingival and periodontal status and presence of dentures. Of these, a small number were aged over 65 years (8.3%) but the two main psychogeriatric wards were excluded for the reasons mentioned above. A comparison of the results with the oral health data for the general population showed that untreated caries was more frequent in the psychiatric population (55% versus 23%) and this corresponded with previous findings (Stiefel *et al*, 1990). The mean number of teeth with deep periodontal pockets in the study group was twice that of the reference figure for the general population (1.1 versus 0.6). This is also in accordance with Belting and Gupta (1961) who observed a higher periodontal score among psychiatric patients as compared to controls and supports the author's findings of very poor periodontal condition in this group.

Vigild *et al* (1998) carried out a one year follow-up of an oral health programme, having previously examined the residents of a number of special nursing homes in Denmark. In total, 264 residents were included in the final study population of whom 76% were aged 65 years or above. The baseline study showed a substantial need for oral hygiene instruction, dental and prosthodontic treatment, with 44.6% in need of conservation treatment and 82% having plaque visible on routine examination. Of the denture wearers, 79.6% exhibited poor denture hygiene and 32% had denture stomatitis present at the time of examination. Again these figures support the author's own findings of very poor oral health in this dependent group.

Table 4.1 Summary of oral health of 19 psychogeriatric / dementia patients

Male: female ratio		6:13
Mean age (years)		74
Number of smokers [%]		9 [47]
Number of dentate subjects [%]		10 [53]
Number of denture wearers [%]		12 [63]
Number with coronal caries [% of dentate]		7 [70]
Number with root caries [% of dentate]		7 [70]
Xerostomia [%]		15 [79]
Mucosal / soft tissue abnormality [%]		12 [63]
Oral hygiene	**Good**	3
	Fair	2
	Poor	14
Periodontal health	**Good**	1
	Average	0
	Poor	9

4.2.2 Patients receiving treatment for alcohol dependence

A summary of the figures relating to the patients receiving treatment for alcohol dependence is shown in Table 4.2. The raw data are provided in Appendix I (Table 4.2A).

As previously stated for the psychogeriatric group of patients, there is relatively little in the literature about the oral health of alcoholic patients (Hede, 1996), especially alcoholic patients receiving treatment in a psychiatric establishment. Chronic alcoholism is a common condition, thought to affect approximately 10% of the adult male population and 3% of the adult female population of the United States of America (Christen, 1983). The prevalence in the United Kingdom appears to be similar (Brickley & Shepherd, 1990), although there is now a trend towards higher numbers of female alcoholics.

There are many definitions of alcoholism. One simple definition is the consumption of alcohol to such a degree as to cause deterioration in social behaviour or physical illness, and the development of dependence from which withdrawal is difficult or causes adverse effects (Scully & Cawson, 1993). Scully and Cawson (1993) have listed the main medical complications as:

- Liver disease.
- Nutritional and metabolic defects.
- Disorders of the cardiovascular system.
- Neurological dysfunction.

- Gastro-intestinal tract effects.
- Immune system disorders.
- Trauma injuries.
- Social problems.

The main oral and associated problems are the effect on general health. Thus, as the dependency on alcohol increases, the level of personal care taken tends to decrease. Alcoholics commonly display signs of poor oral health such as extensive plaque and calculus deposits, advanced caries with an increase in both coronal and root caries and an increased rate of chronic advanced generalised periodontal disease (Niquille *et al*, 1993). A number of studies have shown that alcoholic patients have a higher DMFT and more missing teeth than their non-alcoholic peers (Dinkley & Carson, 1968; King & Tucker, 1973). Of the patients included in the present study, 80% were dentate of whom 75% had coronal caries and 60% had root caries. Oral hygiene and periodontal health were generally very poor. Only 50% had xerostomia but 76% exhibited some form of oral pathology. An increased level of tooth wear, attributed to attrition and trauma, has also been reported in psychiatric alcoholic patients as compared with psychiatric, non-alcoholic patients (King *et al*, 1973; Harris *et al*, 1996, 1997). It has been suggested that alcoholic stimulation of the brainstem reticuloactivatory system, leading to masseteric muscle activity, causes bruxism during rapid eye movement sleep (Friedlander, Mills & Gorelick, 1987). There have also been reports of advanced dental erosion (Smith & Robb, 1989), affecting predominantly the palatal surfaces of the upper incisor teeth It was postulated that chronic alcoholic gastritis may contribute to subclinical regurgitation and thus erosion (Simmons & Thomson, 1987). Robb and Smith (1990) found an increased level of

erosion on smooth surfaces in alcoholic patients. The wear was more severe in those who drank continuously and also more severe in males. Xerostomia may lead to an increase in toothwear, particularly erosion, due to reduced buffering from a smaller volume of saliva. As psychiatric patients are more likely to be taking at least one of the many drugs known to cause xerostomia as a side-effect, it is difficult to state accurately whether alcohol over-indulgence causes xerostomia *per se*, or whether it is a side-effect of medication.

Orofacial features include an alcohol smell on the breath and spider naevi on the facial skin. Facial oedema and jaundiced skin and mucosa (mouth and eye) may occur in patients with severe liver disease and also redness of the mucosa, glossitis and sometimes angular cheilitis (Scully & Cawson, 1993).

Chronic alcoholism can also lead to impaired healing, with collagen formation and deposition affected. Alcoholic patients have an increased tolerance to a variety of antidepressant drugs therefore a higher than normal dose may be required to achieve a desired degree of sedation or anaesthesia (Scully & Cawson, 1993). The risk of developing oral carcinoma is greater in heavy drinkers, but as many alcoholic patients are also heavy smokers, with 81% patients reporting both habits in one study, the direct role of alcohol in carcinogenesis is difficult to assess. In the present study, 96% of those examined were smokers.

Drug metabolism may be altered with alcoholic liver disease. Those with severe disease, for example cirrhosis, metabolise drugs more slowly due to the loss of liver enzymes. Bleeding disorders can occur in alcoholic patients because the synthesis of

plasma proteins, including most of the blood clotting factors, is depressed in severe liver disease. Thus, if surgery is planned, a full coagulation profile must be performed in consultation with a haematologist.

Lastly, alcoholic patients can exhibit a chronic asymptomatic swelling of the parotid glands. The swelling is usually bilateral and may also be accompanied by submandibular swelling (McDiarmid, 1996; Robb & Smith, 1996).

The alcoholic patient is more likely to seek emergency dental treatment rather than regular routine care. In the author's experience these patients do not comply with preventive therapy and have a poor attendance record for scheduled appointments.

Table 4.2 Summary of oral health of 25 patients receiving treatment for alcohol dependence

Male: female ratio		21: 4
Mean age (years)		50
Number of smokers [%]		24 [96]
Number of dentate subjects [%]		20 [80]
Number of denture wearers [%]		9 [36]
Number with coronal caries [% of dentate]		15 [75]
Number with root caries [% of dentate]		12 [60]
Xerostomia [%]		13 [52]
Mucosal / soft tissue abnormality [%]		19 [76]
Oral hygiene	**Good**	2
	Fair	3
	Poor	20
Periodontal health	**Good**	1
	Average	3
	Poor	16

4.2.3 Patients suffering from acute mental illness

A summary of the figures relating to the patients receiving treatment for acute mental illness is shown in Table 4.3. The raw data are provided in Appendix I (Table 4.3A).

As with the other groups of patients with psychiatric illness discussed in this thesis, relatively little has been written about the oral and dental health of hospitalised psychiatric patients. However, the few published studies available would seem to agree that this group demonstrates extensive unmet needs for dental treatment (Angelillo *et al*, 1995; Barnes *et al* 1988; Ter Horst, 1992; Clark, 1992; Thomas *et al*, 1996; Friedlander & Liberman, 1991). Research from a variety of countries indicates significant increases in risk factors for oral disease and increased oral pathology in people with chronic mental illness who live in community settings compared with similar controls (Stiefel *et al*, 1990). Antidepressant and antipsychotic medication may cause xerostomia which can lead to dental problems such as rampant caries and periodontal disease (Slome, 1984; Bassuk & Schoonover, 1978). Dental fear, neglect of oral hygiene and poor diet are also risk factors for psychiatric patients (Stiefel *et al*, 1990). In the present study looking at hospitalised psychiatric patients, the figures showed 69% of patients with coronal caries and 55% with root caries. Xerostomia was evident in 56% of patients and mucosal pathology in 48%. All of the subjects studied admitted to a smoking habit, with many rolling their own cigarettes. Oral hygiene and periodontal health were poor for at least 50% of the study group. These figures support the findings of Angelillo (1995) who looked at dental health and treatment needs of institutionalised psychiatric patients in Italy, reporting a high caries prevalence, poor oral hygiene and poor periodontal health. The results demonstrated that age was associated with all outcomes of interest, as was length of

institutionalisation. Similar findings have been published by Velasco *at al* (1997) looking at psychiatric patients in Spain and Thomas *et al* (1996) studying chronic schizophrenic patients in Greece.

Barnes and colleagues (1988) assessed dental treatment need among hospitalised adult mental patients in a large state hospital in Virginia. A total of 252 subjects was studied, ranging in age from 21 years to 84 years, of whom 32% were diagnosed as schizophrenic and 24% were recorded as having affective disorders. Of all the subjects studied, only 5.6% required no dental treatment and 31.7% needed urgent treatment. In general, most patients required prophylaxis and calculus removal (69.4%), routine extractions (41.7%), periodontal therapy (59.5%), and permanent restorations (36%). The extremely high requirement for prophylaxis and periodontal therapies are not surprising when one considers the low regard for oral hygiene shown by many hospitalised patients with a psychiatric disorder (Belting & Gupta, 1961; National Centre for Health Statistics 1960-62). In addition, Barnes *et al* (1988) also found that a large proportion of the patients studied lacked the dexterity, physical ability or mental capacity to perform their own oral hygiene adequately.

Schizophrenia is thought to affect 1% of the population of the United States of America at some point in their lives (Friedlander & Liberman, 1991). Schizophrenia causes thought disturbance and aberrant behaviour which lessens an individual's ability to care for himself and to effectively work and communicate with others. It is a distressing condition which occurs most frequently during adolescence or early adulthood although the development of this disorder in later adulthood has been reported (American Psychiatric Association, 1987). The clinical symptoms of

schizophrenia have been divided into positive and negative. The negative symptoms are less dramatic than the positive ones but they are responsible for the chronicity of the disorder and frequently impede rehabilitation. They are also potentially devastating to oral health as they impair the patient's desire and ability to carry out personal oral hygiene (Friedlander & Liberman, 1991). Delusions, hallucinations and thought disturbances are regarded as the positive symptoms of schizophrenia. Hypochondriacal delusions about the mouth are common and usually bizarre in nature. The author's experiences include being accused of transplanting a dead man's tooth into another patient's mouth and being asked to remove radio transmitters from fillings. Acts of orofacial and self-mutilation have also been described in the literature such as multiple auto-extractions (Altom & D'Angelis, 1989), glossectomy (Tenzer & Orozco, 1970), excoriation of the gingivae with sharp fingernails and burning of the gingivae with caustic substances (Mester, 1982). The author has experience of such self mutilation among those she has treated.

Management of schizophrenia involves medication, usually the phenothiazine family of drugs such as chlorpromazine, haloperidol and fluphenazine . Unfortunately, the side- effects of these medications include profound hyposalivation and movement disorders. During the first few weeks of treatment, approximately 75% of patients develop acute extrapyramidal symptoms and a drug-induced parkinsonism may also develop (Friedlander & Liberman, 1991). Tardive dyskinesia, a movement disorder of delayed onset, occurs in approximately 25% of patients treated with neuroleptic agents for more than three months (Jeste & Wyatt, 1985). Usually irreversible, it is characterised by rhythmic involuntary movements of the tongue, face, mouth or jaw, (which can cause difficulty with control of protheses such as complete or partial

dentures) and is sometimes accompanied by involuntary movements of the extremities. Anti-parkinsonian drugs are often prescribed in tandem with the antipsychotic medication in an attempt to prevent or control these symptoms. Unfortunately, the anticholinergic effect of the anti-parkinsonian drugs can increase the incidence and severity of the hyposalivation caused initially by the antipsychotic medication. As the patients feel their mouths very dry, they respond by increasing their consumption of sugary hard sweets and fizzy drinks which have a detrimental effect on the dental hard tissues and contribute to the poor oral and dental health of many of these patients. Thomas *et al* (1996) studied 249 chronic schizophrenic patients with reference to the effect of length of hospitalisation, dose of neuroleptic medication and the extent of negative symptoms on the state of the patient's oral health. They found that long-term hospitalisation was related to an increase in dental caries and a worsening of oral hygiene. They also documented a strong relationship between the negative symptoms of schizophrenia and the deterioration of oral health. A positive relationship between the dose of neuroleptic medication and the amount of dental caries was also reported. They stated that patients with schizophrenia, especially long-term hospitalised in-patients, should be considered as a high-risk group for severe oral disease (Thomas *et al*, 1996).

It is the author's view that dental surgeons and dental hygienists should become part of the multidisciplinary team involved in caring for these individuals. It has been effectively shown that as a group, patients suffering from some form of mental illness have extensive unmet dental need (Barnes,1988; Thomas *et al*, 1996) and preventive dental programmes should be developed which educate not only the patients

themselves but also the psychiatric nursing and medical staff involved in the care of these patients.

Table 4.3 Summary of oral health of 56 patients receiving treatment for psychoses (schizophrenia or severe affective disorder).

Male: female ratio		38:18
Mean age (years)		40
Number of smokers [%]		56 [100]
Number of dentate subjects [%]		49 [88]
Number of denture wearers [%]		19 [34]
Number with coronal caries [% of dentate]		34[69]
Number with root caries [% of dentate]		27 [55]
Xerostomia [%]		33 [56]
Mucosal / soft tissue abnormality [%]		27 [48]
Oral hygiene	**Good**	6
	Fair	12
	Poor	38
Periodontal health	**Good**	4
	Average	17
	Poor	28

4.2.4 Patients receiving treatment for drug addiction

A summary of the figures relating to the patients receiving treatment for drug addiction is shown in Table 4.4. The raw data are provided in Appendix I (Table 4.4A).

Drug abuse is a growing problem in modern international society which has serious social and medical implications. General health problems include poor nutritional intake, infections such as endocarditis, tuberculosis, hepatitis and AIDS. In Amsterdam, 30% of intravenous drug users are HIV seropositive (Molendijk *et al*, 1996). Death from overdose is unfortunately not uncommon (Carter, 1978; Angelillo *et al*, 1991). As drug addicts tend not to eat regular meals, they consume large quantities of refined carbohydrate in the form of quick snacks and this has a detrimental effect on the dental hard tissues. Diminished salivary secretion further predisposes to dental caries and poor oral hygiene rapidly leads to periodontal disease.

Several studies have reported poorer dental health in drug addicts compared to the general population (Angelillo *et al*, 1991; Molendijk *et al*, 1996; Ter Horst *et al*, 1996; Carter, 1978) with the addicts showing a higher caries prevalence, poor oral hygiene and poor gingival health. Angelillo *et al* (1991) studied 124 drug addicts attending a re-educational and rehabilitation programme for addicts in Italy. The majority of the subjects used heroin (96%) but all subjects indicated that they had used more than one substance. A high caries prevalence was found with poor periodontal health and oral hygiene status. The DMFT score in this study was similar to that reported in other studies from America (Silversteen, 1973) and Argentina (Di

Cugno, Perec & Tocci, 1981) but lower compared toAustralia (Carter, 1978), Norway (Hurlen, Jacobsen & Hurlen, 1984) and Denmark (Scheutz, 1984).

