

PROCEEDINGS – School of Oriental and African Studies, London, 6 December 2002

Sensory Impairment

Professor Raman Bedi, Honorary President of BSDH welcomed delegates to SOAS for the Winter Scientific meeting with the morning theme on sensory impairment. He introduced the first speaker, Sally Reynolds from the Royal National Deaf Children's Society. To my knowledge, this is the first time a speaker at a BSDH meeting has presented in British Sign Language (BSL), which was translated by a Sign Language Interpreter.

General health needs of deaf people

Sally Reynolds

Millennium Awards Manager, The National Deaf Children's Society

Ms Reynolds' presentation covered the general health needs of deaf people, the background conditions affecting their access to health, and what needs to be done to improve the situation regarding health access for deaf people. UK Government statistics estimate that over 8.7 million people are deaf or hard of hearing and of these, approximately 64,000 are severely or profoundly deaf. Deaf people have different needs from other people who are defined as hard of hearing. 90% of deaf children are born to hearing parents. Just 5% have deaf parents and 5% have deaf / hearing parents. Deaf people who use BSL see themselves as a linguistic minority group, rather than part of the disability movement.

Deaf people are frequently labelled using the medical

model of disability. They have a long-standing distrust of hearing people in general and the medical profession in particular. For parents of newly diagnosed deaf children, their first professional contact is generally an audiologist, where the emphasis will usually be on auditory or oral cures. A stress on the medical model of disability has implications for young, deaf people who may have late exposure to sign language or deaf peers.

Education has a direct impact on language and understanding. The last major survey, carried out by Conrad in the mid 1970s, demonstrated a lower than average reading age. Ms Reynolds highlighted the fact that an average reading age of 11 years is required to read tabloid newspapers. Poor reading age leads to a lack of comprehension of health information. Deaf people lag behind their peers in virtually all levels of academic achievement.

There has been a significant trend in recent years towards community health. The deaf community has not had the opportunity to capitalise on this, in many ways; research has been quantitative rather than qualitative with a limited review of community initiatives and few guidelines or evidence of best practice for health of deaf people. Deaf people are unable to access a wide variety of health leaflets and tend not to pick up information in an indirect way. Only 10% of helplines have Minicomms, these use the English language, and the person at the end of the line is usually hearing.

Ms Reynolds then addressed the issues of communication access, how deaf people can access health information in BSL. Historically, deaf people used social workers in medical settings. However the solution to communication access is through the provision of sign language interpreters (SLI), a profession that has emerged in recent years. The campaign for recognition of BSL started in 1999. However the ratio of qualified SLIs is 1:700 deaf people. Therefore many deaf people use family members for communication in the medical setting. This is an unsatisfactory situation. Consequently deaf people have a profound dislike of hospitals and health care situations and this creates anxiety. Ms Reynolds vividly illustrated the anxieties generated with quotes from deaf people in relation to the loss of privacy in using a family member as interpreter.

Ms Reynolds referred to the findings from her research. Deaf people did not believe that other deaf people could become doctors and they wanted to see more health professionals using sign language. The most common form of communication was in writing (60%). Deaf people tend to see things in visual format for example, when asked what was the main risk from smoking, all responded 'black lungs' as opposed to cancer. There was an assumption that all communication barriers can be resolved just by writing and using SLIs. Language and words need background contexts for the information to be understood, stressing the need for visual information in leaflets. Ms Reynolds referred to the value of leaflets created by the British Deaf Association (BDA) and community project information led by deaf people.

Ms Reynolds ended her signed presentation with a series of recommendations to address the health problems of deaf people. These included Health Advocates for deaf people, community initiatives led by deaf people and an increase in access to SLIs. Health professionals should ask the deaf person for their preferred communication and preferred SLI but it should also be the responsibility of the health professional rather than the deaf person to arrange communication support. Eye to eye contact with the deaf person rather than the SLI or family member is recommended. Leaflets need to be in plain English with appropriate visual images. These should be developed in liaison with deaf professionals and the deaf community.

Ms Reynolds concluded with a serious reminder of the impact of deafness on people's rights. Access to information is a right not a privilege. Deaf people feel disempowered and lack confidence if denied information that enables them to make an informed choice.

Oral health needs of hearing impaired people

Dr Ruth Holt

Honorary Senior Lecturer, Department of Transcultural Oral Health, Eastman Dental Institute

Dr Holt referred to the importance of disability at the moment in relation to the Disability Discrimination Act and

the European Year of People with Disabilities. She spoke as both a hearing impaired dentist and a patient. There has been a tendency, in Special Care Dentistry, to focus on mobility problems and she welcomed the opportunity to address the needs of people with sensory impairment. Her paper focussed on the issue of communication as a major barrier to addressing the oral health needs of deaf and hearing-impaired people.

