CHAPTER 1. INTRODUCTION

This thesis describes the dental practices and oral health among people aged 18–44 years with physical and intellectual disabilities. It also explores various living arrangements and other factors that are associated with oral conditions, which if modified, could improve the oral health of adults with physical and intellectual disabilities.

This chapter begins with an overview of various definitions of disabilities, changes in living arrangements of adults with disabilities over time, the need for special general health care and oral health care. The thesis rationale is based on the relevance of disability in the adult population and health policy. A conceptual framework is proposed to explain the hypothesised influences on oral health. Finally, the aims and hypothesis of this study are presented.

1.1 Definitions of disability

In Australia, disabilities are classified into broadly categorised groups like ‘physical disability’ and ‘intellectual disability’. This draws on the International Classification of Functioning, Disability and Health (ICF) and the International Classification of Diseases and Related Health Problems (ICD-10) frameworks that consider not only underlying health conditions and impairments, but also activity limitations, participation restrictions and related environmental factors (AIHW, 2003a). The Australian Bureau of Statistics (ABS) 2003 Survey of Disability, Ageing and Carers defined disability as “any limitation, restriction or impairment which has lasted, or is likely to last, for at least six months and restricts everyday activities.” Conditions include, but are not limited to: loss of sensory perception (sight, hearing, speech), which requires the use of aids, difficulty dressing due to chronic pain, loss of limb or motor function, learning difficulties, intellectual impairment, mental illness, disfigurement and deformity, and disorders of the nervous system to advanced dementia requiring constant help and supervision (ABS, 2004). An activity comprises one or more tasks in daily life and includes three core activities:

- self-care – bathing, dressing, using the toilet and managing incontinence
- mobility – moving around at home, getting into or out of a bed or chair, using public transport, and
- communication – understanding and being understood by others.

A core activity restriction may be:
Profound – unable to perform a core activity or always needing assistance,
Severe – sometimes needing assistance to perform a core activity,
Moderate – not needing assistance, but having difficulty performing a core activity, or
Mild – having no difficulty performing a core activity but using aids or equipment because of a disability.

The extent and severity of a disability has also been reported on a scale of support needs. The Support Needs scale was developed and validated by the Disability Services Office in South Australia and used in their 1995–1996 Disability Support Needs Survey of South Australia (Chapman, 1998). This measurement has a scale from 1–9 on which people with a disability rank their ability to function independently (1= little day to day support need and 9= one to one support needed 24 hours of the day). Support received includes both unpaid support from the care recipients' primary carers and paid or voluntary support from service providers.

People with physical and intellectual disabilities are not a homogeneous population and have varying health needs and living arrangements. The heterogeneity of this population and the broad range of classification and definitions add to the challenges of research in this area. Definitions vary across countries and over time. People with disabilities form a sub-group of the 'special needs population', who need 'special care' for everyday activities including self-care, mobility and communication and are referred to as 'care recipients' as in Carers in Australia (AIHW, 2004) or 'service users' as in Disability support services 2004–2005 (AIHW, 2006). In this study, the term "people with disabilities" and "care recipients" have been used interchangeably as appropriate. However, when reporting findings from other studies, the term used in the study has been retained, for examples, "handicapped adults", "people with mental retardation" or "learning disabilities" and "clients" or "residents".

1.1.1 Demographics

In Australia, in 1993, for all ages, the prevalence of intellectual disability was 1.86% (328,000 people) (Wen, 1997) and the prevalence of physical disability was 11.9%, (2,099,600 people) (Wen and Fortune, 1999). This group of people with physical disability includes people with developmental disability such as cerebral palsy, which can also be associated with intellectual disability and other conditions such as spina bifida and quadriplegia. One in five people in Australia had a disability in 2003, unchanged from 1998 (after age standardising), with South Australia having the highest reported disability rate (24%) in the country (ABS, 2004). In

South Australia, the total number of people with physical disabilities registered with agencies like Adult Physical and Neurological (APN) and Brain Injury Options Coordination (BIOC) was estimated to be 75,395 in 1997 (Chapman, 1998). However, these groups include musculoskeletal conditions like arthritis, which are more prevalent in the older age-groups and therefore not included in this study. The most recent estimate is that there are approximately 6,500 people with intellectual disability registered with Disability SA (Disability SA, 2006) and 940 people with a disability live in institutions (Disability Service Office, 2007).

1.1.2 Living arrangements

Institutions or family homes have been the main living arrangement for people with disabilities until the early 1970s when community housing was introduced in Australia (CHCSA, 2007). Institutions (residential care facility) refer to settings in which care recipients reside in an accommodation facility which provides lodging for a number of people, and which has support services provided on a 24 hour basis by rostered carers. In contrast, those living in family homes include people living with parents, partners, relatives and foster families. Community housing refers to community living settings in which care recipients reside in a facility that provides support in some way by staff or volunteers (AIHW, 2006). With the process of 'normalisation' (use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people – Wolfensberger, 1983) and 'deinstitutionalisation' (removal of residents from institutions into group homes or family homes in the community), even those with quite severe disabilities are living in the community or in family homes and are encouraged to look after themselves and be responsible for their personal hygiene including oral hygiene. This study includes care recipients living in family homes, community housing and institutions.

1.1.3 Disability services in South Australia

To provide overall service coordination, five options co-ordination agencies were established in South Australia in 1995 by the South Australian government and non-government agencies (Chapman, 1998).

1. Adult Physical and Neurological (APN),
2. Brain Injury Options Coordination (BIOC),
3. Intellectual Disability Services Council (IDSC),
4. Crippled Children's Association (CCA) and
5. Sensory Options Coordination.

Psychiatric Disability is addressed under South Australian Mental Health Service, not Disability Services. As the title suggests, this study involved adults with physical and intellectual disabilities and therefore people whose care is managed through only the first three coordination agencies.

Under the Disability Reform changes in 2005, the South Australian Government built a “more integrated and responsive system” to coordinate services for people with disabilities by bringing its disabilities services together as Disability SA under the Department for Families and Communities (DFC). Disability SA coordinates support services for South Australians with a disability, their families and carers so that people with disabilities are assisted through all the stages of their lives through centrally coordinated programs. Services provided by IDSC, Julia Farr Services (JFS) and the Independent Living Centre (ILC) are now delivered by the same staff through Disability SA to ensure continuity of care for care recipients (Disability SA, 2007).

1.2 Need for special health care

Health care for people with disabilities, especially with multiple disabilities is complex and challenging. The list of functional and medical problems that need to be addressed is frequently reflected in an even longer list of involved professionals, leading to conflicting advice and problems in co-ordination of care. ‘Professional hierarchies’ stand as barriers to effective collaboration as some professionals have difficulty in accepting important information from other team members of differing levels of training (Pearson, 1983). An ‘overexposure’ to the medical professions may entail management difficulties in addition to any barriers to care directly related to mental or physical impairment (Hennequin et al., 2000). Such unnecessary duplication of medical visits should be reduced.

An important aspect of the barriers to health care experienced by special needs patients is the inability to express their needs to health providers. They often face cognitive challenges in understanding or recognising their own health problems and understanding and adhering to health and behavioural treatments. Many have limited or no communication skills and are unable to express their pain or discomfort (Guisiano et al., 1995; Hennequin et al., 1998). Moreover, cultural and language barriers may further complicate their communications and interactions with health care professionals. They can neither express their wishes nor make rational decisions about health care. Acting ‘in the best interests’ of such persons who refuse or do not understand the purpose of treatment, depends on the attitude and treatment priorities of the carer.

Limitations in adaptive functioning in areas such as self-care, communication and literacy have a significant impact on the ability of people with disabilities to enjoy the same opportunities for good health and health care as non-disabled people. Determinants of general health among people with disabilities include lifestyle factors/behaviours, social networks (particularly the critical role of carers in facilitating access to care and lifestyle choices), living and working conditions (including community attitudes and access to services and facilities), and wider structural determinants of health (economics, policies) (Ouellette-Kuntz, 2005).

1.3 Need for special oral health care

Sanders et al. (2006) showed that dental behaviours (dental visiting and dental self care) accounted for little, if any, of the socioeconomic gradient in oral health, stating that 'if oral health promotion is to reduce social inequalities in adult oral health, efforts need to be directed to factors other than the dental behaviours of individuals and rather than focusing on individuals alone, there needs to be a better balance of targeting both individual level factors and the social environments in which health behaviours of individuals are developed and sustained'. In addition to socio-environmental determinants, oral disease among general population is highly related to these lifestyle factors, which are risks to most chronic diseases as well as protective factors such as appropriate exposure to fluoride and good oral hygiene (Petersen, 2003). Determinants of oral health for people with disabilities would be similar to that of the general population. However, unmanaged oral disease may place individuals who are medically compromised at additional risk and present complex management problems, for their families, carers and for the professionals involved in their care. Though there has been an overall improvement in oral health over the last two decades among Australian adults (Roberts-Thomson and Do, 2007), little is known about adults with disabilities, and their oral health needs are often ignored and active treatment is not provided as a priority.

The prevention and treatment of oral disease depends on self-care, which includes adequate oral cleansing by effective toothbrushing. This is even more important in people with disabilities, in whom natural cleansing by the oral musculature may be impaired. However, this may be difficult and even impossible for the person who has little or no comprehension of the procedure or whose manual dexterity is poor. In the absence of adequate self-awareness and complete understanding by these special patients, an adequate level of oral hygiene is difficult to maintain unaided. Some care recipients have the understanding of what needs to be done, but lack the musculature, dexterity or coordination to do it (Glassman and Miller, 2003). Therefore, preventive measures for special needs population will *always* require the co-operation and continued interest of carers. Even with the assistance of dedicated carers, diminished competency and motor skills may interfere with the care recipients' ability to provide self-care and follow through on oral health instructions. Approaches to health promotion that rely only on personal health behaviours such as oral hygiene and personal dietary choices of care recipients, may not be effective on these disadvantaged groups.

Limited or no communication skills and behavioural problems are major barriers in the assessment of dental problems and hence provision of timely care. Carers may realise that a problem exists but are unable to accurately assess the origin or the degree of discomfort. Even for the dentist, an oral examination may be difficult or impossible due to lack of co-operation and an accurate diagnosis may be difficult to reach in the absence of clinical data and patient communication (Weaver, 1995).

One of the reasons that there is a large amount of unmet need in this population is related to the ability of the care recipients to co-operate with dental treatment. People with disabilities are often referred for treatment under a general anaesthetic with an accumulation of untreated disease (Maestre, 1996). Despite advances in behavioural science and the approaches taken by dentists to enable treatment in the normal setting, such as relative analgesia or conscious sedation, it remains impossible to treat certain patients conventionally. It has been estimated that around 20% of people with a disability need a general anaesthetic to receive dental treatment (Holland and O'Mullane, 1990).

Financial barriers also may prevent many people with disabilities from obtaining needed dental care. Medicare, the universal health insurance programme in Australia, does not cover dental services. Most people with disabilities in Australia are on a Disability Support Pension that does not provide dental insurance.

It has also been noted that the dental need of special care patients is severely underestimated by both their carers and the dental profession (Hennequin et al., 2000). Demand by patients with special needs for oral care may be limited by the ability of the carer to evaluate their oral condition and/or by the persons' inability to express their pain or discomfort. It is possible that people on multiple medications may not be suffering pain from conditions that would otherwise have been painful. For these reasons, oral disease often remains undetected until it reaches such a stage that it is irreversible or presents a serious risk of infection. The degree of advanced pathology found in the population would suggest that pain suffered is also underestimated (Hennequin et al., 2000). Yet, behavioural responses to pain may be reduced in persons with developmental disabilities, as they may not process painful stimulation in the same way as others (Biersdorff, 1994). Thus, there is a need for a structured system to ensure that people with special needs receive preventive oral care.

1.4 Need for interdisciplinary collaboration

Oral health is an integral part of general health. Several oral-systemic interactions occur in people with disabilities. Drug-induced gingival hyperplasia further increases the risk of periodontal disease (Marshall and Bartold, 1998). There is a strong relationship between poor oral hygiene and bacterial pneumonia in special needs populations; however preventive dental care can prevent such serious lung infections (Scannapieco, 2006). Therefore, the maintenance of oral health for this population is extremely important and oral care of the highest standard is necessary as part of their general care.

For adult patients without disabilities, the dentist-patient relationship is relatively simple, involving just the two parties. In cases of adults with disabilities, the additional party(s) may be a complicating factor. This may include government agencies, managers of institutions, health care professionals, care recipients and their families and carers. This study has a focus on carers of care recipients due to their potential influential position in the provision of daily oral hygiene care.

1.4.1 Carers

A carer is a person who provides any informal assistance (unpaid help or supervision) to persons with disabilities, and a primary carer is the main provider of assistance with the core activities (ABS, 1999). There are many different ideas of who is a carer depending on the many caring situations. At policy consultation submissions in Queensland, Australia (Consultation report, 2003), the majority of participants felt very strongly that the policy should only include carers who are not paid and that people who were paid should be called by a name other than “carer”, such as “support worker” (Disability SA refers to paid carers as disability support workers). Although a small number of participants stated that workers in this field also deserve recognition, most reports include only unpaid carers. This study compares carers from family homes, community housing and institutions. Paid carers are also included as carers, but referred to as non-family carers. This collaboration with family and non-family carers is vital because they know their care recipients’ needs best.

In 2003, there were 2.6 million (unpaid) carers who provided some assistance to those who needed help because of disability or age (ABS, 2004). They assisted their care recipients with at least one of the three core activities (ABS 1999). Over 60% of them helped their care recipients with self-care tasks such as feeding, dressing, bathing and toileting; 74% assisted with mobility; and 45% assisted with communication (ABS, 1999). About one fifth of these (19%) were primary carers, most of them females (71%) and most (78%) cared for a person living in the same household (ABS, 2004).

It is important for healthcare professionals to recognise family carers as partners in the management of people with disabilities, the development of programmes and educational materials. The family can reinforce or inhibit the best efforts of health professionals and other carers. Family members are able to lead the care coordination team effectively and/or be active participants when they are knowledgeable about the care recipient's condition and their skills and strengths are supported (Bishop et al., 1993). With great importance attached to 'patient-centred' outcomes in health care (Curtis, 1998), carers' expectations and interactions may provide the most relevant perspective for judging the appropriateness of care.

Cumella et al., 2000 suggest two main ways in which carers play a central role in the oral care of people with disabilities:

1. The gatekeeper role as being a point of contact with the care recipients and making decisions on their behalf and
2. The supportive role involved with daily oral hygiene care and making visits to the dentist.

1.4.2 Dental health professionals

Dentists and dental hygienists play an important role in the provision of clinical oral care to people with disabilities. They require special skills, knowledge, empathy, patience, willingness and motivation to provide quality care. However, they should bear in mind that it is the carer who is best placed to observe small changes in behaviour and seek treatment on behalf of their care recipients and include them as an important part of the health care team. Therefore, carers become important bearers of an implied value system in any setting (CHGAP, 1993). The importance of their role in the health system has been rightfully highlighted in South Australian Generational Health Review (2002).

The South Australian Generational Health Review Discussion Paper (2002) has outlined a future possible health system that focuses on consumer needs, provides appropriate services with compassion and sensitivity, shares information amongst health care professionals efficiently to promote continuity of care, and is well integrated and coordinated between all levels of care in the health system. Consistent with that vision, oral health should be integrated with general health to improve oral health and quality of life of the special needs population.

1.5 Limitations of previous studies

The US Healthy People 2010 chapter on oral health highlights the lack of data for monitoring the health of this group of the population (US Department of Health and Human Services, 2000). Published research on the oral health, behavioural characteristics and needs of adults with disabilities have been limited in several respects as shown by various examples below:

1. Study population – Several studies have reported on groups with specific conditions like Downs syndrome (Fung and Allison, 2005). Others have included broader groups like people with developmental disabilities (Glassman et al., 1996), people with physical or mental retardation or intellectual disability (Cumella et al., 2000), but not clarified specific groups. Some studies have excluded people with specific categories of disabilities and therefore under-represented such groups in research findings. For example, in a study by Thornton et al., (1989) those with Down syndrome was excluded due to high incidence of periodontal disease associated with the syndrome.

   Also, there is a lack of empirical data based upon representative samples of adults with disabilities. Most studies have been based on convenience sampling and/or on small institutional samples and on administrative records of public agencies. Thornton et al., (1989) compared oral hygiene levels and periodontal disease among residents with mental retardation at various residential settings, but it was a pilot study involving only 62 subjects, who were selected according to convenience and availability due to scheduling and transportation difficulties. Francis et al. (1991) conducted a study on dental health and dental care requirements for young handicapped adults in Wessex by randomly selecting one training centre from each of the 10 health districts in Wessex, but visited each centre only once and therefore only those present on that day were available for the study.

2. Location – Although most adults with disabilities live in community settings, only a few studies have compared the oral health status and needs of individuals living in various types of community living arrangements such as group homes, parent/relative homes, foster homes, or independent living settings. Kendall (1991) examined 350 mentally handicapped adults attending social services day centres, of which 60% lived at family homes and 35% in community houses. Gabre and Gahnberg (1994) studied dental health status of 21–40 years old, 132 mentally retarded individuals with various living arrangements, but the subjects were patients at a hospital dental clinic, who were registered as mentally retarded by the Social Services, thereby creating a biased sample.

3. Measurement methods – Due to inconsistent research methods and varying indices in different studies, comparisons between studies have not been easy, especially for oral hygiene and periodontal status. Gabre and Gahnberg (1994) reported the mean number of decayed and filled tooth surfaces and loss of alveolar bone using bitewing radiographs. Other studies have reported dental caries experience by the mean number of decayed, missing and filled teeth (Scott et al., 1998; Cumella et al., 2000). Francis et al. 1991 reported dental cleanliness as good, fair, poor, the presence and absence of calculus and periodontal status as no obvious disease, some gingivitis, some periodontal disease and gross destructive disease. Kendall (1991) reported the mean number of sextants with plaque, gingival inflammation and calculus. Cumella et al. (2000) used only visual criteria to rate poor oral hygiene, healthy gingival condition, reversible gingival condition and gingival disease requiring clinical intervention. Scott et al. (1998) reported periodontal disease with reference to bleeding gums, calculus and periodontal pockets.

4. Scope of enquiry – There is little information on the oral health of people with disabilities cared by different types of carers in differing living arrangements, both of which could influence the oral health of the care recipients. Additional influencing factors on oral health that have not been adequately explored are the effects of ability to perform core activities, medication usage, diet and preventive dental care practices. Also, oral health impacts on general well-being are difficult to determine from those with limited or no communication skills and researchers need to depend on proxy reports from carers.

1.6 Thesis rationale

A premise motivating this research is that every individual has the right to optimal health and participate in social activities, without stigma or embarrassment. People with disabilities have limited ability to be self-advocates and require others to represent their rights. The rationale for studying this research problem is broadly based on two issues.

Relevance of disability in the adult population

Until recently, much of the developmental disabilities were mainly a paediatric concern and as such, research on people with disabilities had focused on children. More recently the concerns of older adults are also being addressed. However, little attention has been given to the children with disabilities who are now surviving to adulthood. In Adelaide, the South Australian capital, most children with special needs up to the age of 18 years live at home with their parents and receive dental services from the South Australian Dental Services (SADS) and specialist dental services from paediatric dentists at the Women' and Children's Hospital (WCH). Little is known about adults with disabilities over the age of 18 years with regards to living arrangement and oral health care. Stiefel (2002) has rightly referred to the adult age group of the special needs population as the sandwich generation that is probably the most disadvantaged and has received far too little attention.

Relevance to health policy

Australia's National Oral Health Plan 2004–13 (NACOH, 2004) includes 'people with special needs" in "Action Area Five" and states that "people with special needs experience substantially higher levels of oral disease" and "have extra barriers to accessing dental care". However, there is limited available data that describes the oral health or dental care of this population. The National Survey of Adult Oral Health 2004–06 (Slade et al., 2007) covers most action areas for target populations like older people, people with low income and social disadvantage, Aboriginal and Torres Strait Islander people, but people with special needs were not included in the survey.

It is intended that this thesis will provide information on oral disease experience in adults with disabilities, identifying sub-groups with relatively greater levels of oral disease or lacking access to adequate care. Information on carers' knowledge, attitudes and dental behaviours will be valuable in the planning and implementation of oral health intervention programmes of carers in the provision of oral care for people with disabilities.

This thesis will assist in building knowledge in an area of research that is underdeveloped but urgently required not only in Australia but worldwide. It will hopefully raise awareness about the oral health status of this disadvantaged population and generate an interest and action by key stakeholders to help improve capacity among service providers so they can meet the oral health needs, and improve the quality of life of the people with disabilities. Also, highlighting the important role of carers could help them be recognised as valuable health care team members and serve as an incentive to continue caring for people with disabilities with dedication.

1.7 Aims and objectives

This project investigated the oral health of 18–44 year olds with physical and intellectual disabilities (described as "care recipients") sampled from three residential settings: family home, community housing and institutions. The overall goal of the project was to identify characteristics of carers, living arrangement and other factors that are associated with oral conditions, which if modified, could improve the oral health of adults with physical and intellectual disabilities. The three specific aims were:

1) Among care recipients sampled from three residential settings, to describe:

- characteristics of care recipients (demographics and general health),
- perceived oral health and treatment needs and impacts on quality of life,
- preventive dental practices and barriers,
- oral disease risk behaviours, including medication usage and
- oral health status, with greatest emphasis on caries experience, as the primary outcome variable, and oral hygiene, gingival status and tooth wear as secondary outcomes.

2) Among carers of the care recipients, to describe:

- socio-demographic characteristics of carers,
- relationship to care recipient,
- carer's knowledge, attitudes and behaviours regarding oral health care for their care recipients,
- carer's attitudes and behaviours regarding their own oral health care and
- care provided to care recipients, including continuity of care and its effects.

3) To determine if the type of residential setting is associated with care recipients' oral health status and if so, to determine whether the association can be attributed to:
  - care recipients' characteristics,
  - preventive dental practices among care recipients,
  - oral disease risk behaviours, including medication usage among care recipients,
  - carer characteristics and
  - care provided to care recipients, including continuity of care.

1.8 Hypothesis

The main hypothesis of this thesis was that the residential setting of adults with physical and intellectual disabilities is associated with variation in perceived oral health problems perceived dental treatment needs, dental practices, and oral health status. The null hypothesis was that there was no difference in oral conditions among the care recipients living in the three residential settings: family home, community and institutions. The expected alternate to the null hypothesis was that care recipients at institutions have higher rates of each oral condition, based on the widely asserted views of clinicians.

1.9 Conceptual framework

The proposed conceptual framework examined in this research is presented in Figure 1.1. Pathways indicated in the framework conceive oral health status of care recipients as being influenced by several factors. Good oral hygiene and diet is necessary to maintain good oral health (König, 2000). In people with disabilities, their general health, and disability may affect their ability to self-care. Moreover, medications to manage their disability and general health may have adverse oral effects. Additional influencing factors could be risk behaviours like poor or no co-operation with oral hygiene care procedures, frequent intake of cariogenic foods and drinks and adverse oral habits such as bruxism.

A majority of the care recipients are likely to depend on their carers for daily oral hygiene care. Quality of care received could be influenced by the carer characteristics, their knowledge, attitudes and dental behaviours, which then affects the oral health of the care recipients. Continuity of care could also have an impact on the quality of care received by the care recipients and therefore their oral health. Oral health also depends on the regular professional care that they receive from dentists and hygienists. However, this study focused on care recipients and their carers because oral health of care recipients depends on the daily oral hygiene care provided by carers. Proposed associations between the oral health of care recipients in various residential settings and characteristics of care recipients and carers and continuity of care are assessed in the results section.

‘Upstream’ social determinants defined as ‘the underlying causes of the causes’ exist (Watt, 2007), but are not included in this thesis as very little is known about this population and possible influences from their carers could add to the methodological complexities.

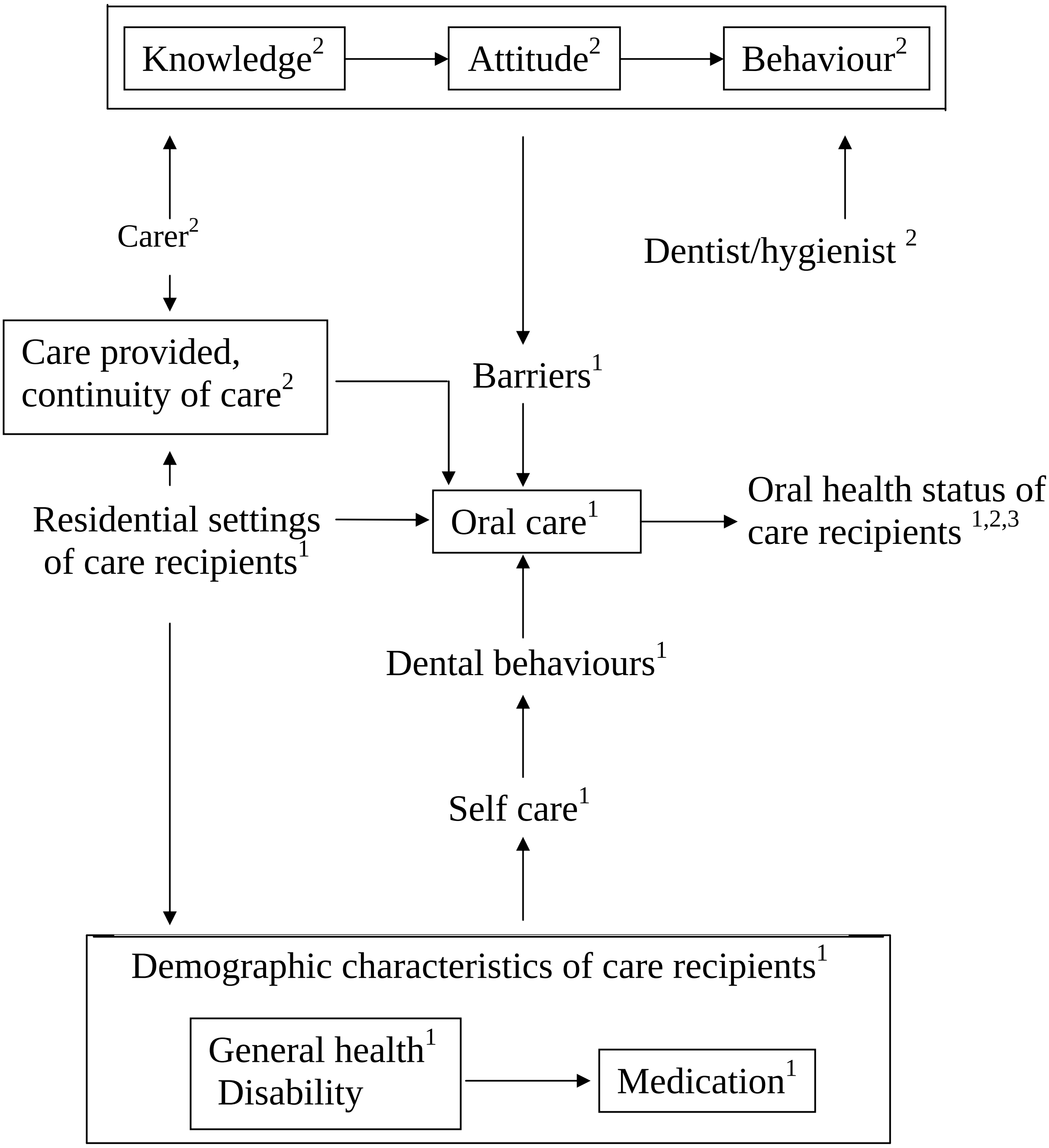

Figure 1.1 Conceptual framework explaining factors influencing the oral health status of care recipients with physical and intellectual disabilities

1. Explains Aim 1
2. Explains Aim 2
3. Explains Aim 3

CHAPTER 2. LITERATURE REVIEW

This chapter reviews available literature on the oral health status and oral health needs of adults with physical and intellectual disabilities. It also reviews studies of oral health impacts on quality of life. This is followed by a review of various factors that influence the oral health of adults with physical and intellectual disabilities.

2.1 Oral health of adults with physical and intellectual disabilities

The results of epidemiological studies of the oral health of people with disabilities vary widely in terms of study populations, types of disabilities, age groups, and living arrangements.