Analysis of the individual components of the mean DMFT value showed that the mean number of decayed teeth generally constituted the major part of the index, indicating a high treatment need among this population (Angelillo *et al*, 1991). The fact that few filled teeth were recorded emphasises the fact that these subjects rarely received comprehensive dental care and when treatment was provided it was likely to be in the form of extractions. These findings supported work performed by Ter Horst *et al* (1996) who looked at the differences in dental treatment plans for drug-addicted and non-drug-addicted patients in the Netherlands. The study showed that extractions were proposed for the addicted patients more than for the non-addicted and that dentures were more likely to be planned than crown and bridge work (Ter Horst *et al*, 1996). The author's own study showed that 93% of the group examined had coronal caries and 79% had root caries. Only 14% of the group exhibited xerostomia which is perhaps lower than expected and 43% had some form of mucosal pathology. The standard of oral hygiene was exceptionally low and periodontal health was generally poor. All of the study group smoked.

Drug addict patients rarely experience pain from their broken down dentition, due to the potent analgesic properties of the drugs they take, and they are therefore frequently unaware of their poor dental state. It is often in the early stages of withdrawal that a patient may become aware of toothache for the first time and due to their fragile mental state, emergency relief of pain is the prime concern. These patients are often unwilling or unable to accept conservative dental treatment and will demand

extraction of the offending tooth. Clark (1978) states that the number of addicts who give up attempts at rehabilitation and return to drug use to alleviate dental pain is of increasing concern to professional staff involved in drug dependence centres.

Many heroin addicts are given methadone to alleviate drug craving and this is often blamed for the breakdown in their dentition. Heroin addiction causes xerostomia with hypoglycaemia, along with social disruption, often including stupor and loss of consciousness. Individuals often combat these problems with frequent but irregular ingestion of sugar, such as sugar cubes and chocolate, resulting in massive tooth decay. All this occurs before treatment with methadone begins (Sheedy, 1996).

Methadone has been implicated, however, in the continuing destruction of the dental hard tissues. Methadone is presented to the addict in syrup form, which is held in the mouth for a prolonged period to aid absorption into the bloodstream via the mucosa. As methadone is highly unpalatable it is often broken down with water containing a sugar cordial syrup (50% sucrose). In 1994, the formulation for methadone syrup was changed in response to concerns regarding its high sugar content and the sucrose was replaced with sorbitol (Sheedy, 1996). Many patients have reported to the author that they find the sugar-free methadone unacceptable and they would prefer to continue with the high-sucrose formulation, though the latter is now difficult to obtain locally.

Drug addicts often lead an erratic lifestyle and thus do not make reliable patients. Missed appointments are common and if they do attend, they often arrive very late for appointments. Oral hygiene is low on their list of priorities and continued deterioration of the teeth is common. One should not be over-ambitious when

formulating a treatment plan for this group of patients. In fact, while the patient's uncontrolled habit continues, little can be achieved. Self-neglect and unreliability are untreatable features of the habit and often only damage limitation is possible. Such a realistic attitude should be appreciated by all carers, without it leading to neglect of the patient. Much more education is needed for both general dental practitioners and community dental staff as well as for those involved in the care of these patients and the patients themselves. This would allow integration of dental prevention and treatment into the addiction-treatment programmes and could only improve the management of this group of patients.

Table 4.4 Summary of oral health of 14 patients receiving treatment for drug addiction

Male: female ratio		6 : 8
Mean age (years)		25
Number of smokers [%]		14 [100]
Number of dentate subjects [%]		14 [100]
Number of denture wearers [%]		1 [7]
Number with coronal caries [% of dentate]		13 [93]
Number with root caries [% of dentate]		11 [79]
Xerostomia [%]		2 [14]
Mucosal / soft tissue abnormality [%]		6 [43]
Oral hygiene	**Good**	0
	Fair	1
	Poor	13
Periodontal health	**Good**	1
	Average	3
	Poor	10

4.2.5 Clinical photographs and case histories of representative patients

The following section contains clinical photographs and mini case histories for six patients receiving care from the dental department run by the author in a psychiatric hospital.

CASE 1

Background

Sex: male.

Age: 52 years.

Underlying medical problems: alcohol dependence and manic-depression.

Smoking history: a heavy cigarette smoker (40-50 'roll ups' per day).

Medication: droperidol, carbamazepine, lithium, procyclidine

Dental history

- Edentulous.
- Complete upper and lower dentures: five years old and ill-fitting.
- Denture hygiene: very poor.
- Dentures were worn continuously.

Oral pathology

At presentation, the following were observed:

- Xerostomia.
- Denture stomatitis.
- Bilateral hyperplastic candidosis (Figure 4.1).

- Angular cheilitis (bilateral).
- Pigmentation of the oral mucosa.

Management

- **1992**

Swabs and oral rinse for microbiological evaluation.

Referred for Oral Medicine consultant opinion:

Biopsy confirmed clinical diagnosis of CHC.

Erythematous candidosis of the palate and angular cheilitis (Culture positive).

Treatment: fluconazole.

Referred back to author for regular review.

New dentures provided.

- **1993**

New dentures had been lost. Patient requested new complete dentures, which were provided.

Oral health had improved, and the hyperplastic candidosis was less florid.

There was still widespread pigmentation and marked xerostomia.

Patient failed to attend next 6-month review, which corresponded with the time when he became an outpatient.

- **1996**

Re-attended (self-referral through the Alcohol Problem Clinic).

Patient complained of pain from the angles, especially the left hand side.

An incisional biopsy confirmed the diagnosis of hyperplastic candidosis with mild epithelial dysplasia.

Treatment: fluconazole.

- **1997 to present day**

Regular attender.

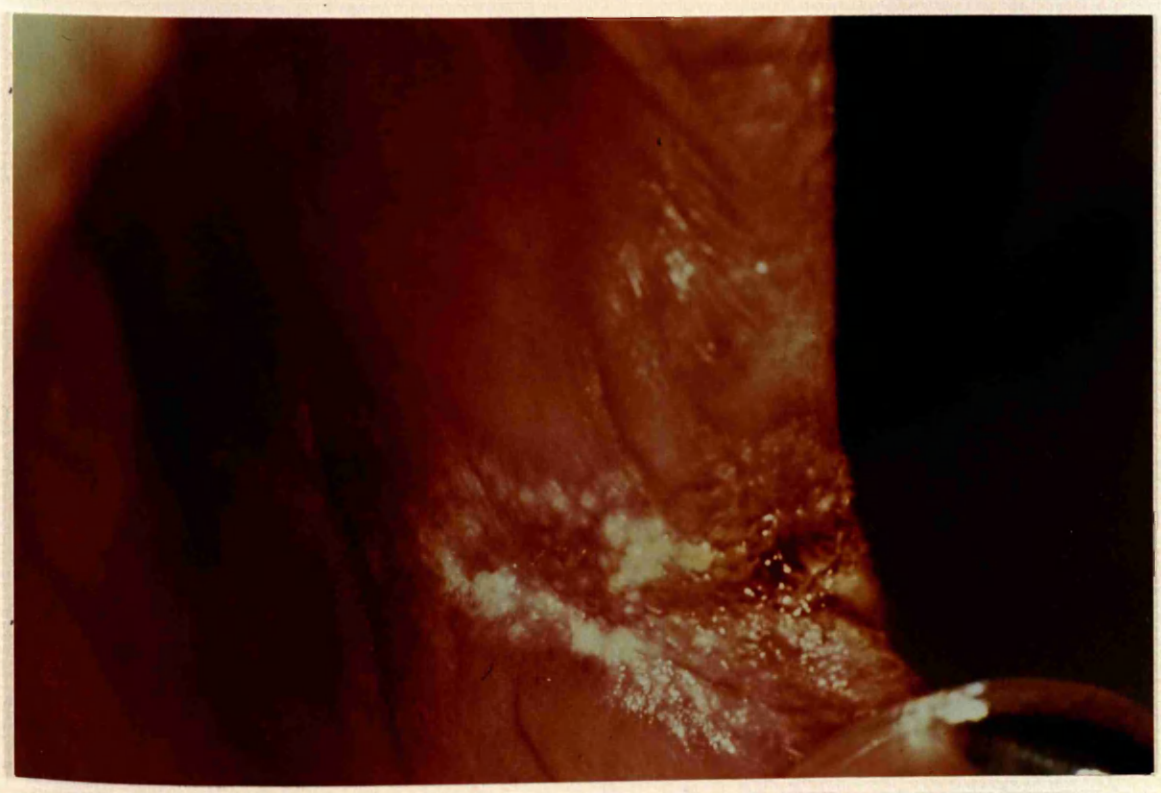
Annual biopsy of hyperplastic candidosis.

Overall, oral health has improved and angular cheilitis has resolved.

Profound xerostomia and marked pigmentation (including palate) persist.

Continues to smoke heavily.

Figure 4.1 Bilateral angular cheilitis, hyperplastic candidosis and pigmentation in Case 1



CASE 2

Background

Sex: male.

Age: 28 years.

Underlying medical problems: an in-patient resident at the hospital following brain damage sustained in a serious road traffic accident. He had also lost a leg in the accident and was wheelchair-bound.

Smoking history: a heavy cigarette smoker.

Medication: chlorpromazine, remoxipride, nitrazepam.

Dental history

- Partially dentate (no dentures).
- Teeth present:

765	1234567
8765432	12345678 (impacted)

- Complaint of pain in upper right quadrant.

Management

- 65| were removed to relieve pain. The patient interfered with the sockets, resulting in protracted healing.
- All of the upper teeth were treatment-planned for extraction.
- Prior to these teeth being extracted, the patient was brought to the Dental Department having self-extracted |34567, on the ward, using a teaspoon handle (Figure 4.2). This behaviour had been triggered when he saw another patient with complete dentures and he decided that he wanted dentures too (Figure 4.3). The remaining fragments of teeth were surgically removed and the wounds sutured.

- Two days later he re-presented having removed all the sutures and extracted or fractured the remaining two upper left teeth. In view of the poor healing of the sockets, which he refused to leave alone, he was prescribed metronidazole by author. The doctors on the ward subsequently prescribed augmentin for the same reason.
- Root caries in the lower teeth was treated by placement of fillings.
- Determined that he wanted dentures, the patient threatened to self-extract his lower teeth.
- A clearance was undertaken during a series of planned extractions and complete dentures were provided. These proved highly successful.
- Subsequently this patient was transferred to a high security facility.

Figure 4.2 Sockets in the upper alveolus of Case 2, after he had self-extracted some of his remaining teeth on the ward by means of a teaspoon.

Figure 4.3 Diagram drawn by Case 2, illustrating the dentures that he hoped would be constructed for him by the Dental Department.

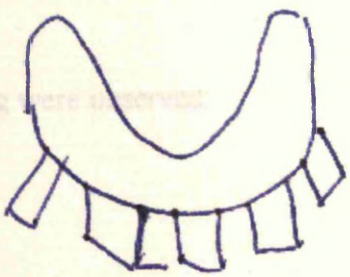
RENFREWSHIRE HEALTHCARE NHS TRUST

COMMUNITY DENTAL SERVICE

YOUR REF:

OUR REF:

DATE:



CASE 3

Background

Sex: female.

Age: 68 years.

Underlying medical problem: in-patient on account of dementia (psychogeriatric).

Dental history

- Edentulous.
- Complete upper denture only: old and ill-fitting.
- Denture hygiene: very poor.
- Dentures were worn continuously.
- Complained of a sore tongue.

Oral pathology

At presentation, the following were observed:

- Xerostomia.
- Denture stomatitis.
- Angular cheilitis.
- Atrophic ulcerated tongue (Figure 4.4), with complaint of soreness for several weeks.

Management

- Full blood count was requested.
- Haemoglobin: 7.8 g/dL

- Replacement iron was prescribed.
- Resolution of lingual ulceration and soreness.
- Ulceration of dorsum of tongue recurred 18 months later and shortly afterwards the patient died from a lower respiratory tract infection.

Figure 4.4 Atrophic glossitis and frank ulceration of the dorsum of the tongue in Case 3. This problem resolved completely following the prescribing of replacement iron.

CASE 4

Background

Sex: female.

Age: 59 years.

Underlying medical problems: an in-patient at the hospital on account of dementia.

Previous cerebrovascular accident and hypertension.

Smoking history: ex-smoker (heavy).

Medication: aspirin, bendrofluazide, procyclidine, trazodone, chlorpromazine, tibolone, betahistine dihydrochloride.

Dental history

- First seen during a routine ward screening, which revealed gross dental neglect.

Oral pathology

At presentation, the following were observed:

- Partially dentate:

543 1	1234 8
654321	12345678

- Very poor oral hygiene.
- Periodontal disease.
- Gross coronal caries in all quadrants.
- Gross root caries in all quadrants

Management

- Extraction of non-restorable teeth: $\overline{432 \mid 5678}$.
- Intensive oral hygiene phase therapy with hygienist.
- Conservative dentistry on all upper teeth and $\overline{65 \mid 34}$
- Provision of partial dentures, which were lost on the ward.
- At a later date, further extractions were necessary: $\frac{4 \mid}{65 \mid 4}$

Chemical burn

Three months after completion of her dental treatment, the patient presented with a sore mouth. On intra-oral examination there was evidence of a widespread chemical burn of the entire oral mucosa (Figure 4.5). This had been caused by the patient drinking a bleach-like substance in the ward, in an attempt to engineer a visit to the dental surgery. The lesion began to resolve, but one week later the patient repeated the exercise, again whilst on the ward.

Figure 4.5 Extensive chemical injury to oral mucosa, thought to be caused by use of undiluted, industrial bleach as a mouthwash.

CASE 5

Background

Sex: male

Age: 45 years.

Underlying medical problem: an in-patient at the hospital on account of alcohol-induced psychosis.

Smoking history: heavy smoker

Dental history

- Dentate.
- Poor oral hygiene.

Oral pathology

- Gross destruction of dental hard tissues through caries and erosion.

Management

1992

Needed 6 extractions: 421|125.

For partial upper denture.

Maintenance by hygienist.

Refused treatment.

1993

Seen again. Now in wheelchair. All upper teeth broken, except |7 (Figure 4.6).

Requested 'screw-in teeth'. When told that this was not possible, he refused all further treatment.

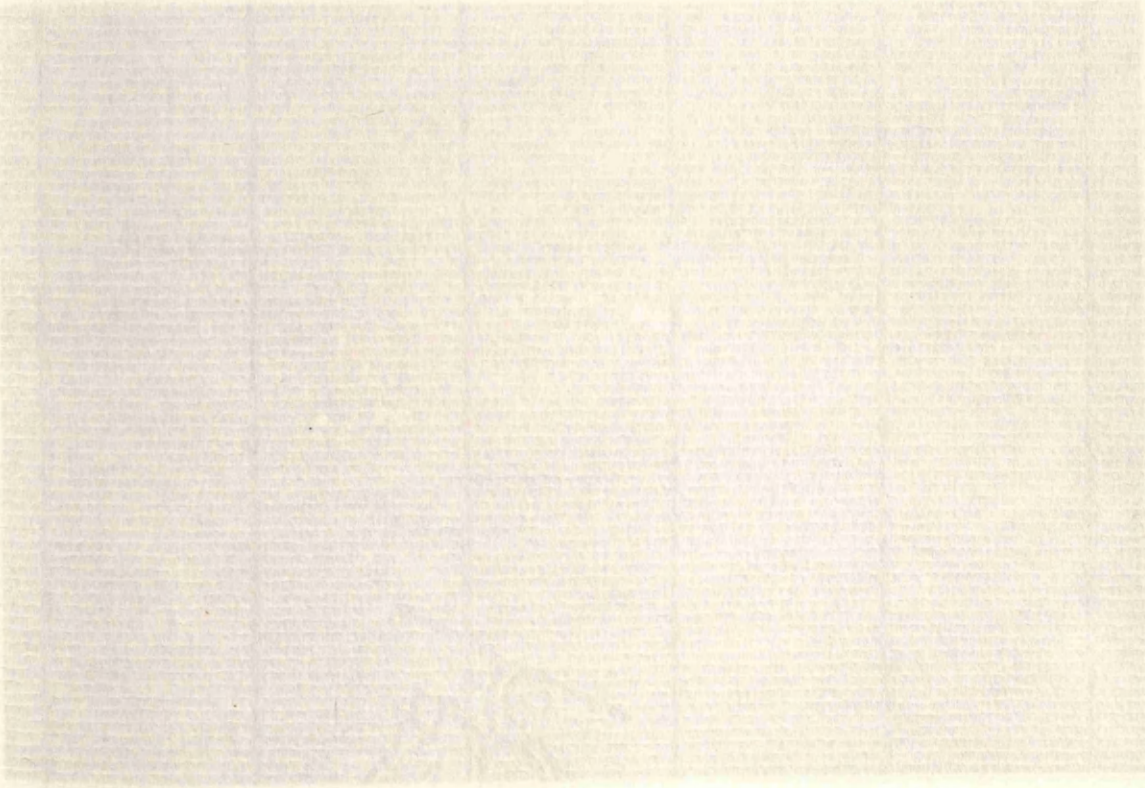


Figure 4.6 Badly broken down dentition of Case 5, who refused all treatment, but requested 'screw-in' teeth.