The problems experienced by people with hearing impairments are clearly centred on communication. Even people with lesser degrees of hearing impairment have similar problems. It is important to think laterally about what that implies in terms of daily living. Communication barriers in everyday life are one of the central issues being addressed by Access Officers and Access Groups in order to provide equality of access. Communication problems both in making appointments and in the dental consultation are barriers to accessing dental care and oral health information. Poor communication may lead to increased fear and anxiety in relation to dental care.

Dr Holt reviewed the literature on oral health and hearing impairment. Most publications focussed on providing advice on communication within the dental setting. She referred to the lack of research that focussed specifically on the views of hearing impaired people and the difficulty in obtaining a large enough, randomly selected, sample. Deaf and hearing-impaired people are not a homogenous group and are scattered throughout society. Therefore research has tended to be carried out through contact with relevant charities. The 1995 British Deaf Association survey asked about dental attendance within the last year. Although 63% of the respondents reported visiting the dentist in the previous year, the survey had a low response rate from a small, highly select sample. The results must therefore be interpreted with caution and also because reported attendance is by no means the same as actual attendance. Furthermore, the results do not identify the reason for dental attendance, whether regular or for pain relief. Communication problems at the dentist were highlighted and attributed to the use of protective spectacles (Lomas and Thomas, 1998).

Lack of research into the views of deaf and hearing impaired people led to the development of research at the Eastman Dental Institute. There was even less information about the experiences of children and young people in terms of dental care, hence research was focussed on this group. The study led by Jackie Champion was carried out in partnership with the National Deaf Children's Society. The aim was to identify what difficulties were encountered in accessing and receiving dental care.

Information was collected via a questionnaire to families of children with hearing impairments, distributed and collected by the local National Deaf Children's Society. Responses were received from families of 84 children. The age range was 2.5 to 22.3 years, 55% were aged under 10. 86% were profoundly or severely deaf and 86% were

pre-lingually deaf. Information was requested on access to dental care, visiting the dentist, treatment experience, problems encountered, perceived anxiety about visits and examples of good practice.

Sixty-nine per cent used some form of oral communication and lip reading. However 30% could not use either of these methods: 98% reported having been to a dentist, of which 57% had only used the GDS, 20% had used the CDS and GDS: 54% had experienced some dental treatment, 29% had experienced extractions and 28% had fillings. Dr Holt speculated that this was a high proportion of extractions relative to fillings.

There was little evidence of problems in accessing care with only 12% reporting some difficulties. However 63% had experienced difficulties at the dentist ranging from communicating with the dentist (52%), problems in understanding what will happen (46%) and problems in communicating with the nurse (41%). Thirty-eight per cent reported problems in being called from the waiting room; Dr Holt suggested that this was a very common problem for deaf and hearing impaired people. Other difficulties related to the dentist wearing a mask while communicating (62%) even though a high proportion of the children depended partly on oral communication or lip reading. A quiet environment is essential to maximise hearing potential, however, 57% reported difficulties due to background noise levels. There was a high level of perceived anxiety about dental visits; 44% reported some anxiety and 4% did not attend due to anxiety.

Examples of perceived good practice included a relaxed and patient dentist with positive attitudes, who established the preferred methods of communication and explained procedures before putting on a mask. Parents preferred the dentist to come to the waiting room to meet the child and to speak directly to the child throughout treatment.

Dr Holt's summary complemented the issues raised by the previous speaker. Recommendations to improve practice included greater deaf awareness, an interpreter for older children, a deaf-friendly calling system for the waiting room and basic sign language training for the dental team. She concluded that there was little evidence of widespread problems in accessing dental care. Most of the common problems related to communication and some could quite easily be resolved. However lack of communication may lead to heightened anxiety in relation to dental care.

The social and general health needs of visually impaired people

Alannah Hogg

Health Promotion Officer, Royal National Institute for the Blind (RNIB)

Ms Hogg presented a summary of the social and general health needs of visually impaired people and addressed the issues of how those needs could best be met. There are

around 2 million people in the UK with a sight problem. Two thirds have additional disabilities. The prevalence of vision impairment will increase with an ageing population. Eighty per cent of people with sight problems are aged over 65 years, however, additional health problems are not always related to age. Within the current climate of patient-centred care and choice, RNIB focus groups looked at the general health needs of blind and partially-sighted adults with a range of visual problems, in order to identify how easy it was for them to manage their own health and identify how they could be best supported to achieve this.

Focus groups were set up in a number of locations to consult different age groups and address issues raised by ethnicity and gender. Although needs varied between individuals, and there were differences between young and old, there were a number of common and important issues in their health experience. Ms Hogg presented the results under a series of headings and vividly illustrated issues with quotes from contributors.