2.1.1 Dental caries

Dental caries experience among people with disabilities has been compared with that of the general population. Within the population of people with disabilities, comparisons have been made between levels of severity within a specific disability and between different living arrangements. Some studies have reported a higher caries experience among people with disabilities, with a higher level of untreated decay than the general population (Pieper et al., 1986; Cumella et al., 2000). In a study of 324 mentally handicapped adults in Hull (UK), Hinchliffe et al. (1988) also reported a higher level of untreated decay than the general population, but the prevalence of caries experience was found to be similar. Others have reported a lower caries experience among the people with disabilities compared with the general population (Scott et al., 1998). Shaw et al. (1990) also reported a lower caries experience among adults with mental handicaps than the general population, but with a higher number of missing teeth than filled teeth.

In a German study of 250 handicapped adults aged 17–64 years, Pieper et al. (1986) reported mean DMFT (based on 28 teeth) ranging from 17.4 in the 17–24 age-group to 19.7 in the 35–44 age-group. In a study of 195 handicapped adults aged 25–34 years living in the community in Wessex, United Kingdom (UK), Francis et al. (1991) found untreated decay in 61% of the subjects with a mean DMFT of 10.8. Kendall examined the oral health of a group of 350 non-institutionalised mentally handicapped adults (15–75 years) in the UK. He reported caries experience by age group (Kendall, 1991) and showed differences between the groups that attended different day centres, depending on the severity of the mental handicap (Kendall, 1992). His results showed a mean DMFT of 9.7 with a higher number of filled than missing teeth, consistent with the proportions found in the general population. There was a lower prevalence of untreated decay of 17.8%. The least handicapped and the most co-operative participants had the highest mean number of filled teeth and the lowest mean number of missing teeth. In another UK study, Cumella et al. (2000) examined 50 adults between 25–44 years of age with intellectual disability sampled from a special needs registry in Warwickshire and reported 58% of the subjects had untreated decay. The mean DMFT was 16.3 and there was a higher proportion of missing to filled teeth. Tiller et al. (2001) examined a random sample of adults (18–65 years) from the Sheffield's (UK) Learning Disability Case Register and reported that adults living in the community had significantly more untreated decay than their counterparts in residential care, while adults in residential care had significantly more missing teeth than those in the community. In a study of 34,505 Special Olympics athletes, (8–81 years), 31% had carious lesions and 33% were missing at least one tooth (Corbin and Wagner, 2003).

In a Swedish study, Gabre and Gahnberg (1994) compared dental health status of 132 mentally retarded adults (21–40 years) in three settings: an institution, integrated units and private homes. However, the subjects were selected from a hospital dental clinic and therefore were not a representative sample. Those living in institutions had lower decayed and filled surfaces but higher loss of alveolar bone compared to those living in other settings. The possibility of other influences was not tested.

All of the studies reviewed above are cross-sectional studies. There has been only one published longitudinal study of oral health conducted among a group of 124 intellectually disabled individuals (21–40 years) over 8.5 years, in Sweden by Gabre and Gahnberg (2001). Caries incidence was lower among the adults with intellectual disability with an average of 0.51 new lesions per year compared with that in the general population. People with mild intellectual disability developed more caries than other subjects.

2.1.2 Tooth wear

Non-carious, pathological loss of tooth tissue has been traditionally described by the terms 'erosion', 'abrasion' and 'attrition' in an effort to characterise the three types of aetiology. Smith and Knight (1984), advocated the use of the term 'tooth-wear' to include all the three aetiological conditions. In young adults with intellectual disability, tooth wear is often overlooked and can cause considerable distress and ultimately tooth loss. Some of the causes of tooth wear include grinding, rumination and pica.

There are few published studies on tooth wear in adults with disabilities. Oilo et al. (1990) evaluated tooth wear among 18–59 year olds with mental retardation, living in a Norwegian institution, based on treatment needs. Tooth wear was observed predominantly in incisors and canines, but the arch was not specified. Wear increased with age, with more than 5% of 30–49 years age-group requiring treatment, which was more prevalent than that observed in an urban population from the same area in a parallel study.

All other reports on tooth wear are based on clinical observations. Grinding is more common in people with intellectual disability (King P, 2005), autism and cerebral palsy (Andersson-Norinder and Sjogreen, 2000). However, it is often in combination with gastro-oesophageal reflux disorder (GORD) that rapid loss of tooth occurs in patients with intellectual disability (King P, 2005).

Rumination means regurgitation, re-chewing and re-swallowing of previously ingested food. This adverse habit that causes acidic stomach contents to cause dental erosion is also common in people with intellectual disabilities (Perlman et al., 1991).

Pica, which means craving for or compulsive eating of non-edible substances like gravel, sand and cigarettes, can also lead to abnormal attrition of teeth (Perlman et al., 1991).

2.1.3 Periodontal problems

As with caries experience, periodontal status among people with disabilities has been compared with that of the general population, between levels of severity within a specific disability, and between different living arrangements. There is a wide range of variability in the periodontal assessment and reporting among people with disabilities. In a study by Tesini (1980) on the oral hygiene status of 184 institutionalised and non-institutionalised mentally retarded individuals (4–25 years), those in institutions had poorer oral hygiene than that of similar non-institutionalised individuals. In a German study of 250 handicapped adults aged 17–64 years, Pieper et al. (1986) reported a high prevalence of periodontitis with 34% of the subjects needing complex periodontal treatment. In a pilot study that compared oral hygiene levels and periodontal disease prevalence among 60 residents with mental retardation (18–45 years) in a large traditional state institution, a small regional facility, and community group homes, Thornton et al. (1989) used simplified oral hygiene index and also reported that adults living in the community had significantly better oral hygiene than their counterparts in institutions. In a study of 195 handicapped adults (25–34 years) in Wessex (UK), Francis et al. (1991) reported dental cleanliness as good (14%), fair (40%) and poor (46%); periodontal condition as no obvious problem (17%), some gingivitis (47%), some periodontal disease (26%) and gross destructive disease (10%); and the presence of calculus in 69% of the subjects. Kendall (1992) compared a group of 350 mentally handicapped adults living in the community attending day centres in UK on the mean number of sextants with plaque, gingival inflammation and calculus and reported that the less handicapped group had better oral hygiene and less gingival inflammation, as they were most co-operative and trainable in self care. In another UK study of a group of 50 adults with intellectual disability (25–44 years) sampled from a special needs registry living in the community, who were not in contact with the Community Dental Service, Cumella et al. (2000) using only visual criteria, reported 58% of subjects with poor oral hygiene, 35% with healthy gingival condition, 40% with reversible gingival condition and 25% requiring clinical intervention. Corbin and Wagner (2003) reported gingival inflammation among 42% of the international Special Olympics athletes aged between 8 and 81 years. Scott et al. (1998) compared the prevalence of periodontal disease among 101 adults (21–53 years) with developmental disabilities with the 1987–88 Australian national oral health survey and showed that they had more severe periodontal disease than the general population, with gingival bleeding of 58.8% versus 38.5% and pocket ≥ 4mm of 46.4% versus 24.1%. In a longitudinal study in Sweden by Gabre and Gahnberg (2001) during the 8.5 year period, on average 1.82 teeth were lost, with periodontitis dominating as the reason for tooth mortality. Individuals with poor co-operation with dental treatment lost more teeth. The average annual bone loss in all subjects was 0.03 mm.

2.1.4 Other oral health problems

2.1.4.1 Oro-facial trauma

Other oral health problems among people with disabilities include adverse oral effects from oro-facial trauma, which could be accidental or self-induced. Although oro-facial trauma is common in people with disabilities there are few published reports. In a study of 324 mentally handicapped adults in Hull (UK), Hinchliffe et al. (1988) found 21% of the subjects had traumatised teeth. Kendall (1991) reported a mean of 0.12 traumatised teeth per person among a group of non-institutionalised mentally handicapped adults in the UK. In a study of 50 adults (25–44 years) with intellectual disability, Cumella et al. (2000) reported a much higher prevalence with 45% of the subjects having one or more traumatised teeth, with a mean of 1.3 per subject affected. More recently, among the international Special Olympics athletes (8–81 years), Corbin and Wagner (2003) reported a much lower prevalence of oral/dental trauma of 12%.

2.1.4.2 Oral side-effects from medication usage

Many people with disabilities take one or more medications which have potentially adverse oral side-effects. Those with epilepsy as an additional disabling condition are at risk of gingival hyperplasia as a side-effect of anti-epileptics drugs like dilantin (Károlyházy et al., 2003), while those on tranquilisers and antipsychotics for behaviour management have a risk of dry mouth, putting them at a higher risk of decay (Perlman et al., 1991). However, among a group of 124 adults with intellectual disability (21–40 years) Gabre et al. (2001) did not find any correlation between use of medication and dental caries, even though almost half of the subjects used medication with a potential to cause hyposalivation.

2.2 Perceived oral health needs

Perceived oral health needs serve as indicators of subjective oral health in the population. People's perception of their need for dental care is a deciding factor in them visiting the dentist. Many epidemiological studies have attempted to define or quantify the treatment needs of special needs patients and to evaluate differences in needs with comparison to the general population (Feldman et al., 1997). Some have shown that the degree of unmet need is much greater in this population than the general population (Holland and O'Mullane, 1990, Scott et al., 1998).

People with disabilities may be unable to express needs and therefore depend on their carers to be their advocates and seek necessary treatment. However, a study by Hennequin et al. (2000) on the accuracy of estimation of dental treatment need in 103 special needs patients aged between 18 months and 47 years, showed that their oral health needs are severely underestimated by both their carers and the dental profession. Carers underestimated treatment need in 99% of cases, suggesting that parents and carers need more education regarding oral health care and should be encouraged to bring their care recipients to the dentist for regular reviews in order to prevent the suffering caused by advanced disease (Hennequin et al., 2000). Treatment need was underestimated by the dentist in 76% and overestimated in 6% of cases. The pre-operative treatment plan and the actual treatment performed matched exactly in only 18% of cases (Hennequin et al., 2000). In a study by Faulks and Hennequin (2000) only 19% of care recipients could tell their carer if they were in pain. The carer may realise that a problem exists but are unable to accurately assess the origin or the degree of discomfort.

In another survey of oral health in a population of developmental studies, over 90% of them were found to require dental treatment, although 58% of subjects felt they needed no dental treatment (Scott et al., 1998). However, dental professionals make treatment plans and decisions on their own perception of the patient's quality of life, and there may be low correlation between the professional's perception and that of the patient (Gift and Redford, 1992).

2.3 Oral health-related quality of life

The importance of oral health to general health and quality of life is often ignored and underestimated, especially in the special needs population. However, there is a growing interest in oral health outcomes in terms of how oral health affects quality of life (QoL). It has been recognised as the most important outcome of health care for people of all ages and abilities. Although oral diseases are rarely life threatening, they do have an impact on the overall health and wellbeing and quality of life. Locker's model categorises impacts into qualitatively different dimensions of ill health based on World Health Organisation (WHO) classification (WHO, 1980), including limitations in function, disabilities and impacts on social roles (Locker, 1988).

In recent years, the concept of oral health-related quality of life (OHRQoL) has been introduced, expanding the array of traditional medical factors such as symptom and functional status that have been assessed when measuring QoL outcomes in health care settings. A complete understanding of OHRQoL outcomes is both a necessary and logical goal to assess and significantly improve the impact of dental care for all individuals. OHRQoL has been described as a multidimensional concept including: (1) survival; (2) absence of symptoms; (3) absence of pain or discomfort; (4) the oral cavity's adequate physical/mechanical functioning; (5) social-emotional functioning; (6) ability to perform self-care; (7) limitation on activities related to role; (8) perceptions of oral health; and (9) satisfaction with oral health (Gift and Atchinson, 1995). Oral symptoms and their effects on well-being provide an indication of OHRQoL.

Declining oral health function can substantially affect nutrition and quality of life. There is also the social aspect of not having a clean mouth and the unpleasant side-effect of halitosis to consider. This is not only embarrassing for the patient but for others close to them (Barnett, 1991). In a qualitative study by Weeks and Fiske (1994), on the views of 22 nursing staff on oral care of people with a disability, a majority of carers expressed the social implications of oral health with comments like "…the only thing that does put you off is bad breath".

Cusick et al. (2001) suggested that where an individual's views are difficult to obtain due to his/her compromised state, proxies or alternative individuals can be used to rate patient health status. Zhu et al., (2008) applied the General Oral Health Assessment Index (GOHAI) and reported that that there is adequate agreement between patient's and their carers in the assessment of the patients' OHRQol during the acute stage of their hospitalisation following acute stroke, although the proxies tended to underestimate the impact of the stroke (disability) on OHRQol compared with patient's own views. From an evaluation of proxy responses to the Stroke Impact Scale, Duncan et al. (2002) suggest that agreement is best for observable rather than subjective attributes. However, OHRQoL measures usually summarise self-perception, rather than objective information. The closer the personal relationship of the carer to the care recipient, the more valid the information (Nelson et al., 1990). For example, spouse carer reliability is reported to be acceptable when measuring functional status (Rothman et al., 1991, Magaziner et al., 1988), but few reports confirm the strong reliability of any type of carer for more complex measures of HRQoL (Epstein et al., 1989).

However, there has been no study on people with disabilities for whom it is difficult to assess the quality of life, especially those with limited or no communication skills who are unable to express pain and discomfort. This study has extracted four questions from the 49 item Oral Health Impact Profile (OHIP) questionnaire developed by Slade and Spencer (1994), with the assumption that observable domains like function (problem eating) or social issues (irritability) are more likely to be validly assessed by the carers.

2.4 Influences on the oral health of people with disabilities

2.4.1 Care recipients

Oral health of people with disabilities can be influenced by their disability and general health, age, living arrangement, oral disease risk behaviours, and ability to co-operate with carers providing their daily oral hygiene care and dental professionals providing dental treatment.

2.4.1.1 Disability, general health and oral health

Oral health is a part of and is influenced by general health. People with disabilities may have multiple disabilities affecting general health. The 'main disabling condition' is the condition reported by each care recipient to be associated with most of the problems that he or she experienced (ABS, 1999). There are a number of medications that are believed to have the potential to cause dry mouth, increasing the risk of dental caries (Smith and Burtner, 1994).

The same group of medications are reported to cause candidiasis (Scully and Bagan, 2004), while others have been reported to be associated with gingival hyperplasia (Károlyházy et al., 2003).

Apart from medications, people with disabilities need assistance with activities of daily living. Some 60% of care recipients always needed assistance with between one and four activities of daily living and a further 24% always needed assistance with between five and nine activities of daily living (ABS, 1999). The degree of assistance required for self-care activities can be used to estimate the severity of the disability.

2.4.1.2 Living arrangements

Earlier studies on oral health of people with disabilities concentrated on children attending special schools and day centres (Gurling et al., 1979) and children and adults who were homebound or living in institutions (Crack et al., 1980). With the process of deinstitutionalisation and movement of people with disabilities into the community, there were studies on groups of non-institutionalised adults living in the community (Francis et al., 1991) or in family homes and institutions (Kendall, 1991). Also, comparisons were made between those living in institutions and in the community (Thornton et al., 1989 and Tiller et al., 2000) and between those living in private homes, institutions and in the community (Gabre and Gahnberg, 1994).

It is important to understand how health and behaviour vary by living arrangements so that appropriate interventions can be targeted to address the specific needs of individuals living in different types of residential settings. Freedman and Chassler (2004) reported that the functional impairments of care recipients differed significantly depending upon where individuals lived, with individuals living in institutional facilities most likely to be older, have severe/profound retardation and additional disabilities such as vision, hearing, and mobility impairments. Rimmer et al. (1995) found significant differences in the health characteristics and behaviours of adults with mental retardation residing in three living arrangements – institutions, group homes, and natural families. They suggest that less restrictive settings such as group homes or family settings may provide less supervision and monitoring of diets, and more opportunities for adults to make their own decisions about food and exercise.

Family homes

Freedman and Chassler (2004) reported that individuals living at home are the least likely to have functional limitations. Oral health and practices of care recipients at homes is most likely dependent on the practices of their family carers.

Institutions (residential care facility)

In recent years, institutions have been markedly downsized as care recipients are being moved into the community. In Australia, between 1981 and 1998, the proportion of people with a severe or profound level of activity restriction living in institutions decreased from 20% to 15% (AIHW, 2003a). Stiefel (2002) reports that the profiles of the remaining care recipients in institutions have also changed with them being older, with more severe and profound disabilities, maladaptive behaviour and complex medical problems.

Tesini (1980) reported that institutionalisation was a greater determinant of oral hygiene status than the degree of mental retardation. In South Australia, oral health of new care recipients is assessed on admission to institutions, which have oral health care plans developed for each care recipient. There is a formal arrangement between the institutions and SADS, whereby dentists and hygienists visit the institution on a weekly basis and provide dental services to the care recipients.

Community housing

Community housing grew in the mid 1970s as a part of deinstitutionalisation and normalisation process, when individuals living in institutions were moved into community based settings. However, they no longer had access to dental services available in institutions (Thornton et al., 1989). Gabre and Gahnberg (1994) reported that due to greater independence among care recipients living in the community, with less rigorous daily oral care and reduced supervision of diet, dental disease is higher among care recipients living in the community compared to those in institutions. Tiller (2001) stated that providers of dental services have a responsibility to ensure that the health of adults with disabilities is not compromised by normalisation. This study describes access to dental services and oral health of care recipients living in family homes, community housing and institutions.

2.4.1.3 Dental practices

2.4.1.3.1 Toothbrushing pattern

The maintenance of optimal oral hygiene in people with disabilities can be difficult due to problems with manual dexterity. They depend on their carers for their daily oral hygiene care. Controlling dental plaque in people with disabilities is a major challenge not only to care recipients and their carers, but also their dentists. Whether in institutions or at home, great demands are placed on carers or parents and plaque control may be an additional burden with a lower priority. Good oral hygiene depends not only on the frequency of toothbrushing but how thorough and effective the cleaning is. This further depends on the cleaning aid used, the ability of the person involved in cleaning (care recipient alone and/or carer) and any associated behavioural problems of care recipients encountered by carers during the procedure, or even organisational problems like lack of time.

In a study of 60 people (25–44 years) with intellectual disability, Cumella et al. (2000) reported 22% of their subjects needed assistance from their carers for oral care for which hand-over-hand technique was used to encourage care recipients to learn and brush their own teeth. In the same study, when manual toothbrushing was not successful, carers used an electric toothbrush and mouthwashes. It has been suggested that they can be taught oral hygiene practices and can carry out the procedure for themselves. However, the teaching of adequate toothbrushing to severely developmentally disabled persons can be time consuming and subject to varying compliance (Steifel et al., 1984).

In an evaluation of a long-term oral health programme by carers of children and adults with intellectual disabilities at three French centres, Faulks and Hennequin (2000) noted that at baseline 79% of care recipients had their teeth brushed only once a day and toothpaste was used for only 71% of them. Carers were able to clean all teeth for only 24% of care recipients, with 42% of them not co-operating with their carers.

2.4.1.3.2 Dental visit pattern

The most widely reported reason for dental attendance is a suspicion on the part of the carer that the care recipient might be experiencing pain (Hennequin et al., 2000). Manifestations of pain include crying or altered facial expression, a defence reaction associated with the painful region, a lack of interest in their surroundings or a refusal to communicate (Guisiano et al., 1995). Oral or dental pain is generally associated with obvious facial swelling, increased halitosis or drooling. Changes in behaviour, particularly at mealtimes, are particularly strong incentives for dental consultation, followed by halitosis, drooling and aspiration of food and/or liquids (Hennequin et al., 2000). Francis et al. (1991) reported that of the 25–34 years old handicapped adults in Wessex, 69% visited the dentist at least once a year and 27% were judged to require a general anaesthetic for dental treatment. In an Australian study, Scott et al. (1998) also reported that 65% of the developmentally disabled adults had a dental visit in the last 12 months. In a study of 60 people with intellectual disability, Cumella et al. (2000) reported 66% of their subjects had visited the dentist in the last 12 months, with carers involved for 61% of the subjects. The same study also highlighted the fact that “carers were often instrumental in subjects going to the dentist”, supported by the fact that those who reported had not been to the dentist, lived with little or no carer support.

In a study of 310 adults (18–65 years) with learning disabilities, Tiller et al. (2001) reported that subjects living in the community were significantly less likely to have a dentist and to use community dental services than their residential counterparts, and were more likely to attend only when having trouble. However, a study by Freedman and Chassler (2004) on the physical and behavioural health of adults with mental retardation across residential settings, showed that individuals living with parents or relatives were the least likely to have had a dental visit within the last six months (72%), while care recipients living in community residences (82%) and in institutional facilities (88%) were more likely to have had recent dental visits.

Several barriers to accessing dental care have been identified. Some barriers include care recipients’ reluctance to accept treatment (Pratelli and Gelbier, 1998). Extreme fear and anxiety could be the contributing factor according to the results of a study by Gordon et al., (1998) in which 28% of the participants reported fear/anxiety about dental visits. Approximately half of those with fear/anxiety reported to be very nervous or "terrified". Aggressive behaviour can be another barrier to routine dental care and dental treatment under oral sedation or general anaesthesia may be the only options. Holland and O’Mullane (1990) reported that about 17% of residential and non-residential adults and children in an Irish study required a general anaesthesia for their dental treatment to be completed. Glassman et al. (1996) reported a similar proportion of people with disabilities screened (19%) as needing general anaesthesia for dental treatment. In a French study of 184 young disabled patients, indications cited for the use of general anaesthesia included severe mental deficiency or behavioural disturbance, failure after several management attempts to undertake treatment or the need for extensive treatment, particularly extractions (Maestre, 1996).

In a review on the treatment accessibility for physically and mentally handicapped people, Wilson (1992) reported transportation to the dental clinic as a barrier for those who are wheel-chair bound, with public transport by bus being difficult and taxis expensive. In another review on dental care considerations for disabled adults (Stiefel, 2002), inability to pay for the cost of dental care due to lack of income and dental insurance, and a lack of trained dentists willing to treat people with disabilities were noted as additional barriers. However, Cumella et al. (2000) reported only four (from a total of 57) carers of people with intellectual disability who had problems accessing dental care, due to dentists unwilling to treat people with intellectual disability.

In the United States, mobile programmes with limited dental care have been suggested for local communities on a sporadic basis (Burtner and Dicks, 1994). Likewise, community based programmes have been developed to improve oral health of people with special needs by utilising resources within the community via good communication and coordination (Glassman et al., 1996). In South Australia, there is a formal arrangement between the institutions and SADS, whereby dentists and hygienists visit the institutions every week to provide dental services to their care recipients.

2.4.1.4 Oral disease risk behaviours

Oral disease risk behaviours include cariogenic diet – a risk factor for dental caries (Bratthall and Petersson 2005), food and drinks with a low pH – a risk factor for caries and dental erosion (Järvinen et al., 1991), and smoking – a risk factor for periodontal disease (Bergstrom et al., 2000). Sweetened drinks are often used as reinforcers in behaviour modification programmes for people with disabilities to manage disruptive behaviours. Less supervision leading to frequent snacking of those living in family homes and community housing may put them at a higher risk for caries and erosion. People with disabilities may place food in the mouth for longer periods of time, increasing the risk of caries (Perlman et al., 1991). Though the prevalence of smoking may be low, it still persists especially in those with acquired physical disabilities. Gabre et al. (2001) reported that in their study, 2% of the adults with intellectual disability were smokers. In addition to grinding of teeth, pica and rumination can cause tooth wear (Perlman et al., 1991).

Behavioural problems and poor compliance with daily oral hygiene care and routine dental visit/treatment can also be considered risk behaviours. Although Stiefel (2002) stated in a review on dental care considerations for disabled adults that care recipients with maladaptive behaviour remain in institutions, Freedman and Chassler (2004) reported in a study of physical and behavioural health of adults with mental retardation across residential settings that care recipients living with parents or relatives had the highest reported rates of problematic behaviours and of medication usage for mood, anxiety, and behaviour problems.

2.4.2 Carers

2.4.2.1 Reasons for taking on primary caring role

Relationship history influences the motivation to care and whether caring can be sustained long term. Carers take on the caring role for a variety of reasons. The ABS survey of disability, ageing and carers (1999) allowed carers to specify one or more reasons for taking on the primary caring role. Responses varied from family responsibility (57%), being able to provide the best possible care (44%), no other family or friends are available or willing (40%), emotional obligation (39%), no choice (22%) and cost of alternative care (21%). The differences in responses depend on the relationship of the carer and the care recipient. Partner and parent carers were more likely than offspring and other carers to take on a primary caring role to provide the best possible care (53% and 49% versus 33% and 24%) to their care recipient (ABS, 1999). This could be an important determinant of the impact and outcome of caring for both the carer and the care recipient.

2.4.2.2 Knowledge, attitude and behaviour of carers

Carer knowledge of oral hygiene measures influences the degree of appropriate oral care provided to their care recipients (Shaw and Shaw, 1991). Frenkel et al. (2002) conducted a randomised clinical trial in the UK on oral health care education and its effect on carers' knowledge and attitudes and showed that oral health care education can lead to significant improvements in overall levels of oral health care knowledge, attitudes and skills among carers that eventually result in better oral health outcomes of care recipients.

Training of carers on oral care for people with disabilities

Oral hygiene can improve significantly with intensified daily brushing by dental professionals, by the development of self-help workshops for residents, by providing effective staff training or combinations of these approaches (Nicolaci and Tesini, 1982). However, a study by Longhurst (1998), on nurse training establishments in the UK, found a worrying lack of formal education on dental health and oral care. She also reviewed 31 textbooks recommended for student nurses and found only one had adequate coverage of oral care. If oral hygiene is given such a low priority in basic training, then perhaps that offers an explanation, at least in part, for its continuing low status.

Faulks and Hennequin (2000) conducted an oral health program in three French centers for people with special needs to educate the carers about dental disease, to motivate them with regard to prevention, and to improve the oral hygiene and oral health of the residents. They evaluated the impact of the program in terms of change in attitudes and behaviour expressed by the carers using a questionnaire presented at the beginning of the first workshop and then repeated between 9 and 12 months later. They reported that following demonstration of oral hygiene techniques on an individual basis, the number of residents who had their teeth cleaned more than once a day rose from 24% to 52%. The percentage of carers able to clean both posterior and anterior teeth of their key residents increased from 24% to 60%. The intervention was thus deemed moderately successful, although the carers continued to take better care of their own oral health than that of the residents. The need for ongoing training was emphasised, both for the carers of those with special needs and for the dental profession. The lack of validated means of measuring the impact of such interventions on care providers for this population was highlighted.

According to Hennequin et al. (2000), it is important that carers understand the importance of ensuring an optimal level of oral hygiene and are motivated to carry out daily oral hygiene procedures, for satisfactory results. They should be encouraged to bring their charges to the dentist for regular reviews in order to prevent the suffering caused by advanced disease (Hennequin et al., 2000). Training and educating carers in oral hygiene is essential as they are likely to be familiar with the behaviour and habits of their care recipients and policies of the institution or the environment in which the care recipient resides. However, Stiefel et al. (2002) comment that due to the high rate of staff turn-over, it is difficult to train and retrain staff. Glassman et al. (1996) suggest training managers and agency administrators who can then train carers. Alternately, Faulks and Hennequin (2000) suggest that carers who have been trained could train new staff.

Knowledge

Glassman et al. (1994), and Weeks and Fiske (1994), state that although carers may hold certain common misconceptions about oral health, their knowledge is often good, however, they often fail to put knowledge into practice. That gums bleed as a result of traumatic tooth brushing was a widely held misconception by carers on a qualitative exploration of the views of nursing staff by Weeks and Fiske (1994). Even after oral health education intervention, Frenkel et al. (2002) reported that carers persisted in believing that they should stop brushing when there was gingival bleeding.

Attitudes towards oral health

An attitudinal scale has been developed and evaluated by Bedi et al. (2000) to determine attitudes of trained dental personnel towards dental care for people with learning disabilities. This scale can be used to determine attitudes towards treating people with learning disabilities and to determine differences in attitudes among dental personnel.

Oral care assistance is often viewed as more disagreeable than other nursing activities. Ritoli et al. (1990) stated that oral care is a disliked task for nurses, is therefore, a lowly ranked activity compared to other tasks, similar to giving an enema, although it is acknowledged to be of significant benefit to the residents. In a qualitative study by Weeks and Fiske (1994), a nurse reported that when she started nursing, the two things she dreaded most was to lay out someone who has just died and brushing somebody's teeth and touching dentures, while another compared oral care to emptying bedpans. The same study identified "enabling factors" as most nursing staff seeing routine mouth care as a part of their role, having empathetic and caring approach, equating oral health with self esteem and being aware of its impact on social acceptability. Likewise, a study by Wardh et al. (1997) reported that 91.5% of the nurses described oral care as good nursing, but over 40% found oral care repulsive and specified toothbrushing as the most undesirable activity. Frenkel et al. (2002) also reported that only 16% of carers agreed strongly that they felt comfortable brushing teeth for their care recipients and about 50% felt fairly or very uncomfortable.