CASE 6

Background

Sex: male.

Age: 58 years.

Underlying medical problems: in-patient at the hospital on account of schizophrenia.

Smoking / alcohol history: heavy smoker and drinker.

Dental history and oral pathology

Gross periodontal disease (Figure 4.7).

Edentulous upper (no denture).

$_{x}8\ 5\ 32 \mid 12345\ 7$

Caries.

Appalling oral hygiene.

Management

Refused all treatment.

Figure 4.7 Gross periodontal disease in Case 6, who refused all treatment offered.

4.3 PROVIDING ORAL CARE FOR PATIENTS WITH PSYCHIATRIC ILLNESS

Good oral health contributes to general health, self-esteem and quality of life. Whether institutionalised or in the community, people with mental health problems are entitled to the same standards of care as the rest of the population. However, there are several reasons why they may not receive it.

To begin with many of the patients are beyond normal reasoning, thus making it difficult to discuss various treatment options (Clark, 1992). Often there is a total ignorance of dentistry and dental problems - the patients do not understand the scope of possible treatment. This ignorance of dental issues is often shared by the staff, a feature reported in other studies of carers in long stay institutions (Blank, Arvidson-Bufano & Yellowitz, 1996; Chalmers *et al*, 1996). Patients with mental illness, especially schizophrenia, frequently have a total disregard for simple health messages, such as the importance of a good diet. Many patients with mental illness eat a high carbohydrate diet, often because their medication causes carbohydrate craving (Paykel, Mueller & de la Vergne, 1973).

They also often drink huge quantities of carbonated drinks (Clark, 1992), sometimes as much as three or four litres per day, but xerostomia is the commonest side-effect of their psychotropic medication (Peeters, de Vries & Vissink, 1998). Many patients with mental illness smoke heavily, as shown by the data in this thesis and the reports of others (Murphy, Gass-Sternas & Knight, 1995), often rolling their own cigarettes or chewing tobacco, again resulting in reduced oral health (Anonymous, 1998).

As described elsewhere in this thesis, oral health is given low priority by significant numbers of health professionals and carers, who have described it as an unrewarding, unpleasant and problematic task (Eadie & Schou, 1992). However, simple mouth care protocols should be in place in all ward settings for all categories of patient, including those with mental illness. Oral care practices must become part of the total patient care routine if the situation illustrated by the data in this thesis and the findings of others (Rudolph & Chikte, 1993; Hede, 1995a and b; Murphy, Gass-Sternas & Knight, 1995) is to improve. Is the mouth really such a difficult area to deal with or are there other reasons for this neglect?

One of the main reasons is fear. People are often very frightened of dentistry - not just those with mental illness (Lautch, 1971). The public, in general, has a love/hate relationship with its dental practitioners and frequently details stories of horrific experiences. We need to imagine what it is like for patients with mental health problems whose fear may be completely illogical and extreme. The carers often share this traditional aversion, so can understand why their patients might not actively seek dental advice. 'These patients are difficult enough to deal with without adding in the trauma of a visit to the dentist' is a popular response from carers. Patients with mental illness lack motivation, again a symptom of their illness, so they do need to be encouraged by those looking after them. If the staff, too, perceive dentistry as a threat, there will be no motivation. Often carers who accompany patients to the dental surgery refuse to enter with the patient. Their fear is so great that they cannot cross the threshold. What sort of message does this give to a vulnerable, unstable patient?

Some of these patients are paranoid and delusional (Clark, 1992). They receive transmissions through their teeth (Friedlander & Liberman, 1991), hear voices, are suspicious of anyone or anything new and also, or as a result of this, can be potentially or actually violent. Providing dental treatment is difficult as they often have ingrained prejudices and are impervious to reasonable argument, thus causing more problems for ward staff as well as for the dentist.

Unfortunately, even the healthiest of mouths can deteriorate after a few weeks of neglect and patients can suffer excruciating pain from their mouths at a time when they are least able to deal with it and their fragile mental state collapses. Often, the only answer is emergency sedation or general anaesthesia which may necessitate the patient being transferred to another hospital, possibly for an overnight stay. Consenting the patient can be problematic and arranging theatre time for dental general anaesthesia is always difficult for what is obviously a short-term solution to the problem.

Provision of emergency treatment only is certainly one way of dealing with the problem of oral disease in patients with mental illness and is also the most common solution. However, if we believe that these patients are entitled to the same standards of care as we would expect for ourselves, then we must recognise that the oral health of a highly vulnerable section of the community is being neglected and that attitudes to oral health and to dentistry need to change. Many of the problems arise as a result of poor communication between dental staff (if available), medical staff and carers. The expectations of staff and patients alike are often unrealistic because of lack of knowledge. They read articles in magazines and newspapers, or watch television

programmes about veneers, implants, fixed bridges and other elaborate types of cosmetic dentistry, but do not really understand the implications of such treatment with respect to lack of oral hygiene, poor diet and smoking habits. Recent work discussed elsewhere in this thesis, looking at the provision of oral care by nurses for cancer patients across Scotland showed that nurses received little education about the mouth and oral disease (Sweeney *et al*, 1996). Further studies have shown that this is also true of medical students, medical practitioners and associated staff (McCann *et al*, submitted for publication). Provision of educational material in a variety of formats to all levels of staff involved in caring for patients is essential (Rudolph & Chikte, 1993). Community dental services and area health boards also have specialised oral health promotion teams available who can provide input at in-service training days and other training courses.

Oral health may seem unimportant when dealing with profound mental illness but a significant proportion of these patients do recover and return to a relatively normal life (Murphy, Gass-Sternas & Knight, 1995). It is important that patients, their families and health care workers appreciate that severe damage to the dentition during the period of their illness will impact on their lives at a later date.

4.4 ADVOCACY

Another way forward would be to enlist the aid of the hospital advocacy groups. These are patient-led groups which give patients, their families or representatives a voice. Advocacy is recognised as an important way of enabling people to make informed choices about, and to remain in control of, their own healthcare. It gives

them a chance to ask questions, to voice an opinion and may help to instigate changes in practice.

Advocacy refers to the process of pleading the cause of and/or acting on behalf of another person to secure services they require and/or rights to which they are entitled. Advocates are independent of services and represent their "partner's" interests as if they were their own. Advocates owe those they represent a duty of confidentiality, loyalty and a commitment to be zealous in the promotion of their cause (Good Practices in Mental Health, Advocacy Information Pack, 380-384, Harrow Road, London, W9 2HU). Advocacy has become very fashionable. Few service providers for clients with disabilities fail to include a proposal to permit or encourage advocacy. But advocacy has many meanings and it can take, significantly, many forms. Unless we are explicit about what we expect from advocacy and choose the appropriate form, we will cause considerable harm and discredit a potentially very useful tool for protecting clients, enhancing standards and encouraging change (Carson, 1989).

Advocacy is normally considered to have two main themes :

- Protecting vulnerable people.
- Giving the vulnerable a stronger voice to make their wishes and needs known.

4.4.1 Types of advocacy

There are two main types of advocacy (Scottish Health Advisory Service, 1998):

*1. **Advocacy alongside or on behalf of someone***

There are various forms of this type of advocacy:

- **Citizen advocacy** is a one-to-one, ongoing partnership between a trained volunteer citizen and a person who is not in a strong position to exercise or defend his or her rights, or who is at risk of being mistreated or excluded. Citizen advocates should be free from conflicts of interest with service providers and should represent the interests of their partners as if they were their own.
- **Crisis advocacy** shares the same principles as citizen advocacy but, as its name implies, is short term. This tends to be one-off involvement, centred upon a particular task or specific situation in which a person needs the support of an advocate.
- **Peer advocacy** takes place when one person advocates for another who has experienced, or is experiencing, similar difficulties or discrimination.
- **Complaints advocacy** focuses on helping individuals to pursue complaints within and about a particular service.
- **Public advocacy** refers to the activities of organisations which campaign on behalf of a particular group of people. These are often national bodies with local branches.
- **Professional advocacy** is perhaps most widely recognised as legal advocacy undertaken by lawyers. However, it may also include others who are paid to provide a particular service, for example, welfare and housing rights workers.

2. ***Advocacy by a person or group for themselves***

- **Self advocacy** works by individuals speaking for themselves on a common cause. Self advocates may need a lot of support in standing up for themselves, especially if their views have not previously been respected or acknowledged.
- **Group or collective advocacy** usually refers to a self advocacy group or organisation offering mutual support, skill development and a common call for change. This might include a small group of people who use local services, patients' councils or large bodies such as the National Pensioners' Convention.

4.4.2 The components of advocacy

The different components of advocacy are as follows (Scottish Association for Mental Health, 1991):

- **Empowerment:** enabling people to take the opportunity to regain power and control over their own lives whilst recognising the imbalance of power.
- **Representation:** enabling people to be represented at all levels by themselves, another individual, or by a group.
- **Participation:** enabling people to be involved in decision making at all levels. Personal, planning, evaluating and management of services.
- **Consultation:** letting people know what is happening to them, for them, with them.
- **Access:** giving people access to information, professional workers, complaints procedures, buildings, case notes, advice, independent advocates, telephones, resources.

- **Resources:** letting people know what is available, for example occupational therapy, transport, community resources, user only facilities.
- **Information:** making information easily and readily available in plain English without jargon. Sharing information and respecting confidentiality.
- **Choice:** letting people know what alternatives are available and supporting them in their choice.
- **Acceptance:** an acceptance of user views, opinions, needs and experience as valid. Supporting user initiatives, for example, patient councils or advocacy groups.
- **Independence:** an advocacy scheme or advocate should be independent of the service provider.

4.4.3 Barriers to advocacy

Their are still many barriers to advocacy. One of the main barriers is the belief of many psychiatric nurses that they are already advocating for their patients. Many statutory workers feel that they know best what is in a patient's best interest and that to allow patient choice would hamper daily routine. 'Giving a demented geriatric a simple choice of what to wear could take hours' remarked one nurse. 'They don't understand anyway' stated another (Bardsley, 1991). Nurses may play an important role in making representations on behalf of patients but nurses are not, and cannot be, true advocates. Gostin (1990) describes the true advocate or representative as '... someone who will roll up their sleeves and fight for the consumer's right to choose ...without making a judgement about the wisdom of the choice to be made. It should not matter that the consumer's choice is different to the decision that would be made by the advocate or the service provider' (Gostin, 1990).

Psychiatric patients have a right to respect for their choices. That can only come about if nurses understand the limits to their role in making representations on behalf of patients and make way for the development of self and citizen advocacy, improved access to legal advice and truly independent representation (Dyer, 1991).

Other barriers include a lack of clarity about what advocacy really means, what empowerment means and who can be an advocate. Prejudice and suspicion about both users and ex-users of mental health services are widespread in Scotland. One project detailed by Bardsley (1991) found that negative stereotypes, derogatory language and blatant disrespect were still commonplace. Users and ex-users who spoke on behalf of themselves or others were likely to be seen as having an axe to grind - or as the 'unlucky' exception who got a bad deal from the system.

Lack of information and training is the other major barrier to advocacy in Scotland. As recently as 1991 there was no Scottish literature available on advocacy in mental health and no central funding available. This has now been addressed and funding has been made available though individual health boards.

Advocacy is not easy. However, because it involves a service recognising that it may be wrong, that its clients' individual wishes and needs may not always be recognised or met, and is developed to encourage clients to be more assertive, it is a sign of considerable organisational maturity (Carson, 1989).

4.5 RELEVANT AUTHORED PAPER

Sweeney MP (1999) Oral healthcare for patients with mental illness. *Journal of Nursing Care* **2(1)**: 4-6.

CHAPTER 5

TRAINING IN ORAL HEALTH FOR THE NON-DENTAL HEALTHCARE PROFESSIONAL

5.1 INTRODUCTION

The preceding chapters of this thesis have highlighted the important role of medical and nursing staff in providing mouth care for patients with special needs. However, there is a significant literature which indicates that oral health care is frequently afforded a very low priority in the overall care of such patients. The literature further suggests that one of the major obstacles to good mouth care is a lack of knowledge on the part of the carers. This chapter will review the need for education in this area and will describe approaches to the problem, which have been developed by the author.

5.2 EVIDENCE OF NEED FOR EDUCATION

5.2.1 Nursing staff

Maintenance of oral hygiene and provision of mouth care are considered basic but essential nursing interventions (Holmes & Mountain, 1993). The importance of a basic oral assessment and of oral care by nursing staff has been highlighted by several authors (Pope, Reitz & Patrick, 1975; Hilton, 1980; Speedie, 1983; Shepherd, Page & Sammon, 1987). However, as indicated by Macleod-Clark & Hockey (1979), "it is often the simplest procedures that are most in need of scrutiny, for these are the aspects of nursing practice which are taken for granted and have become formally incorporated into the routinised fabric of nursing". Mouth care fits very much into this mould.

As described in earlier chapters of this thesis, oral disease can impact adversely on general health and the consequences may drastically affect function, morbidity and even survival (White, 1995). Oral care has a specific role in maintaining well-being

and quality of life. It can increase quality of life by keeping the mouth free of infection, and by restoration of the dentition when appropriate can enable "normal" eating and restore appearance (Ettinger, 1992). In particular, it has been suggested that an improvement in patients' oral hygiene and removal of oral latent infections and potential problems may reduce the risk of respiratory tract infections among dependent elderly subjects (Mojon *et al*, 1997).

Many patients are unable to undertake their own oral care because of physical / mental disability (Felder *et al*, 1994) and an associated inability to manage personal care (Martin, Meltzer & Elliot, 1998). Therefore these dependent patients rely on carers to ensure oral health. However, although levels of untreated dental caries, periodontal disease and tooth loss are significant and indicate a need for both preventative and restorative dentistry (Weyant *et al*, 1993) such factors are often overlooked by nurses when providing care for dependent patients. As stated previously (Chapter 2) oral health procedures are often given low priority compared to other tasks by nurses and other healthcare providers (Mojon *et al*, 1998). Thus, although there is often marked dental need associated with significant oral disease and poor levels of oral hygiene (Wilkieson *et al*, 1991) studies have shown that dental care is rarely provided in institutional settings. Such care is often sought only when patients or others experience or discover a particular oral health problem (de Baat, Kalk & Schuil, 1993).