In making use of health services, the attitude of healthcare staff was the most important factor, specifically a lack of understanding of the social implications of vision impairment. Recommendations included visual awareness training for health-care professionals and guiding skills, together with improvements in reception systems and clearer communication. The accessibility of information was a fundamental problem as most health care systems rely upon the written word for communication. Eleven million people have trouble reading medicine labelling or letters from doctors and hospitals and yet 86% of visually impaired people only receive appointment letters in standard print. Managing medication is also a problem because of labelling and instructions. Coping strategies include large print, Braille and tape recordings. Ms Hogg referred to the *See it Right* guidelines for improving communication. Problems were also reported in identifying illness as most symptoms are based on visual descriptions. This could lead to uncertainty and anxiety. Greater awareness amongst health professionals, of non-visual symptoms in making a diagnosis, was considered essential.

The broader determinants of health were more difficult to achieve. There was good awareness of the importance of nutrition in disease prevention and the importance of a healthy diet in preventing obesity and heart disease. However diets were limited by difficulties with shopping, food labelling and preparation, and lack of low-vision aids in the kitchen. The inability to see 'best before' and 'sell by' dates was also a problem. In the best-case scenario this involved people eating food that was bad and in the worst case scenario, people had frequently experienced food poisoning. Ms Hogg described a multitude of low-vision aids for use in the home, for example, contrasting surfaces and liquid level indicators.

Exercise may be restricted by the frustration of obstructions in the environment and difficulties in accessing leisure

facilities in terms of transport, lack of facilities for care of a guide dog, and a complete lack of awareness on the part of the staff. There is a large aspect to exercise that promotes social contact. Therefore, lack of exercise led to a tendency towards social isolation. Buddy schemes were described to alleviate this problem.

Surveys report that 90% of people say that sight is the sense they fear losing most. Loss of sight influences emotional health and affects all areas of their lives. Common feelings were frustration at loss of independence. This ranged from people saying that they had over-bearing relatives or that they had not received adequate support from health or social services. Depression was commonly cited by blind and partially sighted people. It was conceptualised differently by young and older people. The latter were more likely to complain that they were 'feeling down' or 'unwell' whereas younger people were more likely to use the word depression, and had expressed suicidal feelings after the diagnosis of permanent sight loss. Emotional support is of real importance in regaining mental and emotional health. This was obtained in various ways, often informally through local support groups, peer counselling from other people with sight loss, and more formalised counselling or psychotherapy. Often it was described as just having someone to talk to who understood what they had been through. Regaining independence was of enormous importance in terms of social and emotional well-being.

Accidents were a particular problem for people with vision impairment. Quantitative data from the York Health Economics Consortium shows that those with reduced visual acuity are 1.7 times more likely to have a fall and 1.9 times more likely to have multiple falls, compared with fully sighted populations. Hip fracture is between 1.3 and 1.9 times greater for those with reduced visual acuity. In terms of Accident and Emergency admissions, there are 89,000 falls each year that are directly attributable to vision impairment, even after controlling for other factors such as ageing and arthritis. The cost to the NHS is £127 million a year. Much of the cost could be avoided with timely rehabilitation, mobility training and low vision aids in their homes. Often there is a gap of up to six months between diagnosis and receiving visits from social services for low vision assessment and home adaptations. There are ethical reasons why people should be given health information, help and support. There is also a strong financial case for people being given aids in their home and health information. Accidents reported at home included burns, poisonings and electrical injuries often attributed to the fact that homes were not adapted to vision loss.

Access to transport was also a fundamental problem, particularly for older people in accessing health care services. The importance of domiciliary services to compensate for this was an important issue in the context of an ageing population.

Ms Hogg concluded that people with vision impairment

generally have the knowledge and motivation to look after their own health and they do this effectively most of the time but there are aspects about the way services are provided that often causes unnecessary frustration and anxiety.

Orthodontic and oral health needs of visually / sensory impaired people

Professor Nigel Hunt

Head of Orthodontic Unit, Eastman Dental Institute

Professor Hunt began his presentation by summarising the Index of Orthodontic Treatment Need (IOTN). This consists of two components. The Dental Health Component (DHC) is considered to be a true objective measure of the most important or most discrepant feature of a malocclusion. It is based on five measures of need that include an assessment of missing teeth, overjet, crossbite, contact point displacement and overbite. Equally important is the Aesthetic Component (AC). DHC is classified as:
Grade 1 – No need
Grade 2 – Little need
Grade 3 – Borderline need
Grades 4 and 5 – Definite need.

The Aesthetic Component of IOTN is based on a photograph of the anterior dentition in occlusion. The range extends from an acceptable Class I occlusion with normal overjet and overbite, with minimal contact displacement through to ranges 8, 9 and 10 that include severe malocclusions, severe overjets, perhaps traumatic overbites and severe irregularities of the dentition, including changes in axial inclination and rotations. On the basis of the Aesthetic Component, it is generally accepted that in the range of 1 to 4, there is no need for treatment, 5 to 7 are considered as a having a possible need for treatment and 8 to 10 considered as a definite need for treatment. The Aesthetic Component not only assists in determining the priority of treatment need, it gives the patient an opportunity to gain a realistic impression of their own relative dental attractiveness compared to the rest of the population. This is of particular relevance to children with sensory impairment.