Although Wardh et al. (1997) found that registered nurses have more positive attitudes toward oral care assistance than the other nursing groups – nursing assistants and homecare aides, they were rarely involved in the daily practice of oral hygiene care, indicating a gap between knowledge and practice in nursing personnel's attitudes toward oral health care of severely disabled patients. Faulks and Hennequin, (2000) also reported that carers rated dental health as most important for the prevention of pain and infection for themselves and their care recipients, but 40% of them found tooth cleaning to be unpleasant.

Dental behaviours

In the French study by Faulks and Hennequin (2000), only 3% of carers brushed their teeth once a day compared to 79% of care recipients. The remaining 97% brushed their teeth at least twice a day. In the same study, all the carers used a toothbrush and toothpaste for cleaning their teeth, but used a toothbrush for only 87% of their care recipients, a swab for the rest and toothpaste for only 71% of their care recipients. Lack of time for providing oral hygiene care was reported by Wardh et al. (1997) and Weeks and Fiske (1994).

No data is available to compare dental visit pattern of carers. It is likely that dental visiting pattern of carers will be reflected on that of their care recipients. This study, therefore, includes information on dental behaviours of carers.

2.4.2.3 Continuity of care

In a variety of settings, carer-care recipient relationship is developmental in that it resembles the interactions between a parent and a child, and transactional in that the care recipients' responses affect the carer and vice versa, so that both care recipients and carers are influenced in and through the process (CHGAP, 1993). Just as relationships between a parent and a child evolves over time, so do carer-care recipient relationships, however, transactions over time between a care recipient and his/her variety of carers can become complicated, especially when there is “splitting” of carers as being good and bad (CHGAP, 1993). Even when the care recipient is an adult with a disability, the carer has to care for him/her as an infant, while responding to the person as an adult (CHGAP, 1993).

Some carers provide care for a short time, while for others it is a life's work. In the 1998 ABS survey, duration of care ranged from 1 month to 50 years, with carers of children most likely to have provided care for 5 years or more. Over one-half of primary carers spent 20 or more hours per week in the caring role, over one-third of carers spent 40 or more hours per week on unpaid caring work and 27% of carers reported spending over 100 hours per week in direct care (AIHW, 2004).

Continuity of care and extracurricular social support networks in the community are vital to any rehabilitation effort (CHGAP, 1993). It is helpful that the same carer cares for the care recipient for daily hygiene care and accompanies the care recipient at his/her medical/dental appointments. The better the rapport between the health professional, the care recipient and the carer, the better the communication and the more easily the health professional is able to detect potential problems. Continuity of care helps to build good rapport between carer and care recipient as supported by Cumella et al. (2000). On the other hand, turnover is believed to have many adverse effects on the organisational effectiveness, including the discontinuity of treatment and care, withdrawal of significant relationships from the dependents, low productivity and shortage of staff, consumption of administrative and financial resources in the staff replacement process, increased job stress and reduced job satisfaction of staff (Bersani and Heiftz, 1985; Lakin, 1988). Results of the 1999 national survey of carer health and well-being also agree that the constancy and time consuming nature of long-term caring is a cause of carer stress (CAA, 2000). This can then adversely the affect the quality of care provided to their care recipients.

2.4.2.4 Effects of caring role

Many factors influence the impact of the caring role on carers, including the personal characteristics and circumstances of the carer and the care recipient, the nature and strength of their relationship, living arrangements, and the level of support available from social networks and formal services. The 1998 ABS survey asked primary carers to assess the impact of caring on various aspects of physical and emotional well-being. High proportions reported on the adverse effects of caring, including a changed overall state of well-being (29%); feelings of dissatisfaction (67%); fatigue and weariness (34%); and feelings of worry or depression (31%) (AIHW, 2004). Hence, carer support from informal networks and formal respite care services are essential.

Carer support

The past two decades have seen a growing awareness of both the importance of the role of carers and the challenges they face. With the downsize of institutions and the expansion of community care programs, there was an increase in the availability of programs supporting carers, including respite services and income support through the Carer Payment and Carer Allowance (AIHW, 2003b). Carer Payment (adult and child) is an income-support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments such as the Age Pension. It is set at the same rate as the Age Pension, and is subject to the same income and asset tests. Carer Allowance (adult and child) is currently payable to co-resident carers who provide full-time care on a daily basis for up to two people who need substantial amounts of care because of a disability, severe medical condition or age-related frailty. In September 2004, eligibility for Carer Allowance was extended to carers who are not co-residents if they provide a minimum of 20 hours per week of personal care assistance to a person who is in need of personal care. Carer Allowance can be paid to carers in receipt of a government pension or benefit, including the Carer Payment. It is not income- or asset-tested, but eligibility is determined according to an assessment of the care recipient’s care needs. The level of Carer Allowance, adjusted on 1 January each year, is designed to help meet additional costs involved in caring for a person with a disability.

2.4.3 Dental professionals

Dentists who have been providing oral health services to care recipients in institutions for several years indicate that the difficulties encountered during the provision of treatment are far greater than those when treating the general population of individuals with mild disabilities, and require special skills, knowledge, and equipment (Burtner and Dicks, 1994). They can provide regular check-ups and provide preventive services, including professional application of fluoride varnish once every six months as recommended by Glassman and Miller (2003). Professional application of fluoride varnish takes very little time, making it ideal for patients with special needs. At every visit, dentists can demonstrate oral hygiene methods (toothbrushing and/or use of fluoride/chlorhexidine swabs as appropriate) and encourage carers to maintain oral health of their care recipients as best as possible. It is challenging and requires empathy, patience, willingness and motivation to provide quality care.

It is helpful that the same dentist/hygienist sees the patient each time, for check-ups and routine dental care appointments. The better the rapport between the dentist, the patient and the carer, the better the communication and the more easily the dentist is able to detect potential problems (Mitchell et al., 1985). The attitude, the ability and enthusiasm of the dental operator and the facilities available for treatment influences the oral health outcomes. In a UK study by Pratelli and Gelbier (1998), that investigated 75 care managers' experiences of dental services for adults with a learning disability, continuity of care between carers and dentists were seen as facilitating co-operation. In another UK study on the needs for oral care among people with intellectual disability, Cumella et al. (2000) also reported that time and continuity with the same staff were needed to build a good relationship between the dentist and the subjects.

However, Stiefel et al. (1981 and 1987) reported that the number of dentists willing to treat people with disabilities is very low. Stiefel et al. (1987) reported that the number of dental auxiliaries prepared to treat people with disabilities is even lower. Burtner and Dicks (1994) also noted the lack of dental hygienists trained to treat people with disabilities, especially those with severe disabilities.

Legal concerns regarding the management of disruptive behaviour serve as a disincentive to the general dental private practitioner (Burtner and Dicks, 1994). Additional barriers are lack of time, physical barriers, and the lack of domiciliary equipment (Oliver and Nunn, 1996; Edwards and Merry, 2002). In a recent study by Tsai et al. (2007) in Taiwan, the main reasons for dentists choosing not to treat people with disabilities were being unable to interact with patients and family members, the treatment procedure being more complicated, and a lack of encouragement from hospital policies. The same study also showed that implementation of a dental care financial reward program significantly increases the willingness of most hospital-based dentists to treat the severely disabled patients.

2.5 Summary

Most studies reviewed indicate that people with disabilities suffer multiple oral health problems, face barriers in achieving and maintaining good oral health and therefore have unmet needs. Comparisons have been made on the oral health of people with disabilities living in family homes, community housing and institutions with the general population and between one or more living arrangements. Some studies have reported a higher caries experience among people with disabilities; some have reported a similar prevalence of caries experience; while others have reported a lower caries experience than the general population. Some studies have reported that adults living in the community have significantly more untreated decay than their counterparts in residential care, while adults in residential care have significantly more missing teeth than those in the community. As with caries experience, there is a wide range of variability in the periodontal assessment and reporting among people with disabilities across various residential settings.

This research has attempted to overcome one of the main limitations of available research, mainly a lack of a representative sample, and to determine if the oral health of care recipients does differ between the three residential settings: family home, community housing and institutions. This research also explored care recipient and carer factors that are associated with oral conditions, which if modified, could improve the oral health of adults with physical and intellectual disabilities.

CHAPTER 3. METHODS

This chapter explains the methods used to conduct the study. It describes the study design, sampling frame and data collection methods, provides details of mail questionnaire and oral examinations of care recipients, and a summary of the analytical approaches undertaken. Data management includes data weighting, recording of medications and response formats. Ethical implications and approvals are also mentioned.

3.1 Study design

The study was a cross-sectional design to describe oral health status and factors thought to influence oral health in a population of adults with physical and intellectual disabilities, living in various residential settings in Adelaide, South Australia.

3.1.1 Sampling frame

Target population

The target population comprised adults aged 18–44 years who were registered with one or more disability service organisations that represent people with diabilities in South Australia. There are twenty-one such organisations that range in scope from institutions that house and/or provide care for large numbers of people with disabilities (eg. Minda Inc., representing 255 adults with disabilities) through to self-help groups (eg. Community Living Project Inc., representing 26 adults with disabilities). The latter represent people with disabilities themselves and parents, family members and others who care for them, thereby reflecting the living arrangements of many people with disabilities who live at home. A two-stage sampling methodology was used, first to select appropriate organisations, and second to sample people with disabilities registered with those organisations.

Inclusion criteria

Organisations that represent specific disabling conditions were selected during the first stage of sampling. The conditions selected were those where partial or complete assistance for oral care typically is required from their carers. These conditions were also noted to be the most prevalent and needing more regular/daily support in the physical and intellectual disability categories among the 18–44 age-group in the South Australian Survey of Disability Prevalence 1996–1997 (Taylor et. al, 1998).

To achieve this, organisations interacting with care recipients with one or more of the following conditions were selected for inclusion in the study.

1. Autism
2. Brain injury
3. Cerebral palsy
4. Intellectual disability
5. Spina bifida
6. Quadriplegia

Exclusion criteria

Musculo-skeletal conditions like arthritis and muscular dystrophy were excluded as these conditions are more prevalent in individuals above the age of 44 years.

3.1.1.1 Sampling organisations associated with people with disabilities

As a sampling frame of people with physical and intellectual disabilities is not available in South Australia, information was obtained from the Disability Information and Resource Centre and Community Information Strategies Australia Inc. A list of all known disability organisations in Adelaide that provides accommodation and/or support services to adults with disabilities was constructed. Beginning in August, 2004, the chief administrator of each organisation was then contacted by phone to explain the purpose of the study and to seek assistance of the organisation in contacting people with disabilities registered with them as care recipients. Over a one-month period, twenty-one organisations were identified. They were approached with an introductory letter (Appendix 1) and were requested to provide information on the number and type of care recipients they interact with and indicate whether their organisation was willing to participate in the selection process. Twelve of them agreed to participate. From the information from the organisations, there were 1448 care recipients in the 18–44 years old age-group living in the community, institution or with families. They reported care recipient populations that ranged from 9 people (Individual Supported Accommodation Service Inc.) to 391 people (Autism SA). The organisations were categorised into three strata according to the type of care recipients they interact with: i) those living at family homes; ii) those living in community housing; or iii) those living in institutions.

3.1.1.2 Sampling people with disabilities for mail questionnaire

Beginning in February 2005, participating organisations were asked to send an information package to the primary carer of each registered care recipient in their database, with envelopes headed “To the carer of” each care recipient. The cover letter specified that the questionnaire was to be completed by the primary (key) carer (Appendix 2).

The following materials were included inside the envelope:

- an information sheet on the study for the carer (Appendix 3)
- an information sheet on the study for the care recipient (Appendix 4)
- an information sheet on ‘Contact for information on project and independent complaints procedure’ from The University of Adelaide Human Research Ethics Committee (Appendix 5)
- a questionnaire for the carer (Appendix 6)
- consent forms for the care recipient (Appendix 7) and for the parent or guardian or person responsible (Appendix 8) for an oral examination of the care recipient (see further information in 3.2.2, below); and
- a reply-paid envelope addressed to the researchers at The University of Adelaide for the return of completed questionnaire and consent form.

When questionnaires were returned to the researchers, they were logged and on two-week intervals, organisations were sent a list of those respondents. Organisations then removed those names from their survey mailing list, and sent a reminder card (Appendix 9) after two weeks and a final follow-up letter (Appendix 10) after four weeks to any sampled care recipient for whom the carer had not responded. In a few cases there were two responses for the same care recipient from two carers at different organisations as the care recipient was associated with both the organisations. In such cases the “more complete” questionnaire was selected.

3.1.1.3 Sampling people with disabilities for oral epidemiological examinations

When all reminder and follow-up questionnaires had been returned, all respondents who provided consent were contacted to arrange an oral examination. This included calls at different times of the day and follow-up calls when they failed to attend, with up to five re-appointments.

Justification

Age was limited to 18 and 44 years of age to represent the adult population. Furthermore, selecting this age-group would provide access to a range of carers, including siblings, parents, partners and other carers and include care recipients living in different residential settings. However, this sampling method excludes people who are not registered with a disability organisation, for example, people with disabilities who are cared for by a parent who is not a member of any of the listed organisations.

3.2 Data collection

3.2.1 Mail questionnaire to carers

Due to the physical and intellectual disability of the care recipients, the questionnaires were mailed to their primary carers. The 12-page questionnaire (Appendix 6) completed by carers was developed by the research team because of a lack of a previously developed and tested instrument. It was based on the research questions, a review of the literature, and suggestions from staff at the Australian Research Centre for Population Oral Health (ARCPOH). It contained 50 questions that enquired about the following factors:

- Carer: age, sex, country of birth, general health, income, living arrangement, relationship to care recipient, length of contact between carer and care recipient, priority to oral care, training in oral care, oral health care behaviours, problems encountered when providing oral hygiene care and work details.
- Care recipient: age, sex, country of birth, general health, income, living arrangement, main and other disabling conditions, self-care skills, perceived oral health problems, treatment needs and negative impacts, oral disease risk behaviours (diet, medication usage and risk habits), preventive dental practices (toothbrushing and dental visit patterns).

Conforming to the reports of Australia’s welfare 2003 (AIHW, 2003a), that recommend ‘consistent core definitions’ and ‘comparability’, several questions were based on ‘Disability, Ageing and Carers: Australia’ conducted by ABS 1998 for information on:

- Carer and care recipient details including care recipient’s main and other disabling conditions,
- Means of communication
- Need for personal help with self care activities
- Factors that influenced carers to take on caring role
- Effects of caring role
- Weekly hours of care provided and
- Need for more support to assist in caring role.

In addition there were four questions from the Oral Health Impact Profile (OHIP) developed by Slade and Spencer (1994), to determine if dental problems had an impact on quality of life. These four questions were selected from the 49 item OHIP questionnaire with the assumption that observable domains like function (problem eating) or social issues (irritability) are more likely to be validly assessed by the carers.

Responses to most questions were recorded by ticking one pre-coded response. Some needed specifying numbers – number of carers providing care to the main care recipient on a daily basis, number of care recipients under charge. Questions like ‘other disabling condition’, specifications of certain answers, and medication usage were completed in longhand.

3.2.2 Oral epidemiological examinations of care recipients

3.2.2.1 Appointment for oral examination

Care recipients who were regular patients of the South Australian Dental Service (SADS), were identified and their carers were contacted to confirm that the oral examination for the study would be carried out at the time of their regular visit as explained in the cover letter of the questionnaire. A reminder note was made to the treating dentist (Mark Gryst/Steven Carr/ Archana Pradhan) to complete the consent form and examination forms at that time. All other carers of participating care recipients were contacted by phone to arrange the most suitable time for the examination. Every effort was made to reassure that experienced dentists would be conducting the examination at the time of their regular visit. They were then sent an appointment card, a medical history form and a consent form to be completed by the care recipient/carer/person responsible. Those who failed to attend were contacted again up to five times to arrange another suitable time.

3.2.2.2 Oral examination procedure

All examinations were conducted at SADS clinics. Standard infection control measures were adopted. Care recipients were examined in the dental chair or in their own wheel chair, if they were not able to be easily transferred to the dental chair. Those examined at Adelaide Dental Hospital had the advantage of being on the wheel chair platform, which raises and drops by 45cm and tilts up to 45° for better access for examination. Standard clinic lighting was used in all cases except one where the care recipient suffered from erythropoietic protoporphyria, which causes a distinctive photosensitivity. In this case, curtains were drawn, fluorescent lights turned off and a torch light used for the oral examination. Internationally, estimates of 1 case of erythropoietic protoporphyria in 75,000–200,000 have been reported for some western European populations (Poh-Fitzpatrick, 2006).

Examination kits included two dental mirrors (one for retraction), a toothbrush to remove debris, when necessary and a triplex syringe. Whenever possible, a systematic approach was adopted by commencing examination from the upper right quadrant, moving to upper left, lower left and lower right quadrant. However, if behavioural difficulties were encountered, the most accessible areas were examined first. Examination time varied from 10–30 minutes depending on the level of co-operation of the care recipient.

Data from the oral examinations were collected by one of two methods:
a) For people who were patients of SADS and who were scheduled for a dental visit during the period June 2005–June 2006, oral epidemiological data was recorded by the SADS dentist (who had experience in managing people with disabilities, but not calibrated) during that visit, using the criteria listed below. This included data recorded under sedation or general anaesthesia when those procedures were used routinely for such SADS visits.

b) For other people, appointments were scheduled for one examiner (AP) to record the same information at the time of their regular recall visits at the nearest SADS dental clinic. Permission for use of the clinics was sought from SADS.

Examinations conducted by both methods recorded the following oral epidemiological indices. Visual oral examination of care recipients by a dentist:

- Decayed (D), missing (M) and filled (F) permanent teeth
- Plaque index
- Calculus index
- Gingival index
- Tooth wear.

World Health Organisation (WHO) criteria (1997) were used to record dentition status. Teeth with fissure sealants were charted but counted as sound for analysis. For calculation of DMFT, the third molars were excluded because neither the carers nor the care recipients could confirm the cause of missing third molars.
The criteria for coding were as follows:

- Sound teeth, if there was no evidence of treated or untreated caries.
- Decayed teeth, if there was evidence of unmistakable cavity, undermined enamel, or softened floor or wall. If there was any doubt, the tooth was coded as sound. Filled teeth with decay were counted as decayed teeth.
- Missing teeth – There was no distinction made for teeth missing due to decay or any other reasons like congenitally missing teeth, unerupted teeth, or teeth extracted for orthodontic reasons as accurate information would be difficult to obtain directly from care recipients mainly due to communication problems.
- Filled teeth, if there were one or more restorations and no caries on the crown.

Ramfjord's Periodontal Disease Index (PDI) (1967) was modified to assess plaque, calculus and gingival status, using visual criteria. PDI utilises 4 assessments: plaque index, calculus index, gingivitis index and sulcular depth, on six teeth: 16, 21, 24, 36, 41 and 44. The criteria for coding were as follows:

Ramfjord's Plaque Index
0= absence of dental plaque
1= dental plaque present on some but not all approximal, buccal and lingual surfaces of the tooth
2= dental plaque, present on all approximal, buccal and lingual surfaces of the tooth, but less than half of these surfaces
3= dental plaque covering all approximal, buccal and lingual surfaces and more than half of these surfaces.

Ramfjord's Calculus Index
0= No calculus present
1= supragingival calculus extending only slightly below the free gingival margin (not more than 1mm)
2= moderate amount of supra and subgingival calculus or subgingival calculus alone
3= an abundance of supra and subgingival calculus.

Ramfjord's Gingivitis Index
0= absence of signs of inflammation
1= mild to moderate inflammatory gingival changes, not extending all around the tooth
2= mild to moderately severe gingivitis, extending all around the tooth
3= severe gingivitis characterised by marked redness, swelling, tendency to bleed and ulceration, whether or not it extends completely around the tooth.
Signs of inflammation include redness, blunted papilla and spongy consistency.

No substitutions were made for missing teeth. In this study periodontal pocket depth was excluded. No periodontal probing was undertaken and no radiographs were taken for this project. If radiographs were taken as part of the usual SADS examination, that information was used by the SADS dentist when recording data.

Tooth wear severity was visually noted on each sextant as one of three categories: 0= ‘none to little’ if less than 2mm of dentine was exposed, 1= ‘moderate’ if more than 2mm of dentine was exposed in any direction and 2= ‘severe’ if there was complete loss of enamel on incisal /occlusal surface or more than 3mm cervical wear.

Data from the oral examination were recorded by a dental assistant onto a paper form containing pre-coded categories for tooth-level DMFT status, sextant-level tooth wear and index tooth-level plaque, calculus and gingivitis indices (Appendix11).

3.2.2.3 Report of the oral examination

A signed report of the findings (Appendix12) was given and a referral arranged if necessary or arrangements for routine oral care confirmed. If a complete examination was not possible, but no obvious problem was noted, the participant was put back on a shorter recall. If there were any doubts/obvious problems needing attention, an appointment was arranged for examination under oral sedation or general anaesthesia as deemed necessary by the examining dentist.

Justification

The examination protocol was simplified from the WHO criteria and Ramfjord’s PDI to accommodate the difficulties that frequently arise when conducting intra-oral examinations of people with disabilities. The WHO pathfinder methodology provides a satisfactory degree of precision on the oral health status of a population for planning purposes, with additional advantage of requiring only modest and flexible technical support (Burgeouis et al., 1992). Only tooth-level and sextant-level recordings were carried out so as to obtain as much information in the shortest possible time during the examination, considering possible behavioural problems and short attention span of the care recipients. Periodontal probing was excluded as a high proportion of this population would have medical conditions that contra-indicates subgingival probing. Also, sudden, involuntary movements could make the use of probes difficult and sometimes even dangerous.

3.3 Data management

Questionnaires and oral examination forms were keypunched into a Microsoft Access database. The data from the questionnaires and examinations were imported into SPSS for Windows (version 13). As care recipients took several types of medications with varying oral health effects, a different method was adopted for the recording of medications.

3.3.1 Recording of medications

The MedCap database (Thomson, 1997) was used to code medications. The aim was to identify major categories of medications that potentially could affect oral health. Each named medication recorded on the questionnaire was given a 5-digit code by therapeutic category (eg anticholinergics, anaelgesics, etc.). Medications not listed in the MedCap database were searched at www.drugs.com and www.medicinenet.com and added to the respective category in the medication list. A lookup file of 1546 medications was then created with six groups of medications causing potential oral effects – dry mouth (xerostomia and/or hyposalivation), candidiasis, gingival hyperplasia, mucosal disorders, cheilitis and halitosis. For each medication, its potential oral effects were identified using four references – Scully and Bagan (2004), Abdollahi and Radfar (2002), www.drugs.com and www.medicinenet.com. The drugs were listed alphabetically and given a code of 1 if the drug was associated with the potential oral effect(s) and 0 otherwise as shown with examples of some commonly used medications like aropax, aspirin and dilantin (Table 3.1).

Table 3.1 Excerpt from drug lookup file

Drug	Code	Xerostomia	Gingival_ Hyperplasia	Mucosal_ disorders	Candidiasis	Cheilitis	Halitosis
aropax	41109	1	0	0	1	0	0
aspirin	39205	0	0	1	0	0	0
dilantin	21102	1	1	0	1	0	0

The drug codes and lookup file were created on a Microsoft Access database and the data were exported to SAS and merged by drug identity. This resulted in each drug receiving a binary classification (yes/no) for each of six oral effects: dry mouth, candidiasis, gingival hyperplasia, mucosal disorders, cheilitis and halitosis.

3.3.2 Data weighting

There were unequal probabilities of inclusion for the questionnaire and the oral examination from each residential setting in different organisations. In order to generate statistical estimates that could be generalised to the target population, two unit record weights were computed from the information obtained on the number of care recipients in each residential setting in every participating organisation. One weight was relevant for the sample of 485 care recipients for whom a mail questionnaire was completed (Table 4.2a, chapter 4). The second weight was relevant for the 267 care recipients who were examined (Table 4.2b, chapter 4). Weights were calculated using the formula below:

Weight = Stratum population in scope count/Stratum sample count.

The numerator was obtained from the sampling frame used to select care recipients in each residential setting (stratum) in every participating organisation, while the denominator was the number of care recipients for whom a questionnaire or examination was completed. For example, the questionnaire weight for family setting in Autism SA was 5.5 (Table 4.2a), that represented 274 care recipients in scope (Table 4.1c) divided by 50 care recipients with valid questionnaires (Table 4.1d).

In a few strata, outlying values were generated for weights and they were replaced by the mean weight for that stratum of residential setting. For example, for the questionnaire, care recipients from Autism SA living in community housing were given a weight of 2.7 instead of 7.5 and those from Minda Inc. living at community housing a weight of 2.7 instead of 10.3. Likewise, for the examination, care recipients examined from Autism SA living in community housing were given a weight of 5.7 instead of 15.0 and those from Minda Inc. living at community housing a weight of 5.7 instead of 25.7. ‘NA’ denotes that there were no care recipients at that setting in that organisation.

Finally, weights were normalised to the fixed sample size for both the questionnaire and the oral examination, by dividing each stratum-specific weight by the mean weight for the entire sample.

Weights were used in statistical analyses in order to generate prevalence calculations that adjusted for different probabilities of inclusion, thereby yielding estimates that could be generalised to the target population. Also, inferences could be made about the associations within the target population of adults with disabilities in South Australia and not just the sample that was studied.

3.3.3 Response formats

The completeness of responses on information on the care recipients was good with missing values per data item being less than 5%. However, the completeness of responses on information on the carers was poor with a very high percentage of missing values, especially when responses depended on whether the responding carer was a family or non-family carer. This included, for example, factors influencing caring role and difficulties encountered in providing oral hygiene care. Such responses were filtered, selecting only family carers or only non-family carers and a summary information provided but no further analysis carried out. Skip questions (G4 to G9, Appendix 6) were also filtered to select responses only from carers who were involved in the provision of oral care for their care recipients.

Several data items were recoded or collapsed for analyses.

- Carer's age was grouped as ≤ 44, 45–54 and 55+ years.
- Care recipient's age was grouped as 18–24, 25–34 and 35–44 years.
- Due to a very low response on country of birth for the carers and care recipients, country of birth was removed from analysis.
- Individuals coded as living alone were few in number and included as living in the community.
- Source of income for carers was dichotomised into wages or salary and carer allowance/payment/other.
- Source of income for care recipients was dichotomised into disability support pension and worker's compensation/other.
- Self reported general health was reduced to three categories – very good-excellent, good, and poor-fair.
- As there had been no change in the living arrangement for almost 90% of the care recipients in the last five years, residential movements were not considered for analysis.
- From the list of primary (main) disabling conditions, spina bifida, quadriplegia and head injury were grouped together as 'Other primary disabling condition'. People with Down syndrome were included in the intellectually disabled category but not those with Autism as they do not uniformly have intellectual disability.
- Number of carers providing care was grouped as 1 carer, 2–4 carers and 5+ carers.
- Three types of communication were analysed – verbal, non-verbal and little or no effective communication.
- Two types of 'relationship to main care recipient' were identified – family carers and non-family carers.
- Length of contact was entered in months and converted to years for analysis.
- Number of care recipients under charge was grouped as 1 care recipient and 2+ care recipients.
- For toothbrushing frequency for both the carers and care recipients, several times a week, less than once a week and once a day were recoded as once a day or less, labelled as infrequent toothbrushing.
- Time to clean teeth/dentures per session was coded as ≤ 1 minute, 2–5 minutes and ≥ 6 minutes.

- Cleaning ability of carers was dichotomised to able to clean all teeth and able to clean only some teeth.
- Frequency of dental visits among care recipients was initially described as never had a dental visit, only with a dental problem, every 2 years, every year and every 6 months and don’t know. Later the first two categories were collapsed as “never/only with a problem”, every 2 years and every year collapsed as ‘every 1–2 years’. Only six people responded ‘don’t know’ and so were treated as missing.
- Dental check-up/treatment pattern was described as without sedation, with sedation and under general anaesthetic. Never had a dental treatment was treated as missing.
- Frequency of dental visits among the carers was also recoded as ‘never/only with a problem’, ‘every 1–2 years’ and every 6 months.
- Responses for effects of caring role on carers (satisfied, stressed, angry, frustrated, weary/lack of energy, muscle pain in neck/back/limbs) were dichotomized to ‘not at all/rarely’ and ‘sometimes/fairly often/very often’.
- A summary score was calculated for the five individual questions on negative effects of caring role on carers – stress, anger, frustration, weariness/lack of energy and muscle pain in neck/back/limbs, which was recoded as one or more negative effects for scores over 20 (response of agree, strongly agree).
- For weekly hours of care provided by carer, ‘< 20 hours’ and ‘20–39 hours’ was collapsed as ‘< 40 hours’ and labeled as low weekly hours of care, ‘40–100 hours’ was labeled as medium weekly hours of care and ‘> 100 hours’ was labeled as high weekly hours of care.