Reasons for this low priority of oral health procedures include neglect in nursing school curricula, lack of emphasis within nursing organisations and absence of standardised training (Benson, Maibusch & Zimmer, 1980; Hunt, 1987; Arvidson-

Bufano, 1995). Lack of understanding and awareness of oral health seem to be the main reasons for nurses not routinely assessing and caring for this aspect of patients' needs (Schweiger, Lang & Schweiger, 1980). Wardh and colleagues (1997) carried out a study to compare differences in attitude to oral health care of nursing personnel working with dependent elderly. They found that having information about oral and dental health did not guarantee that the skills would be practised. This finding has also been recorded by others (Logan *et al*, 1991; Fiske & Lloyd, 1992).

Oral care assistance seems to be an irritant shared by all staff members even though they may express their attitudes in different ways. It has been suggested that working with personnel attitudes to oral health care probably gives more successful results than if these are denied. Once the desired behaviour change has occurred, then lack of knowledge about oral health care can be addressed (Weeks & Fiske, 1994). Certainly in the author's experience in both geriatric and psychiatric health care establishments, no amount of education will change carers' behaviour if their mind is set against oral care. Much more work is required looking at the reasons for this negative attitude surrounding oral health and dispelling many of the myths about dental care that abound in the West of Scotland and, apparently, beyond.

Oral care must be given high priority in the education of nurses and nurse carers. In addition to theoretical knowledge, practical training and opportunities to discuss the problems involved should become a major part of the education programme. Another study (Rak & Warren, 1990) tried to establish whether the level of dental and mouthcare knowledge amongst different grades of nurse was adequate and to identify areas of deficiency. In addition, the role played by formal training was investigated.

The authors found that the respondents in the study appeared to have adequate theoretical knowledge of mouthcare in general, but were lacking in specific knowledge of dental disease (Rak & Warren, 1990). The obvious paucity of specific dental knowledge was a cause for concern, because without the basic knowledge of dental disease the nurses did not understand the reason why certain dental procedures were important, nor the implication of failure to undertake these procedures regularly and meticulously. The investigators concluded that nursing education should include basic information on dental disease and an explanation of the rationale behind oral hygiene procedures (Rak & Warren, 1990). Such educational initiatives can be successful and Vigild (1990) reported improvement of oral health and the increased utilisation of oral health services following the implementation of a comprehensive oral health programme in a nursing home.

Providing patients with facilities for brushing teeth and rinsing is often regarded as "appropriate" oral care. As stated previously, many nurses and carers find cleaning mouths or handling dentures socially unacceptable (Gronert, 1995) while others find these tasks unpleasant (Boyle, 1992). It is also suggested that dirty mouths and halitosis may evoke feelings of disgust (Barnett, 1991). Such responses may have far-reaching effects (Trenter-Roth & Creason, 1986). The author finds it difficult to comprehend how handling a set of dentures or aiding a patient with simple oral hygiene techniques can be considered more unpleasant or unacceptable than dealing with the other end of the alimentary canal, which is also considered a nursing duty!. Blaney (1986) suggests that inadequate performance of simple procedures such as oral care could extend the length of hospitalisation due, for example, to systemic infection gaining entry through the mouth (McElroy, 1984). Thus, since oral

problems may have both human and financial implications, the need for good oral care is clear. Nevertheless, many nurses would appear to lack either the interest or the knowledge to provide this effectively (Miller & Rubinstein, 1987).

It is most commonly nurses who decide when assistance with oral care is needed and the frequency with which it is required. It has, therefore, been suggested that the overall standard of nursing care can be judged by the state of patients' mouths (Henderson, 1960; Crosby, 1989). However, the basis on which nurses make decisions related to oral care is unclear, and several studies have identified a need to establish its scientific basis (Ettinger & Manderson, 1975; Holmes, 1991; Holmes & Mountain, 1993).

The literature contains many references to the lack of research concerning the agents and tools that should be employed in nurse provision of oral care, and many of the procedures are anecdotal, rarely validated and often contradictory (Gronert, 1995). Thus, much of the care provided cannot be substantiated. As a result there has been little change in oral care practices for many years (Krishnasamy, 1995).

Provision of oral care is also important for those patients being cared for at home, who may be visited by District or Community nurses. District and Community nurses are actively involved in day-to-day patient care, have a high degree of public contact and confidence and as such are in an ideal position to mediate in the delivery of oral health education and increased dental awareness (Sweeney & Zoitopoulos, 1995). A study in 1995 by Sweeney and Zoitopoulos determined attitudes to oral dental health and basic dental knowledge of District / Community nurses. Of 210

questionnaires sent via nurse managers, 117 (56%) were returned. The nurses displayed a positive attitude to health in general but were less positive about oral health. Overall, 79.4% strongly agreed that everyone should see their dentist at least once a year and 65.8% strongly agreed, or agreed that poor dental health would affect their daily routine. However, they did not share the same sentiments for their clients, since 24.2% agreed or strongly agreed with the statement that 'the state of someone's teeth would not stop them socialising with a friend'. The answers to the dental knowledge questions indicated a good understanding in certain areas but some confusion in others. For example although they were well aware of the importance of regular toothbrushing, only 41.7% knew what dental plaque actually was. Similarly, the role of sugar in causing dental caries and its dietary control emerged as areas that needed some clarification.

These findings supported those of the author and colleagues (Sweeney *et al*, 1996). A study was undertaken to determine the level of mouthcare practised by nurses of patients with cancer in Scottish hospices and in the community within Scotland. Questionnaires were sent to 112 district nurses, 52 Macmillan nurses and 15 hospices throughout Scotland. There was an 81% response rate for the district nurses alone. Few district nurses (22%) worked to a written nursing standard for mouthcare and only 46% of the respondents had received any training at all in mouthcare. Further analysis revealed that only 10% of the district nurses had received specific mouthcare training, much of which had taken place many years previously (Sweeney *et al*, 1996). Results of a follow-up questionnaire after receipt of a training pack also proved interesting, with 20% of district nurses stating that they had made large changes to clinical practice as a result of receiving the pack and 46% admitting to moderate

changes. Thirty four per cent felt that further training in mouth care would be beneficial to them (Sweeney *et al*, 1996). This study and others have shown that nurses have inadequate training in oral disease and oral care but that many are keen to learn the necessary skills. The willing participation of the nurses involved in this study and their positive response to the training material provided showed a real awareness of the need for improvement.

5.2.2 Medical staff

Whilst much has been written in recent years of the holistic approach to patient care, awareness of oral disease and the need for routine mouth care have both been largely neglected by significant segments of the medical community. This is worrying, not only because of the unnecessary discomfort and functional problems for the patients themselves, but because oral complications of medical interventions, for example chemotherapy induced mucositis (Symonds, 1998) and oral manifestations of systemic disease, for example HIV infection (EC-Clearinghouse on Oral Problems Related to HIV Infection and WHO Collaborating Centre on Oral Manifestations of the Immunodeficiency Virus, 1993), are increasingly common. The ever growing elderly population also has significant oral health needs (Sweeney *et al*, 1995) including a much greater chance of developing oral cancer (see Chapter 2).

If mouth care is to be given a higher priority in the overall care of adults with special needs, then it is critical that medical staff have a better understanding of the subject. In a recent review in the *Lancet* (Frankel, 1997) of a textbook entitled '*The Mouth. Diagnosis and Treatment*' by D Eisen and DP Lynth, David Frankel, a dermatologist, wrote '...I suspect readers from other specialties will agree that they too are only

slightly less relieved than their patients when the perfunctory "stick out your tongue" part of the exam is over, as they move to more familiar territories like the chest...'. He went on to describe the book as '... a godsend for other practitioners for whom the mouth is also a diagnostic wilderness'.

The author has been involved in a recent study that aimed to determine the ability of a group of medical staff to diagnose common oral disorders relevant to medicine. A series of ten clinical photographs of oral conditions, together with short clinical histories, was devised and collated by Drs P McCann and J Gibson, Glasgow Dental School. The clinical conditions covered were:

- Geographic tongue.
- Primary herpetic gingivostomatitis.
- Oral presentation of acute leukaemia.
- Atenolol drug reaction.
- Angina bullosa haemorrhagica.
- Squamous cell carcinoma.
- Oral Crohn's disease.
- Oral Kaposi's sarcoma in HIV infection.
- Oral hairy leukoplakia in HIV infection.
- Stevens-Johnson syndrome.

These illustrated scenarios were issued individually to 48 accident and emergency physicians working in Glasgow hospitals. Twenty one were Senior House Officer 1

and Senior House Officer 2 grades, 12 were Senior House Officer 3 / Registrar / Specialist Registrar and 15 were non training grades. A structured questionnaire accompanied the clinical photographs which sought, for each condition, the diagnosis, investigations required, details of management, whether or not a further referral was necessary and, if so, to whom.

In order to provide a control group, the same illustrated scenarios and questionnaire were issued to 22 hospital dental staff. Three were Junior House Officer grade, nine were Senior House Officer grade, three were Specialist Registrar / Senior Registrar grades and seven were non-training grades.

The responses of the medical and dental staff to the 10 clinical scenarios are summarised in Table 5.1. Dentally qualified staff demonstrated good diagnostic awareness for both common and rarer conditions of the oral mucosa, though there was apparent reluctance to make a clinical diagnosis of squamous cell carcinoma. Nevertheless, the investigation, management and referral patterns of the patient with carcinoma were appropriate. Correct diagnoses by medical staff ranged from 6% for primary herpetic gingivostomatitis to 71% for oral cancer. These figures were surprisingly low given that a number of the scenarios represented oral manifestations of systemic diseases and not purely rare entities confined to the oral cavity. These responses to the case scenarios demonstrated significant deficiencies in diagnostic awareness of physicians versus dentists in recognition of many common oral diseases and oral manifestations of systemic disease. The most likely reason for the poor performance of the medical staff in diagnosing oral disease is their lack of training, as discussed below (Section 5.4).

These findings are of great importance. Numerous studies have identified the benefit of physicians recognising oral diseases in all sections of the population - paediatric (Cooley & Sanders, 1991), geriatric (Pyle & Terezhalmy, 1995) and the general adult population (Westman, Duffy & Simel, 1994). In particular, the importance of physicians being able to recognise oral malignancy at an early (and therefore treatable) stage has been acknowledged (Alvi, 1996). It has also been demonstrated that, owing to selective attendance by patients for dental care, physicians are likely to see more high risk patients for oral cancer, particularly in the primary care setting (Yellowitz & Goodman, 1995). It is, therefore, significant that the physicians were more skilled at recognising oral cancer than any of the other conditions, although on the basis of these figures, both doctors and dentists should increase their index of suspicion.

Organisation of mouth care for hospitalised patients and many receiving care in the community is ultimately the responsibility of medical and nursing staff. As discussed in earlier chapters, many studies have identified deficiencies in the provision of mouth care for the systemically ill (Eadie & Schou, 1992; Sweeney *et al*, 1995; Sweeney *et al*, 1996). If awareness of this problem is to increase and the situation to improve, then doctors are key players in promoting and supporting changes in practice. Medical staff working in the palliative care setting have been especially active in raising the profile of mouth care (Kirkham, 1995), but this will only spread to other areas of medicine if training opportunities for both medical undergraduates and qualified doctors are substantially improved.

Table 5.1 The responses of 48 medical staff and 22 dental staff to the clinical scenarios

Clinical condition	Correct diagnosis (%) Med [Dent]	Correct investigation (%) Med [Dent]	Correct management (%) Med [Dent]	Correct referral (%) Med [Dent]
Geographic tongue	8 [100]	8 [96]	6 [96]	31 [96]
Primary herpetic gingivostomatitis	6 [96]	0 [91]	2 [91]	30 [91]
Acute leukaemia	27 [77]	35 [86]	34 [73]	56 [82]
Atenolol drug reaction	35 [95]	23 [86]	29 [77]	36 [96]
Angina bullosa haemorrhagica	8 [91]	8 [92]	11 [86]	27 [86]
Squamous cell carcinoma	71 [68]	58 [91]	67 [90]	88 [95]
Crohn's disease	21 [100]	17 [100]	21 [100]	56 [100]
Kaposi's sarcoma in HIV infection	38 [68]	33 [82]	40 [64]	65 [100]
Stevens-Johnson syndrome	38 [95]	31 [95]	31 [77]	54 [86]
Oral hairy leukoplakia in HIV infection	27 [92]	27 [86]	34 [77]	46 [95]

5.3 TRAINING MATERIAL

If the training issue for non-dentally qualified health care workers is to be addressed, then it is clearly important that up to date, high quality training aids are available to those providing the education. Ideally, these should be devised by members of the dental team, who are knowledgeable about the evidence base for mouth care procedures. This is especially important in nursing, where many oral health care procedures have been in place for many years and are based purely on anecdote.

Unfortunately there is a paucity of appropriate written material on mouth care for those without a dental background. The following sections describe some of the teaching aids that have been devised by the author in an attempt to provide educational tools for oral health care training of medical and nursing staff and other carers.

5.3.1 Journal articles

Written articles presented in professional journals are an important way of stimulating interest and promoting changes in practice. Not surprisingly, dentists tend to write mainly for dental journals which are so specialised that they are circulated to and read only by dental staff. There is an obvious need to reach a wider audience with articles relating to oral health and disease, but a dentist's academic standing is often judged by the journals in which he achieves publication. In the dental academic community, it is often felt that nursing journals may not be of sufficient academic calibre to merit the publication of quality research papers. Thus, important aspects of evidence-based practice are often presented only to dental practitioners rather than to the wider health-care community.

Nursing journals, including specific research-based journals, enjoy a large circulation to hospital, hospice and community-based nurses. Thus, articles relating to the mouth, published in these journals could potentially reach a wide and varied audience and hopefully stimulate an interest in improving mouthcare for dependent patients.

The author has recently published a series of articles in a nursing journal. The articles were written specifically for nursing staff and contained information on common oral conditions, oral mucosal infections, oral care for dependent patients and oral care for patients with mental illness. The feedback received following publication was extremely positive and encouraging. The circulation list of the journal included geriatric units, general hospitals and hospices with both medical and nursing staff being targeted. The articles have stimulated interest nationwide and many phone calls and letters have been received requesting further information and clarification of certain points.

There is no doubt that nurses are aware of the problem that they, as a profession, have with mouthcare. They do, however, seem keen to improve their level of knowledge and to move away from anecdotal practice. It is the author's view that the production of concise, well-written, evidence-based articles is a useful way of facilitating this move.

5.3.2 Laminated oral health sheets

In response to the pleas of many nurses with whom the author and colleagues were working, for some help with understanding oral disease, a simple training aid was devised (Sweeney, Blair & Bagg, 1994). This consisted of a series of encapsulated,

full-colour, illustrated sheets, entitled "Making Sense of the Mouth". The twenty sheets illustrated features of a healthy mouth together with sixteen common oral disorders. The set was held in an A4 size ring binder which was brightly coloured to make it readily noticeable on the ward. The folder also had the team logo "Partnership in Oral Care" on the front cover and spine to aid identification and also to promote the idea of multidisciplinary working. It was hoped that receipt of the folder would encourage nursing staff to become more aware of oral problems and to be more at ease with examination of the mouth.

The teaching aid was designed to be largely pictorial with minimal text. Each sheet contained 1-3 full colour clinical photographs with simple bullet points relating to diagnosis, clinical features, contributory factors, prevention, treatment and prognosis listed below. If a professional dental opinion was deemed necessary, a highlighted box of text was inserted at the bottom of the sheet to indicate this. It was hoped that this non-threatening format would make the folder seem attractive and accessible for all grades of staff involved in mouthcare of dependent patients. As previously stated, the sheets were laminated to make them robust in use and they were placed in a ring binder so that individual sheets could be removed for consultation at the bedside if required, or for training purposes. The A4 size was selected to fit in with other ward documentation and full colour with high resolution scanning was chosen for the photographic reproduction, despite the extra cost, to make the pictures as accurate as possible. Initially one hundred sets of laminates were produced and these were distributed to long-stay wards of the hospitals and trusts which provided financial support for the project. The laminates were well received and feedback indicated a wide readership of both medical and nursing staff.