Professor Hunt proceeded to report on a study of a population based in the Middle East. He felt that there was a considerable degree of evidence that the findings in this study were equally applicable to populations in western societies. The sample consisted of 781 children aged 11–16 years, of whom 77 were visually impaired, 210 were hearing impaired, with 494 controls. There was no statistically significant difference between the distribution of treatment needs between the three groups, based on the Dental Health Component. The proportion of children deemed to have an acceptable malocclusion, with no need for treatment, was fairly representative of the majority of findings as they relate to the treatment needs in the UK population.

Around 30% of subjects, based on DHC alone, had an orthodontic treatment need. On the basis of the Aesthetic

Component, far fewer children fell into the category of having an acceptable occlusion. The visually impaired children demonstrated a greater increase in unacceptability of malocclusion. Professor Hunt again stressed the value of the Aesthetic Component in assessing subjective need.

Self perception of dental appearance is a major factor in the individual's decision to obtain orthodontic treatment. For example the presence of a large mid-line diastema can be considered to be aesthetically displeasing and yet on the Dental Health Component, it would not rate particularly highly. Self-examiner perceived need is usually less than examiner derived need except in visually impaired children where self-perceived need usually exceeds examiner derived need.

As part of this study, in conjunction with the Royal National Institute for the Blind, tactile graphics or 'Braille Maps' were constructed of the Aesthetic Component of the IOTN, specifically for use with children with severe visual impairment. In the design of the tactile graphic, which is three-dimensional and represents the various anterior images of the Aesthetic Component, the alignment and relationship of the teeth can be felt.

When this was applied to an examiner-perceived need for treatment compared with the children's perception of the need for treatment, in visually impaired children, perception of need fell. Professor Hunt felt that there were other extraneous factors in the psychology and make-up of children with visual impairment, and in their life-styles that lead to a perception of a greater need for treatment than objective measures and examiner trained measures may demonstrate.

The conclusions drawn from the research indicate that in terms of the Dental Health Component, sensory impaired children have similar orthodontic need to non-visually impaired patients. Assessment based upon the Aesthetic Component alone shows a greater need than that derived from the Dental Health Component alone. Self-perception of need tends to be lower than an examiner's assessment except in visually impaired children who consider themselves to have a greater need compared with an examiner's assessment. The tactile graphics or 'Braille Maps' helped self-perception for visually impaired children. However, Professor Hunt concluded that further development is required.

Oral health needs of visually / sensory impaired people

Dr Pauline Watt-Smith

Department of Clinical Dentistry Nuffield Orthopaedic Centre, Oxford

This paper concentrated on clinical examples of auditory and visual impairment, mainly from patients with paraesthesias associated with inherited diseases, trauma and malignancy. It also discussed methods of treatment.

The trigeminal nerve is the main nerve implicated in sensory and motor loss in the face and oro-facial muscula-

ture. It is important to establish whether problems are intra-cranial in origin, at the skull base or due to peripheral nerve damage that is inherited, due to trauma or malignancy. In persons with visual or auditory impairment, any paraesthesia should be investigated because it may lead to ulceration or be a precursor for malignancy. The trigeminal nerve, if affected by disease, produces sensory defects that are related quite specifically to the size of the lesion. Congenital intra-cranial lesions with sensory deficit include conditions such as Hunter-Turner syndrome.

Congenital blindness is not rare. Dr Watt-Smith illustrated this with slides of a child with normal IQ, with hemifacial microsomia and a facial cleft passing through the eye socket with the eye missing. This type of severe developmental abnormality needs specialist intervention in order to prevent further physical and psychological problems developing. It is recommended that all congenitally blind patients notify the practice so that appropriate advice and support can be offered. Other intra-cranial examples illustrated included intra-oral paraesthesia and absent corneal reflex associated with demyelination of the trigeminal nerve diagnosed with MRI, and facial palsy associated with intra-cranial bleeds in a patient on warfarin. Traumatic blindness is also a common outcome of facial injury. The importance of investigating the cause of paraesthesia was stressed.

Tumours at the skull base produce numbness and paraesthesia due to pressure on the trigeminal nerve as it exits the cranium. Pressure anywhere on the peripheral trigeminal nerves produces sensory disturbance and if affecting more than one branch, it is necessary to consider diseases that are closer to the trigeminal ganglion or intra-cranial in origin. A specialist referral is strongly recommended. However, the most frequent cause of peripheral trigeminal sensory loss is dental sepsis. Dental treatment can also cause sensory loss, for example, the extraction of impacted wisdom teeth may cause lingual nerve damage. The risks involved must be documented and in order to obtain informed consent and avoid litigation, the patient must be advised that the benefit will outweigh the risk. Instructions in Braille may be necessary for patients with vision impairment. Iatrogenic damage to the nerve is not always restricted to surgery. This was illustrated with a case of incomplete endodontic treatment that caused paraesthesia. Tumours rarely present with discrete sensory loss, producing symptoms in any of the trigeminal branches. Throughout this paper, case studies were used to vividly illustrate many of the causes of facial sensory loss.