Food

As there were several carers who responded that their care recipients ‘never’ ate anything by mouth, a new category 0= never was added. Then, responses for each food item were recoded as follows:

0 = never = 0 times a week
1 = less than twice a week = 1.5 times a week
2 = 2–4 times a week = 3 times a week
3 = 5–7 times a week = 6 times a week
4 = more than once a day = 10.5 times a week

Then, individual food items were combined into 3 categories of food as follows:

- The frequency of sweetened tea/coffee and flavoured milk (Milo, chocolate milk, Nesquik, etc.) were combined as frequency of sweet drinks.

- The frequency of soft drinks, cordials and juices were combined as frequency of acidic drinks.
- The frequency of biscuits, cakes, puddings, chocolate – and sugar-based confectionery, sweetened dairy products (ice-cream) and syrups, jams, and sweet spreads were combined as frequency of sweet solids.

A summary variable was computed for the frequency of different types of food (sweet drinks, acidic drinks, sweet solids), ranging from no such food to low, moderate and high.

Oral Health Impact Profile (OHIP)

Four questions were asked from the Oral Health Impact Profile (OHIP). They were:

How often during the last year, has your main care recipient…

Had trouble sleeping (psychological disability)

Had pain and discomfort (physical pain)

Had unsatisfactory diet (physical disability)

Been irritable (social disability)

…because of a dental problem?

Response options were on a 5-point Likert scale, never= 1, rarely= 2, sometimes= 3, 'fairly often= 4 and very often= 5. 'Sometimes', 'fairly often' and 'very often' were coded as negative impact on quality of life. It was felt that the many 'don't know' responses were meaningful, for example as an indicator of the care-providers awareness of the care recipients' everyday experiences. Therefore, they were retained and reported as a sixth category. For all other associations, the "don't know" responses were treated as "missing".

3.3.4 Analyses

Unweighted data were used to describe organisation participation and yield of participants. Subsequent analyses were undertaken using weighted data. For questions with multiple items/responses, initially, distributions of responses were first tabulated. Examples include:

- how often care recipients needed help with self-care activities (mobility, bathing/showering/washing, eating/feeding, toileting)
- how often carers provide assistance with self-care activities (mobility, bathing/showering/washing, eating/feeding, toileting)
- frequency of behavioural difficulties encountered as behavioural problems
- prevalence of negative oral health impacts on care recipients, and
- quality of dental care provided by dentist/hygienist, measured by 5 questions on a
- 5-point Likert scale from strongly disagree coded as 1 through strongly agree coded as 5.

Then, they were summarised in order as:

- always needing help with one or more activities and sometimes or never needing help for any of the self-care activities
- always providing help with one or more activities and sometimes or never providing help for any of the self-care activities
- prevalence of behavioural problems by counting behavioural difficulties encountered ‘fairly often’ and ‘very often’ as one or more behavioural problems
- prevalence of one or more negative impacts by counting those who ‘sometimes’, ‘fairly often’ or ‘very often’ had trouble sleeping or had pain and discomfort or had unsatisfactory diet or had been irritable because of a dental problem, and
- quality of dental care provided as neutral/negative (total score $\leq$ 19) and positive (total score $\geq$ 20).

Finally each of the study aims was analysed. For aim 1, contingency table analyses were created to examine the bivariate relationships between type of residence (family home, community housing, or institution) and the following variables:

- care recipient characteristics – age, sex, main disabling condition, means of communication, general health, income, need for help with self-care activities
- perceived oral health problems and treatment needs and impacts on quality of life
- dental practices (toothbrushing patterns and dental visit patterns) and barriers (problems associated with behaviour and access to dental care)
- oral disease risk behaviours (diet, medication usage, risk habits), and
- oral health status (dental health, tooth wear and periodontal health).

Participants were classified as having:

- decayed teeth (D>0), if one or more teeth were found at oral examination to be decayed, otherwise they were classified as not having decay
- missing teeth (M>0), if one or more teeth were found at oral examination to be missing, otherwise they were classified as not having a missing tooth
- filled teeth (F>0), if one or more teeth were found at oral examination to be missing otherwise they were classified as not having a filled tooth
- caries experience (DMFT>0), if one or more teeth were found at oral examination to be decayed, missing or filled, otherwise they were classified as not having past or present caries experience

- anterior tooth wear, if score of one or more was recorded in anterior sextant
- posterior tooth wear, if a score of one or more was recorded in posterior sextant
- extensive plaque, if dental plaque was present on all surfaces of any of the index teeth, with a score of 2 or more
- extensive calculus, if there was moderate or abundant amount of supra and subgingival calculus or subgingival calculus alone in any of the index teeth, with a score of 2 or more, and
- extensive gingivitis, if there was mild, moderate or severe gingivitis, extending all around any of the index teeth, with a score of 2 or more.

The plaque index was derived by averaging the scores recorded for the plaque status of each index tooth. The calculus index was derived by averaging the scores recorded for the calculus status of each index tooth. The gingivitis index was derived by averaging the scores recorded for the gingival status of each index tooth.

To evaluate overall differences in care recipient characteristics, perceived oral health problems, treatment needs and impacts on quality of life, dental practices, and oral-disease risk behaviours between the three residential settings, chi-square statistic was used, with an alpha level of p=0.05 as the standard for statistical significance. For oral health status, proportions (% of people with untreated decay, missing teeth, filled teeth and caries experience DMFT, thresholds of plaque, calculus and gingivitis, and tooth wear) and means (DMFT index, PDI index) were described using their associated 95% confidence intervals (CI). For detecting differences in means and proportions in the oral health outcomes between groups, the level of statistical significance was guided by non-overlapping CIs. This is a conservative method for identifying bivariate relationships, in that some 95% CIs with a small degree of overlap may nevertheless represent group differences that would be statistically significant (P<0.05) if evaluated using the t-test or the chi-square test. Yet, using the "non-overlapping 95% CI" criterion, any degree of overlap would be judged to be non-significant. This conservative approach was justified in view of the large number of variables being compared among the three residential settings.

For aim 2, contingency table analyses were created to examine the bivariate relationships between type of residence (family home, community housing, or institution) and the following variables:

- carer characteristics – age, sex, income
- relationship to care recipient
- knowledge of carers – training of carers in oral care for people with disabilities
- attitude of carers – carers' interest in training in oral care for people with disabilities attitude towards providing oral care and importance of oral health to carers for care recipients and themselves and decision to take on caring role
- dental behaviours of carers – tooth brushing frequency, frequency of dental visits
- care provided by carers for self-care activities of care recipients
- effects of caring role on carers – satisfied, stressed, angry, frustrated, weary/lack of energy, muscle pain in neck/back/limbs
- carer burden– absence of a fall-back carer, carers who reported need for more support (respite, financial, physical, emotional and other), negative effects of caring and no pay, and
- continuity of care – weekly hours of care, length of contact, number of care recipients under charge and number of carer providing care.

For aim 3, the analysis sought to estimate the association between the residential settings and various oral heath outcomes, recognising that the crude relationship might be confounded by variables shown in Figure 1.1 (conceptual framework, chapter 1). To adjust for potential confounding by variables found to have statistically significant associations with mean DMFT, stratified analyses were undertaken. To adjust for potential confounding by multiple variables, logistic regression models were constructed in which the dependent variables were log (odds) of decayed teeth (D>0), missing teeth (M>0), filled teeth (F>0) and caries experience (DMFT>0); anterior tooth wear (score 1+) and posterior tooth wear (score 1+); plaque, calculus and gingivitis scores of 2+. As the mean values of decayed, missing and filled teeth were very low, logistic regression models were used. In addition, a linear regression model was constructed with mean DMFT as the dependent variable.

The selection of variables into the models was based on the possibility of those variables having influences on each of the oral health outcomes and whether these variables had a significant association in the bivariate analyses (i.e. non-overlapping 95% confidence intervals). These variables were entered in blocks, for example care recipient characteristics, dental practices, risk behaviours, carer characteristics and factors associated with continuity of care. Age and sex were included in all models, even when bivariate relationships showed associations to be non-significant. Family home was the reference group, which therefore estimated effects of institution and community settings, each one relative to family home. The effects were expressed as odds ratios for oral health outcomes described as proportions, and parameter estimates of mean differences for DMFT. At each step, if the difference in parameter estimate for the three residential settings was greater than 10%, the variables were considered to be confounders and retained and the next block of variables were added to the new model, otherwise, they were removed from the model. In the final model, odds ratios and 95% CI are reported for community housing and institution relative to family home and other significant variables.

3.4 Ethical implications and approvals

The Human Research Ethics Committee of the University of Adelaide approved the study conducted from February 2005 to June 2006 (Appendix 13).

A “Research Impact Statement” was submitted to and reviewed by the South Australian Dental Service Board of Directors prior to the commencement of field work. This additional approval was necessary because the study used SADS clinics and dental assistants for recording for oral examination of care recipients.

Parents/guardians/person responsible signed consent for the participation of their care recipients in the study, when the participants themselves were unable to do so.

CHAPTER 4. RESULTS

This chapter includes responses from the organisations in the sampling frame and results from the mail questionnaire completed by carers and oral examinations of care recipients.

4.1 Information from organisations

Table 4.1a provides information from the approached twenty-one organisations regarding the number of care recipients registered with them according to their living arrangement. Some organisations did not want to participate in the study, but still provided information on the number of care recipients registered with them at the three residential settings. Orana did not have anyone in the 18–44 age-group and therefore was out of scope for this study. One of the organisations agreed to participate initially, but did not take part because the majority of its care recipients were from non-English speaking background whilst the survey materials were offered only in English.

Table 4.1a Information from organisations on the number of care recipients by living arrangement

	No. of people living in:			
Organisation	Family	Community	Institution	Total
1 Autism SA	276	106	9	391
2 Community Accommodation for Intellectually Disabled (CAID)	0	10	0	10
3 Community Accommodation & Respite Agency (CARA)	163	73		236
4 Community Living Project Inc.	12	14	0	26
5 Home Link SA	54	0	0	54
6 Individual Supported Accommodation Service	2	7	0	9
7 Julia Farr Services	14	5	39	58
8 Levada	0	42	0	42
9 Life's for Living Inc.	0	27	0	27
10 Minda Inc.		155	100	255
11 Spina Bifida & Hydrocephalous Assoc. of SA	70	73	5	148
12 Strathmont Centre	2	104	86	192
	593	616	239	1448
No response				
13 Barkuma				
14 Paraplegic and Quadriplegic Assoc.				
Negative responses				
15 Orana				
16 Malsa	50			50
17 Brain Injury Network SA				
18 Centacare Disability Services	80	23	0	103
19 Centennial Court (Salvation Army)	0	0	22	22
20 Community Living for the Disabled				
21 Head Injured Society of SA				
	723	639	261	1623

4.2 Response

As there were only five responses from Spina Bifida and Hydrocephalous Association of SA, which if included would adversely affect the weights, all of the 148 care recipients from this organisation were excluded from the study (Table 4.1b). Some care recipients had multiple disabilities and were registered with more than one organisation, creating thirteen duplicate responses. Additionally, six care recipients were over the age of 44 years and therefore out of scope for this study. Another care recipient had died by the time questionnaires were mailed. The total number of people excluded from the study was 168 (Table 4.1b) leaving 1280 in scope (Table 4.1c).

Table 4.1b Number of care recipients excluded from study

Reasons	No. of people
Spina Bifida & Hydrocephalous Assoc. of SA	148
Duplicates	13
Over 44 years old	6
Death	1
Total	168

Table 4.1c In scope study population

	No. of people living in:			
Organisation	Family	Community	Institution	Total
Autism SA	274	105	8	387
CAID	0	10	0	10
CARA	162	68	0	230
Community Living Project	11	14	0	25
Home Link SA	52	0	0	52
Individual Supported Accommodation Service	2	7	0	9
Julia Farr Services	14	5	38	57
Levada	0	41	0	41
Lifes for Living	0	27	0	27
Minda Inc.	0	154	100	254
Strathmont Centre	3	99	86	188
Total	518	530	232	1280

4.2.1 Questionnaire to carers

From the 1280 care recipients in the sampling frame, valid responses were received for 485 care recipients producing a yield of 37.9% of all adults with disabilities in scope for the study (Table 4.1d). Table 4.1e summarises the responses from each residential setting. Often, one carer responded for multiple care recipients, completing a separate questionnaire for each person. The highest response was from carers at institutions (60.8%) and the lowest from those at family homes (28.4%).

Table 4.1d Valid questionnaire responses

	No. of people living in:				
Organisation	Family	Community	Institution	Responses	Yield
Autism SA	50	14	4	68	17.6
CAID	0	9	0	9	90.0
CARA	73	50	0	123	53.5
Community Living Project	3	0	0	3	12.0
Home Link SA	13	0	0	13	25.0
Individual Supported Accommodation Service	2	6	0	8	88.9
Julia Farr Services	3	2	11	16	28.1
Levada	0	33	0	33	80.5
Life's for Living	0	7	0	7	25.9
Minda Inc.	0	15	42	57	22.4
Strathmont Centre	3	61	84	148	78.7
	147	197	141	485	37.9

Table 4.1e Summary table of responses from each residential setting

Residential setting	Target	Responses	Yield (%)
Family	518	147	28.4
Community	530	197	37.2
Institution	232	141	60.8
Total	1280	485	37.9

Table 4.1f provides some of the reasons for non-response to the questionnaires reported by care recipients by phone or in questionnaires that were returned incomplete. “Not willing” and “can’t” respond to the questionnaire were the main reasons for non-response. Some were returned blank and others because of wrong address.

Table 4.1f Reasons for non-response

Reasons	No. of care recipients
Not willing/Can’t respond	18
Blanks	5
Wrong address	3
Total	26

4.2.2 Oral examination of care recipients

Among the 485 questionnaire respondents, oral examinations were completed for 267 care recipients (Family home= 76, Community housing= 93, Institution= 98). The main reasons for non-participation in the oral examinations were that the carers felt it would be impossible due to aggressive or resistive behaviour or that it would cause undue distress to the care recipient. Among people whose carers consented to an examination, 17 could not be examined by the study dentists due to care recipients' behavioural issues. Others lived in country South Australia and were geographically not accessible for the study. Some visited private dentists or other SADS clinics and their carers said they did not want to be examined, while some failed to attend or cancelled up to five times, with sickness being the main reason. Two care recipients had died since the questionnaire was completed. Some did not give any contact details, while others did not respond to multiple phone messages.

4.3 Analyses

In the results that follow, the number of subjects analysed for different aspects of the study vary depending upon the number of valid responses to the specific survey items. However, all results are weighted to reflect the distribution of people living in three residential settings among the sampled organisations. Weights for care recipients in each participating organisation for the questionnaire and the oral examination are shown in Tables 4.2a-b. Computation of the weights have been described in chapter 2, section 3.3.2.

Table 4.2a Questionnaire weights

	Residential setting		
Organisation	Family	Community	Institution
Autism SA	5.5	2.7	2.0
CAID	NA†	1.1	NA
CARA	2.2	1.4	NA
Community Living Project	3.7	NA	NA
Home Link SA	4.0	NA	NA
Individual Supported Accommodation Service	1.0	1.2	NA
Julia Farr Services	4.7	2.5	3.5
Levada	NA	1.2	NA
Life's for Living	NA	3.9	NA
Minda Inc.	NA	2.7	2.4
Strathmont Centre	1	1.7	1.0
All	3.5	2.7	1.6

Table 4.2b Examination weights

	Residential setting		
Organisation	Family	Community	Institution
Autism SA	13.7	5.7	NA
CAID	NA†	2.5	NA
Comm Acc & Respite Agency	4.0	2.4	NA
Comm Living Project	5.5	NA	NA
Homelink SA	5.2	NA	NA
Indi Supp Acco Service	NA	NA	NA
Julia Farr Services	14.0	5.0	6.3
Levada	NA	2.7	NA
Life's for Living	NA	13.5	NA
Minda	NA	5.7	3.6
Strathmont	1.5	3.3	1.3
All	6.8	5.7	2.4

† NA denotes that there were no care recipients at that setting in that organisation.

4.3.1 Characteristics of carers

Over 30% of carers were aged 55 years or more and 82.3% were females (Table 4.3). Carer age ranged from 20–74 years, with the average age of carers at family homes being the highest at 53 years. The older carers in community housing and institutions predominantly were parents who continued to be the primary carer for their care recipients, even if the carer did not live with the care recipient. A significantly lower proportion of family carers received wages compared to other carers. However, the majority of them received carer allowance/payment or were on other source of income. There were 51.9% of family carers and 48.1% of non-family carers.

Table 4.3 Characteristics of carers

Characteristics	All people n (%)	Residential setting			Chi-square p value
		Family home n (%)	Community n (%)	Institution n (%)	
Age (Yrs)					<0.001
≤ 44	90 (22.5)	30 (13.3)	41 (31.5)	19 (42.2)	
45–54	177 (44.3)	111 (49.3)	51 (39.2)	15 (33.3)	
55+	133 (33.3)	84 (37.3)	38 (29.2)	11 (23.9)	
Sex					<0.001
Male	78 (17.7)	24 (10.5)	39 (27.1)	15 (22.1)	
Female	362 (82.3)	204 (89.5)	105 (72.9)	53 (77.9)	
Income from wages					<0.001
Yes	242 (58.7)	69 (31.7)	124 (89.2)	49 (89.1)	
No	170 (41.3)	149 (68.3)	15 (10.8)	6 (10.9)	
Carer allowance/payment/other					<0.001
Yes	196 (47.7)	175 (80.3)	15 (10.9)	6 (10.9)	
No	215 (52.3)	43 (19.7)	123 (89.1)	49 (89.1)	
Relationship to care recipient					<0.001
Family carer	251 (51.9)	221 (96.5)	21 (13.8)	9 (8.7)	
Non-family carer	233 (48.1)	8 (3.5)	131 (86.2)	94 (91.3)	

4.3.2 Characteristics of care recipients

There were 47.4% of care recipients who lived in family homes, 31.4% in community housing and 21.2% in institutions (Table 4.4). The majority of the 18–24 age-group lived in family homes, while the majority of the 35–44 age-group lived in institutions. There were more males than females (61.9% males, 38.1% females) but there was no significant difference in the sex distribution across the three residential settings. The main disabling conditions were intellectual disability (38.5%), autism (31.7%), cerebral palsy (19.5%) and others (spina bifida, quadriplegia, head injury) (10.4%). Care recipients with spina bifida included in this category were selected from other participating organisations. Nearly 50% of the care recipients had other disabling conditions like epilepsy, diabetes, and hearing and visual impairments. The majority of the care recipients with intellectual disability lived in community housing and institutions, while those with autism lived at family homes (p<0.001, Table 4.4). While 21.3% communicated non-verbally, almost a third (30.3%) of the care recipients had little or no effective communication. Non-verbal means of communication included sign language, use of picture cards/boards, writing or typed/computer messages. Some 17.1% of care recipients were reported to have either "fair" or "poor" health. Overall health status varied significantly by residential setting, with less people with "fair" or "poor" health living in the community (p<0.001, Table 4.4). Some 95.1% of care recipients received a disability support pension, while about 13.8% had other sources of income, including worker's compensation. Care recipients living at family homes were more likely to have other sources of income compared to those living in the community and institutions (p<0.05, Table 4.4).

Table 4.4 Characteristics of care recipients

		Residential setting			
Characteristics	All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
All	485 (100)	230 (47.4)	152 (31.4)	103 (21.2)	
Age (Yrs)					<0.001
18–24	155 (33.1)	133 (58.3)	17 (11.6)	5 (5.3)	
25–34	154 (32.9)	74 (32.5)	61 (41.8)	19 (20.2)	
35–44	159 (34.0)	21 (9.2)	68 (46.6)	70 (74.5)	
Sex					0.137
Male	299 (61.9)	153 (66.5)	87 (57.6)	59 (57.8)	
Female	184 (38.1)	77 (33.5)	64 (42.4)	43 (42.2)	
Main disabling condition					<0.001
Intellectual disability	186 (38.5)	45 (19.6)	76 (50.3)	65 (63.7)	
Autism	153 (31.7)	110 (47.8)	27 (17.9)	16 (15.7)	
Cerebral palsy	94 (19.5)	51 (22.2)	39 (29.8)	4 (3.9)	
Other (Spina bifida, quadriplegia, head injury)	50 (10.4)	24 (10.4)	9 (6.0)	17 (16.7)	
Means of communication					0.097
Verbally	234 (48.4)	122 (53.3)	61 (40.4)	51 (49.5)	
Non-verbally	103 (21.3)	41 (17.9)	42 (27.8)	20 (19.4)	
Little or no effective communication	146 (30.2)	66 (28.8)	48 (31.8)	32 (31.1)	
General health					<0.001
Very good-Excellent	199 (42.6)	106 (47.1)	68 (46.9)	25 (25.8)	
Good	188 (40.3)	75 (33.3)	64 (44.1)	49 (50.5)	
Poor-Fair	80 (17.1)	44 (19.6)	13 (9.0)	23 (23.7)	
Income from Disability support pension					0.416
Yes	443 (95.1)	209 (93.7)	141 (95.9)	93 (96.9)	
No	23 (4.9)	14 (6.3)	6 (4.1)	3 (3.1)	
Worker's compensation and other					0.027
Yes	64 (13.8)	39 (17.5)	19 (13.0)	6 (6.3)	
No	401 (86.2)	184 (82.5)	127 (87.0)	90 (93.8)	

Over 30% of care recipients always needed help with each of the four self-care activities, with more care recipients needing help with bathing/showering/washing than with other activities (Table 4.5a). Some 62.7% of care recipients always needed help with one or more activities. There was no statistically significant difference across the three settings (Table 4.5b).

Table 4.5a Care recipients' need for help with self-care activities

Activities	Always n (%)	Sometimes n (%)	Does not need help but uses aid or equipment n (%)	Does not need help and does not use aid or equipment n (%)
a) Mobility	148 (31.0)	87 (18.3)	24 (5.0)	218 (45.8)
b) Bathing/showering/washing	297 (61.7)	68 (14.1)	6 (1.3)	110 (22.8)
c) Eating/feeding	149 (31.2)	80 (16.7)	18 (3.7)	230 (48.4)
d) Toileting	183 (38.3)	87 (18.3)	17 (3.5)	191 (39.9)

Table 4.5b Summary table of care recipients needing help with self-care activities

		Residential setting			
	Full sample n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Never/only sometimes needs help	181 (37.3)	89 (38.7)	57 (37.5)	35 (34.0)	0.712
Always needs help for one or more activities	304 (62.7)	141 (60.0)	95 (62.5)	68 (66.0)	

4.3.3 Perceived oral health problems and treatment needs of care recipients and impacts on quality of life

About 50% of carers thought that their care recipient presently had an oral health problem and a similar percentage of carers thought their care recipients needed dental treatment (Tables 4.6 and 4.7). Some 11.8% of carers reported not knowing whether their care recipient had an oral health problem. A significantly higher proportion of carers at institutions reported oral health problems than those at family homes and community housing, but it must be noted that a significantly higher proportion of carers at family homes reported not knowing if their care recipients had an oral health problem or not ($p<0.02$, Table 4.6). The most frequent oral health problem reported was bad breath followed by tooth problems and bleeding gums (Table 4.6). Tooth problems included decayed/loose/broken teeth and lost/broken fillings. Other problems included ulcers, infection, calculus build-up, tooth wear and impacted wisdom teeth. A significantly higher proportion of carers in community housing and institutions reported bad breath among care recipients compared to those in family homes, while carers in family homes reported significantly more other problems ($p<0.05$, Table 4.6). There was no difference in the prevalence of tooth problems and bleeding gums across the residential settings.

Table 4.6 Prevalence of oral health problems

Oral health problems	All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
All problems					
Yes	228 (48.9)	104 (47.7)	70 (46.4)	54 (55.7)	0.02
No	183 (39.3)	79 (36.2)	71 (47.0)	33 (34.0)	
Don't know	55 (11.8)	35 (16.1)	10 (6.6)	10 (6.3)	
Specific problems					
Bad breath					0.033
Yes	100 (44.6)	35 (35.0)	37 (52.9)	28 (51.9)	
No	124 (55.4)	65 (65.0)	33 (47.1)	26 (48.1)	
Tooth problems					
Yes	75 (33.6)	39 (38.6)	22 (31.9)	14 (26.4)	0.293
No	148 (66.4)	62 (61.4)	47 (31.9)	39 (73.6)	
Bleeding gums					0.309
Yes	122 (32.7)	50 (49.5)	39 (55.7)	33 (62.3)	
No	102 (45.5)	51 (50.5)	31 (44.3)	20 (37.7)	
Other					0.003
Yes	71 (31.4)	41 (39.8)	23 (32.9)	7 (13.2)	
No	155 (68.6)	62 (60.2)	47 (67.1)	46 (86.8)	

Some 14.7% responded 'don't know' to questions about perceived dental treatment needs. Carers at family homes reported more perceived dental treatment needs than carers at other settings (p<0.05, Table 4.7).

Table 4.7 Prevalence of perceived dental treatment needs

Treatment needs	All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
All treatment needs					0.022
Yes	234 (49.9)	121 (54.5)	64 (43.2)	49 (49.5)	
No	166 (35.4)	63 (28.4)	67 (45.3)	36 (36.4)	
Don't know	69 (14.7)	38 (17.1)	17 (11.5)	14 (14.1)	
Specific treatment needs					
Scaling					0.361
Yes	198 (89.6)	102 (87.9)	54 (88.5)	42 (95.5)	
No	23 (10.4)	14 (12.1)	7 (11.5)	2 (4.5)	
Fillings					0.091
Yes	47 (21.2)	28 (24.1)	15 (24.2)	4 (9.1)	
No	175 (78.8)	88 (75.9)	47 (75.8)	40 (90.9)	
Other					0.030
Yes	40 (18.1)	26 (22.4)	12 (19.7)	2 (4.5)	
No	181 (81.9)	90 (77.6)	49 (80.3)	42 (95.5)	

The perceived dental treatment need reported most frequently was scaling (89.6%), followed by fillings (21.2%) (Table 4.7). Other treatment needs included general check-up, extractions and capping of worn teeth. There was no statistically significant difference in the reported perceived treatment needs for fillings and scaling across the three settings. Care recipients at family homes and community housing reported significantly more other treatment needs than those in institutions (p<0.05, Table 4.7).

In spite of the fairly high prevalences of perceived oral health problems and perceived treatment needs, the prevalence of negative impacts attributed to dental problems was low, with only 9.2% related to pain and discomfort, 7.7% for irritable behaviour, 6.1% for trouble sleeping and 3.0% for unsatisfactory diet. The proportion of 'don't know' for each question was slightly higher than the prevalence of reported negative impacts (Table 4.8a).

Table 4.8a Prevalence of negative oral health impacts on care recipients reported by carers

Oral health impacts	Negative impact n (%)	Don't know n (%)
Pain and discomfort	42 (9.2)	42 (9.4)
Irritable behaviour	35 (7.7)	46 (10.2)
Trouble sleeping	27 (6.1)	47 (10.6)
Unsatisfactory diet	13 (3.0)	39 (8.7)

One or more negative impacts were reported in 13.5% of care recipients, with carers at family homes reporting more negative impacts compared to carers from other settings (p<0.01, Table 4.8b).

Table 4.8b Summary of negative oral health impacts on care recipients reported by carers

		Residential setting			
Negative impact	All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
No impact	397 (86.5)	177 (81.9)	128 (88.3)	92 (93.9)	0.012
One or more impacts	62 (13.5)	39 (18.1)	17 (11.7)	6 (6.1)	

Negative impacts were reported significantly more frequently for those who could communicate verbally, than for those with non-verbal and little or no communication (p<0.001, Table 4.9).