As the laminated sheets were proving to be useful within the ward setting, it was postulated that they could also prove useful to community nurses and health visitors caring for dependent patients in their own homes. Further funding was sought to produce another run of the folders, but to incorporate, in addition, a set of oral hygiene protocols. These had been specifically requested by many of the recipients of the original folders. Initially four protocols were produced:

- Oral hygiene procedures for dentate patients.
- Oral hygiene procedures for edentulous patients.
- Management of oral infections.
- Management of dry mouth.

A fifth sheet contained key points to be considered when carrying out routine mouth care. The sheets again contained minimal text and were designed to guide nurses towards a standard for mouth care and also to help those who were already trying to produce their own protocols for use within their own sphere of practice.

The new "Making Sense of the Mouth" packs were distributed across Scotland to all Scottish hospices and to a random sample of district and Macmillan nurses. Again, feedback proved positive and many of the nurses reported changes in practice after receipt of the pack (Sweeney *et al*, 1996). However, 34% of those who responded to the questionnaire sent with the pack felt that further training would still be beneficial and that the most popular format for this training would be a videotape. It was in response to these comments that the author and a colleague sought funding to

develop a multimedia resource pack on oral disease, which is described in Section 5.3.3.

5.3.3 Multi-media resource pack

Following one of the studies described above (Section 5.2.1) of nurse provision of mouth care for cancer patients in Scotland, it became clear that most were providing mouth care in the absence of written protocols and that further educational material was required as a matter of urgency (Sweeney *et al*, 1996). In particular, there was an indication of a need for good quality and highly illustrated written material, together with a videotape (Sweeney *et al*, 1996).

In order to address this problem the author developed, with colleagues, a multimedia resource pack on oral disease and mouth care for use by non-dentally qualified health care workers. The project was funded by Grant RDC/961/A from the Scottish Office Oral Health Strategy Fund and administered by The Scottish Council for Postgraduate Medical and Dental Education. This permitted production of a pack suitable for use by individuals or in a group setting and also funded a formal external evaluation of 100 copies of the pack.

5.3.3.1 *Development of the resource pack*

The components of the pack (Figure 5.1) were developed over a period of 12 months. A custom-pressed plastic box was produced to house the individual items and the colour scheme and design for the packaging of all the components were devised with the co-operation of a graphic artist.

Figure 5.1 The multi media resource pack contained a videotape, a CD-ROM disc, an A5 sized spiral bound pocket book, a journal supplement on oral fungal infections, three ward posters and a list of useful addresses for those planning mouth care protocols.

- **Videotape**

The videotape was planned to illustrate the practical aspects of mouth care and was aimed at nursing auxiliaries, in addition to qualified nursing staff. The author, together with a second dental surgeon and a dental hygienist developed the script. Following consultation with the producer assigned to the project, initial plans to employ a professional presenter were dropped. The producer felt that with the aid of autocue, two dental members of the project team could deliver a professional performance to camera that would be made more credible by the fact of the obvious sympathy and knowledge of the subject matter.

In order to add realism and vitality to the videotape the footage was filmed on location in a specialised hospital unit for care of the elderly. A dental surgery was also available at this facility for filming the key features of a healthy mouth. Editing was undertaken on the Avid non-linear digital editing platform MC Xpress®, at which time graphics were created and added on a separate channel that could be combined with the final programme. This was particularly useful for adding annotation to the intra-oral camera shots, filmed separately. The distinct sections of the video were numbered in the top left-hand corner of the screen.

The completed videotape was selected for Honourable Mention in the 46th Columbus International Film and Video Festival, 1998.

- **CD-ROM**

The CD-ROM was designed to supply some of the elements that were not possible through any of the other linear parts of the package. Specifically, it was designed to allow users to find quickly those items of information that were of immediate use and interest to them and to provide links between these items where appropriate. In addition, the interactive *'Test your Knowledge'* section provided feedback on what had been learned, in a non-threatening environment. The programming and design of the CD-ROM disc were undertaken by Mr. George Kirkland, Dissolve Interactive Media Solutions, Glasgow, based on text and illustrations provided by the author.

The material was divided into five main sections. The first, entitled *'Making Sense of the Mouth'*, contained high resolution, colour illustrations of different anatomical sites in a healthy mouth and a selection of common oral disorders. In total, 32 sets of images were employed. The second section contained details on mouth care protocols for different patient groups, which could be adapted by nurses writing their own sets of standards. The third section, called *'Prescribing for the Mouth'*, gave guidance on the use of drugs to manage oral disease, for example the prescribing of anti-fungal agents for management of oral candidosis. This section contained further clinical photographs to reinforce the material illustrated in the first section. The fourth section, entitled *'Test your Knowledge'*, was an interactive self-assessment exercise based on illustrated clinical scenarios, with separate strands for medical and nursing staff. The final section contained a glossary of terms used frequently by dental staff, but which may be unfamiliar to other groups of health care workers.

Following research into the likely specification of the computers available to typical members of the target audience, a minimum PC hardware specification was set as a 486 DX2-66 processor (75MHz Pentium preferred); 8Mb RAM (16Mb preferred); 16Mb (minimum) free hard disc space; and screen resolution of 640 x 480 at 16 bit depth (thousands of colours).

Tests with the clinical images at a screen resolution of 256 colours (8 bit) proved to give an image quality unsuitable for the recognition or diagnosis of many of the conditions included in the disc and indicated that a display resolution of thousands of colours was the minimum acceptable. The program was, therefore, set up to test the display settings of the user's computer at the outset and not to run if it were set to 256 colours or less. Because it was unlikely that the users' computers would be guaranteed to have sound cards, the use of audio was ruled out. Similarly, no video was included since the ability to replay it could not be guaranteed. However, since the date of production of the CD-ROM, the nature of the installed base of computers has steadily improved in specification and any new CD-ROM would now have options allowing users to select audio and video sequences.

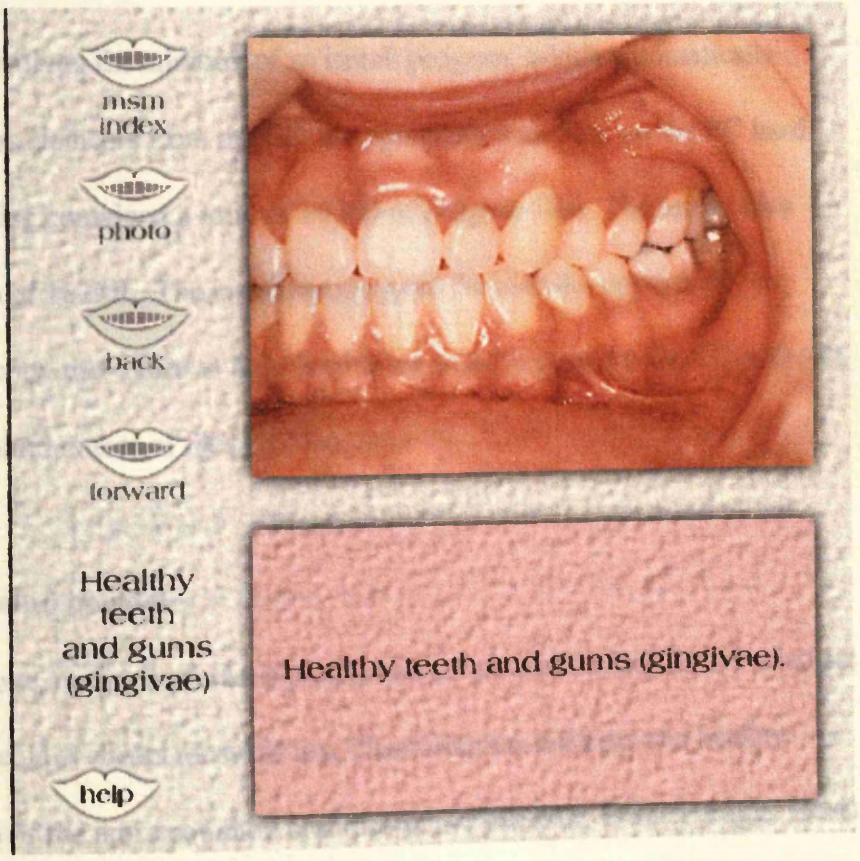
The program was produced using Authorware 4® software, which is particularly well suited to educational and training applications. Each of the screens in the *'Making Sense of the Mouth'*, *'Prescribing for the Mouth'* and *'Test Your Knowledge'* sections of the disc consists of:

- An image of 334 x 252 pixels at screen resolution of 72 pixels per inch.

- One or more text boxes.
- A variety of clickable buttons to access various aspects of the content depending on user needs or preferences.
- An option to examine a larger version of the image (465 x 350 pixels) if greater detail is required.

A typical screen from the *'Making Sense of the Mouth'* section of the CD-ROM is illustrated (Figure 5.2).

Figure 5.2 A typical screen from the *'Making Sense of the Mouth'* section of the CD-ROM. The option illustrated provides details of the clinical features of healthy teeth and gingivae. Each of the lip symbols is an active button which can be activated by use of the computer mouse. All text appears in the dialogue box beneath the clinical photograph.



The images were scanned from 35mm transparencies using a Nikon slide scanner at a resolution of 200 pixels per inch and subsequently cropped, re-sized and processed in PhotoShop®. A prototype version of the program was initially produced to test the interactive design and the functionality of the user interface. The program was then tested rigorously to ensure that all of the programming links were functioning properly and that it was stable on a variety of hardware configurations running under both Windows 3.1 and Windows 95. The program was also converted to a Macintosh version for some users.

The final stage involved the addition of an install program, which automatically installs the various elements from the CD to appropriate locations on the PC hard drive. The final disc contained a total of 16 Mb of program files. The image files occupied a space of 162Mb. The install option gave the user the opportunity to decide either to copy these files to their hard drive or leave them on the CD and only install the minimum number of files (16Mb).

- **A5 spiral bound booklet**

As described above, during a previous project the author had devised an A4 sized set of 20 laminated colour sheets for ward use, illustrating the features of a healthy mouth and some of the more common oral disorders (Sweeney, Blair & Bagg, 1994). Feedback from users of this initial pack was positive, but many felt that its size reduced its usefulness, especially for groups such as community nurses who require a portable reference aid (Sweeney *et al*, 1996).

For the current project the new A5 sized, spiral-bound version was divided into sections comparable to those on the CD-ROM, with the exception of the self-assessment section. Thus, the 48-page book contained full colour high-resolution scans of the clinical conditions illustrated, a section on prescribing for the mouth, a series of single mouth care protocols and a glossary.

- **Other components**

The packs also contained three ward posters relating to mouth care (kindly donated by Pfizer Ltd), a journal supplement on oral fungal infections and a list of useful addresses, both professional and commercial, for those wishing to establish good quality mouth care protocols.

5.3.3.2 *Evaluation of the resource pack*

Funding was available for the production of 100 packs, which were then formally evaluated. The evaluation was undertaken independently of the authors by the Scottish Council for Research in Education (15, St John Street, Edinburgh, EH8 8JR). Considerable time was spent by the project team on the identification of recipients of the pack, to ensure a wide coverage of appropriate health care professions in locations across the whole of Scotland. Each individual recipient was telephoned by a member of the project team to ensure co-operation in using the pack for training and to make clear that an external evaluation would be taking place. Ultimately the 100 packs were distributed among 81 institutions including hospitals, community settings, universities, health boards and National Health Service Trusts. These recipients have retained the packs for their own long-term use. The evaluation was carried out by a postal survey of all recipients of the pack. The structured

questionnaire related to how the pack had been used, the format, content and usefulness of the pack, previous training, awareness of good practice and suggestions for further training. In addition, a number of telephone interviews were held to follow up comments and issues raised in responses to the questionnaire.

The completion rate for the questionnaires was 68%. The overall responses, as valid percentages, are shown in Table 5.2.

Table 5.2 Responses to the questionnaire by 55 users of the mouth care resource pack (valid percentages)

Ease of use	Easy to use	Not easy	Not used
Video	91	2	7
CD ROM	46	9	44
Book	91	6	4
Posters	83	0	17

Video content	Informative	More explanation	Not used
Healthy mouth	91	4	5
Decay & gum disease	93	2	6
Denture care	89	5	5
Dry mouth	87	8	6

CD ROM content	Informative	More explanation	Not used
Healthy mouth	56	0	44
Oral disease	54	2	44
Prescribing	49	7	44
Management of oral disease	56	0	44
Oral hygiene	51	5	44
Mouth care protocols	49	7	44
Glossary	49	4	47
Self-assessment	53	2	45

Book content	Informative	More explanation	Not used
Healthy mouth	100	0	0
Clinical conditions	91	5	4
Prescribing	84	5	11
Mouth care protocols	92	8	0
Glossary	87	4	9

Of those who responded to the questionnaires, 76% had a role in the training of health care professionals or carers in oral health care. The pack had been used in training both single and multi-professional groups. Trainees included nursing and

medical staff at all levels as well as dental staff, health visitors, nursing auxiliaries, teachers, carers, volunteers, patients and patients' relatives. Eighty two per cent of the group had used the pack for their own training while 52% had used it for training other professionals or carers.

There was overwhelming agreement (96%) that the pack was attractive and well laid out. Over 90% found the video and book easy to use. However, a large percentage (44%) had not used the CD-ROM and a further 9% had found the CD-ROM difficult to use. In most cases the problems lay with availability of the necessary technology to run the CD-ROM and / or the degree of computer literacy of the user, particularly the requirement of the CD-ROM for thousands of colours (as described above). More detailed instructions on changing the computer colour setting to allow the disc to run will be necessary on future production runs. However, of those who were able to access and use the CD-ROM, over 90% found the content informative. Suggestions to make the CD-ROM more useful included the addition of a voice track and a print out facility.

Respondents were asked to tick one of five statements used to describe possible reactions to the training pack with regard to their own practice in oral care. The results are summarised in Table 5.3. Several others referred to the continuing use of the pack for training in the long term.

A copy of the full report from SCREE is available in Appendix II

Table 5.3 Responses to the questionnaire regarding users' current oral care practices in relation to the content of the resource pack (valid percentages)

Current situation	Agree
Already in line with pack	48
Have changed my approach	28
Planning to change my approach	7
Need more study	9
Have not changed	4

5.3.3.3 *Future directions*

The interviews made it clear that there was a real need for a resource pack dealing with oral health care, particularly in the light of the current emphasis on evidence-based medicine. Overall, the pack was generally agreed to be an excellent training resource for trained and untrained staff in a range of health care professions. Whilst designed primarily for use in hospital and community settings by doctors, nurses and carers, the pack also has potential for use in undergraduate medical and nursing courses, particularly in view of the case scenarios on the CD-ROM which could form an element of problem based learning exercises.

It has come as a surprise to the author that many dental personnel have also expressed a wish to receive a pack, both to update their own knowledge of basic oral medicine and to use as a training aid with ancillary dental staff. Since each element of the pack

has been assigned an individual ISBN number, it will be possible in due course to provide users with the CD-ROM, video or book as single items if they wish.

Following development and evaluation of this pack, funding has now been made available from a pharmaceutical company for production of 1000 copies of the pack, which will be distributed across the United Kingdom. A further 100 copies have also been funded by the Scottish Council for Postgraduate Medical and Dental Education, for distribution within Scotland. The possibility of making the content of the pack available on the Internet is also being examined. It is hoped that this initiative will have a significant and beneficial impact on the oral health and comfort of those with systemic illness.