Oro-facial dysfunction can cause many problems that affect quality of life. As part of a rehabilitation team, Dr Watt-Smith reinforced the practical guidance stressed by earlier speakers in managing and improving communication with patients with sensory impairments. Notification of the type of sensory impairment prior to the first consultation is very helpful so that staff members are made aware of the patient's requirements. In summary, a commitment

to providing patients with adequate time to discuss treatment and their concerns, and simple treatment plans heavily focussed on prevention, are the foundation of good practice for people with sensory impairment.

The History of the British Society of Disability and Oral Health

Professor Stanley Gelbier

Head of Division of Dental Public Health & Oral Health Care Services Research, King's College School of Medicine and Dentistry

Professor Gelbier provided a fascinating and comprehensive summary of the historical development and the first 25 years of BSDH since it was established in 1976. However, the foundation for setting up the society arose from a small group of enthusiasts in a positive political climate that fostered some major changes. In 1968, Arnold Franks and Crawford Macfarlane met to discuss dental care for handicapped patients (See Editorial, *J Disabil Oral Health* 2001; **2**: 50). They documented two main issues; first the poor oral health status of handicapped patients and second, the lack of information on how to provide dental care. At that time, most handicapped patients were treated by child dental health services.

In the 1960s, Franks had himself been involved in a group called 'The Younger Foundation for the Mentally Handicapped' and he began to discover the problems that handicapped people experienced and had a real concern for the treatment of older patients. He developed an interest in special needs patients and set up postgraduate clinical training in adult restorative dentistry with an emphasis on gerontology, gerodontics and the development of professional services for special needs patients, especially older people. Franks was author of the first text book on the subject. After his appointment to a Consultant post in Birmingham Dental Hospital, he visited the USA and commented on the variety of initiatives for providing care for disabled people. On his return, Franks invited a number of health professionals to discuss their experiences and concerns about special needs patients.

Crawford Macfarlane, who had a strong interest in the care of handicapped adults was appointed as the first full-time Senior Hospital Dental Officer to care for some 4,500 deprived mentally handicapped patients in hospital. He established dental units in two hospitals and established GA services for in-patients and out-patients. He was invited to join Franks' group. During this period, Macfarlane established links with David Rule and Gerald Winter at the Eastman and conducted the first piece of research into dental services at long-stay hospitals. At a USA meeting, where he presented a paper, he met Manny Album who was a leading paediatric dentist who provided care for a wide group of disabled patients, and was acknowledged as the leading light in the US in developing special care dental services.

In the UK, Neil Swallow also had a history of working

with disabled children. He established clinics for children with disabilities in London, provided treatment under GA at Brentwood Hospital and provided a London wide service constructing feeding plates for children born with cleft lip/palate. Later, in Cardiff Dental School, Swallow established a strong tradition of care for disabled children and adults. He subsequently worked in Amsterdam and later took up a Chair at Belfast Dental School continuing to provide special care services to children and adults.

Professor Gerry Winter was a major contributor to the development of care for disabled children. He was dually qualified and gained a Diploma in Child Health. He was later appointed as Professor of Children's Dentistry. Winter and his colleagues at the Eastman made important practical advances in managing comprehensive restorative care for children with disabilities.

Manchester Dental School also provided some care for children with disabilities. Phil Holloway was another key player. After his arrival in Manchester, formal arrangements were made to develop services for children with mental and physical disabilities, and medically compromised children. Pam Hobson, also at Manchester was invited by the Director of the Haemophilia Unit to join the multi-disciplinary team to plan services. It was a major achievement for a dentist to be invited to join with medical colleagues in planning services. Hobson attended paediatric clinics and ward rounds and noted the harmful effects of sugars-based medication in chronically sick children.

Roy Storer at Liverpool developed an interest in the problems of ageing and the oral health care of older people. Storer was perhaps the first person to regard ageing as a normal life process, not an illness or disease. He later moved to Newcastle where he was Dean until his retirement. He published the first papers on gerodontology in the mid 1960s, identifying certain groups as needing special help, namely the homebound, chronic sick, mentally retarded and physically handicapped.

The time was right to address some of the issues; in 1968, Franks, Macfarlane and Winter, formed a multi-disciplinary study group of professionals in dentistry, medicine, associated professions and social welfare. The group met annually in Birmingham until 1971, to discuss how to improve the oral health of disadvantaged patients. Professor Gelbier suggested that in fact it was this group of interested and committed academics that formed the foundation for the Society.