Table 4.9 Prevalence of negative impacts by means of communication

Means of communication	Negative impact n (%)	Don't know n (%)	Chi-square p value
Verbal	44 (20.0)	1 (0.5)	<0.001
Non-verbal	6 (6.1)	12 (12.2)	
Little or no communication	11 (7.9)	25 (18.0)	

4.3.4 Dental practices among care recipients

4.3.4.1 Toothbrushing pattern

Complete assistance for toothbrushing was needed by 46.2% of care recipients, partial assistance by 26.2%, while 27.7% of care recipients cleaned their own teeth. A higher proportion of care recipients at institutions received assistance from their carers than other settings (p<0.05, Table 4.10). Nearly 40% of care recipients had their teeth brushed once a day or less, which was more common among care recipients at family homes compared to community housing and institution (p<0.001, Table 4.10). The majority of the care recipients (81.1%) spent about 2 to 5 minutes cleaning teeth and used a toothbrush and paste (92.6%) for cleaning, while a few (<10%) used fluoride/chlorhexidine gels and mouthrinses. Very few (2.7%) used other aids like swabs and cloth.

Table 4.10 Frequency of toothbrushing pattern among care recipients across residential settings

			Residential setting			
Toothbrushing pattern		All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
(All care recipients)						
Who cleaned teeth						0.002
Carer only		222 (46.2)	92 (40.2)	79 (52.7)	51 (50.0)	
Care recipient with carer assistance		126 (26.2)	58 (25.3)	33 (22.0)	35 (34.3)	
Care recipient without any assistance		133 (27.7)	79 (34.5)	38 (25.3)	16 (15.7)	
Frequency of toothbrushing						<0.001
Once/day or less		182 (39.3)	124 (55.9)	31 (21.7)	27 (27.6)	
Twice/day		281 (60.7)	98 (44.1)	112 (78.3)	71 (72.4)	
(Care recipients needing carer help)						
Time taken to clean by carer						0.018
≤ 1 minute		44 (13.8)	24 (17.8)	7 (7.0)	13 (15.7)	
2–5 minutes		258 (81.1)	103 (76.3)	85 (85.0)	70 (84.3)	
≥ 6 minutes		16 (5.0)	8 (5.9)	8 (8.0)	0 (0.0)	
Cleaning aids						0.402
Toothbrush only	Yes	22 (6.8)	10 (7.4)	9 (8.5)	3 (3.7)	
	No	302 (93.2)	126 (92.6)	97 (91.5)	79 (96.3)	
Toothbrush and toothpaste	Yes	302 (92.6)	126 (92.0)	97 (90.7)	79 (96.3)	0.308
	No	24 (7.4)	11 (8.0)	10 (9.3)	3 (3.7)	
Gel	Yes	28 (8.6)	10 (7.3)	13 (12.3)	5 (6.1)	0.252
	No	297 (91.4)	127 (92.7)	93 (87.7)	77 (93.9)	
Mouthrinse	Yes	25 (7.7)	7 (5.1)	14 (13.2)	4 (4.9)	0.034
	No	300 (92.3)	130 (94.9)	92 (86.8)	78 (95.1)	
Adequacy of time to clean by carer						<0.001
Adequate		255 (83.6)	90 (74.4)	97 (93.3)	68 (85.0)	
Inadequate		50 (16.4)	31 (25.6)	7 (6.7)	12 (15.0)	
Carer's cleaning ability						0.838
All teeth		142 (46.1)	58 (46.8)	48 (47.5)	36 (43.4)	
Only some teeth		166 (53.9)	66 (53.2)	53 (52.5)	47 (56.6)	

Of the few 7.7% of care recipients that used mouthrinses, it was more commonly used by care recipients in community housing compared to those at family homes and institutions ($p<0.05$, Table 4.10). About 16.4% of carers reported inadequate time to clean and 62.0% of these were carers at family homes. Only 46.1% of carers were able to clean all teeth and the cleaning ability among carers was similar across the three settings.

4.3.4.1.1 Organisational difficulties when providing oral hygiene care

There were several organisational difficulties faced by carers when providing oral hygiene care (Table 4.11). Among all carers, about 26.4% of them reported lack of time in their usual routine (response of sometimes, fairly often and very often). Among paid carers, 17.4% of carers reported lack of staff and about 19.7% of carers reported lack of communication among staff between shifts (response of sometimes and fairly often). However, as there was over 26% of missing responses, no further analyses were conducted.

Table 4.11 Frequency of organisational difficulties when providing oral hygiene care

Difficulties when providing oral hygiene care (*all carers*)	Never	Rarely	Sometimes	Fairly often	Very often
a. Lack of time in usual routine	173 (48.2)	91 (25.3)	67 (18.7)	24 (6.6)	4 (1.1)
(paid carers only)					
c. Lack of staff	125 (69.1)	24 (13.1)	26 (14.5)	5 (2.9)	0
d. Lack of communication among staff between shifts	96 (56.8)	40 (23.6)	30 (17.8)	3 (1.9)	0

4.3.4.1.2 Behavioural difficulties when providing oral hygiene care

Several behavioural problems were encountered by carers when providing oral hygiene care for their care recipients. The most frequent problem, reported for 57.9% of care recipients, was inability to rinse with mouthwash, followed by inability to spit after using toothpaste (50.5%). Other problems included – bites toothbrush/swab/carer, drools, moves head or body around excessively, refuses oral hygiene care, does not open mouth, faces head down towards chest, kicks or hits during oral care and uses offensive language (Table 4.12a).

Table 4.12a Prevalence of reported behavioural problems

Problems	Never n (%)	Rarely n (%)	Sometimes n (%)	Fairly often n (%)	Very often n (%)
1. Does not or is unable to rinse with mouthwash	75 (24.0)	20 (6.4)	16 (5.0)	21 (6.7)	181 (57.9)
2. Does not or is unable to spit after using toothpaste	88 (28.2)	16 (5.1)	25 (7.9)	26 (8.3)	158 (50.5)
3. Bites toothbrush/swab/carer	136 (44.1)	55 (18.0)	58 (18.8)	29 (9.4)	30 (9.8)
4. Drools	181 (58.9)	34 (11.1)	43 (14.0)	23 (7.6)	26 (8.4)
5. Moves head or body around excessively	134 (43.5)	50 (16.3)	74 (24.1)	21 (6.8)	28 (9.2)
6. Refuses oral hygiene care	132 (43.1)	51 (16.6)	75 (24.5)	24 (7.9)	24 (7.9)
7. Does not open mouth	121 (39.2)	68 (22.0)	76 (21.7)	24 (7.8)	20 (6.4)
8. Faces head down towards chest	169 (55.1)	45 (14.7)	64 (20.7)	14 (4.6)	15 (4.9)
9. Kicks or hits during oral care	245 (80.6)	31 (10.3)	19 (6.2)	3 (1.0)	6 (1.9)
10. Uses offensive language	278 (90.7)	12 (3.8)	11 (3.5)	3 (1.1)	3 (0.9)

One or more behavioural problems (a response of fairly often or very often) was present in 75.5% of care recipients and the percentage was similar across the three settings (P= 0.43, Table 4.12b). The mean number of behavioural problems reported per care recipient was 1.8 (Table 4.12b).

Table 4.12b Summary table of reported behavioural problems

		Residential setting			
Behavioural problems	All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
No problems	79 (24.5)	28 (21.1)	27 (25.7)	24 (28.6)	0.43
One or more problems	243 (75.5)	105 (78.9)	78 (74.3)	60 (71.4)	
Mean number of problems	1.8	1.8	1.7	1.7	

4.3.4.2 Dental visit pattern

Nearly one fifth of care recipients (18.6%) either never visited the dentist or had not attended after turning 18 years of age or visited only because of a dental problem, most of whom were from family homes (Table 4.13). Care recipients in institutions were seen most frequently at six-monthly recalls. Some 18.8% of care recipients required a general anaesthetic for routine dental examination and treatment, and 13.1% said they were usually treated in the chair under oral sedation.

Table 4.13 Frequency of dental visit pattern among care recipients

Dental visit pattern	All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Frequency of dental visits					<0.001
Never/not after 18 yrs /only with a problem	87 (18.6)	68 (30.4)	14 (9.6)	5 (5.1)	
Every 1–2 years	190 (40.5)	81 (36.2)	76 (52.1)	33 (33.3)	
Every 6 months	192 (40.9)	75 (33.5)	56 (38.4)	61 (61.6)	
Usual dental visit pattern					<0.001
Without sedation	301 (68.1)	161 (76.7)	94 (68.6)	46 (48.4)	
With sedation	58 (13.1)	5 (2.4)	18 (13.1)	35 (36.8)	
Under GA	83 (18.8)	44 (21.0)	25 (18.2)	14 (14.7)	
Carer involvement at dental visit					<0.001
Yes	357 (75.8)	189 (84.4)	93 (62.4)	75 (76.5)	
No	114 (24.2)	35 (15.6)	56 (37.6)	23 (23.5)	

About 75.8% of carers accompanied their main care recipient(s) for their dental visit. Carers from family homes were most likely to be present at the dental visit compared to carers at other settings (p<0.001, Table 4.13).

The most frequently reported dental services provided to care recipients included check-up, followed by scaling, fillings, extractions and other treatments including dentures and radiographs (Table 4.14). Care recipients in institutions were more likely to have received scaling, fillings, extractions and other treatments compared to care recipients at other settings (p<0.001, Table 4.14).

Table 4.14 Frequency of usual dental services provided to care recipients

Services		All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Check-up	Yes	340 (72.8)	164 (74.5)	99 (66.9)	77 (77.8)	0.123
	No	127 (27.2)	56 (25.5)	49 (33.1)	22 (22.2)	
Scaling	Yes	276 (59.1)	92 (41.8)	101 (68.2)	83 (83.8)	<0.001
	No	191 (40.9)	128 (58.2)	47 (31.8)	16 (16.2)	
Fillings	Yes	182 (39.0)	70 (31.8)	50 (33.8)	62 (62.6)	<0.001
	No	285 (61.0)	150 (68.2)	98 (66.2)	37 (37.4)	
Extractions	Yes	108 (23.3)	28 (12.7)	32 (21.8)	48 (50.0)	<0.001
	No	355 (76.7)	192 (87.3)	115 (78.2)	48 (50.0)	
Other	Yes	56 (12.0)	24 (11.0)	9 (6.1)	23 (23.2)	<0.001
	No	410 (88.0)	195 (89.0)	139 (93.9)	76 (76.8)	

Some 43.6% of carers reported one or more problems in obtaining dental care, the most frequent being dentists with inadequate skills in managing people with disabilities followed by cost, location of dental clinic, lack of dentists willing to treat people with disabilities and transportation problems (Table 4.15). Carers at family homes experienced the most number of problems in obtaining care, while those at institutions reported minimal problems in obtaining dental care for their care recipients (p<0.001, Table 4.15).

Other problems included carers not being aware of services available for people with disabilities and not knowing where to take their care recipients, or having the impression that there was a long waiting list to be seen at government clinics and inadequate disabled parking outside dental clinics. Some carers at institutions acknowledged that there were too many patients to be seen by one dentist in the single morning dental clinical session offered at the institution every week.

Table 4.15 Prevalence of problems obtaining dental care

			Residential setting			
Problems		All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Inadequate skills	Yes	89 (19.7)	55 (25.8)	30 (21.4)	4 (4.0)	<0.001
	No	363 (80.3)	158 (74.2)	110 (78.6)	95 (96.0)	
Cost	Yes	69 (15.3)	53 (24.9)	14 (10.0)	2 (2.0)	<0.001
	No	383 (84.7)	160 (75.1)	126 (90.0)	97 (98.0)	
Location	Yes	66 (14.7)	40 (18.9)	24 (17.3)	2 (2.0)	<0.001
	No	384 (85.3)	172 (81.1)	115 (82.7)	97 (98.0)	
Lack of dentists willing	Yes	63 (13.9)	40 (18.8)	18 (12.9)	5 (5.1)	0.004
	No	389 (86.1)	173 (81.2)	122 (87.1)	94 (94.9)	
Transport	Yes	58 (12.8)	40 (18.8)	15 (10.7)	3 (3.0)	<0.001
	No	394 (87.2)	173 (81.2)	125 (89.3)	96 (97.0)	
Other	Yes	35 (7.8)	21 (9.9)	13 (9.4)	1 (1.0)	0.017
	No	416 (92.2)	192 (90.1)	126 (90.6)	98 (99.0)	
One or more	Yes	197 (43.6)	122 (57.3)	67 (47.9)	8 (8.1)	<0.001
	No	255 (56.4)	91 (42.7)	73 (52.1)	91 (91.9)	

Reported quality of dental care provided by dentist/hygienist was measured by 5 questions, with responses recorded on a 5-point Likert scale that ranged from "strongly disagree" coded as 1 through to "strongly agree" coded as 5 (Table 4.16a). Of the care recipients who visited the dentist, most carers reported that the dentist/hygienist showed sensitivity to the special needs of their care recipients, conducted a proper dental examination, diagnosis and treatment, fully explained treatment choices and offered clear oral hygiene instructions to them and their care recipients. Recall visits for care recipients were also arranged.

Table 4.16a Frequency of ratings of reported quality of dental care provided by dentist/hygienist (%)

At your care recipient's dental visit, the dentist/hygienist….	Strongly Disagree (1) n (%)	Disagree (2) n (%)	Neutral (3) n (%)	Agree(4) n (%)	Strongly agree (5) n (%)
1. Shows sensitivity to the special needs of your care recipient	8 (1.9)	4 (1.0)	27(6.8)	180 (44.9)	182 (45.4)
2. Conducts a proper dental examination, diagnosis and treatment	11 (2.7)	11 (2.8)	30 (7.7)	184 (46.5)	160 (40.4)
3. Fully explains treatment choices to carer and care recipient	10 (2.6)	5 (1.3)	34 (8.7)	197 (49.8)	149 (37.6)
4. Offers clear oral hygiene instructions to carer and care recipient	8 (2.0)	9 (2.2)	35 (9.0)	200 (51.1)	140 (35.7)
5. Arranges recall visits for care recipient	15 (3.8)	10 (2.6)	42 (10.6)	148 (37.5)	179 (45.5)

From the responses in Table 4.16a, quality of dental care provided was dichotomised as neutral/negative (total score ≤ 19) or positive (total score ≥ 20) (Table 4.16b). Generally, most carers had positive reports, however, carers at family homes were either more neutral or negative about their reports compared to carers from other settings (p<0.001, Table 4.16b).

Table 4.16b Summary report of quality of dental care provided by dentist/hygienist

		Residential setting			
	All people	Family	Community	Institution	Chi-square
Report	n (%)	n (%)	n (%)	n (%)	p value
Positive	303 (74.4)	123 (63.4)	97 (83.6)	83 (85.6)	<0.001
Neutral/Negative	101 (25.6)	71 (36.6)	19 (16.4)	14 (14.4)	

4.3.5 Oral disease risk behaviours among care recipients

4.3.5.1 Diet

A few care recipients never consumed any of the food types listed in the questionnaire because they were either peg fed (fed with specially prepared liquid feeds through a tube into the stomach) or diabetics who did not have anything sweet. Among the remainder, sweetened tea/coffee was the most frequently consumed food. Nearly 50% of them drank soft drinks/cordials more than once a day (Table 4.17a). Within residential settings, a higher proportion of care recipients at institutions took a high intake of sweet drinks compared to care recipients at other settings (p<0.01, Table 4.17b). However, there was no difference in the frequency of acidic drinks and sweet solids.

Table 4.17a Frequency of food consumption among care recipients

Food types	Never n (%)	< twice /week n (%)	2–4 times /week n (%)	5-7 times /week n (%)	>once /day n (%)
1. Sweetened tea/coffee	33 (8.0)	157 (32.3)	40 (9.7)	60 (14.5)	127 (30.4)
2. Flavoured milk (Milo, chocolate milk, Nesquik, etc.)	30 (6.7)	194 (43.4)	120 (26.7)	69 (15.3)	35 (7.8)
3. Biscuits, cakes, puddings	23 (5.2)	172 (38.5)	142 (31.8)	81 (18.2)	28 (6.3)
4. Chocolate- and sugar-based confectionery	27 (6.2)	273 (62.4)	99 (22.6)	20 (4.6)	18 (4.1)
5. Sweetened dairy products (ice-cream)	27 (6.2)	208 (48.2)	138 (28.5)	42 (9.7)	17 (3.9)
6. Syrups, jams, and sweet spreads (Nutella, honey, jam, maple syrup etc.)	28 (6.6)	237 (54.9)	81 (18.8)	70 (16.2)	16 (3.6)
7. Fruit juice	24 (5.3)	134 (29.6)	113 (23.4)	130 (28.9)	50 (10.3)
8. Soft drinks, cordials a) diet	24 (6.3)	101 (26.7)	74 (19.5)	75 (19.8)	106 (27.8)
b) non-diet	25 (9.2)	94 (34.9)	66 (24.3)	35 (13.0)	51 (18.7)

Table 4.17b Frequency of food consumption among care recipients across residential settings

		Residential setting			
	All people	Family	Community	Institution	Chi-square
Risk food types	n (%)	n (%)	n (%)	n (%)	p value
Sweet drinks					0.002
None	18 (7.1)	7 (5.9)	7 (8.9)	4 (7.1)	
Low	67 (26.5)	42 (35.6)	19 (24.1)	6 (10.7)	
Moderate	89 (35.2)	41 (34.7)	31 (39.2)	17 (30.4)	
High	79 (31.2)	28 (23.7)	22 (27.8)	29 (51.8)	
Sweet solids					0.072
None	16 (6.3)	7 (5.8)	6 (7.7)	3 (5.5)	
Low	90 (35.4)	43 (35.5)	35 (44.5)	12 (21.8)	
Moderate	90 (35.4)	41 (33.9)	27 (34.6)	22 (40.0)	
High	58 (22.8)	30 (24.8)	10 (12.8)	18 (32.7)	
Acidic drinks					0.939
None	16 (6.2)	7 (5.6)	6 (7.6)	3 (5.5)	
Low	84 (32.6)	44 (35.5)	25 (31.6)	15 (27.3)	
Moderate	84 (32.6)	40 (32.3)	25 (31.6)	19 (34.5)	
High	74 (28.7)	33 (26.6)	23 (29.1)	18 (32.7)	

4.3.5.2 Medication usage

Some 77.9% of care recipients took one or more medications, with 72.8% of them taking medications that have been associated with dry mouth and candidiasis, 44.4% of them taking medications associated with gingival hyperplasia and 25.2% of them taking medications associated with mucosal problems (Table 4.18). Within the residential settings, the proportion of care recipients taking such medications with potential adverse oral effects was higher at institutions than those at family homes and community housing (p<0.01, Table 4.18).

Table 4.18 Percentage of care recipients taking medications

			Residential setting			
		All people	Family	Community	Institution	Chi-square
Medications		n (%)	n (%)	n (%)	n (%)	p value
Any medication	Yes	370 (77.9)	151 (66.2)	126 (84.6)	93 (94.9)	<0.001
	No	105 (22.1)	77 (33.8)	23 (15.4)	5 (5.1)	
Medications causing dry mouth	Yes	324 (72.8)	142 (63.7)	103 (75.2)	79 (92.9)	<0.001
	No	121 (27.2)	81 (36.3)	34 (24.8)	6 (7.1)	
Medications causing candidiasis	Yes	324 (72.8)	142 (63.7)	103 (75.2)	79 (92.9)	<0.001
	No	121 (27.2)	81 (36.3)	34 (24.8)	6 (7.1)	
Medications causing gingival hyperplasia	Yes	198 (44.4)	80 (35.9)	72 (52.2)	46 (54.1)	0.001
	No	248 (58.6)	143 (64.9)	66 (47.8)	39 (45.9)	
Medications causing mucosal problems	Yes	112 (25.2)	34 (15.2)	39 (28.5)	39 (45.9)	<0.001
	No	333 (74.8)	189 (84.8)	98 (71.5)	46 (54.1)	

4.3.5.3 Prevalence of other risk behaviours

Reports on other risk behaviours were obtained for smoking and adverse oral habits. Only 15 (3.1%) of the care recipients were reported to be current smokers while 19 (3.9%) of them were past smokers. Due to the very small numbers, no further analyses were carried out with this risk habit. However, 42.0% of the care recipients had one or more risk habits, with clenching, grinding or tapping teeth (32.4%) being the most prevalent (Table 4.19). Some 9.6% placed food/medicine/other products in mouth for lengthy periods of time, 7.5% regurgitated, re-chewed and re-swallowed food, while 4.9% craved for and ate non-edible substances like cigarette butts.

Table 4.19 Prevalence of other risk habits

Risk habits	n	% of cases
One or more risk habits	202	42.0
Clenches, grinds or taps teeth	155	32.4
Places food/medicine/other products in mouth for lengthy periods of time	46	9.6
Regurgitates, re-chews and re-swallows food	36	7.5
Craves for and eats non-edible substances	24	4.9

4.3.6 Knowledge, attitude and behaviour of carers across residential settings

4.3.6.1 Knowledge

Very few carers (14.8%) had received training in oral care for people with disabilities, with most of these receiving training at community and institutional settings (Table 4.20). Virtually none of the carers in family homes had received any training. Also, from the few that had any training, some reported having received the training as far back in time as 1975 when they received training from the School of Nursing. The most recent training was conducted at Minda Inc. in 2004. The training period ranged from 30 minutes to six months.

Table 4.20 Training of carers in oral care for people with disabilities

Training of carers in oral care		All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Had training	Yes	66 (14.8)	3 (1.4)	39 (26.9)	24 (27.3)	<0.001
	No	381 (85.2)	211 (98.6)	106 (73.1)	64 (72.7)	
Interested in training	Yes	228 (49.0)	73 (33.5)	87 (59.2)	68 (68.0)	<0.001
	No	237 (51.0)	145 (66.5)	60 (40.8)	32 (32.0)	

Less than 50% of the carers were interested in any training, with carers at family homes showing the least interest compared to carers at community and institutional settings (p<0.001, Table 4.20). Those who showed interest in training stated they would want to learn new techniques in oral hygiene and how to manage uncooperative behaviour.

4.3.6.2 Attitude of carers to oral health

Most carers had a positive attitude to oral health, stating it was important, very important or extremely important for themselves and their care recipients (Table 4.21). In an additional comment written on the questionnaire, one of the carers said “There are times when it is so rewarding that lots of us stay but it is taxing on your family and health”.

Some 72.3% of carers reported that they were not uncomfortable providing oral care and only 12.8% were uncomfortable providing oral care. More carers at family homes and community settings reported being uncomfortable providing oral care compared to carers at institutions; however, the difference was not statistically significant.

Table 4.21 Frequency of attitude of carers to oral health

Attitude of carers to oral health	All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Importance of oral health for care recipients					0.216
Important	86 (18.1)	46 (20.4)	27 (18.1)	13 (12.7)	
Very important	173 (36.3)	78 (34.7)	49 (32.9)	46 (45.1)	
Extremely important	217 (45.6)	101 (44.9)	73 (49.0)	43 (42.2)	
Importance of oral health for carers					0.044
Important	73 (15.8)	46 (20.2)	21 (14.1)	6 (7.1)	
Very important	165 (35.8)	78 (34.2)	50 (33.6)	37 (44.0)	
Extremely important	223 (48.4)	104 (45.6)	78 (52.3)	41 (48.8)	
Uncomfortable providing oral care					0.080
No	289 (72.3)	137 (70.3)	104 (75.9)	48 (70.6)	
Rarely	60 (15.0)	28 (14.4)	16 (11.7)	16 (23.5)	
Yes	51 (12.8)	30 (15.4)	17 (12.4)	4 (5.9)	

There were several factors that influenced family and non-family carers' decisions to take on the caring role (Table 4.22a, Table 4.22b). However, due to the large percentage of missing observations ranging from 12.2% – 48.3%, no further analyses were carried out.

Table 4.22a Frequency of factors influencing family carers' decision to take on caring role

Influencing factors	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)	N/A n (%)
1. To provide better care	2 (1.3)	-----	8 (4.9)	37 (22.1)	88 (52.1)	33 (19.6)
2. Family responsibility	12 (5.3)	1 (0.3)	2 (0.7)	42 (18.9)	155 (70.5)	10 (4.3)
3. Emotional obligation	9 (5.5)	-----	5 (3.0)	33 (20.4)	93 (56.7)	24 (14.4)
4. No other family or friends available	8 (3.5)	7 (5.4)	22 (16.4)	26 (19.5)	49 (31.8)	42 (27.4)
5. No other family or friends willing	9 (6.2)	8 (5.6)	22 (15.1)	26(17.7)	30 (20.4)	52 (34.9)
6. Alternative care too costly	11 (7.5)	8 (5.4)	22 (15.8)	12 (8.1)	42 (29.5)	48 (33.7)
7. No other care arrangements available	7 (4.5)	5 (3.3)	28 (18.9)	16 (10.8)	52 (35.1)	41 (27.3)
8. Had no other choice	10 (6.1)	6 (3.7)	18 (10.5)	27 (15.6)	65 (38.3)	44 (25.8)
9. To make a living	29 (22.2)	12 (9.0)	11 (8.7)	2 (2.0)	1 (0.8)	75 (57.5)

Table 4.22b Frequency of factors influencing non-family carers' decision to take on caring role

Influencing factors	Strongly disagree n (%)	Disagree n (%)	Neutral n (%)	Agree n (%)	Strongly agree n (%)	N/A n (%)
To provide better care	5 (3.0)	….	6 (3.6)	48 (28.6)	68 (41.2)	39 (23.6)
To make a living	11 (5.9)	1 (0.3)	10 (5.5)	72 (39.1)	75 (40.4)	16 (8.7)

4.3.6.3 Dental behaviours of carers

Assessment of dental behaviours among carers included their frequency of toothbrushing and dental visit pattern. A significantly higher percentage of carers in family homes brushed their own teeth only once a day or less, compared to carers at community and institutional settings ($p<0.001$, Table 4.23).

Table 4.23 Frequency of dental behaviours among carers

Dental behaviours	All people n (%)	Residential setting: Family n (%)	Residential setting: Community n (%)	Residential setting: Institution n (%)	Chi-square p value
Frequency of toothbrushing among carers					<0.001
Once/day or less	135 (29.9)	100 (44.1)	20 (13.6)	15 (19.5)	
Twice/day	316 (70.1)	127 (55.9)	127 (86.4)	62 (80.5)	
Dental visit pattern among carers					<0.001
Never/problem only	146 (32.3)	101 (44.5)	31 (21.2)	14 (17.7)	
Every 1–2 years	196 (43.4)	86 (37.9)	72 (49.3)	38 (48.1)	
Every 6 months	110 (24.3)	40 (17.6)	43 (29.5)	27 (34.2)	

Some 43.4% of the carers visited the dentist every 1–2 years, while a smaller percentage (24.3%) visited the dentist every 6 months. There was a significantly higher number of carers from family homes who never visited the dentist or visited only because of a dental problem than carers at community and institutions ($p<0.001$, Table 4.23).

4.3.7 Care provided, continuity of care and effects of caring role on carers

4.3.7.1 Care provided and continuity of care

Most of the carers (58.3%) in all three settings always/sometimes provided assistance with self-care activities. Some 41.7% of the carers provided over 100 hours of weekly care, of whom 75.3% were carers at family homes which was significantly more than those at other settings ($p<0.001$, Table 4.24). Some 54.3% of the carers had been the primary carer for over 10 years. Carers in family homes had spent a significantly longer time as the main carer compared to carers at community and institutional settings ($p<0.001$, Table 4.24).

Most carers at family homes had only one care recipient under their charge, while most carers at community and institutional settings cared for two or more care recipients ($p<0.001$, Table 4.24). Over 50% of care recipients were cared for by two to four carers, with more care recipients at community and institutional settings cared for by more than five carers on a daily basis, compared to those at home, most of whom were cared for by one or two to four carers.