5.4 CURRICULUM CHANGES AND POSTGRADUATE TRAINING

As discussed earlier, many doctors exhibit poor diagnostic abilities when faced with oral disease and with medical problems involving the oral cavity. In order to examine whether sub-optimal education was an underlying factor, the author undertook a study to examine the training in oral disease currently provided for medical undergraduates and qualified doctors in the United Kingdom. An anonymous, partially closed questionnaire (Appendix III) was mailed to the deans of all 29 British medical schools. Information was requested on the teaching provided in the current medical curriculum covering oral anatomy and pathology and the prevention of oral disease. The stage of the course at which such training was provided and the professional background of the individuals undertaking the teaching were also examined. A specific question sought any formal interactions with a dental school or

other dental personnel in the planning or provision of relevant parts of the medical curriculum. Finally, space was allocated for any general comments.

A second questionnaire (Appendix III) was sent to the deans of the 16 British university dental schools to determine how many academic dental staff were involved in undergraduate medical education. In addition, there was a question to determine how many dental staff were involved in postgraduate courses for medical staff.

Finally, a third questionnaire (Appendix III) was posted to the 24 postgraduate medical deans to determine whether postgraduate courses in oral disease exist for qualified medical staff.

The questionnaires and covering letters were all mailed in November 1997 and a stamped addressed envelope was enclosed for the replies. A second copy of the questionnaire with a reminder letter was sent four weeks later.

The response rates to the questionnaires mailed to the medical, dental and postgraduate deans were 72%, 100% and 83% respectively. Training related to the mouth provided in current undergraduate medical curricula is summarised in Table 5.4.

Table 5.4 Summary of training on the mouth for undergraduate medical students in the 21 responding medical schools

Subject	Number (%) providing instruction	Stage of course	Number (%) with dental staff input
Normal oral anatomy	15 (71)	Pre-clinical (1st and 2nd Year)	5 (24)
Oral pathology	11 (52)	Clinical (3rd and 4th Year)	4 (19)
Prevention of oral disease	6 (29)	Pre-clinical (2 schools) and Clinical (4 schools)	6 (29)

Only 52% of 21 responding UK medical schools incorporated formal teaching on oral disease in their curricula. Six (29%) of the 21 medical schools that responded had some type of formal interaction with a university dental school or with other dental personnel for provision of teaching on the mouth. General comments were provided by 12 schools, three of which intimated that the questionnaire had stimulated them to consider incorporating appropriate material into their courses.

The responses from the deans of dental schools concurred with those from the medical deans. Dental staff from nine (56%) of the UK dental schools were involved in teaching medical undergraduates and 6 (38%) dental schools were involved in consultation on content of the local medical course. Dental staff from 12 (75%) of the

dental schools were involved in postgraduate education for qualified medical staff. This was a surprisingly high figure in the light of the responses from postgraduate medical deans, only 3 (15%) of whom claimed to organise postgraduate courses dealing with the mouth for doctors in their area.

Whilst three quarters of the medical curricula included oral anatomy, this was taught at a very early stage in the course and would not impart a useful working knowledge of the topographic anatomy of the mouth in a living person. Patients are frequently referred to oral medicine departments by medical staff for specialist opinions on normal anatomical features such as lingual tonsil and circumvallate papillae. Other common and completely harmless variants of normal are also frequently referred, and in this context only 8% of the medical staff in the present study correctly identified geographic tongue in the case scenarios. A small amount of training during the clinical part of the medical course to familiarise students with the clinical features of a healthy mouth and also the more common and most significant oral diseases (currently discussed in only 52% of medical courses) could transform their diagnostic abilities as qualified doctors.

With the current changes to many medical curricula, including the shift towards problem-based learning, the inclusion of elements relating to the mouth would be apt and timely. Indeed, the resource pack discussed above (Section 5.3.3) would have a useful place in undergraduate training.

Interdisciplinary postgraduate seminars in this field, funded by industry and organised by the authors, have already been extremely successful and the same structure could

be employed at a local level by postgraduate deans. With time, such training initiatives will shed light into this important cavity, which for so many medical personnel remains at present a black hole.

All of these training issues are equally applicable to nursing staff (see Section 5.2.1). Increased interaction with dental personnel during the undergraduate training of nurses and at a postgraduate level are essential if mouth care for dependent patients is to improve.

5.5 MEASURING CHANGE IN PRACTICE

There is general agreement in the literature that one of the determining factors in gaining control over oral problems in dependent adult patients is effective oral care (Holmes, 1998). However, promoting more effective oral hygiene practices is a complex issue and, as described earlier in this thesis, a number of barriers have been identified against advancing standards of care in this area. Eadie and Schou (1992) suggest that these barriers cannot be diminished by written educational material alone. Indeed, such a route could prove counter-productive, since it places the burden of responsibility solely upon the carer, thus provoking the kind of entrenched attitudes that can hinder any further initiatives.

Instead, it is important to appreciate that the problems will only be resolved following a fundamental change in attitude towards the issue. Such a change can only be achieved by developing a comprehensive oral health care programme that aims to imbue the carers with more concern for oral hygiene, as well as providing them with the necessary skills and resources to take the appropriate action. Important elements

in such a programme would include universal standards of oral hygiene practice, positive reinforcement and formal training to cover both students and those already qualified (Eadie & Schou, 1992). Collaboration with other health care professionals and community care providers would also be required. If a high rate of staff turnover is expected, continuing dental education must be included at regularly scheduled in-service training programmes.

Dental personnel must be seen to take the lead not only in provision of care for dependent adult patients but also by designing and implementing educational and practical strategies to improve the level of oral care provided by others. It is, however, not enough merely to introduce new practices and training materials. The dental profession must also be involved in measuring the true effectiveness of these new strategies, by introducing audit tools which would allow any changes in practice to be recorded and their overall effect on oral health to be measured. This aspect of the process is, perhaps, the most difficult. In one recently published study involving 116 dependent, dentate, elderly patients, half of the group were exposed to a preventive programme for 18 months (Mojon *et al*, 1998). This programme included an oral hygiene course for the health care providers together with regular recalls to a dental hygienist (Mojon *et al*, 1998). After the 18 months, the plaque indices were not statistically significantly different from baseline in either group, but mutans streptococci counts and active root caries were lower in the group receiving the preventive regime (Mojon *et al*, 1998). There are very few well designed investigations of this type reported in the literature. It is the author's intention to undertake similar studies in the near future, using the multi-media resource pack described in this thesis, to determine the most effective use of training materials for

optimising oral health gain.

5.6 RELEVANT AUTHORED PAPERS

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* The factual content of these two submitted papers is included in the text of Chapter 5 of this thesis.

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APPENDICES

APPENDIX I

RAW DATA FOR THE ORAL HEALTH OF 114 CONSECUTIVE PATIENTS RECEIVING TREATMENT FROM THE DENTAL DEPARTMENT RUN BY THE AUTHOR IN A SCOTTISH PSYCHIATRIC HOSPITAL

Table 4.1A Oral health status of 19 psychogeriatric / dementia patients

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	68	No	Yes	No dentures	Poor	Yes	Yes	Poor	Yes	Generalised atrophy.
M	67	Yes	No	F/F dentures	Fair	-	-	-	No	Healthy mucosa. Macroglossia
M	70	Yes	No	F/F dentures	Very poor	-	-	-	No	Large lingual ulcer. Coated tongue.
F	71	No	Yes	No dentures	Very poor	Yes	Yes	Poor	Yes	Generally unhealthy at all sites
F	83	No	Yes	F/- only	Poor	Yes	Yes	Poor	Yes	Nil

Table 4.1A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	75	No	Yes	P/P dentures	Poor	Yes	Yes	Poor	No	Desquamative gingivitis
F	80	No	Yes	No dentures	Very poor	Yes	Yes	Very poor	Yes	Marginal gingivitis
M	76	Yes	No	F/F dentures	Very poor	-	-	-	Yes	Chronic erythematous candidosis
M	88	Yes	No	F/F dentures	Very poor	-	-	-	Yes	Nil
F	59	No	Yes	P/P dentures	Poor	Yes	Yes	Poor	Yes	Mucosa badly damaged by bleach burn

Table 4.1A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	75	Yes	No	F/- only	Poor	-	-	-	Yes	Gross denture induced hyperplasia (upper and lower ridges). Angular cheilitis.
M	79	Yes	No	No dentures	Good	-	-	-	Yes	Gross atrophy of ridges. No mucosal lesions.
F	64	Yes	No	F/F dentures	Good	-	-	-	Yes	Nil
F	70	No	No	F/F dentures	Very poor	-	-	-	Yes	Impetigo: lips and chin
F	72	Yes	Yes	P/- denture	Poor	-	-	Poor	-	Chronic erythematous candidosis

Table 4.1A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	75	Yes	Yes	F/- denture	Very poor	-	-	Poor	Yes	Red ,angry and swollen around erupting canine in midline
F	70	No	No	No dentures	Fair	-	-	-	Yes	Left- sided parotitis
F	83	No	Yes	F/- denture	Good	-	-	-	Yes	Nil
F	83	No	Yes	No dentures	Very poor	Yes	Yes	Poor	Yes	Nil

Table 4.2A Oral health status of 25 patients receiving treatment for alcohol dependence

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	29	Yes	Yes	No dentures	Fair	Yes	No	Good	Yes	Nil
M	48	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	No	Nil
M	38	Yes	Yes	No dentures	Poor	Yes	Yes	Very poor	Yes	Generally thin, atrophic mucosa
M	54	Yes	Yes	No dentures	Very poor	Yes	Yes	Very poor	No	Oral cancer (tongue)
M	34	Yes	Yes	No dentures	Good	Yes	No	Average	Yes	Nil

Table 4.2A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	59	Yes	Yes	F/- denture	Poor	No	No	Average	Yes	Chronic erythematous candidosis.
M	37	Yes	Yes	No dentures	Very poor	Yes	Yes	Poor	No	No
M	69	Yes	No	F/F dentures	Good	No	No	-	Yes	Smoker's mucosa
M	40	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	No	Nil
M	66	Yes	Yes	No dentures	Poor	No	-No	Very poor	No	Gross swelling associated with lower right wisdom tooth

Table 4.2A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	52	Yes	Yes	P/- denture	Poor	Yes	Yes	Poor	No	Chronic erythematous candidosis
F	44	Yes	Yes	No dentures	Very poor	No	No	Poor	Yes	Dry, shiny mucosa
M	34	Yes	Yes	No dentures	Very poor	Yes	Yes	Very poor	No	Atrophic mucosa at all sites
M	65	Yes	No	F/F dentures	Poor	-	-	-	No	Bilateral smokers keratosis. Coated tongue.
F	68	Yes	No	No dentures	Fair	-	-	-	No	Smokers keratosis (longstanding)

Table 4.2A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	30	Yes	Yes	No dentures	Fair	Yes	Yes	Average	No	Nil
M	59	Yes	No	F/F dentures	Poor	-	-	-	Yes	Candidal leukoplakia. Pigmentation. Cobblestoning of mucosa
M	49	Yes	Yes	F/- denture	Poor	Yes	No	Very poor	Yes	Atrophic mucosa all sites
M	47	Yes	Yes	No dentures	Very poor		Yes	Poor	Yes	Atrophic mucosa all sites
M	36	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	No	Poor. Abscess and large swelling present.

Table 4.2A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	49	Yes	Yes	F/- denture	Poor	Yes	Yes	Poor	No	Chronic erythematous candidosis. Angular cheilitis. Smokers keratosis.
F	48	Yes	Yes	P/- denture	Poor	Yes	No	Very poor	Yes	Chronic erythematous candidosis. Cobblestoning of palate.
M	65	No	No	F/F dentures	Poor	-	-	-	Yes	Bilateral keratosis. Coated tongue
M	40	Yes	Yes	No dentures	Poor	Yes	No	Poor	Yes	Lower lip crusting. Smoker's mucosa.
M	78	Yes	Yes	No dentures	Poor	No	Yes	Very poor	Yes	Lichen planus. Gross palatal erythema. Leukoplakia.

Table 4.3A Oral health status of 56 patients receiving treatment for psychoses (schizophrenia and severe affective disorder).

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	60	Yes	Yes	No dentures	Fair	Yes	Yes	Average	Yes	Nil
M	43	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Yes	Persistent angular cheilitis
F	49	Yes	Yes	No dentures	Fair	No	No	Average	No	Trauma due to toothbrushing
F	17	Yes	Yes	No dentures	Good	No	No	Average	No	Nil
F	22	Yes	Yes	No dentures	Poor	Yes	yes	Very poor	No	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	33	Yes	Yes	P/- denture	Poor	Yes	Yes	Poor	No	Chronic erythematous candidosis beneath denture. Sublingual keratosis.
M	59	Yes	yes	F/- denture	Very poor	Yes	Yes	Very poor	Yes	Poor condition. Florid mucosal erythema. Ropy saliva.
M	21	Yes	Yes	No dentures	Good	Yes	No	Average	No	Healthy
M	44	Yes	Yes	F/P dentures	Poor	Yes	No	Poor	No	Generalised erythema and atrophy of mucosa.

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	24	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Yes	Nil
M	49	Yes	Yes	F/- denture	Poor	No	Yes	Poor	No	Flabby, fissured, inflamed anterior ridge.
F	50	Yes	No	No dentures	Poor	-	-	-	Yes	Very poor. Dry cracked angles. Coated tongue. Smoker's keratosis.
M	30	Yes	Yes	No dentures	Poor	No	No	Poor	Yes	Smoker's keratosis.
M	23	Yes	Yes	No dentures	Poor	No	No	Poor	Yes	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	37	Yes	Yes	No dentures	Very poor	Yes	Yes	Very poor	No	Generally unhealthy all sites
F	56	Yes	No	F/- only	Very poor	No	No	-	Yes	Chronic erythematous candidosis. Smoker's mucosa.
F	50	Yes	Yes	No dentures	Fair	No	No	Good	Yes	Nil
M	34	Yes	Yes	No dentures	Fair	Yes	Yes	Average	Yes	Nil
M	41	Yes	Yes	No dentures	Fair	Yes	No	Average	No	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	19	Yes	Yes	No dentures	Poor	No	No	Poor	Yes	Nil.
F	21	Yes	Yes	No dentures	Fair	Yes	No	Average	No	Nil
M	33	Yes	Yes	No dentures	Faire	Yes	No	Average	No	Nil
M	37	Yes	Yes	P/- denture	Very poor	Yes	Yes	Poor	Yes	Chronic erythematous candidosis. Smokers keratosis
M	19	Yes	Yes	No dentures	Poor	Yes	Yes	Average	Yes	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	35	Yes	Yes	No dentures	Fair	No	No	Poor	Yes	Nil
M	39	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Yes	Candidal leukoplakia
M	30	Yes	Yes	No dentures	Fair	No	No	Average	No	Bilateral smoker's keratosis
M	44	Yes	Yes	No dentures	Poor	Yes	No	Average	Yes	Nil
F	37	Yes	Yes	No dentures	Poor	Yes	No	Average	Yes	Multiple abscesses. Shiny, dry, inflamed mucosa.