Professor Gelbier continued to describe other members of the profession who contributed towards the climate for change, raising the profile of Special Care Dentistry up to the inaugural meeting of the then British Society of Dentistry for the Handicapped, in June 1976. He went on to describe the significant milestones and influences in the evolution of the Society up to the 25th anniversary in 2001.

It was a fascinating insight into the historical development of Special Care Dentistry in the UK and the forma-

tion of a forward thinking successful organisation which in 1997, to conform with political correctness, changed its name to the British Society for Disability and Oral Health. It would be presumptuous of me to try and summarise Professor Gelbier's detailed historical description of the first 25 years, more so because he has been commissioned by BSDH to write the history of the Society. It will make fascinating reading and I urge you all to read it.

Cerebrospinal fluid shunts: a case study

Dr Rachel Proctor

Eastman Dental Institute

Dr Proctor presented the case of a 54-year-old female with a relatively complex medical history. The patient had suffered a subarachnoid haemorrhage in 1994, which was treated with a ventriculo-peritoneal shunt (VPS). The patient complained of dental pain. The provisional treatment plan included measures to improve oral hygiene, supra and sub-gingival scaling, extractions, long term periodontal therapy and possibly a partial denture. This raised the question of the necessity for antibiotic prophylaxis for patients with cerebro-spinal fluid (CSF) shunts undergoing invasive dental treatment.

The main reason for placement of a CSF shunt is hydrocephalus, which is the accumulation of cerebro-spinal fluid in the ventricles. This can be caused by an over-production of fluid, defective flow within the brain or poor drainage of CSF. It leads to raised intra-cranial pressure and therefore is potentially fatal. It occurs in approximately 1 in 750 live births. The number of children with hydrocephalus is increasing because of improvements in neonatal care and operative techniques. Adults can develop hydrocephalus in association with infection, intra-cranial bleeding and brain tumours. The standard treatment for hydrocephalus is the placement of a shunt, which drains excess CSF from the brain.

There are two commonly used types of shunt, the ventriculo-atrial (VA) shunt and the ventriculo-peritoneal (VP) shunt. The VA shunt, the first type used successfully, drains from the lateral ventricle by a tube, through the internal jugular vein and into the right atrium. There is a risk of bacterial colonisation of the tubing because it lies within the vascular system and potential for infection ascending into the central nervous system. The VP shunt is more frequently used because it involves a simpler surgical procedure than the VA shunt. There may be a lower rate of infection with the VP shunt although this is debatable. The VP lies sub-cutaneously and drains into the abdominal cavity. It is not within the vascular tree and unlikely therefore to contribute to a bacteraemia.

Dr Proctor reviewed the few papers that discuss CSF shunt infections in relation to dental treatment. Croll *et al* (1979) recommended that because there is a very high morbidity associated with shunt infections, antibiotic prophylaxis should be used for invasive dental treatment.

However Gardener *et al* (1988) looked at different types of shunt and the risk of bacteraemia to each type of shunt. They concluded that a bacteraemia is unlikely to affect the VP shunts although there is a potential risk with the VA shunts.

A clinical study by Helpin *et al* (1998) looked at 14 children with VP shunts. They undertook dental prophylaxis and topical fluoride treatment. Subjects were excluded if they had antibiotics during the period three months before the trial and one year after the trial. Subjects were reviewed at one year at which time there had been no evidence of shunt infection. In addition, a 30-year review of the literature reported no cases of infection of any CSF shunt caused by a dental procedure.

Currently there are no formal guidelines and there is a paucity of dental literature on this subject. Dr Proctor concluded that for VA shunts, it is advisable to contact the patient's neuro-surgeon about the need for, and choice of, antibiotics. The reasons for this are that there may be local policies, the patient may have had antibiotics recently which could influence the choice and also the issue of penetration since not all antibiotics penetrate the CSF as well as others. The guidelines used for endocarditis prophylaxis may not be transferable to ventricular shunts because although they concentrate on a bacteraemia, they do not focus on CSF penetration.

Patients with special needs – A case history

Barbara Hylton

Senior Dental Officer, Birmingham PDS

Dr Barbara Hylton presented a case study of a young male with a learning disability, to highlight the problems and challenges encountered when a patient attends for dental treatment with inadequate information.

The only information available at the first visit was a list of the patient's medication which comprised of Trifluoperazine, Procyldine and Depot Clopixol which suggested that the patient might have behavioural problems. The patient was escorted by a carer who was not known to him. The Home Manager had ticked the form indicating a learning difficulty as opposed to a learning disability.

First impressions on escorting the patient (J) from the waiting room into the surgery were of a tall, slightly uncoordinated young man who walked unassisted. He had only one eye, seemed very agitated and anxious, and was talking loudly. J sat in the dental chair and announced that he went to the dentist every six months and that his teeth were fine. On examination, there was no evidence of caries or missing teeth, a considerable amount of sub-gingival calculus, no tooth mobility and halitosis. J stated that he brushed his teeth twice a day. On the basis of the history given by the patient, it was assumed that J attended the dentist regularly and used to receive treatment such as a scale and polish.