Table 4.24 Care provided and continuity of care

		Residential setting			
	All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Carer assistance with self-care activities					0.630
Never/sometimes	199 (41.7)	90 (40.0)	62 (41.6)	47 (45.6)	
Always	278 (58.3)	135 (60.0)	87 (58.4)	56 (54.4)	
Weekly hours of care					<0.001
< 40 hours (low)	165 (37.8)	34 (15.3)	90 (63.4)	41 (56.9)	
40–100 hours (medium)	89 (20.4)	51 (23.0)	25 (17.5)	13 (18.3)	
>100 hours (high)	182 (41.7)	137 (61.7)	27 (18.9)	18 (25.4)	
Length of contact					<0.001
≤ 10 years	206 (45.7)	23 (10.3)	106 (75.2)	77 (89.5)	
>10 years	245 (54.3)	201 (89.7)	35 (24.8)	9 (10.5)	
No. of care recipients under charge					<0.001
1 care recipient	223 (47.8)	197 (86.4)	20 (13.7)	6 (6.5)	
2+ care recipients	244 (52.2)	31 (13.6)	126 (86.3)	87 (93.5)	
No. of carers providing care					<0.001
1 carer	116 (27.2)	95 (46.3)	18 (13.6)	3 (3.3)	
2-4 carers	216 (50.6)	102 (49.8)	65 (49.2)	49 (54.4)	
5+ carers	95 (22.2)	8 (3.9)	49 (37.1)	38 (42.2)	

4.3.7.2 Effects of caring role on carers

There were varying effects of caring role on the carers (Table 4.25a). With a response of ‘sometimes’, ‘fairly often (FO)’ or ‘very often (VO)’, most carers (94.6%) were satisfied with their caring role, but many were also stressed (85.8%), frustrated (77.1%), angry (43.0%), weary/lack of energy (77.7%) and suffered muscle pain (69.3%).

Table 4.25a Frequency of effects of caring role on carers (%)

Effects of caring role on carers	Not at all n (%)	Rarely n (%)	Sometimes n (%)	Fairly often n (%)	Very often n (%)
1. Satisfied	3 (0.7)	20 (4.8)	99 (23.3)	185 (43.6)	117 (27.5)
2. Stressed	19 (4.6)	40 (9.6)	202 (48.5)	78 (18.8)	77 (18.5)
3. Angry	80 (19.7)	152 (37.5)	128 (31.6)	32 (7.9)	14 (3.3)
4. Frustrated	33 (7.9)	62 (14.9)	205 (49.6)	76 (18.3)	38 (9.2)
5. Weary/lack of energy	32 (7.8)	60 (14.5)	185 (44.8)	81 (19.6)	55 (13.3)
6. Muscle pain in neck/back/limbs	56 (13.6)	70 (17.1)	137(33.4)	74 (18.1)	73 (17.9)

Two additional comments written onto questionnaires were: “We have difficulty recruiting good people as the pay and conditions are not great, but the job satisfaction is worth it”; “It is a difficult job for paid workers. There are very high, unrealistic expectations from parents, who do not realise that carers have more people to care for at once – not just their child”.

Many more carers at family homes reported that they frequently felt angry, frustrated, weary, lack of energy and experienced muscle pain in neck/back/limbs compared to those at community housing and institutions (p<0.001, Table 4.25b).

Table 4.25b Frequency of effects of caring role on carers across residential settings

Effects	All people n (%)	Residential setting Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Satisfied					0.283
Not at all/rarely	23 (5.4)	15 (7.1)	6 (4.2)	2 (2.9)	
Sometimes/Fairly often/Very Often	400 (94.6)	195 (92.9)	137 (95.8)	68 (97.1)	
Stressed					0.108
Not at all/rarely	59 (14.2)	22 (10.6)	25 (18.0)	12 (17.4)	
Sometimes/Fairly often/Very Often	357 (85.8)	186 (89.4)	114 (82.0)	57 (82.6)	
Frustrated					<0.001
Not at all/rarely	95 (22.9)	32 (15.6)	34 (24.1)	29 (42.0)	
Sometimes/Fairly often/Very Often	320 (77.1)	173 (84.4)	107 (75.9)	40 (58.0)	
Angry					<0.001
Not at all/rarely	231 (57.0)	83 (41.7)	92 (66.7)	56 (82.4)	
Sometimes/Fairly often/Very Often	174 (43.0)	116 (58.3)	46 (33.3)	12 (17.6)	
Weary/lack of energy					<0.001
Not at all/rarely	92 (22.3)	22 (10.7)	46 (33.1)	24 (34.8)	
Sometimes/Fairly often/Very Often	321 (77.7)	183 (89.3)	93 (66.9)	45 (65.2)	
Muscle pain					<0.001
Not at all/rarely	126 (30.7)	35 (17.3)	68 (48.9)	23 (33.3)	
Sometimes/Fairly often/Very Often	284 (69.3)	167 (82.7)	71 (51.1)	46 (66.7)	

4.3.7.3 Carer burden

Some 27.5% of the carers did not have a fall-back carer (Table 4.26). Of them 87.8% were carers at family homes, who also needed significantly more support (respite, financial, physical, emotional and other) to assist in their caring role than the carers at community housing and institutions (p<0.01, Table 4.26). Other support included accommodation, transport, post-school options and assistance for carers at family homes and more staffing for carers at community housing and institutions.

Nearly 50% of carers reported negative effects of caring with more carers at family homes being affected than the carers at other settings.

Of the 47.6% of carers who did not receive any pay, 89.7% were carers at family homes. The few carers with no pay at community and institutions were also family providing care for their children at community housing and institutions.

Table 4.26 Carer burden across residential settings

			Residential setting			
Carer burden factors		All people n (%)	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
Fall-back carer	Yes	303 (72.5)	118 (53.9)	121 (92.4)	64 (94.1)	<0.001
	No	115 (27.5)	101 (46.1)	10 (7.6)	4 (5.9)	
More support needed	Yes	231 (53.5)	163 (73.4)	36 (25.9)	32 (45.1)	<0.001
One or more	No	201 (46.5)	59 (26.6)	103 (74.1)	39 (54.9)	
Respite care	Yes	122 (28.6)	120 (54.8)	2 (1.4)	0	<0.001
	No	305 (71.4)	99 (45.2)	136 (98.6)	70 (100.0)	
Financial	Yes	107 (25.0)	89 (40.6)	13 (9.4)	5 (7.1)	<0.001
	No	321 (75.0)	130 (59.4)	126 (90.6)	65 (92.9)	
Physical	Yes	68 (15.9)	51 (23.3)	10 (7.2)	7 (9.9)	<0.001
	No	361 (84.1)	168 (76.7)	129 (92.8)	64 (90.1)	
Emotional	Yes	82 (19.2)	69 (31.5)	9 (6.5)	4 (5.7)	<0.001
	No	345 (80.8)	150 (68.5)	129 (93.5)	66 (94.3)	
Other	Yes	80 (18.6)	47 (21.4)	14 (10.1)	19 (20.8)	0.005
	No	349 (81.4)	173 (78.6)	124 (89.9)	52 (73.2)	
Negative effects of caring	Yes	210 (49.3)	138 (63.9)	54 (38.0)	18 (26.5)	<0.001
One or more	No	216 (50.7)	78 (36.1)	88 (62.0)	50 (73.5)	
Carer pay	Yes	215 (52.4)	39 (18.2)	123 (90.4)	53 (88.3)	
	No	195 (47.6)	175 (81.8)	13 (9.6)	7 (11.7)	<0.001

4.4 Oral epidemiological examinations

This section reports the frequency of oral conditions and its relationship with factors hypothesised to influence those conditions. Disease frequency is expressed using means or proportions (as appropriate) and their associated 95% CIs. Greatest emphasis is given to findings regarding caries experience, indexed using the mean DMFT per person, which is the primary outcome variable for this study. Accordingly, findings regarding the relationship between residential setting and DMFT are subject to additional stratified analyses that are not presented for other oral health indices that form secondary outcomes. At the end of the subsection for each oral condition, a summary table is provided using symbols that show if there is any significant difference between each variable category and its reference group. Unless otherwise stated, references to "significant" differences signify a statistically significant finding, where the probability of type I error (P-value) is less than 0.05.

4.4.1 Dental status

4.4.1.1 Relationship between dental status and care recipient characteristics

The prevalence of untreated decay among the care recipients in this target population was 16.9% and 76.3% had caries experience (Table 4.27). Care recipients at family homes had a higher prevalence of untreated decay (20.0%) followed by those in community housing (17.1%) compared to those at institutions (10.7%), but the difference was not statistically significant. Those with autism had a higher prevalence of untreated decay compared to those with other disabling conditions like spina bifida and quadriplegia. However, there was no significant difference in the prevalence of untreated decay across the three age-groups, sexes, means of communication, general health or care recipients’ need for help with self-care activities (Table 4.27).

The prevalence of missing teeth was significantly higher among those living in institutions and the 35–44 years age-group compared to those living in family homes and in younger age-groups. Those with intellectual disability had a higher prevalence of missing teeth compared to those with cerebral palsy. However, the prevalence of missing teeth did not vary between groups categorized according to sex, means of communication, general health or care recipients’ need for help with self-care activities (Table 4.27).

The proportion of care recipients with filled teeth was significantly higher among the 35–44 years age-group compared to the younger age-groups. However, the prevalence of filled teeth did not vary across the three residential settings, between sexes, disabling conditions, means of communication, general health or care recipients’ need for help with self-care activities (Table 4.27).

The mean DMFT among care recipients in this population was 5.2 [95% CI = 4.5, 5.6]. Those at institutions had the highest mean DMFT of 8.6 [95% CI = 6.8, 10.4]. The prevalence and mean of DMFT was significantly higher among care recipients in institutions, the 35–44 years age-group and those with intellectual disability compared to those in community settings, the younger age-groups and those with cerebral palsy, respectively. The prevalence and mean DMFT did not vary between sexes, means of communication and general health or care recipients’ need for help with self-care activities (Table 4.27).

Table 4.27 Relationship between dental status and care recipient characteristics

		Prevalence — % of people with:				Mean DMFT
		D>0	M>0	F>0	DMFT>0	per person
	N	% [95%CI]	% [95%CI]	% [95%CI]	% [95%CI]	Mean [95% CI]
All	267	16.9 [12.7, 21.7]	49.8 [43.6, 55.6]	57.1 [51.2, 63.0]	76.3 [71.0, 81.2]	5.2 [4.5, 5.6]
Residential setting						
Family	130	20.0 [13.1, 26.9]	42.3 [33.8, 50.8]	53.8 [45.3, 62.4]	74.0 [66.5, 81.6]	4.2 [3.2, 5.1]
Community housing	81	17.1 [8.9, 25.2]	46.9 [36.0, 57.8]	52.4 [41.6, 63.3]	69.1 [59.1, 79.2]	4.6 [3.5, 5.8]
Institution	56	10.7 [2.6, 18.8]	70.9 [58.9, 82.9]	71.4 [59.6, 83.3]	91.1 [83.6, 98.5]	8.6 [6.8,10.4]
Age						
18–24	92	19.6 [11.5, 27.7]	41.3 [31.2, 51.4]	48.4 [38.2, 58.6]	71.0 [61.7, 80.2]	3.5 [2.6, 4.5]
25–34	81	18.5 [10.1, 27.0]	37.8 [27.3, 48.3]	46.3 [35.6, 57.1]	63.4 [53.0, 73.8]	3.6 [2.5, 4.7]
35–44	93	12.8 [6.0, 19.5]	68.8 [59.4, 78.2]	75.3 [66.5, 84.0]	92.6 [87.2, 97.9]	8.3 [6.9, 9.6]
Sex						
Male	165	19.9 [13.8, 26.0]	46.4 [38.8, 54.0]	57.6 [50.0, 65.1]	76.5 [70.1, 83.0]	4.9 [4.1, 5.6]
Female	102	11.8 [5.5, 18.0]	55.9 [46.2, 65.5]	55.9 [46.2, 65.5]	75.5 [67.1, 83.8]	5.8 [4.5, 7.1]
Disabling condition						
Autism	83	25.3 [16.0, 34.7]	47.0 [36.3, 57.7]	62.2 [51.7, 72.7]	81.9 [73.7, 90.2]	4.9 [3.8, 6.1]
Cerebral palsy	63	11.1 [3.4, 18.9]	33.3 [21.7, 45.0]	39.7 [27.6, 51.8]	60.3 [48.2, 72.4]	2.9 [1.9, 3.9]
Intellectual disability	90	16.7 [9.0, 24.4]	66.7 [56.9, 76.4]	61.5 [51.5, 71.5]	84.4 [77.0, 91.9]	7.2 [5.8, 8.6]
Other	31	6.5 [-2.2, 15.1]	41.9 [24.6, 59.3]	64.5 [47.7, 81.4]	71.0 [55.0, 87.0]	4.9 [2.9, 6.9]
(Spina bifida, quadriplegia, head injury)						
Communication						
Verbally	122	20.5 [13.3, 27.7]	48.4 [39.5, 57.2]	65.9 [57.5, 74.2]	79.5 [72.4, 86.7]	5.6 [4.6, 6.7]
Non-verbally	61	14.8 [5.9, 23.7]	47.5 [35.0, 60.1]	52.5 [39.9, 65.0]	75.4 [64.6, 86.2]	5.1 [3.7, 6.5]
Little/no effective communication	83	12.0 [5.1, 19.1]	53.6 [42.9, 64.2]	47.0 [36.3, 57.7]	72.3 [62.7, 81.9]	4.7 [3.4, 6.0]
General health						
Ex-Very good	109	21.1 [13.4, 28.8]	48.6 [39.2, 58.0]	57.3 [48.0, 66.5]	80.7 [73.3, 88.1]	4.6 [3.7, 5.5]
Good	109	14.7 [8.0, 21.3]	50.5 [41.1, 59.9]	57.8 [48.5, 67.1]	74.3 [66.1, 82.5]	5.5 [4.4, 6.7]
Fair/poor	41	9.8 [0.7, 18.8]	48.8 [25.8, 52.6]	55.0 [39.6, 70.4]	72.5 [47.5, 77.5]	5.8 [3.6, 8.1]
Help needed for self-care activities						
Never/sometimes	77	23.4 [13.9, 32.8]	48.1 [36.9, 59.2]	75.0 [65.3, 84.7]	85.5 [77.6, 93.4]	5.4 [4.1, 6.7]
Always	190	14.2 [9.3, 19.2]	50.5 [43.4, 57.6]	50.0 [42.9, 57.1]	72.8 [62.0, 75.2]	5.2 [4.3, 6.0]

4.4.1.1.1 Summary of findings on dental status and care recipient characteristics

In these bivariate analyses, the prevalence of missing teeth, any caries experience (DMFT>0) and mean DMFT were significantly higher among the care recipients at institutions than those at family homes. The 35–44 age-group had a significantly higher prevalence of missing and filled teeth and caries experience and a higher mean DMFT than their younger counterparts. Care recipients with intellectual disability had significantly more missing teeth, caries experience and a higher mean DMFT compared to those with cerebral palsy. Care recipients with autism also had a significantly higher caries experience compared to those with cerebral palsy. There was no significant association between dental status and sex, means of communication, general health or care recipients' need for help with self-care activities.

Table 4.28 Relationship between dental status and care recipient characteristics

	Prevalence – % of people with:				Mean DMFT
	D>0	M>0	F>0	DMFT>0	per person
Residential setting					
Family (Ref)					
Community housing	~	~	~	~	~
Institution	~	↑	~	↑	↑
Age					
18–24 (Ref)					
25–34	~	~	~	~	~
35–44	~	↑	↑	↑	↑
Sex					
Male (Ref)					
Female	~	~	~	~	~
Disabling condition					
Cerebral palsy (Ref)					
Autism	~	~	~	↑	~
Intellectual disability	~	↑	~	↑	↑
Other	~	~	~	~	~
(Spina bifida, quadriplegia, head injury)					
Communication					
Little/no effective communication (Ref)					
Non-verbally	~	~	~	~	~
Verbally	~	~	~	~	~
General health					
Very good-Ex (Ref)					
Good	~	~	~	~	~
Poor-Fair	~	~	~	~	~
Help needed for self-care					
Never/sometimes (Ref)					
Always	~	~	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.1.1.2 Stratified analyses of mean DMFT

Among the 18–24 age-group, care recipients in family homes had a significantly higher mean DMFT compared to those in community settings (Figure 4.1). However, that difference was not observed in older age groups. Instead, in the two older age-groups, care recipients in institutions had significantly higher mean DMFT compared to those at community settings. In all age-groups, there was no significant difference in mean DMFT between care recipients at family homes and institutions. This latter finding was in contrast to the result in Table 4.27, where the unadjusted mean DMFT in family settings was significantly lower than the mean DMFT in institutions. The difference in interpretation for Figure 4.1 compared with Table 4.27 comes about because care recipients in the family settings had a much younger age distribution than those in institutions (Table 4.4), and because younger age was strongly associated with a lower mean DMFT (Table 4.27). In other words, the unadjusted findings in Table 4.27 are confounded due to differing age compositions, most notably between family and institutional settings.

Among care recipients with cerebral palsy and intellectual disability, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.2). Similarly, among care recipients with ‘other’ disabling conditions, those living in institutions had a significantly higher mean DMFT compared to those in family homes. However, among those with autism, there was no statistically significant difference in mean DMFT across the residential settings. This latter finding was in contrast to the result in Table 4.27, where the unadjusted mean DMFT in family homes and community housing was significantly lower than the mean DMFT in institutions. The unadjusted findings in Table 4.27 are therefore confounded by differing proportions of disabling conditions in the three residential settings. A high proportion of care recipients with intellectual disability living in institutions (Table 4.4), (associated with a higher mean DMFT compared to other disabling a conditions, Table 4.27) and only four care recipients with cerebral palsy living in institutions (Table 4.4), (associated with a lower mean DMFT compared to other disabling a conditions, Table 4.27), may have resulted in the apparent high unadjusted mean DMFT among care recipients in institutions.

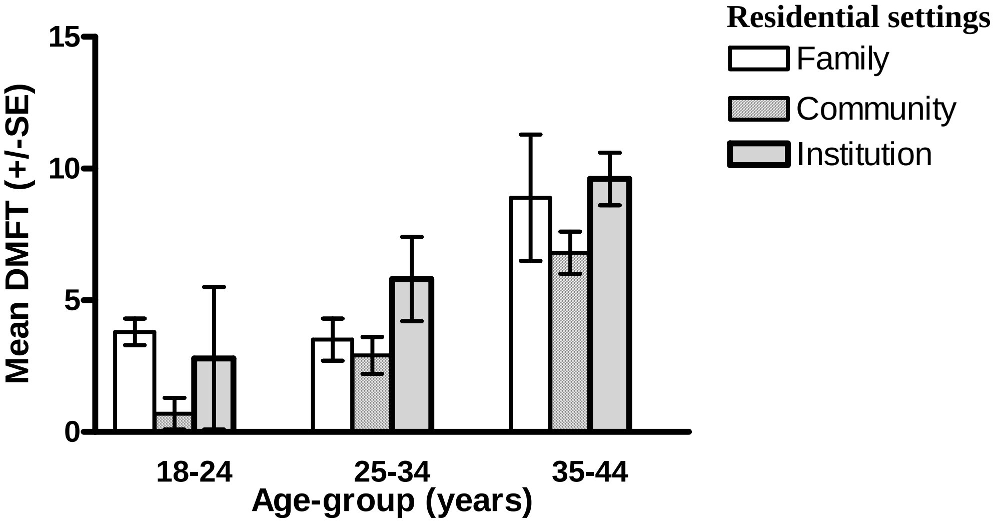

Figure 4.1 Mean DMFT in the three residential settings, stratified by age-group

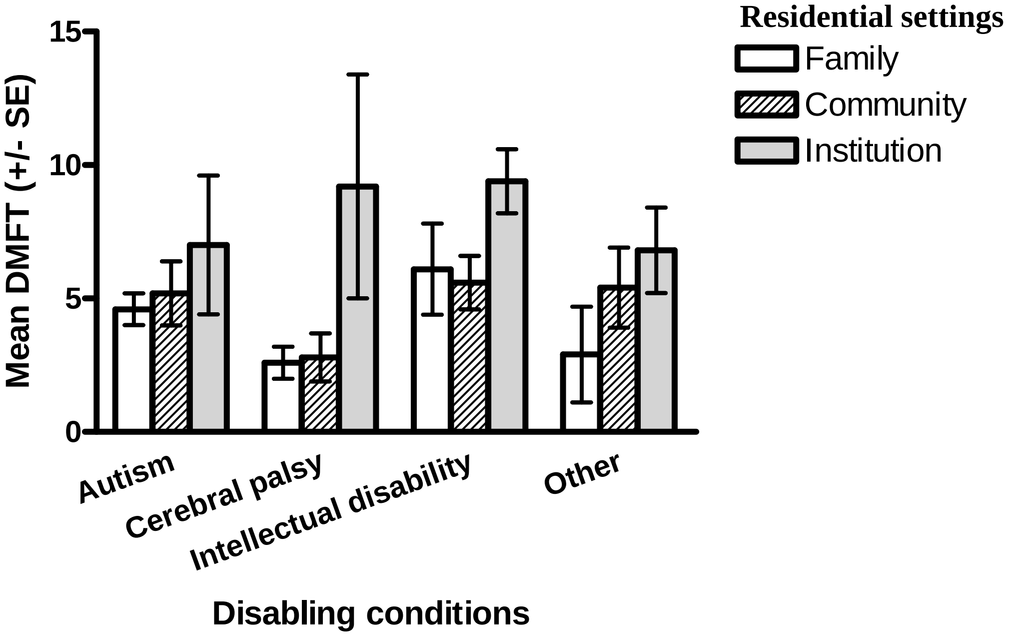

Figure 4.2 Mean DMFT in the three residential settings, stratified by disabling condition

4.4.1.2 Relationship between dental status and dental practices of care recipients

Other factors influencing the dental status were dental practices of care recipients: toothbrushing pattern and dental visit pattern.

4.4.1.2.1 Relationship between dental status and toothbrushing pattern of care recipients

There was no significant association between untreated decay and mean DMFT and toothbrushing pattern of care recipients – toothbrushing frequency, who cleaned teeth, time to clean teeth and carer’s cleaning ability or behavioural problems of care recipients during oral hygiene care (Table 4.29). However, there was a significantly higher prevalence of missing teeth among care recipients whose teeth were brushed twice a day compared to those whose teeth were brushed only once a day or less. There was a significantly higher prevalence of filled teeth and caries experience among care recipients who cleaned their teeth themselves compared to those who received assistance from their carers. Care recipients with one or more behavioural problems also had a significantly higher caries prevalence than those with no behavioural problems during oral hygiene care (Table 4.29).

Table 4.29 Relationship between dental status and toothbrushing pattern of care recipients

		Prevalence – % of people with:				Mean DMFT
	N	D>0 % [95%CI]	M>0 % [95%CI]	F>0 % [95%CI]	DMFT>0 % [95%CI]	per person Mean [95% CI]
Frequency of toothbrushing						
Once/day or less	109	22.9 [15.1, 30.8]	27.6 [28.5, 46.1]	55.0 [45.7, 64.4]	72.5 [64.1, 80.9]	4.6 [3.5, 5.7]
Twice/day	149	12.8 [7.4, 18.1]	57.0 [49.1, 65.0]	56.4 [48.4, 64.3]	77.2 [70.4, 83.9]	5.7 [4.7, 6.6]
Who cleaned teeth						
With carer assistance	215	14.0 [9.4, 18.7]	49.3 [42.6, 56.0]	52.1 [45.4, 58.8]	72.9 [45.4, 58.8]	5.2 [4.3, 5.9]
Carer recipient only	52	28.8 [16.5, 41.2]	51.9 [38.3, 65.5]	76.9 [65.5, 88.4]	90.4 [82.4, 98.4]	5.5 [4.1, 6.9]
(Care recipients needing carer help) Time to clean by carer						
Adequate	154	12.3 [7.2, 17.5]	52.9 [45.0, 60.8]	54.5 [46.7, 62.4]	76.6 [69.9, 83.3]	5.2 [4.3, 6.1]
Inadequate	36	19.4 [6.5, 32.4]	47.2 [30.9, 63.5]	33.3 [17.9, 48,7]	61.1 [45.2, 77.0]	4.4 [2.2, 6.7]
Carer's cleaning ability						
Only some teeth	104	17.3 [10.0, 24.6]	56.3 [46.7, 65.9]	46.6 [37.0, 56.2]	71.2 [62.4, 79.9]	5.8 [4.5, 7.1]
All teeth	95	8.5 [2.9, 14.2]	44.2 [34.2, 54.2]	56.8 [46.9, 66.8]	75.8 [67.2, 84.4]	4.8 [3.7, 5.8]
Behaviour problems						
None	48	14.3 [4.5, 24.1]	50.0 [35.9, 64.6]	51.0 [37.0, 65.0]	66.7 [53.3, 65.0]	6.6 [4.4, 8.7]
Problems	158	13.3 [8.0, 18.6]	48.7 [40.9, 56.5]	50.0 [42.2, 57.8]	74.1 [67.2, 80.9]	4.7 [3.9, 5.6]

4.4.1.2.2 Relationship between dental status and dental visit pattern of care recipients

The prevalence of decay was significantly lower among care recipients who visited the dentist every 1–2 years compared to those who never visited the dentist (Table 4.30). Care recipients who visited the dentist every six months or every 1–2 years had a significantly higher prevalence of missing teeth than those who never visited the dentist or visited only with a problem. Those who needed an oral sedation or a general anesthesia (GA) for routine dental treatment also had a higher prevalence of missing teeth compared to those who did not need any sedation. The mean DMFT was significantly higher among those who visited the dentist every six months compared to those who never visited the dentist or visited only with a problem. The prevalence of filled teeth and caries experience was not associated with frequency of dental visits and usual dental treatment pattern (Table 4.30).

Table 4.30 Relationship between dental status and dental visit pattern of care recipients

		Prevalence — % of people with:				Mean DMFT per person
		D>0	M>0	F>0	DMFT>0	
Dental visit pattern	N	% [95%CI]	% [95%CI]	% [95%CI]	% [95%CI]	Mean [95% CI]
Frequency of dental visits						
Every 6 months	106	16.0 [9.1, 23.0]	53.8 [44.3, 63.3]	63.2 [54.0, 72.4]	76.4 [68.3, 84.5]	6.3 [5.1, 7.6]
1–2 years	115	9.6 [4.2, 15.0]	54.8 [45.7, 63.8]	55.2 [46.1, 64.2]	75.9 [68.1, 83.7]	4.9 [3.9, 5.9]
Never/problem only	40	32.5 [18.0, 47.0]	30.0 [15.8, 44.2]	42.5 [27.2, 57.8]	75.0 [61.6, 88.4]	3.5 [2.0, 5.0]
Usual treatment pattern						
Without sedation	163	21.5 [15.2, 27.8]	40.5 [33.0, 48.0]	57.1 [49.5, 64.7]	74.8 [68.2, 81.5]	4.9 [4.0, 5.8]
With sedation	33	15.2 [2.9, 27.4]	69.7 [54.0, 85.4]	66.7 [50.6, 82.8]	87.9 [76.7, 99.0]	7.8 [5.4,10.1]
Under GA	48	8.2 [0.5, 15.8]	70.8 [58.0, 83.7]	60.4 [46.6, 74.3]	85.7 [75.9, 95.5]	5.6 [3.9, 7.2]

4.4.1.2.3 Summary of findings on dental status and dental practices among care recipients

There was no statistically significant association between untreated decay and toothbrushing pattern of care recipients, but the prevalence of decay was lower among care recipients who visited the dentist every 1–2 years (Table 4.31).

Table 4.31 Summary of findings on dental status and dental practices among care recipients

	Prevalence — % of people with:				Mean DMFT per person
	D>0	M>0	F>0	DMFT>0	
Frequency of toothbrushing					
Once/day or less (Ref)					
Twice/day	~	↑	~	~	~
Who cleaned teeth					
With carer assistance (Ref)					
Carer recipient only	~	~	↑	↑	~
Time to clean by carer					
Adequate (Ref)					
Inadequate	~	~	~	~	~
Carer's cleaning ability					
All teeth (Ref)					
Only some teeth	~	~	~	~	~
Behaviour problems					
None (Ref)					
One or more problems	~	~	~	↑	~
Frequency of dental visits					
Never/problem only (Ref)					
Every 1–2 years	↓	↑	~	~	~
Every 6 months	~	↑	~	~	↑
Usual dental treatment pattern					
Without sedation (Ref)					
With sedation	~	↑	~	~	~
Under GA	~	↑	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

A higher prevalence of missing teeth was associated with twice a day toothbrushing frequency, frequent dental visit and need for sedation or general anaesthesia for usual dental treatment. There was a higher prevalence of filled teeth and caries experience among care recipients who cleaned their teeth themselves. A higher prevalence of caries experience was also associated with one or more behavioural problems. Frequency of dental visits was associated with a higher mean DMFT. However, time taken to clean by carers and carers' cleaning ability were not associated with any component of the DMFT index.