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	44	Yes	Yes	No dentures	Good	No	No	Good	Yes	Nil
M	37	Yes	Yes	P/- denture	Fair	No	No	Good	Yes	Nil
M	40	Yes	Yes	No dentures	Very poor	Yes	Yes	Poor	Yes	Dry, shiny, sticky mucosa.
F	29	Yes	Yes	No dentures	Poor	Yes	Yes	Average	Yes	Smoker's keratosis.
M	52	Yes	Yes	No dentures	Poor	-	-	Poor	No	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	57	Yes	No	F/F dentures	Very poor	-	-	-	Yes	Chronic erythematous candidosis. Angular cheilitis. Flabby ridges.
F	35	Yes	Yes	P/- CoCr denture	Poor	Yes	Yes	Poor	Yes	Sticky, erythematous mucosa.
F	78	Yes	No	F/F dentures	Good	-	-	-	Yes	Ulcers and swelling associated with bilateral fractured mandible
M	31	Yes	Yes	P/- denture	Poor	Yes	Yes	Poor	No	Nil
M	32	Yes	Yes	No dentures	Poor	No	No	Poor	No	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	50	Yes	Yes	P/F dentures	Poor	Yes	Yes	Poor	Yes	Chronic erythematous candidosis.
M	74	Yes	Yes	No dentures	Fair	Yes	Yes	Average	No	Nil
F	29	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Yes	Dry, sticky mucosae. Brown tongue.
M	22	Yes	Yes	P/- denture	Poor	Yes	Yes	Poor	No	Abscess. Sinus tracking from lower molar.
M	53	Yes (cigarette and pipe)	Yes	F/- denture	Poor	Yes	Yes	Poor	Yes	Large ulcer lateral border of tongue.

Table 4.3A (Continued

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	30	Yes	Yes	No dentures	Poor	Yes	No	Poor	No	Nil
F	28	Yes	Yes	No dentures	Good	No	No	Impacted wisdom teeth and pericoronitis	No	Nil
M	51	Yes	Yes	No dentures	Poor	Yes	Yes	Very poor	No	Sinus above central incisor. Atrophic, erythematous mucosae. Coated tongue.
F	44	Yes	Yes	P/- denture	Poor	Yes	Yes	Very poor	Yes	Nil
M	42	Yes	Yes	F/- denture	Poor	Yes	Yes	Poor	Yes	Smoker's keratosis. Angular cheilitis.

Table 4.3A *(Continued)*

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	49	Yes	No	F/F dentures	Poor	-	-	-	Yes	Gross atrophy of mucosa. Smoker's keratosis.
F	76	Yes	No	F/F dentures	Poor	-	-	-	Yes	Chronic erythematous candidosis. Smoker's keratosis.
M	39	Yes	Yes	No dentures	Poor	-	-	Average	Yes	Pseudomembranous candidosis. Fissured tongue
M	30	Yes	Yes	No dentures	Poor	Yes	Yes	Average	Yes	Nil
M	41	Yes	Yes	No dentures	Fair	Yes	Yes	Poor	No	Nil

Table 4.3A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	47	Yes	No	F/F dentures	Good	-	-	-	No	Lingual ulceration (denture-induced)
M	48	Yes	Yes	No dentures	Poor	Yes	Yes	Average	No	Nil

Table 4.4A Oral health status of 14 patients receiving treatment for drug addiction

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
M	30	Yes	Yes	P/- CoCr denture	Very poor	Yes	yes	Very poor	No	Erythematous candidosis of the paiate.
M	25	Yes	Yes	No dentures	Poor	Yes	No	Poor	No	Red mucosa all sites. Abscesses present.
F	25	Yes	Yes	No dentures	Poor	Yes	Yes	Very poor	No	Chronic erythematous candidosis.
F	25	Yes	Yes	No dentures	Poor	Yes	No	Very poor	No	Nil
F	17	Yes	Yes	No dentures	Fair	No	No	Good	No	Healthy but impacted wisdom tooth causing pericoronitis.

Table 4.4A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	25	Yes	Yes	No dentures	Very poor	Yes	Yes	Poor	No	Atrophy and erythema all sites
M	34	Yes	Yes	No dentures	Poor	Yes	Yes	Average	Yes	Smoker's mucosa
F	26	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Nil	Nil
M	20	Yes	Yes	No dentures	Very poor	Yes	Yes	Average	Yes	Atrophy of mucosa. Dry and shiny.
M	34	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	No	Nil

Table 4.4A (Continued)

Sex	Age	Smoker	Dentate	Denture status	Oral hygiene	Coronal caries	Root caries	Periodontal health	Dry mouth	Mucosal condition and soft tissues
F	26	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	Nil	Nil
M	21	Yes	Yes	No dentures	Poor	Yes	Yes	Average	No	Nil
F	21	Yes	Yes	No dentures	Very poor	Yes	Yes	Very poor	No	Nil
F	25	Yes	Yes	No dentures	Poor	Yes	Yes	Poor	No	Nil

APPENDIX II

THE EXTERNAL EVALUATION OF THE MULTI-MEDIA ORAL HEALTH TRAINING PACK, UNDERTAKEN BY THE SCOTTISH CENTRE FOR RESEARCH IN EDUCATION

Making Sense of the Mouth: A Resource Pack

Evaluation Report

Marion Devine
Jacqueline Mapp

July 1998

The Scottish Council for Research in Education

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Marion Devine
Jacqueline Mapp

1 Introduction

Background

In 1996, the Partnership in Oral Care project team based at the Glasgow Dental Hospital and School submitted a proposal to the Scottish Office to design and produce a resource pack on oral health care. The pack aimed to improve the education of nursing staff and doctors in both hospital and community settings and hence to improve the quality of oral health of their patients.

The proposal included a commitment to an independent evaluation of the pack and in August 1997, as the pack was nearing completion, the Scottish Council for Research in Education was asked to carry out this evaluation.

Content of resource pack

The resource pack contains the following training materials:

1 A video tape on routine mouth care for use by nursing staff and carers.

2 A CD ROM presentation including strands appropriate for both nursing and medical staff illustrating normal and harmless conditions of the mouth as well as various pathological conditions with appropriate management, treatment and prescribing information.

3 A spiral bound book for quick reference containing some of the information presented in the video tape and the CD ROM.

4 Poster material for display.

Dissemination of resource packs

During the development of the resource pack, a series of nation-wide seminars on oral health care was held at which the pack was introduced to members of various health care professions. These seminars were used to gather suggestions for improvement on the earlier drafts of the resource and the final package took account of these suggestions. The full package was available by December 1997.

It was considered essential that the first 100 packs should be targeted at named individuals who would have the responsibility for ensuring that the pack was used appropriately in training. Some considerable time was spent by members of the project team identifying recipients of the package to ensure a wide coverage of appropriate health care professions in locations across Scotland. Each individual recipient was contacted personally by a member of the project team in order to ensure co-operation in using the pack and to advise the recipients that an external evaluation of the pack would be taking place.

Evaluation of the pack

The aim of the evaluation was to determine the answers to a number of research questions related to the format, content and usefulness of the pack. Additional questions related to how the pack had been used and respondents were also asked to indicate the extent to which using

the pack had changed their practice. Non-dental professionals were asked about their previous training and practices in oral health care.

Method

The evaluation was carried out by a postal survey of all recipients of the initial distribution of the pack. The questionnaire, which is included as Appendix 1, is in two sections. The first section which related to how the pack had been used and to the format, content and usefulness of the pack, was to be answered by all recipients. The second section which covered previous training, awareness of good practice and suggestions for further training was directed at recipients from non dental-related occupations. In addition a small number of telephone interviews were held with staff in non-dental occupations to follow up comments and issues raised in the responses to the questionnaires.

Results

Appendix 2 lists the responses to the questionnaire as valid percentages. The comments written on the questionnaires and the information from the telephone interviews are used to supplement and illuminate the quantitative results.

2 Evaluation findings

A mailing list of those who had received a resource pack was provided to the evaluators. A total of 81 questionnaires and accompanying letters requesting assistance with the evaluation were distributed. Two reminders were sent at approximately one month intervals. The number of completed questionnaires returned was 55 with an additional three responses which indicated that the pack had been placed in a resource centre for use when appropriate. The completion rate for the questionnaires was 68%.

The characteristics of the respondents were checked against the original mailing list. The characteristics checked and how they compared were as follows:

- The areas covered by the returners closely matched that of the full list. In particular roughly the same proportions were from Glasgow, Edinburgh, Renfrewshire and Lanarkshire. These areas accounted for the largest proportion of the original list.
- Respondents from dental-related occupations were over-represented in the completion list (27% compared with 17% of full list).
- The non dental-related occupations of the respondents included the same cross section of health care professionals as in the full list.
- The workplaces of the respondents included all those in the original list ie hospitals, community settings, universities, health boards and NHS Trusts.

The findings

Use of pack in training

Of those who responded to the questionnaires, 76% had a role in the training of health care professionals or carers in oral health care. The pack had been used in training both single and multi professional groups. Trainees included nursing and medical staff at all levels as well as dental staff, health visitors, nursing auxiliaries, teachers, carers, volunteers, patients and patients' relatives. 82% of the group had used the pack for their own training while 52% had used it for training other professionals or carers. More than two thirds of the group (69%) used the pack for training alongside others in the same profession, while 15% used it with people from different professions. Examples of mixed groups included:

teachers, school nurses and volunteers

GPs, health visitors and school nurses

health visitors, nurses, carers of elderly long stay patients.

Format of pack

There was almost unanimous agreement (96%) that the pack was attractive and well laid out. Comments on the format and layout of the pack were positive.

excellent pack with variation in style

The pack content and general design are excellent

well presented resource, clearly defined and illustrated

The only suggestion for improvement in format was from one respondent who would have welcomed smaller posters.

A small number of respondents also mentioned that the pack would have been improved by a more extensive introduction particularly for non-dentists which would show how the pack should be used.

Use of different media

Respondents were asked about the ease of use of the various media - video, CD ROM, book and posters. Over 90% found the video and the book easy to use. A large percentage (44%) had not used the CD ROM and a further 9% had found the CD ROM difficult to use. In most cases the problems lay with availability of the necessary technology to run the CD ROM and/or the degree of computer literacy of the user. The biggest problem seemed to be that in order to provide the best illustrations of mouth conditions, the CD ROM needed thousands of colours to run and this was not available to many respondents.

CD ROM was not compatible. Could not use it because of colours.

I have a modern Pentium computer but the CD ROM would not run because of insufficient colours.

We do not have facility for CD ROM.

Those users who had little familiarity with computers or CD ROMs found the instructions inadequate in telling them how to change the colour setting so that the disk could run.

Some of those who found it easy to use commented on possible difficulties.

The CD ROM is easy to use but requires massive amount of disk space.

Although I found no problem with the CD ROM many other users may not be so familiar with the technology. More instructions would be useful for those.

One respondent had found the CD ROM useful not only for updating his/her knowledge of oral care but for developing better IT skills.

The content of the pack

Respondents were asked about the information provided in the various media and how informative they found it. Approximately 90% of respondents found that the content of the video was informative. Those sections which were commented on as being particularly informative were on the healthy mouth and on dry mouth. A small number of suggestions were included to improve the video.

An older person's healthy mouth would have been better.

Would have been beneficial to show complete oral mouth routines for each category of patient.

The video did not show how to deal with unco-operative demented patients, nor did it show how to remove dentures safely which have not been removed for months at a time.

A small number of respondents would have welcomed more explanation about denture care. One of the dentists who responded thought that denture care was not detailed enough for non-dental personnel.

Of those who were able to access and use the CD ROM, over 90% found the content informative. The section on the management of common mouth problems was most appreciated. Suggestions to make the CD ROM more useful included the addition of a voice track, a print out facility and clinical pictures of target groups.

Over 90% of respondents found the following sections of the book informative

Normal/harmless conditions

Clinical conditions

Mouth care protocols.

The section on mouth care protocols was most frequently mentioned as particularly informative. Typical comments included:

[The book is] informative with ideal photographs. The information is short but to the point.

[I would] recommend the picture book. It's very good people can see at a glance, the picture, the treatment, the prognosis. I've shown it to doctors in the hospital and they have thought it very useful.

Omissions from the pack

Apart from requests for fuller instructions for trainers on how to use the pack, a few specific omissions were noted by individuals both in the questionnaire and during telephone interviews. These included the provision of information on what should be done with patients who cannot rinse out their own mouth, the need to lengthen the video to include full oral mouth routines, how to deal with unco-operative patients and various specific conditions.

The pack probably provides 75% of what we need. It falls down in that it only deals with patients who are able to help themselves to some extent. Does not deal with unconscious patients or patients with severe strokes who are unable to help themselves.

Would have liked more on fungal infections including treatment of dentures.

Good for basic care perhaps additional material for more advanced care of immun-suppressed patients or patients with oral tumours.

Something on severely compromised mouths- radiotherapy, chemotherapy etc.

Immediate influences of training pack

Respondents were asked to tick one of five statements used to describe possible reactions to the training pack with regard to their own practice in oral care. The results were as follows

Situation after using training pack	Percentage
Mouth care provision already in line with recommended practices	48
Approach to the provision of mouth care changed	28
Changes in approach to the provision of mouth care planned	7
More study required before making decision about changes in practice	9
No changes in practice planned	4

Respondents who had changed or planned to change their practice (35%) were asked to indicate what these changes were. Some of the changes were at the individual level, others were changes applied to groups of carers or institutions within the sphere of influence of the respondent. Respondents altered practices to:

check patients' mouths routinely

address the use of Telodent tablets in the Trust

no longer use Telodent tablets or glycerine and honey swabs

make sure protocols are up to date for the clinical area worked in

implement oral hygiene assessments, protocols and individual care plans for patients

introduce health promotion pack to include section on dental hygiene

introduce protocol for routine examination of all patients.

Several others referred to the continuing use of the pack:

To make staff aware of information in pack and adapt care accordingly.

Will use the pack when training care staff in nursing and residential homes.

We are introducing problem-based learning and the pack will be a useful resource.

A small number of respondents referred to concerns with some of the recommendations contained in the pack

Some concerns about the use of Milton from a health and safety viewpoint

Would need to discuss with multi professional groups before making some recommended changes

Comments about the use of Sodium Bicarb could be misleading. Needs clarification

The need for multi-professional consensus

A few respondents to both the questionnaire and the telephone interviews referred to some debates with other professionals such as pharmacists and microbiologists about some of the substances recommended in the pack.

Chlorhexidine is expensive and pharmacy are not willing to make it up. Microbiologists say there is no need. You need pharmacy and microbiology behind you.

We had moved away from using Milton on the wards for health and safety reasons. You cannot leave it on a locker as some patients will drink it. Also problems with ensuring correct concentration. Recommended substance for metal denture is expensive and has cost implications. Microbiologist like to know more about the evidence on which these substances are recommended.

Previous training and experience of non-dental staff

Non-dental staff were asked to complete a further section of the questionnaire dealing with their previous training and experience in oral health care. 80% of respondents had previously received training in mouth care and 75% had been given information on the features of a healthy mouth. However, less than one quarter described recent training related specifically to mouth care.

When asked about their practice prior to using the training pack, 70% of non-dental respondents reported that they routinely checked the health of the mouth of the people they cared for. A further one quarter only did so if the patient complained about mouth problems. The great majority (over 90%) were aware of various methods for the prevention of decay including the use of regular brushing with fluoride, chlorhexidine mouthwash and the restriction of sweets and sugary drinks . A slightly lower percentage (80%) were aware of the benefits of fluoride rinses or tablets.

Almost two thirds of the group (62%) had previously been shown a methodical approach to clean other people's teeth. Some individuals who had not had this experience indicated that it was only by a long process of trial and error that they had eventually developed a satisfactory method.

When dealing with edentulous patients, only 42% of respondents were very aware of the problems which can result from wearing dentures. Less than half (42%) routinely asked denture wearers about mouth problems. Over two thirds of respondents (70%) had been shown how to remove and replace patients' dentures and 80% were aware of the need to check the health and cleanliness of oral mucosa before replacing dentures. Much smaller percentages were aware of recommendations which advised that plastic dentures should be soaked overnight in dilute Milton (48%) and metal dentures in chlorhexidine (25%). The great majority (95%) were aware that where people were staying in institutions, each person's dentures should be individually named and soaked in their own named containers.

Although 92% of respondents were involved in caring for patients who were at risk of dry mouth, less than half of respondents (45%) were very aware of the causes of dry mouth and 50% were very aware of salivary substitutes which could be used to help people with dry mouth.