Following the usual principles of show, tell and do, treatment was commenced with an air-scaler. The sound of

suction generated an extreme reaction in J, and he became totally uncooperative for further treatment that day.

Subsequently it was identified that J was registered blind with some residual colour vision. J had been living independently in a care home for the last six years. He had normal mobility within his home environment and was able to make himself hot drinks using a special sensor. Although illiterate, J was described as having a vivid imagination, listening to several books on tape each week, and drank shandy when out socialising.

At the next visit, J was accompanied by his key-worker who explained that J relied on a continuous verbal commentary and time to accept and understand new situations as he relied to a large extent on audio rather than visual memory. At times, J also exhibited psychotic behaviour that was related to the frustration associated with the sensory impairment. Due to vision impairment, J relied entirely on satisfactory verbal explanations and verbal reassurance. Conversely, the clinician could only gauge J's confidence in her and in the situation by J's level of cooperation.

It was challenging to provide a constant running commentary during treatment, and at the same time to include the dental nurse, who needed to stand and face J so that he could hear her. It was essential to use relatively simple language, and ensure that only one person spoke at a time. Treatment was completed at subsequent visits. Care staff were impressed with the reduction in halitosis and agreed to support and prompt J with daily tooth brushing. The home manager developed an individual care plan for J. The patient's notes contained a comprehensive risk assessment that would not have been clearly understood by the clinician at the first visit but became clear by the completion of treatment. Care staff were of great assistance in understanding J's behaviour and the impact of vision impairment. Close collaboration and working with J and his carers provided an opportunity to learn through the insight and experience gained in managing J's dental care.

A pilot study to address barriers to physical intervention for oral hygiene

Janet Griffiths

Associate Specialist, University Dental Hospital, Cardiff

This project was initiated by a working group consisting of five clinicians working in Special Care Dentistry in adjacent health authorities. It arose out of collective concern for falling standards of oral hygiene in dependent adults. Conflict with carers was frequently encountered over the degree of physical intervention that was considered acceptable for oral hygiene despite the assertion that in order to provide care in the 'best interests' of the patient, it may be necessary to control behaviour in some way (Bridgeman and Wilson, 2000), for example, shaving or tooth brushing.

The aim therefore was to address barriers to physical intervention for oral hygiene. The project took place in a long-stay hospital for adults with a learning disability. Stand-

ards for oral hygiene had been agreed and staff training provided. However, due to changes in personnel associated with decommissioning, morale was low, standards were falling and oral hygiene was deteriorating. The situation was exacerbated by a training programme in preventing and responding to aggressive behaviour based on guidance published by the British Institute for Learning Disabilities (BILD).

Concern was being expressed that physical interventions for oral hygiene contravened the Health Authority's guidance on restraint. A multi-disciplinary work group representing medical, dental, nursing, therapy, advocacy and support services was established. To develop this project, the group worked closely with Intensive Support Services, the department responsible for providing training in dealing with aggression.

Elements of risk may be identified through an assessment process.

Three risk assessment tools were developed to identify the risks and benefits of providing oral hygiene, the possible outcome of inadequate oral hygiene and the problems identified by staff. The first, a Nursing Oral Health Risk Assessment, had been previously piloted successfully with adults with acquired brain injury and mental health problems. It focused on identifying risk factors for oral health based on guided nursing observation and included dental and denture status, observed and reported oral problems, diet, stressors for oral health, prescribed medication and potential cooperation for treatment. It classified the level of dependence and support for oral hygiene into four categories which included the need for more than one person to provide oral hygiene.

The second, an Oro-dental Assessment was based on a detailed analysis of the medical and dental notes. It recorded oral and dental status, medical factors affecting dental treatment, medication with oral side-effects and a past history of treatment modalities, including GA. Because of the difficulty in carrying out a detailed assessment of oral hygiene, a simple visual scoring system was agreed. All subjects in the study were examined by a dentist and hygienist and there was agreement between the two examiners.

The third, an Individual Behavioural Assessment was developed with the psychologist. It addressed issues of how, when and where oral hygiene was carried out, what equipment was being used, positions for providing oral hygiene, any positive or negative influences on the client's behaviour, and the degree of distress exhibited during oral hygiene. Possible harm to the client or staff was also identified.

Eight residents with 20 or more natural teeth, who were not due for resettlement within a specified period, were selected by examining dental notes. Both ambulant and wheelchair users were included but clients with severe challenging behaviour were excluded. Oro-dental assessments were completed on eight residents but due to the pace of closure, only four were included in the final project. Tech-

niques advocated for physical intervention and access to the mouth were risk assessed by the MD team and found to be quite acceptable. They included hands on hands and techniques for head support, as well as brushing techniques.