4.4.1.2.4 Stratified analysis of mean DMFT

Among the care recipients who usually visited the dentist once every year or 2 years, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.3). Similarly, among the care recipients who usually visited the dentist once every six months, those living in institutions also had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.3). Among the care recipients who never visited the dentist or visited only with a problem, there was no difference in mean DMFT between those in family homes and community settings (Figure 4.3). There were no care recipients living in institutions who never visited the dentist or visited only with a problem and therefore, mean DMFT for that group is not shown in the graph. Therefore, incomplete stratification limits the inferences that can be drawn.

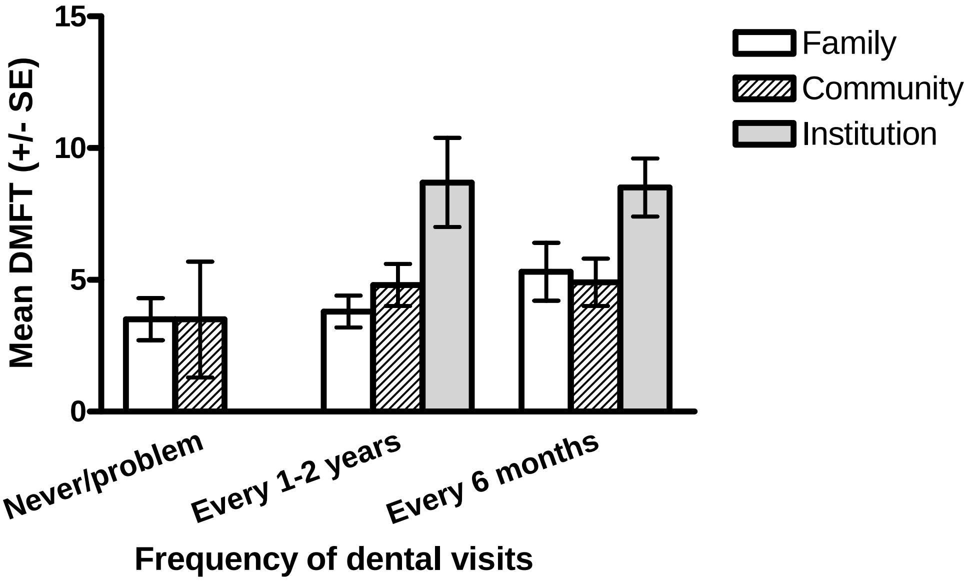

Figure 4.3 Mean DMFT in the three residential settings, stratified by frequency of dental visits

4.4.1.3 Relationship between dental status and potential risk factors

Potential risk factors for oral health include diet and medications.

4.4.1.3.1 Relationship between dental status and diet of care recipients

There was no untreated decay for those who were tube-fed and did not eat anything by mouth. Their dental status is shown in italics and they were excluded from further analyses (Table 4.32). There was significantly greater prevalence of decayed teeth and mean DMFT for groups with successively greater intake of sweet drinks (sweetened tea/coffee, flavoured milk). However, the prevalence of decayed, missing and filled teeth, caries experience and mean DMFT did not vary by frequency of sweet solids (sweetened dairy products, chocolate and sugar-based confectionery) or acidic drinks (soft drinks and fruit juice) (Table 4.32).

Table 4.32 Relationship between dental status and frequency of various food types among care recipients

		Prevalence — % of people with:				Mean DMFT
		D>0	M>0	F>0	DMFT>0	per person
Foods	N	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	Mean [95% CI]
Sweet drinks						
Not fed by mouth	*17*	*0 [0, 0]*	*33.3 [11.6, 55.1]*	41.2 *[17.8, 64.6]*	55.6 *[32.6, 78.5]*	*1.7 [0.6, 2.9]*
Low	67	7.5 [1.2, 13.8]	56.7 [44.9, 68.6]	62.7 [51.1, 74.3]	83.6 [74.7, 92.5]	3.5 [2.4, 4.6]
Moderate	89	21.6 [13.0, 30.2]	52.3 [41.8, 62.7]	46.1 [35.7, 56.4]	69.3 [59.7, 79.0]	5.6 [4.5, 6.7]
High	79	24.1 [14.6, 33.5]	51.9 [40.9, 62.9]	62.0 [51.3, 72.7]	79.7 [70.9, 88.6]	6.4 [4.9, 7.0]
Sweet solids						
Not fed by mouth	*16*	*0.0 [0,0]*	25.0 *[3.8, 46.2]*	37.5 *[13.8, 61.2]*	50.0 [25.5, 74.5]	*1.6 [0.5, 2.7]*
Low	90	13.3 [6.3, 20.6]	47.2 [36.8, 57.6]	60.0 [49.9, 70.1]	82.2 [74.3, 90.1]	4.7 [3.7, 5.8]
Moderate	90	20.2 [11.9, 28.6]	52.8 [42.4, 63.2]	55.6 [45.3, 65.8]	73.0 [63.8, 82.3]	5.7 [4.4, 6.9]
High	58	19.0 [8.9, 29.1]	62.7 [50.4, 75.1]	62.7 [50.4, 75.1]	84.5 [75.2, 93.8]	6.7 [5.1, 8.4]
Acidic drinks						
Not fed by mouth	*16*	*0.0 [0, 0]*	*25.0 [3.8, 46.2]*	*37.5 [13.8, 61.2]*	*50.0 [25.5, 74.5]*	*1.6 [0.5, 2.7]*
Low	85	12.9 [5.8, 20.1]	54.8 [44.1, 65.4]	59.5 [49.0, 70.0]	79.8 [71.2, 88.4]	5.7 [4.5, 7.0]
Moderate	84	15.5 [7.7, 23.2]	51.2 [40.5, 61.9]	53.6 [42.9, 64.2]	75.9 [66.7, 85.1]	5.0 [3.7, 6.3]
High	75	28.0 [17.8, 38.2]	52.7 [41.3, 64.1]	59.5 [48.3, 70.7]	78.4 [69.0, 87.8]	5.9 [4.4, 7.3]

4.4.1.3.2 Relationship between dental status and medication intake of care recipients

The prevalence of decayed, filled and missing teeth, and caries experience (DMFT>0) did not vary by the intake of one or more medications or even medications that have potential to cause adverse oral effects (Table 4.33). However, mean DMFT was significantly higher among those taking one or more medications compared to those who did not take any medications.

Table 4.33 Relationship between dental status and medication intake among care recipients

Potential risk factors	N	Prevalence — % of people with: D>0 % [95% CI]	M>0 % [95% CI]	F>0 % [95% CI]	DMFT>0 % [95% CI]	Mean DMFT per person Mean [95% CI]
No. of medications						
None	62	27.0 [16.0, 37.9]	42.9 [30.6, 55.1]	58.1 [45.8, 70.3]	80.6[70.8, 90.5]	3.7 [2.8, 4.68]
1+	184	13.0 [8.2, 17.9]	51.1 [43.9, 58.3]	55.4 [48.3, 62.6]	73.9 [67.6, 80.3]	5.6 [4.69, 6.5]
Medications causing xerostomia						
None	69	24.6 [14.5, 34.8]	44.9 [33.2, 56.7]	53.6 [41.9, 65.4]	79.7 [70.2, 89.2]	3.8 [2.9, 4.8]
1+	177	13.5 [8.5, 18.5]	50.3 [42.9, 57.7]	56.7 [49.5, 64.0]	73.6 [67.1, 80.1]	5.6 [4.7, 6.6]

4.4.1.3.3 Summary of findings on dental status and risk factors among care recipients

A high frequency of sweet drinks was associated with a higher prevalence of decayed teeth and a higher mean DMFT while frequency of sweet solids and acidic drinks were not significantly associated with any component of the DMFT index (Table 4.34). Intake of one or more medications was significantly associated a higher mean DMFT.

Table 4.34 Summary of findings on dental status and risk factors among care recipients

	Prevalence — % of people with: D>0	M>0	F>0	DMFT>0	Mean DMFT per person
Sweet drinks					
Low (Ref)					
Moderate	~	~	~	~	~
High	↑	~	~	~	↑
Sweet solids					
Low (Ref)					
Moderate	~	~	~	~	~
High	~	~	~	~	~
Acidic drinks					
Low (Ref)					
Moderate	~	~	~	~	~
High	~	~	~	~	~
No. of medications					
None (Ref)					
1+	~	~	~	~	↑
Causing dry mouth					
None (Ref)					
1+	~	~	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.1.3.4 Stratified analyses of mean DMFT

Among the care recipients who had a moderate or high intake of sweet drinks, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.4). However, among those care recipients who had a low intake of sweet drinks there was no difference in mean DMFT across the residential settings. This finding varies from the result in Table 4.27, in which unadjusted mean DMFT in family settings was significantly lower than the mean DMFT in institutions, which may be confounded due to differing consumption pattern of sweet drinks across the three settings. Very few care recipients (n=6) with a low intake of sweet drinks living in institutions (Table 4.17b), (associated with a lower mean DMFT compared to those with a moderate and high intake of sweet drinks, Table 4.32) may have resulted in the apparent high unadjusted mean DMFT among the care recipients in institutions.

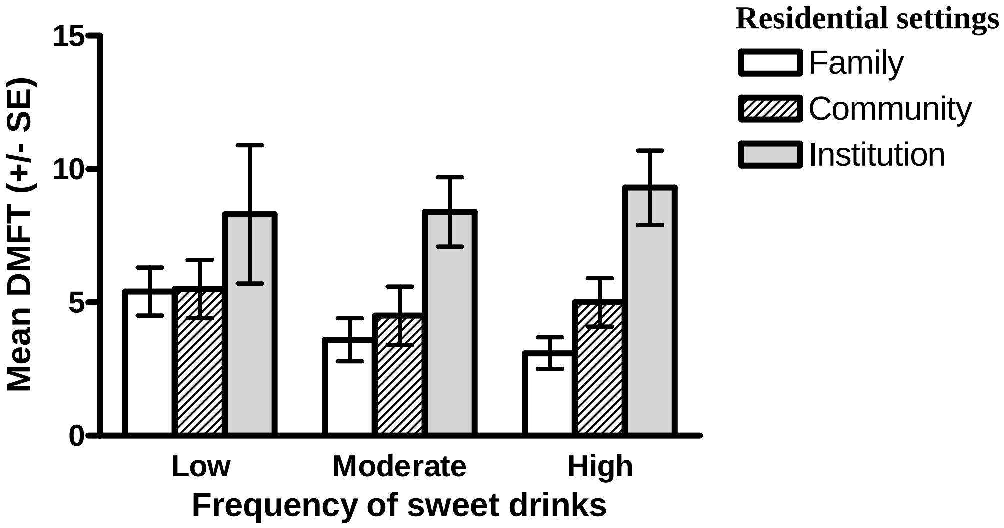

Figure 4.4 Mean DMFT in the three residential settings, stratified by frequency of sweet drinks

Among the care recipients who took one or more medications, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.5). Among the care recipients who did not take any medications, those living in community housing had a significantly higher mean DMFT compared to those in family homes. This finding differs from the result in Table 4.27, where the unadjusted mean DMFT in family homes and community housing did not differ significantly. However, there were only two care recipients living in institutions who took no medications and results for that group are not shown in the graph. Therefore, incomplete stratification limits the inferences that can be drawn.

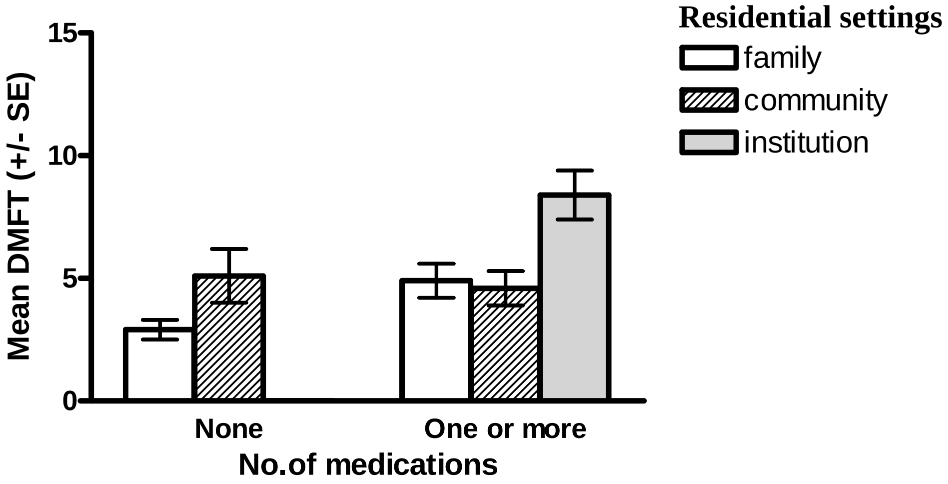

Figure 4.5 Mean DMFT in the three residential settings, stratified by number of medications

4.4.1.4 Relationship between dental status of care recipients and carer characteristics

The prevalence of all five measures of caries among the care recipients did not vary by age and sex of carers (Table 4.35). However, care recipients of non-family carers had significantly more missing teeth and a higher mean DMFT than care recipients of family carers. Training of carers or interest in training in oral care for people with disabilities was not significantly associated with any component of the DMFT index. Carer’s attitude to oral health and providing oral care to care recipients also did not have any significant association with any component of the DMFT index.

Table 4.35 Relationship between dental status of care recipients and carer characteristics

		Prevalence — % of people with:				Mean DMFT per person
		D>0	M>0	F>0	DMFT>0	
	N	% [95%CI]	% [95%CI]	% [95%CI]	% [95%CI]	Mean [95% CI]
Age (Yrs)						
≤ 50	105	14.3 [7.6, 21.0]	43.3 [33.8, 52.8]	48.6 [39.0, 58.1]	72.4 [63.8, 80.9]	4.5 [3.4, 5.6]
50+	119	21.8 [14.4, 29.3]	46.6 [37.6, 55.6]	59.3 [50.5, 68.2]	73.9 [66.1, 81.8]	4.6 [3.7, 5.6]
Sex						
Male	37	75.7 [61.9, 89.5]	16.7 [4.5, 28.9]	55.6 [39.3, 71.8]	55.6 [39.3, 71.8]	5.2 [3.3, 7.2]
Female	209	74.2 [68.2, 80.1]	16.8 [11.8, 21.9]	45.5 [38.7, 52.2]	55.6 [39.3, 71.8]	4.7 [3.9, 5.4]
Relationship						
Non-family carer	122	13.9 [7.8, 20.1]	60.7 [52.0, 69.3]	60.7 [52.0, 69.3]	81.1 [74.2, 88.1]	6.5 [5.4, 7.6]
Family carer	145	19.3 [12.9, 25.7]	40.7 [32.7, 48.7]	54.2 [46.0, 62.3]	71.7 [64.4, 79.1]	4.1 [3.3, 5.0]
Training of carers						
Had training	42	19.0 [7.2, 30.9]	59.5 [44.7, 74.4]	52.4 [37.3, 67.5]	78.6 [66.2, 91.0]	6.4 [4.3, 8.6]
No training	212	17.5 [12.4, 22.7]	48.6 [41.9, 55.3]	58.8 [52.1, 65.4]	76.9 [71.2, 82.6]	5.0 [4.2, 5.7]
Interest in training						
Interested	143	19.6 [13.1, 26.1]	50.3 [42.2, 58.5]	55.9 [47.8, 64.1]	75.5 [68.5, 82.6]	5.4 [4.4, 6.4]
Not interested	114	14.0 [7.7, 20.4]	50.4 [41.2, 59.7]	57.0 [47.9, 66.1]	76.3 [68.5, 84.1]	5.1 [4.1, 6.2]
Uncomfortable providing oral care						
No	148	16.3 [10.4, 22.3]	47.3 [39.3, 55.3]	60.5 [52.6, 68.4]	79.6 [73.1, 86.1]	5.4 [4.5, 6.3]
Yes	73	12.3 [4.8, 19.9]	54.8 [43.4, 66.2]	49.3 [37.9, 60.8]	67.6 [56.9, 78.2]	4.6 [3.2, 6.1]
Importance of oral health for care recipients						
Important	44	27.9 [14.5, 41.3]	38.6 [24.3, 53.0]	59.1 [44.6, 73.6]	79.1 [66.9, 91.2]	4.8 [3.0, 6.5]
Very important	92	8.7 [2.9, 14.5]	50.0 [39.8, 60.2]	50.0 [39.8, 60.2]	68.5 [60.0, 78.0]	4.8 [3.6, 6.0]
Extremely important	130	19.1 [12.4, 25.8]	53.1 [44.5, 61.7]	60.8 [52.4, 69.2]	80.8 [74.0, 87.5]	5.7 [4.7, 6.7]
Importance of oral health for carers						
Important	38	16.2 [4.3, 28.1]	42.1 [26.4, 57.8]	62.2 [46.5, 77.8]	73.7 [59.7, 87.7]	4.7 [2.6, 6.7]
Very important	92	13.0 [6.2, 19.9]	45.2 [35.1, 55.3]	50.0 [39.8, 60.2]	66.3 [56.6, 76.0]	4.0 [3.0, 5.1]
Extremely important	124	20.8 [13.7, 27.9]	53.2 [44.5, 62.0]	58.9 [50.2, 67.5]	83.1 [76.5, 89.7]	5.8 [4.8, 6.8]

4.4.1.4.1 Summary of findings on dental status of care recipients and carer characteristics

There was no significant association between the prevalence of all five measures of caries and carer characteristics like age, sex, training, interest in training, attitude to providing oral care or the importance they gave to oral health for their care recipients or themselves (Table 4.36). However, care recipients of non-family carers had significantly more missing teeth and a higher mean DMFT than care recipients of family carers.

Table 4.36 Summary of findings on and dental status of care recipients and carer characteristics

	Prevalence — % of people with:				Mean DMFT per person
	D>0	M>0	F>0	DMFT>0	
Age (Yrs)					
≤ 50 (Ref)					
50+	~	~	~	~	~
Sex					
Male (Ref)					
Female	~	~	~	~	~
Relationship to care recipient					
Family carer (Ref)					
Non-family carer	~	↑	~	~	↑
Training of carers					
No training (Ref)					
Had training	~	~	~	~	~
Interest in training					
Not interested (Ref)					
Interested	~	~	~	~	~
Uncomfortable providing oral care					
No (Ref)					
Yes	~	~	~	~	~
Importance of oral health to carers for care recipients					
Important (Ref)					
Very important	~	~	~	~	~
Extremely important	~	~	~	~	~
Importance of oral health to carers for themselves					
Important (Ref)					
Very important	~	~	~	~	~
Extremely important	~	~	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.1.4.2 Stratified analysis of mean DMFT

Among the care recipients who were cared for by non-family carers, those living in institutions had a significantly higher DMFT compared to those in both community settings and family homes. Among the care recipients who were cared for by family carers, those living in institutions had a significantly higher DMFT compared to those in community settings, but not in family homes (Figure 4.6). The latter finding varies from the result in Table 4.27, in which unadjusted mean DMFT in family settings was significantly lower than the mean DMFT in institutions, which may be confounded due to differing distribution of family and non-family carers across the three settings. The majority of the care recipients in family homes were cared for by family carers (Table 4.3) and this was strongly associated with a lower mean DMFT (Table 4.35).

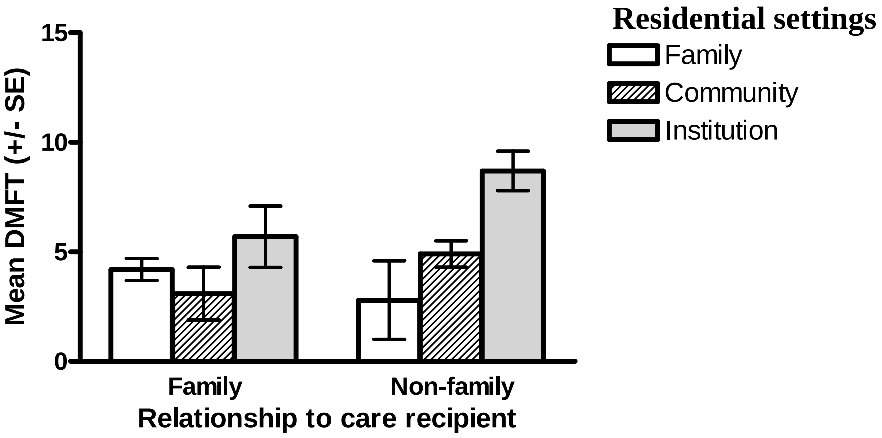

Figure 4.6 Mean DMFT in the three residential settings, stratified by relationship to care recipient.

4.4.1.5 Relationship between dental status of care recipients and continuity of care

There was no significant association between measures of caries and: how often carers provided care with self-care activities, length of contact between carer and care recipient or number of carers providing care (Table 4.37). However, the relationship between weekly hours of care and caries experience was not monotonic, with most indicators being more frequent among people receiving < 40 hours or > 100 hours compared with people receiving 40–100 hours of care.

Table 4.37 Relationship between dental status of care recipients and continuity of care

		Prevalence — % of people with:				Mean DMFT per person
		D>0	M>0	F>0	DMFT>0	
	N	% [95%CI]	% [95%CI]	% [95%CI]	% [95%CI]	Mean [95% CI]
Carers provided help with self-care activites						
Never/sometimes	90	15.6 [8.1, 23.1]	50.0 [39.7, 60.3]	59.3 [49.3, 69.4]	78.0 [69.5, 86.5]	5.0 [3.8, 6.1]
Always	172	15.7 [10.3, 21.1]	51.2 [43.7, 58.6]	55.2 [47.8, 62.7]	75.0 [68.5, 81.5]	5.4 [4.5, 6.3]
Weekly hours of care provided by carer						
<40 hours (low)	89	12.4 [5.5, 19.2]	52.8 [42.4, 63.2]	57.3 [47.0, 67.6]	75.3 [66.3, 84.2]	5.1 [3.9, 6.4]
40–100 hours (medium)	56	14.3 [5.1, 23.5]	28.1 [16.4, 39.7]	35.1 [22.7, 47.5]	57.1 [44.2, 70.1]	3.2 [2.0, 4.4]
>100 hours (high)	99	23.2 [14.9, 31.6]	55.0 [42.3, 64.8]	68.7 [59.6, 77.8]	87.9 [81.5, 94.3]	6.0 [4.7, 7.2]
Length of contact between carer and care recipient						
≤ 10 years	105	11.4 [5.3, 17.5]	58.7 [49.2, 68.1]	58.7 [49.2, 68.1]	78.8 [71.0, 86.7]	6.1 [4.9, 7.2]
>10 years	151	19.9 [13.5, 26.2]	42.7 [34.8., 50.6]	54.0 [44.2, 63.8]	72.8 [65.8, 79.9]	4.4 [3.6, 5.3]
No. of care recipients under charge						
1 care recipient	132	19.1 [12.4, 25.8]	41.2 [32.8, 49.7]	55.3 [46.8, 63.8]	74.0 [66.5, 81.6]	4.0 [3.2, 4.8]
2+ care recipients	131	13.1 [7.3, 18.9]	58.8 [50.4, 67.2]	59.5 [51.1, 68.0]	78.6 [71.6, 85.7]	6.5 [5.3, 7.6]
No. of carers providing care						
1 carer	69	17.4 [8.5, 26.3]	40.6 [29.0, 52.2]	54.3 [42.6, 66.0]	68.1 [57.1, 79.1]	4.1 [2.8, 5.4]
2–3 carers	99	15.3 [8.2, 22.4]	55.1 [45.3, 65.0]	57.6 [47.8, 67.3]	82.8 [75.4, 90.3]	5.7 [4.5, 6.8]
4+ carers	77	10.4 [3.6, 17.2]	51.9 [40.8, 63.1]	59.7 [48.8, 70.7]	72.7 [62.8, 82.7]	5.8 [4.4, 7.3]

The prevalence of missing and filled teeth and caries experience (DMFT>0) and mean DMFT were significantly higher among those with high weekly hours of care compared to those with medium weekly hours of care (Table 4.37). The prevalence of missing teeth was significantly higher among those with low weekly hours of care compared to those with medium weekly hours of care. When carers had two or more care recipients under charge, those care recipients had a significantly higher prevalence of missing teeth and mean DMFT than those care recipients whose carers had only one care recipient under their charge (Table 4.37).

4.4.1.5.1 Summary of findings on dental status of care recipients and continuity of care

The DMFT components did not vary by how often carers provided help with self-care activities, the length of contact between carer and care recipient or number of carers providing care. However, high weekly hours of care provided by carer was significantly associated with a higher prevalence of missing and filled teeth, caries experience and mean DMFT. Low weekly hours of care provided by carer was also significantly associated with a higher prevalence of missing teeth. Having two or more care recipients under charge was significantly associated with a higher prevalence of missing teeth and mean DMFT (Table 4.38).

Table 4.38 Summary of findings on dental status of care recipients and continuity of care

	Prevalence — % of people with:				Mean DMFT per person
	D>0	M>0	F>0	DMFT>0	
Carers provided assistance with self-care activites					
Never/sometimes (Ref)					
Always	~	~	~	~	~
Weekly hours of care provided by carer					
< 40 hours (low)	~	↑	~	~	~
40–100 hours (medium) (Ref)					
>100 hours (high)	~	↑	↑	↑	↑
Length of contact between carer and care recipient					
> 10 years (Ref)					
≤ 10 years	~	~	~	~	~
Number of care recipients under charge					
1 care recipient (Ref)					
2+ care recipients	~	↑	~	~	↑
Number of carers providing care					
1 carer (Ref)					
2–3 carers	~	~	~	~	~
4+ carers	~	~	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.1.5.2 Stratified analyses of mean DMFT

Among the care recipients who received less than 40 hours of weekly care or 40–100 weekly hours of care, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings (Figure 4.7). Among the care recipients who received more than 100 weekly hours of care, there was no significant difference in mean DMFT across the three settings. This finding differs from the result in Table 4.27, in which unadjusted mean DMFT in family and community settings were significantly lower than the mean DMFT in institutions, which may be confounded due to differing weekly hours of care provided by carers in the three settings. The majority of the care recipients in institutions received low weekly hours of care (Table 4.24) and this was associated with a higher mean DMFT (Table 4.37).

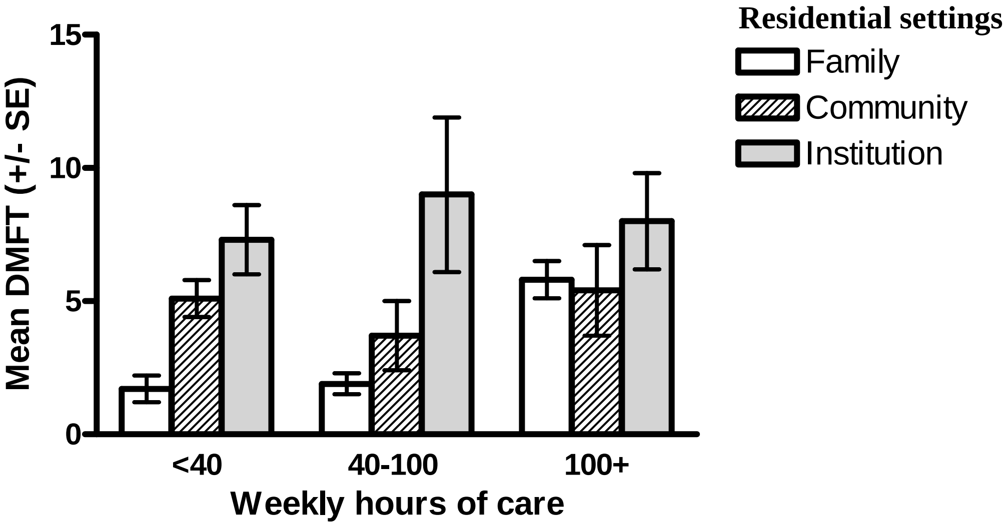

Figure 4.7 Mean DMFT across the three residential settings, stratified by weekly hours of care provided by carers

When carers had two or more care recipients under charge, those living in institutions had a significantly higher mean DMFT compared to those in family homes and community settings. Among the care recipients whose carer had only one care recipient under charge, there was no significant difference in mean DMFT across the three residential settings (Figure 4.8). This latter finding was in contrast to the result in Table 4.27, where the unadjusted mean DMFT in family and community settings were significantly lower than the mean DMFT in institutions. The unadjusted findings in Table 4.27 may be confounded due to differing number of care recipients under charge across the three settings. The majority of the care recipients in family homes were cared for by carers in charge of only one care recipient (Table 4.3) and this was strongly associated with a lower mean DMFT (Table 4.37).