Telephone interviewees were asked if they believed that there was a need for this pack, who it was that would benefit most from the pack and the extent to which the pack met the needs of the health care professions. There appeared to be a definite need for the pack.

Very much so it is a subject which is much talked about but often ignored.

Oh yes, there is a need. Tradition dies hard. So much of your life is experienced through the mouth.

Definitely [there is a need] oral hygiene literature is confusing. You read conflicting evidence from different journals - research-based articles which give no evidence.

Nursing staff talked about the number of unresearched substances that were still in use for mouth care in some hospitals such as pineapple chunks, vitamin C, gin and tonic cubes, glycerine and honey and a great variety of solutions.

There was a feeling that the pack should be used with trained staff first of all to ensure that they were aware of best practices.

Need to teach the trained staff because care assistants will do what staff tell them.

Further training needs

One third (33%) of non dental respondents felt that they needed further training in mouth care. Those who indicated what further training would be useful mostly referred to the need for continued updating to keep in touch with relevant research and developments or to

ongoing and regular use of the pack. Of those who felt that they did not need further training a few made it clear that their use of the pack had already fulfilled their training needs.

Probably my knowledge is adequate after using the pack - it certainly was not before.

The value of the training pack

General comments at the end of the questionnaire referred to the value of the training pack for various groups and institutions. Several respondents have already recommended the pack for use to other colleagues.

Excellent pack suitable for a range of different groups and professions. Have recommended it to colleagues in the University Medical school and College of Nursing.

This is an excellent pack for training sessions ... with staff caring for the elderly.

Useful for first year nurses and nurses on Diploma in HE.

Well presented and useful pack for induction of nursing auxiliaries and education of clinical support workers.

[I have] suggested to our colleagues in hospice care that it would be an excellent resource.

3 Conclusions

Need for an oral health care package

Interviews with non-dental professional staff made it clear that there was a real need for a resource pack dealing with oral health care. The emphasis on evidence-based medicine had made several respondents aware of the unsubstantiated and contradictory advice contained in much of the existing nursing and hospice literature. They commented on the tendency for oral health care to be based on tradition and trial and error and for the mouth to almost be ignored unless the patient complained of problems. Several nurses who responded to the questionnaire and who provided information through telephone interviews were of the opinion that oral health care had been much neglected in the past partly because of the lack of good training materials and welcomed the fact that health professionals generally could now begin to take care of the mouth seriously.

Those respondents who were responsible for training qualified and unqualified staff were particularly appreciative of the pack indicating that it would form an essential resource which could be used as part of their ongoing training programme.

Respondents highlighted the need for trained staff, particularly, to be kept up to date with recent developments as carers , voluntary workers, patients and patients' relatives depended on trained staff for advice on best practice.

Strengths of the pack

The pack was generally agreed to be an excellent training resource for trained and untrained staff in a range of health care professions. The CD ROM was most useful for self training or for one-to-one tuition while the video had been successfully used by groups of up to 20 participants engendering lively debate about old fashioned remedies still in use in some institutions and about the need to base their practice on sound evidence. Demonstrations of good practice came as a revelation to some respondents:

just seeing someone work behind a patient. I had not thought of doing that.

The spiral bound book was reported to be of a handy size for reference and contained clear illustrations accompanied by short but informative text. Perhaps above all the pack was welcomed as raising the importance of mouth care and highlighting the comfort to patients of a healthy mouth.

Although almost half of those who commented on the pack felt that their practices were already in line with the recommendations, more than one third of all respondents had already changed their practice or planned to do so. In many cases this had involved staff in the preparation of oral assessment tools or protocols designed to be used routinely to the benefit of all patients in their care.

Concerns about the pack

There were some technical concerns about the installation and running of the CD ROM and it may be that more instructions of a trouble shooting kind need to be provided to help less computer-literate users to gain access.

Other concerns related to the need for consensus with other professionals about some of the recommendations contained in the resource which had cost or health and safety implications. Pharmacists and microbiologists were mentioned as needing to be clear about the research evidence for some recommended substances before they would co-operate in assisting with implementing change.

Improvements to the pack

The pack was seen as providing most of what was needed for basic oral health care. The recommendations for improvement suggested that a more advanced pack would be welcomed by many in non-dental professions who were keen to extend their knowledge to more difficult clinical conditions or to more difficult types of patients.

Measuring success

To some extent the success of the pack can be measured by the positive responses to the various components of the package as outlined in this evaluation. Other indications of success and satisfaction with the pack can be derived from the number of respondents who had already made changes or who planned to make changes to their current practice, who requested information on buying extra copies of individual sections separately, who had already lent their copy of the pack to other members of their profession or who had recommended its purchase to other institutions. A longer term measure of success, beyond the scope of this evaluation, will depend on the improved quality of oral health care of the patients in those institutions where the pack has been used in training. Those who have seen and used the pack appeared to have little doubt that it will have a beneficial impact on the patients in their care.

I am just so pleased that people are beginning to take the mouth seriously. You get a lot of instant satisfaction from making patients comfortable.

Making Sense of the Mouth
Oral Care Resource Pack

☐☐☐

Background

1. What is your role/profession? _____

2. Where is your place of work? eg hospital, community. _____

3. Do you have a role in training health professionals/carers in oral health care? yes ☐ no ☐

   If yes, which kind of professionals/carers do you train? _____

4. Did you use the package

   for your own training? yes ☐ no ☐

   for the purpose of training others? yes ☐ no ☐

Use and format of resource pack

5. How did you use the pack?

   on your own ☐ with other people in the same profession ☐ with people from different professions ☐

6. Is the pack attractive and well laid out? yes ☐ no ☐

   If no, how could the pack be improved? _____

7. The pack provides information in different media. How easy were they to use?

		Easy to use	Not easy to use	Not used
A	Video	☐	☐	☐
B	CD ROM	☐	☐	☐
C	Book	☐	☐	☐
D	Posters	☐	☐	☐

Please add a comment on your response to this question if you wish.

Content of pack

8. How useful did you find the information provided in the **VIDEO** component of the pack?

		Informative	Needed more explanation	Not used
A	Healthy mouth	☐	☐	☐
B	Dental decay and gum disease	☐	☐	☐
C	Denture care	☐	☐	☐
D	Dry mouth	☐	☐	☐

Which section(s) did you find particularly informative or significant?

9. How useful did you find the information provided in the **CD ROM**?

		Informative	Needed more explanation	Not used
A	Features of a healthy mouth	☐	☐	☐
B	Common oral diseases	☐	☐	☐
C	Prescribing for the mouth	☐	☐	☐
D	Management of common mouth problems	☐	☐	☐
E	Oral hygiene	☐	☐	☐
F	Mouth care protocols	☐	☐	☐
G	Glossary	☐	☐	☐
H	Test your knowledge	☐	☐	☐

Which section(s) did you find particularly informative or significant?

10. How useful did you find the information provided in the **SPIRAL BOUND BOOK**?

		Informative	Needed more explanation	Not used
A	Illustrations of normal and harmless conditions	☐	☐	☐
B	Illustrations of various clinical conditions	☐	☐	☐
C	Prescribing for the mouth	☐	☐	☐
D	Mouth care protocols	☐	☐	☐
E	Glossary	☐	☐	☐

Which section(s) did you find particularly informative or significant?

11. In both the book and the CD ROM, information relating to the mouth is included. How useful was this information?

		Useful	Not useful	Not used
A	Illustrative photographs	☐	☐	☐
B	Diagnosis	☐	☐	☐
C	Cause	☐	☐	☐
D	Clinical features	☐	☐	☐
E	Contributory factors	☐	☐	☐
F	Prevention	☐	☐	☐
G	Treatment	☐	☐	☐
H	Prognosis	☐	☐	☐

12. Which **one** of the following statements **best** describes your current situation?

A My mouth care provision was already in line with the practices promoted in the package. ☐

B I have changed my approach to the provision of mouth care. ☐

C I am planning to change my approach to the provision of mouth care. ☐

D I need to study sections of the package further before making up my mind about changing my approach to the provision of mouth care. ☐

E I have not changed and do not plan to change my approach to the provision of mouth care. ☐

13. Please note any changes or planned changes you intend to make to your mouth care methods.

14. Please add any other comments about the pack: its format, content or value to health professionals.

The final section is to be answered only by health professionals who are NOT dentists or in dental related occupations.

Making Sense of the Mouth
Oral Care Resource Pack

ADDITIONAL QUESTIONS TO BE ANSWERED ONLY BY HEALTH PROFESSIONALS WHO ARE NOT DENTISTS OR IN DENTAL RELATED OCCUPATIONS

☐☐☐

1. Before receiving the mouth care pack had you previously received training in mouth care for the people you care for? yes ☐ no ☐

   If yes, describe this training briefly and when it was received

Mouth Care

2. Before using the pack had you ever been given information on the features of a healthy mouth? yes ☐ no ☐

3. How often do you check the health of the mouth of the people you care for?

   routinely ☐ only if they complain ☐ never ☐

Decay

4. Which of these methods were you aware of for the prevention of decay before using the pack?

A regular brushing with fluoride toothpaste yes ☐ no ☐

B fluoride rinses/fluoride tablets yes ☐ no ☐

C use of chlorhexidine mouthwash or gel yes ☐ no ☐

D restriction of sweets and drinks yes ☐ no ☐

Brushing the teeth

5. Before using the pack had you been shown a methodical approach to clean other people's teeth? yes ☐ no ☐

Dry mouth

6. Are you involved in caring for someone who has an increased risk of dry mouth?

   yes ☐ no ☐ not sure ☐

Dry mouth (contd)

7. Before using the pack how aware were you of the causes of dry mouth?

very aware ☐ aware to some extent ☐ not at all aware ☐

8. Before using the pack how aware were you of the salivary substitutes which can be used to help people with dry mouth?

very aware ☐ aware to some extent ☐ not at all aware ☐

Dentures

9. Before using the pack how aware were you of mouth problems which can result from wearing dentures?

very aware ☐ aware to some extent ☐ not at all aware ☐

10. How often do you ask denture wearers if they have any mouth problems?

routinely ☐ only if they complain ☐ never ☐

11. Before using the pack which of the following recommendations were you aware of ?

A the method of removing and replacing other people's dentures yes☐ no☐

B plastic dentures should be soaked overnight in dilute Milton yes☐ no☐

C metal dentures should be soaked overnight in chlorhexidine yes☐ no☐

D the health and cleanliness of the oral mucosa should be inspected before re-insertion of people's dentures yes☐ no☐

In a group situation eg hospital, residential home

E each person's dentures should be individually named yes☐ no☐

F each person's dentures should have their own named container yes☐ no☐

Further training

12. Do you feel you need any further training in mouth care?

yes ☐ no ☐ not sure ☐

If yes, what further training would be useful?

Thank you for your co-operation in completing this questionnaire

Questionnaire responses (Valid percentages)

Number of responses = 58* (72%)
Number of completed questionnaires = 55 (68%)

Involved in training	Yes
Trainer in oral health care	76
Used for own training	82
Used for training others	52
Used on your own	51
Used with others in same profession	69
Used with others in different professions	15

Good layout and format	96

Ease of use	Easy to use	Not easy	Not used
Video	91	2	7
CD ROM	46	9	44
Book	91	6	4
Poster	83	0	17

Video content	Informative	More explanation	Not used
Healthy mouth	91	4	5
Decay and gum disease	93	2	6
Denture care	89	5	5
Dry mouth	87	8	6

CD ROM content	Informative	More explanation	Not used
Healthy mouth	56	0	44
Oral disease	54	2	44
Prescribing	49	7	44
Management of disease	56	0	44
Oral hygiene	51	5	44
Mouth care protocols	49	7	44
Glossary	49	4	47
Test	53	2	45

Book content	Informative	More explanation	Not used
Normal/harmless conditions	100	0	0
Clinical conditions	91	5	4
Prescribing	84	5	11
Mouth care protocols	92	8	0
Glossary	87	4	9

CD ROM and Book	Useful	Not useful	Not used
Illustrative photos	91	0	9
Diagnosis	89	2	9
Cause	91	0	9
Clinical features	89	2	9
Contributory factors	89	2	9
Prevention	91	0	9
Treatment	91	0	9
Prognosis	87	0	13

Current situation	Agree
Already in line with pack	48
Have changed my approach	28
Planning to change my approach	7
Need more study	9
Have not changed	4

* Includes three who have not used the pack but who have recommended it for inclusion in a resource library.

APPENDIX III

POSTAL QUESTIONNAIRES USED TO DETERMINE THE AMOUNT OF TRAINING ON ORAL HEALTH AND DISEASE PROVIDED FOR MEDICAL STUDENTS AND DOCTORS IN THE UNITED KINGDOM

- **QUESTIONNAIRE SENT TO ALL UNDERGRADUATE DEANS OF UK MEDICAL SCHOOLS**

SURVEY OF MOUTH CARE TRAINING IN UK UNDERGRADUATE MEDICAL COURSES

1. Do undergraduate medical students attending your university receive any training in:

Normal anatomy of the oral cavity Yes*☐ No☐ *Year of course:_____

Oral pathology Yes*☐ No☐ *Year of course:_____

Prevention of oral disease Yes*☐ No ☐ *Year of course:_____

2. By whom is the teaching provided?

_____

_____

3. Do you have any formal interaction with a University Dental School or with other dental personnel for provision of training for medical undergraduates?

Yes☐ No ☐

_____

4. Any other comments:

_____

_____

_____

_____

5. Academic position of staff member completing questionnaire:_____

PLEASE RETURN THE QUESTIONNAIRE IN THE STAMPED ADDRESSED ENVELOPE SUPPLIED

THANK YOU VERY MUCH FOR YOUR ASSISTANCE

- **QUESTIONNAIRE SENT TO ALL UNDERGRADUATE DEANS OF UK DENTAL SCHOOLS**

SURVEY OF MOUTH CARE TRAINING IN UK UNDERGRADUATE MEDICAL COURSES

1(a) Do any of the dental staff in your dental school provide teaching to undergraduate medical students?

Yes*☐ No☐

1(b) If yes*, how many of your staff are involved in such activities?

_____

2. Do undergraduate medical students attending your university receive any training in:

Normal anatomy of the oral cavity	Yes☐	No☐	Don't know ☐
Oral pathology	Yes☐	No☐	Don't know ☐
Prevention of oral disease	Yes☐	No ☐	Don't know ☐

Other relevant material (please provide details):

_____

_____

3. Are you involved in consultation on medical course content?

Yes☐ No☐

_____

_____

4. Are any of your staff involved in postgraduate education for qualified medical staff?

Yes☐ No ☐

_____

5. Any other comments:

_____

_____

_____

_____

6. Academic position of staff member completing questionnaire:_____

PLEASE RETURN THE QUESTIONNAIRE IN THE STAMPED ADDRESSED ENVELOPE SUPPLIED

THANK YOU VERY MUCH FOR YOUR ASSISTANCE

- **QUESTIONNAIRE SENT TO ALL POSTGRADUATE MEDICAL DEANS IN THE UK**

POSTGRADUATE TRAINING ON THE MOUTH FOR DOCTORS

1(a) Do you organise any Section 63 or similar postgraduate courses dealing specifically with the mouth for doctors in your area?

Yes*☐ No☐

1(b) If yes*, please give details

_____

_____

_____

_____

2. By whom is the teaching provided?

_____

_____

3. Do you have any formal interaction with a University Dental School or with other dental personnel for provision of postgraduate training?

Yes☐ No ☐

_____

4. Any other comments:

_____

_____

_____

5. Academic position of staff member completing questionnaire:_____

PLEASE RETURN THE QUESTIONNAIRE IN THE STAMPED ADDRESSED ENVELOPE SUPPLIED

THANK YOU VERY MUCH FOR YOUR ASSISTANCE