At the three-month review, the oral hygiene of all the residents had improved. There was no evidence of spontaneous gingival bleeding. Staff reported that adverse behaviour and resistance to oral hygiene were reduced. Staff found the techniques acceptable and confirmed their awareness of improvements both in oral hygiene and cooperation.

In conclusion, this pilot study was effective in reducing barriers to physical intervention to oral hygiene. Assessment tools appeared to be effective in highlighting short and long term risk factors for oral health, the importance of individual MD assessment, of recognising carers' concerns and of working with carers to support them with the challenges of effective oral hygiene. All residents were re-settled with a detailed description of the individual techniques. These continue to be applied to three clients now living in the local community.

Impact of HIV on dental care in the UK

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Dr Gray's paper focussed on changes in the way that health care is provided for people living with HIV infection. AIDS was first described 21 years ago. There are 42 million people living with HIV infection around the world. Last year, 3.1 million people died of AIDS. Approximately 52,000 people with HIV live in the UK. This paper focussed on the burdens on health care, the policies that have been developed in response to HIV and the changes in pathways for care.

HIV is a retrovirus which suppresses cell-mediated immunity, leading to a greater propensity to develop opportunistic infections and an increased susceptibility to oral tumours such as Kaposi's and Non-Hodgkins lymphoma. Because of these factors and others, there is a much greater need for people with HIV to access medical and dental care, and for more clinical resources to deliver care. For people with HIV infection, care is mainly provided by Genito-urinary Medicine Clinics (GUM). Dr Gray reported seven dedicated HIV dental units in London. An essential aspect of HIV care lies in constant monitoring and testing for viral loads and CD4 count. Highly Active Anti-retroviral Therapy (HAART) has turned HIV from a death sentence into a chronic disease. However HAART has had a serious impact on health budgets because it is very expensive. The burdens on health care are therefore financial and manpower.

There is a different and new response by governments and public health policy makers to the threat posed by AIDS in comparison with how infectious diseases such as cholera and TB were managed in the nineteenth century, when there was compulsory testing and treatment, quarantining, and

contact tracing. That has not happened with HIV because there is a much better understanding and protection of the civil rights of people with HIV, prevention has been far more liberal and pragmatic, such as needle exchange programmes and safe sex education. Dr Gray described this as a more innovative and pragmatic response to the threat posed by HIV.

Methods of providing care for all patients has changed since the advent of HIV. Because the discrimination and stigma that there has been, and is still associated with HIV, there has been greater concern for the recording and storage of data to protect patients' rights to confidentiality. This is now a legal requirement under the Data Protection Act. In 1987, Universal Infection Control Guidelines were first published by the Centre for Disease Control, establishing the principle of treating all patients as being 'at risk'. The GDC in 1991 stated that failure to employ adequate cross-infection control would render a dentist liable to a charge of professional misconduct. This involved a lot of training and investment in changing practice from wet sterilisation methods to autoclaves.

Risk of infection from blood products has also been significantly reduced. Blood screening for multiple viruses, including HIV started in 1984. People 'at risk' of HIV were encouraged not to become blood donors from 1983 and there is a much lower acceptance of blood transfusions among the general public especially amongst haemophiliacs.

In summary, HIV has increased the burden on health care. It has also been the driving force behind very important changes in healthcare provision and policies for the general public, possibly leading to improvements in the quality of health care provision. However, current changes will create problems for the provision of care especially within Special Care Dentistry. In 2002, the number of new diagnoses of HIV has increased by 25% compared with 2001. People with HIV are living longer and reliant for longer periods on expensive drugs. Therefore there is an increase in prevalence of HIV, limited resources and expensive treatment. The 'at risk' groups for HIV are changing. Heterosexual transmission is the most common form of transmission in the UK. Ethnic minorities and new immigrants are particularly 'at risk'. These groups usually have problems accessing dental care but cultural differences and expectations are issues also and there may also be language barriers and a fear of impacting on health care. Research has demonstrated that many dentists do not want to provide care for HIV patients. Research has also demonstrated that many patients with HIV do not like going to the dentist because they do not like disclosing their HIV status, of fear of loss of confidentiality and discrimination. More than half the people in this study stated that they did not want to access General Dental Services.

Compared with the early 1980s, when exceptional policies and funding were developed, HIV care has now moved into mainstream care. Budgeting for HIV care, which in the

past has been ring-fenced has now become part of general health funding. People with HIV are being encouraged to access primary care services for their general oral health care which means that the dedicated HIV dental units are confronted with difficult decisions to make about their roles, rationing of care and how to prioritise care for patients. Dr Gray concluded that people with HIV have problems accessing dental care, and that the background to these problems have changed as people with HIV are being encouraged to seek primary dental care. Ethnic minorities

and recent immigrants are not particularly well known for their effectiveness for lobbying for health care. This scenario must be viewed in the context of the increasing numbers of people living with HIV in the UK. It is uncertain what effect mainstreaming will have on the impact of oral health care for individuals with HIV. Dr Gray's research is focussing on these issues.

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