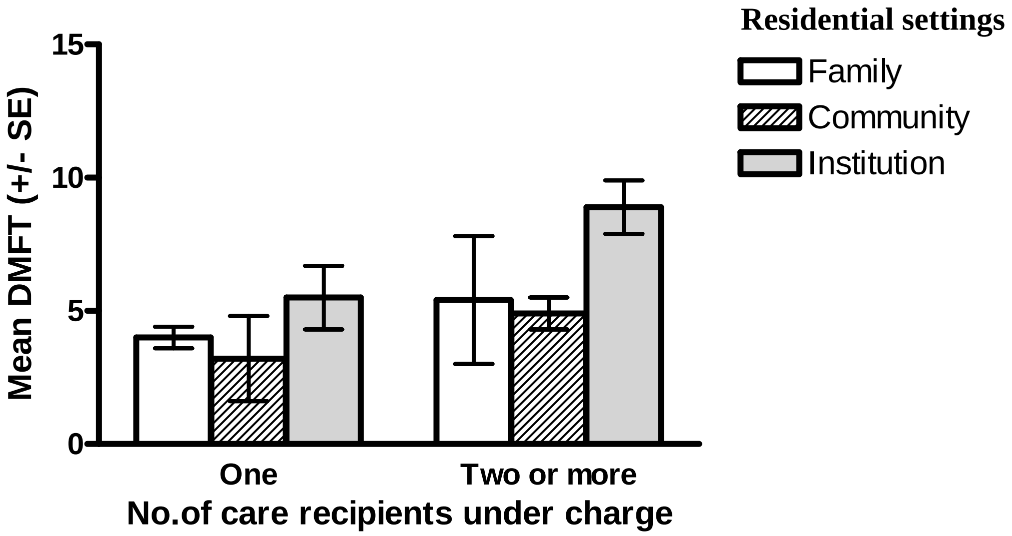

Figure 4.8 Mean DMFT in the three residential settings, stratified by number of care recipients under charge

4.4.2 Tooth wear

4.4.2.1 Relationship between tooth wear and care recipients

Prevalence of tooth wear was measured for each sextant with the highest rates found in the upper second anterior sextant (Table 4.39). Nonetheless, the most frequent finding for each sextant was "none" or "little" wear. ‘Missing’ denotes there were no teeth in that sextant.

Table 4.39 Prevalence of tooth wear among care recipients in each sextant

	Sextants					
Tooth wear	1 n (%)	2 n (%)	3 n (%)	4 n (%)	5 n (%)	6 n (%)
None-little	215 (80.6)	150 (56.1)	214 (80.0)	213 (79.9)	185 (69.2)	208 (78.0)
Moderate	32 (12.0)	85 (31.7)	33 (12.5)	37 (13.8)	67 (24.9)	42 (15.7)
Severe	15 (5.6)	29 (10.9)	16 (6.1)	13 (4.8)	11 (4.0)	13 (4.7)
Missing	5 (1.8)	4 (1.3)	4 (1.3)	4 (1.6)	5 (1.9)	4 (1.6)

When data were combined from among sextants, there were 45.1% of care recipients who had anterior tooth wear (a score of one or more in sextant 2 or 5) and 23.9% who had posterior tooth wear (a score of one or more in sextant 1 or 3 or 4 or 6) (Table 4.39). Care recipients in community housing and institutions had significantly more anterior tooth wear compared to care recipients at family homes. Care recipients in community housing also had significantly more posterior tooth wear compared to care recipients at family homes (Table 4.40).

Table 4.40 Prevalence of anterior and posterior tooth wear among care recipients by residential setting

	N	Anterior tooth wear % [95%CI]	Posterior tooth wear % [95%CI]
All	264	45.1 [36.1, 53.9]	23.9 [18.7, 29.0]
Family	128	32.0 [24.0, 40.1]	15.6 [9.3, 21.9]
Community	81	56.8 [46.0, 67.6]	35.8 [25.4, 46.2]
Institution	55	58.2 [45.1, 71.2]	25.5 [13.9, 37.0]

Prevalence of anterior tooth wear was greater among the older age-groups compared with the younger age groups (Table 4.41). However, age was not associated with posterior tooth wear. Main disabling condition was associated with anterior tooth wear, with the highest prevalence of anterior tooth wear among those with intellectual disability. There was no difference in anterior and posterior tooth wear between males and females.

Table 4.41 Relationship between tooth wear and characteristics of care recipients

Characteristics	N	Anterior tooth wear % [95%CI]	Posterior tooth wear % [95%CI]
Age (Yrs)			
18–24	91	24.2 [15.4, 33.0]	14.4 [7.1, 21.5]
25–34	81	55.6 [44.7, 66.4]	27.2 [17.5, 36.9]
35–44	93	58.1 [48.0, 68.1]	30.1 [20.8, 39.4]
Sex			
Male	164	48.2 [40.5, 55.8]	26.2 [19.5, 33.0]
Female	100	41.0 [31.4, 50.6]	20.0 [12.2, 27.8]
Main disabling condition			
Autism	83	36.1 [25.8, 46.5]	28.0 [18.1, 37.3]
Cerebral palsy	61	37.7 [25.5, 50.0]	16.1 [7.1, 25.7]
Intellectual disability	88	59.1 [48.8, 69.4]	28.1 [19.0, 37.8]
Other (Spina bifida, quadriplegia, head injury)	32	46.9 [29.6, 64.1]	16.1 [3.1, 28.2]

4.4.2.2 Relationship between tooth wear and oral habits of care recipients

Care recipients with the habit of ‘regurgitating, re-chewing and re-swallowing food’ had a higher prevalence of anterior tooth wear than those without such a habit (Table 4.42). Care recipients who placed food/medicine/other products in mouth for lengthy periods of time were less likely to have anterior tooth wear than those who did not have such a habit. However, clenching, grinding or tapping teeth and craving for and eating non-edible substances were not significantly associated with anterior and posterior tooth wear.

Table 4.42 Relationship between tooth wear and oral habits of care recipients

Oral habits		N	Anterior tooth wear % [95%CI]	Posterior tooth wear % [95%CI]
Regurgitates, re-chews and re-swallows food	Yes	24	70.8 [52.6, 89.0]	45.8 [25.9, 65.8]
	No	240	42.9 [36.7, 49.2]	21.8 [16.5, 26.9]
Places food/medicine/other products in mouth for lengthy periods of time	Yes	34	26.5 [11.6, 41.3]	29.4 [14.1, 44.7]
	No	230	48.3 [41.8, 54.7]	23.5 [18.0, 29.0]
Clenches, grinds or taps teeth	Yes	92	47.8 [37.6, 58.0]	33.7 [24.0, 43.4]
	No	172	43.9 [36.2, 51.0]	19.2 [13.3, 25.1]
Craves for and eats non-edible substances	Yes	13	46.2 [19.1, 73.3]	23.1 [0.2, 46.0]
	No	251	45.4 [31.3, 51.6]	24.0 [18.6, 29.2]

4.4.2.3 Summary of findings on tooth wear among care recipients

Anterior tooth wear was more prevalent among care recipients living in community housing and institutions, older age-groups, those with intellectual disability and those with the habit of regurgitating, re-chewing and re-swallowing food (Table 4.43). Anterior tooth wear was less prevalent among care recipients with the habit of placing food/medicine/other products in mouth for lengthy periods of time. Posterior tooth wear was also more prevalent among care recipients living in community housing.

Table 4.43 Summary of findings on tooth wear among care recipients

		Anterior tooth wear	Posterior tooth wear
Residential setting			
Family (Ref)			
Community housing		↑	↑
Institution		↑	~
Age (Yrs)			
18–24 (Ref)			
25–34		↑	~
35–44		↑	~
Sex			
Male (Ref)			
Female		~	~
Main disabling condition			
Autism (Ref)			
Cerebral palsy		~	~
Intellectual disability		↑	~
Other (Spina bifida, quadriplegia, head injury)		~	~
Oral habits			
Regurgitates, re-chews and re-swallows food	No (Ref)		
	Yes	↑	~
Places food/medicine/other products in mouth for lengthy periods of time	No (Ref)		
	Yes	↓	~
Clenches, grinds or taps teeth	No (Ref)		
	Yes	~	~
Craves for and eats non-edible substances	No (Ref)		
	Yes	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.3 Periodontal status

The periodontal examination included assessment of plaque and calculus (oral hygiene) and gingivitis. Three care recipients did not have periodontal examinations because of behavioural problems during the examination. To allow for comparisons with the few previous studies, the means and proportions of plaque index, calculus index, and gingivitis index as well as proportions of plaque, calculus and gingivitis scores of two or more for the 264 care recipients who had a periodontal examination are presented in this section.

4.4.3.1 Relationship between periodontal status and care recipient characteristics

Mean values for the plaque index (0.9), calculus index (0.5) and gingivitis index (0.8) were relatively low, although mean plaque index was significantly higher for care recipients in institutions and community housing compared to those in family homes (Table 4.44a). The mean calculus index and gingivitis index did not vary across the residential settings.

The prevalence of plaque scores of 2 or more was 40.0%, calculus scores of 2 or more was 41.9% and gingivitis scores of 2 or more was 36.0% (Table 4.44b). The prevalence of all components was significantly higher for care recipients in institutions and community housing compared to those in family homes.

Table 4.44a Relationship between periodontal status among care recipients and residential setting (mean scores)

	N	Plaque Index Mean [95% CI]	Calculus Index Mean [95% CI]	Gingivitis Index Mean [95% CI]
All	264	0.9 [0.8, 0.9]	0.5 [0.4, 0.6]	0.8 [0.7, 0.9]
Residential setting				
Family	128	0.6 [0.5, 0.8]	0.4 [0.3, 0.6]	0.6 [0.5, 0.7]
Community housing	81	1.1 [0.9, 1.2]	0.6 [0.4, 0.8]	0.9 [0.8, 1.1]
Institution	55	1.2 [1.1, 1.4]	0.4 [0.4, 0.8]	1.1 [0.9, 1.2]

Table 4.44b Prevalence of extensive plaque, calculus and gingivitis among care recipients across residential settings

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
All	106 (40.0) [34.1, 45.9]	111 (41.9) [36.0, 47.8]	95 (36.0) [30.2, 41.8]
Residential setting			
Family	34 (26.4) [18.8, 34.0]	38 (29.5) [21.6, 37.3]	28 (21.9) [14.7, 29.0]
Community housing	39 (48.1) [37.3, 59.0]	43 (53.1) [42.2, 64.0]	38 (46.9) [42.2, 64.0]
Institution	33 (60.0) [34.1, 45.9]	30 (54.5) [41.4, 67.7]	29 (52.7) [41.4, 67.7]

Other factors associated with periodontal measures were care recipient characteristics (Table 4.45). The prevalence of extensive plaque, calculus and gingivitis (ie. scores of 2 or more) was significantly higher in the 35–44 age-group compared to the 18–24 age-group; among those with intellectual disability compared to those with autism; and among those with good and poor-fair general health compared to those with very good-excellent general health. Likewise, the prevalence of extensive calculus and gingivitis was significantly higher among those care recipients who had little or no effective communication compared to those who could communicate verbally; and among those who always needed help with one or more self-care activities compared to those who never or only sometimes needed help. Similarly, the prevalence of extensive calculus and gingivitis was significantly higher among those with cerebral palsy and other disabling conditions respectively, compared to those with autism. However, there was no significant difference in the prevalence of extensive plaque, calculus and gingivitis between males and females.

Table 4.45 Prevalence of extensive plaque, calculus and gingivitis and care recipient characteristics

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Age (Yrs)			
18–24	20 (22.0) [13.5, 30.5]	16 (17.8) [9.9, 25.7]	12 (13.3) [6.3, 20.3]
25–34	28 (34.6) [24.2, 44.9]	38 (46.9) [36.4, 57.8]	33 (40.7) [30.0, 51.4]
35–44	58 (62.4) [52.5, 72.2]	57 (61.3) [51.4, 71.2]	51 (54.8) [44.7, 65.0]
Sex			
Male	57 (34.5) [27.3, 41.8]	63 (38.4) [31.0, 45.6]	53 (32.3) [25.2, 39.5]
Female	49 (49.0) [39.2, 58.5]	48 (48.0) [38.2, 57.8]	42 (42.0) [32.3, 51.7]
Main disabling condition			
Autism	19 (23.2) [14.0, 32.3]	19 (22.9) [13.9, 31.9]	15 (18.1) [9.8, 26.4]
Cerebral palsy	24 (38.7) [26.6, 50.8]	28 (45.9) [33.4, 58.4]	21 (33.9) [22.0, 45.7]
Intellectual disability	52 (59.1) [48.8, 69.4]	49 (55.1) [44.7, 65.4]	47 (52.8) [42.4, 63.2]
Other (Spina bifida, quadriplegia, head injury)	10 (32.3) [15.8, 48.7]	15 (48.4) [30.8, 66.0]	14 (43.8) [26.6, 60.9]
Means of communication			
Verbally	43 (35.0) [26.5, 43.4]	39 (31.7) [23.5, 39.9]	34 (27.6) [19.7, 35.5]
Non-verbally	23 (38.3) [26.0, 50.6]	30 (50.0) [37.4, 62.7]	24 (40.0) [27.6, 52.4]
Little or no effective communication	40 (48.8) [38.0, 59.6]	42 (51.9) [41.0, 62.7]	38 (46.3) [35.6, 57.1]
General health			
Very good-Excellent	29 (26.6) [18.3, 34.9]	27 (25.0) [16.8, 33.2]	20 (18.5) [11.2, 25.6]
Good	51 (47.2) [37.8, 56.6]	57 (52.8) [43.4, 62.2]	52 (47.7) [38.3, 57.1]
Poor-Fair	21 (52.5) [37.0, 68.0]	23 (57.5) [42.2, 72.8]	21 (52.5) [37.0, 68.0]
Help needed			
Never/sometimes	27 (35.5) [24.8, 46.3]	22 (28.9) [18.8, 39.1]	18 (23.7) [14.1, 33.2]
Always	78 (41.5) [34.5, 48.5]	89 (47.3) [40.2, 54.5]	77 (41.0) [33.9, 48.0]

4.4.3.1.1 Summary of findings on periodontal status and care recipient characteristics

The prevalence of extensive plaque, calculus and gingivitis were significantly higher among care recipients living in community housing and institutions, in the older age-groups, with intellectual disability and with poorer general health (Table 4.46). Similarly, the prevalence of extensive calculus and gingivitis were also significantly higher among care recipients with little or no effective means of communication, and those who always needed help with self-care activities. However, there was no significant difference between males and females. A higher prevalence of extensive calculus was also associated with cerebral palsy while a higher prevalence of extensive gingivitis was associated with other disabling conditions (Table 4.46).

Table 4.46 Summary of findings on periodontal status and care recipient characteristics

	Plaque score ≥ 2	Calculus score ≥ 2	Gingivitis score ≥ 2
Residential setting			
Family (Ref)			
Community housing	↑	↑	↑
Institution	↑	↑	↑
Age (Yrs)			
18–24 (Ref)			
25–34	~	↑	↑
35–44	↑	↑	↑
Sex			
Female (Ref)			
Male	~	~	~
Main disabling condition			
Autism (Ref)			
Cerebral palsy	~	↑	~
Intellectual disability	↑	↑	↑
Other (Spina bifida, quadriplegia, head injury)	~	~	↑
Means of communication			
Verbally (Ref)			
Non-verbally	~	~	~
Little or no effective communication	~	↑	↑
General health			
Very good-Excellent (Ref)			
Good	↑	↑	↑
Poor-Fair	↑	↑	↑
Help needed			
Never/sometimes (Ref)			
Always	~	↑	↑

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.3.2 Relationship between periodontal status and dental practices of care recipients

Dental practices of care recipients included toothbrushing patterns and dental visit patterns of care recipients.

There was no significant association between extensive plaque and calculus and care recipients' toothbrushing frequency. Contrary to the usual expectation, care recipients whose teeth were brushed twice a day had a higher prevalence of extensive gingivitis compared to those whose teeth were brushed once a day or less. There was no significant association between extensive plaque, calculus and gingivitis and who cleaned the teeth for the care recipients or carers' cleaning ability, or whether carers encountered behavioural problems when providing oral hygiene care. Interestingly, the prevalence of extensive plaque was significantly higher among care recipients for whom carers reported adequate cleaning time compared to those whose carers reported inadequate cleaning time. For the same group, extensive calculus and gingivitis were also higher but not statistically significant (Table 4.47).

Table 4.47 Relationship between extensive plaque, calculus and gingivitis and toothbrushing pattern of care recipients

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Frequency of toothbrushing			
Once/day or less	34 (31.8) [23.0, 40.6]	37 (34.3) [25.3, 43.2]	28 (25.9) [17.7, 34.2]
Twice/day	68 (46.3) [38.2, 54.3]	69 (46.9) [38.9, 55.0]	63 (42.9) [34.9, 50.9]
Who cleaned teeth			
With carer assistance	87 (41.0) [34.4, 47.7]	88 (41.5) [34.9, 48.1]	77 (36.3) [29.9, 42.8]
Carer recipient only	19 (36.5) [23.5, 49.6]	23 (44.2) [30.7, 57.7]	18 (35.3) [22.2, 48.4]
(Care recipients needing carer help) Adequacy of time to clean by carer			
Adequate	74 (48.7) [40.7, 56.6]	73 (48.0) [40.1, 56.0]	65 (42.5) [34.7, 50.3]
Inadequate	8 (22.2) [8.6, 35.8]	10 (28.6) [13.6, 43.5]	9 (25.7) [11.2, 40.2]
Carer's cleaning ability			
Only some teeth	48 (47.1) [37.4, 56.8]	51 (50.0) [40.3, 59.7]	45 (44.1) [34.5, 53.8]
All teeth	35 (37.6) [27.8, 47.5]	32 (34.4) [24.8, 44.0]	27 (29.0) [19.8, 38.3]
Behaviour problems			
Problems	66 (42.6) [34.8, 50.4]	73 (47.1) [39.2, 55.0]	63 (40.6) [32.9, 48.4]
None	15 (38.5) [23.2, 53.7]	14 (29.2) [14.0, 42.3]	14 (28.6) [15.9, 41.2]

There was no significant association between extensive plaque, calculus and gingivitis, and frequency of dental visits. However, the prevalence of extensive calculus and gingivitis were significantly higher among care recipients who needed sedation for dental treatment compared to those who were treated without sedation (Table 4.48).

Table 4.48 Relationship between plaque, calculus and gingivitis scores of 2 or more and dental visit pattern of care recipients

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Frequency of dental visits			
Never/problem only	17 (42.5) [27.2, 57.8]	17 (42.5) [27.2, 57.8]	16 (39.0) [24.0, 54.0]
1–2 years	41 (36.6) [27.7, 45.5]	42 (37.5) [28.5, 46.5]	36 (31.9) [23.3, 40.5]
Every 6 months	45 (42.5) [33.0, 51.9]	46 (43.4) [34.0, 52.8]	42 (39.6) [30.3, 48.9]
Usual dental treatment pattern			
Without sedation	63 (38.9) [31.4, 46.4]	62 (38.5) [31.0, 46.0]	53 (32.9) [25.7, 40.2]
With sedation	20 (60.6) [43.9, 77.3]	22 (68.8) [52.7, 84.8]	20 (62.5) [45.7, 79.3]
Under GA	13 (27.1) [14.5, 39.7]	15 (30.6) [17.7, 43.5]	11 (22.4) [10.8, 34.1]

4.4.3.2.1 Summary of findings on periodontal status and dental practices of care recipients

There was no significant association between extensive plaque, calculus and gingivitis, and who cleaned the teeth for the care recipient, carers' cleaning ability, whether carers encountered behavioural problems when providing oral hygiene care and the frequency of dental visits (Table 4.49).

Table 4.49 Summary of findings on periodontal status and dental practices of care recipients

	Plaque score ≥ 2	Calculus score ≥ 2	Gingivitis score ≥ 2
Frequency of toothbrushing			
Once/day or less (Ref)			
Twice/day	~	~	↑
Who cleaned teeth			
Carer recipient only (Ref)			
With carer assistance	~	~	~
(Care recipients needing carer help)			
Adequacy of time to clean by carer			
Inadequate (Ref)			
Adequate	↑	~	~
Carer's cleaning ability			
All teeth (Ref)			
Only some teeth	~	~	~
Behaviour problems			
None (Ref)			
Problems	~	~	~
Frequency of dental visits			
Never/problem only (Ref)			
Every 6 months	~	~	~
1–2 years	~	~	~
Usual dental treatment pattern			
Without sedation (Ref)			
With sedation	~	↑	↑
Under GA	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

The prevalence of extensive calculus and gingivitis were significantly higher among care recipients whose usual dental treatment required sedation. However, unexpectedly, the prevalence of extensive gingivitis was significantly higher among care recipients who reportedly had their teeth brushed twice a day and the prevalence of extensive plaque was significantly higher among care recipients for whom their carers reported adequate time to clean their care recipients' teeth (Table 4.49).

4.4.3.3 Relationship between periodontal status and risk factors

Risk factors for periodontal status included medications and risks habits like placing food/medicine/other products in the mouth for lengthy periods of time. The prevalence of extensive gingivitis was higher in care recipients taking one or more medications compared to those who did not take any medication. The prevalence of extensive plaque and calculus were also higher in this group, but the difference was not statistically significant. There was no significant association between extensive plaque, calculus and gingivitis, and intake of one or more medications that have the potential to cause gingival hyperplasia (Table 4.50).

Table 4.50 Relationship between extensive plaque, calculus and gingivitis and medication intake of care recipients

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
No. of medications			
None	20 (32.8) [21.0, 44.6]	17 (27.9) [16.6, 39.1]	13 (21.3) [11.0, 31.6]
1+	83 (41.9) [35.1, 48.8]	91 (45.7) [38.8, 52.7]	80 (40.2) [33.4, 47.0]
Medications causing hyperplasia			
None	61 (36.5) [29.2, 43.8]	60 (35.9) [28.7, 43.2]	54 (32.1) [25.1, 39.2]
1+	45 (45.9) [36.0, 55.8]	51 (52.0) [42.2, 61.9]	42 (43.3) [33.4, 53.2]

The prevalence of extensive plaque was higher in care recipients who placed food/medicine/other products in mouth for lengthy periods of time compared to those who did not have such habits. The prevalence of extensive gingivitis and calculus were also higher in this group, but the difference was not statistically significant. However, there was no significant association between extensive plaque, calculus and gingivitis, and other risk habits like clenching, grinding or tapping teeth and craving for and eating non-edible substances (Table 4.51).

Table 4.51 Relationship between extensive plaque, calculus and gingivitis and risk habits of care recipients

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Places food/medicine/other products in mouth			
No	83 (36.2) [30.0, 42.5]	92 (40.2) [33.8, 46.5]	78 (34.1) [27.9, 40.2]
Yes	22 (64.7) [48.7, 80.8]	18 (52.9) [36.2, 69.7]	17 (50.0) [33.2, 66.8]
One or more risk habits			
None	64 (45.1) [36.9, 53.3]	59 (41.5) [33.4, 49.7]	55 (38.5) [30.5, 46.4]
Yes	41 (33.9) [25.5, 42.3]	51 (42.1) [33.4, 51.0]	41 (33.9) [25.5, 42.3]

4.4.3.3.1 Summary of findings on periodontal status and risk factors among care recipients

There was a significant association between extensive gingivitis and intake of one or more medications but not with medications that have the potential to cause gingival hyperplasia. Similarly, placing food/medicine/other products in the mouth for lengthy periods of time was associated with a high prevalence of extensive plaque. However, there was no significant association between oral hygiene and intake of one or more medications or medications that have the potential to cause gingival hyperplasia (Table 4.52). Likewise, there was no significant association between extensive plaque, calculus and gingivitis, and other risk habits.

Table 4.52 Summary of findings on influences on periodontal status and risk factors among care recipients

	Plaque score ≥ 2	Calculus score ≥ 2	Gingivitis score ≥ 2
No. of medications			
None (Ref)			
1+	~	~	↑
Medications causing hyperplasia			
None (Ref)			
1+	~	~	~
Places food/medicine/other products in mouth			
No (Ref)			
Yes	↑	~	~
One or more risk habits			
None (Ref)			
Yes	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.3.4 Relationship between periodontal status and carer characteristics

Periodontal status was not associated with the age of carers, interest of carers in training in oral care for people with disabilities, their attitude towards oral health for their care recipients and themselves and whether they were comfortable providing oral care (Table 4.53). However, the prevalence of extensive plaque was significantly lower in care recipients of female carers than male carers. The prevalence of extensive calculus and gingivitis were also lower in care recipients of female carers, but the difference was not statistically significant. Among care recipients cared for by non-family carers, prevalence of extensive plaque, calculus and gingivitis were significantly higher compared to those cared for by family carers. In contrast to what was expected, the prevalence of extensive plaque and gingivitis were higher among care recipients whose carers had received training in oral care than those who had not had any training.

Table 4.53 Relationship between extensive plaque, calculus and gingivitis and carer characteristics

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Age (Yrs)			
=<50	42 (40.8) [31.3, 50.3]	49 (47.6) [37.9, 57.2]	43 (41.7) [32.2, 51.2]
50+	39 (33.3) [24.8, 41.9]	41 (35.0) [26.4, 43.7]	33 (28.2) [20.1, 36.4]
Sex			
Male	22 (61.1) [45.2, 77.0]	21 (60.0) [43.8, 76.2]	17 (47.2) [30.9, 63.5]
Female	75 (36.2) [29.7, 42.8]	79 (38.2) [31.5, 44.8]	69 (33.3) [26.9, 39.8]
Relationship			
Family carer	39 (27.3) [20.0, 34.6]	42 (29.4) [21.9, 36.8]	32 (22.4) [15.6, 29.2]
Non-family carer	67 (54.9) [46.1, 63.8]	68 (56.2) [47.7, 65.0]	63 (52.1) [43.2, 61.0]
Training of carers			
Had training	25 (59.5) [44.7, 74.4]	26 (63.4) [48.7, 78.2]	25 (61.0) [46.1, 75.9]
No training	75 (35.9) [29.4, 42.4]	81 (38.8) [32.2, 45.4]	67 (32.1) [25.7, 38.4]
Interest in training			
Interested	59 (41.5) [33.4, 49.7]	64 (45.1) [36.9, 53.3]	54 (38.3) [30.3, 46.3]
Not interested	44 (38.9) [30.0, 47.9]	45 (39.8) [30.8, 48.9]	39 (34.5) [25.7, 43.3]
Importance of oral health to carers for care recipients			
Important	18 (40.9) [26.4, 57.8]	19 (43.2) [28.5, 57.8]	15 (34.1) [20.1, 48.1]
Very important	37 (40.2) [30.2, 50.2]	43 (46.7) [36.5, 56.9]	37 (40.2) [30.2, 50.2]
Extremely important	51 (39.8) [31.4, 48.3]	49 (38.3) [29.9, 46.7]	44 (34.4) [26.2, 42.6]
Importance of oral health to carers for themselves			
Important	16 (42.1) [26.4, 57.8]	22 (57.9) [42.2, 73.6]	19 (50.0) [34.1, 65.9]
Very important	28 (30.4) [21.0, 39.8]	35 (38.0) [28.1, 48.0]	28 (30.8) [21.3, 40.3]
Extremely important	55 (44.7) [35.9, 53.5]	46 (37.7) [29.1, 46.3]	42 (34.1) [25.8, 42.5]
Uncomfortable providing oral care			
No	62 (41.9) [33.9, 49.8]	58 (39.5) [31.6, 47.4]	51 (34.5) [26.8, 42.1]
Yes	26 (36.6) [25.4, 47.8]	32 (45.1) [33.5, 56.6]	28 (39.4) [28.1, 50.8]

However, it must be noted that the proportion of carers who had any training was very few (14.8%, Table 4.20) and the training period was short and not current. On the other hand, carers may have had training if their care recipients had poor oral hygiene and gingival condition.

4.4.3.4.1 Summary of findings on periodontal status and carer characteristics

Periodontal status was not associated with the age of carers, interest of carers in training in oral care, their attitude towards oral health for their care recipients and themselves and whether they were comfortable providing oral care (Table 4.54). However, the prevalence of extensive plaque was significantly lower in care recipients of female carers. The prevalence of extensive plaque, calculus and gingivitis were significantly higher among care recipients cared for by non-family carers. The prevalence of extensive plaque and gingivitis were also higher among care recipients whose carers had received training in oral care.

Table 4.54 Summary of findings on periodontal status and of carer characteristics

	Plaque score ≥ 2	Calculus score ≥ 2	Gingivitis score ≥ 2
Age (Yrs)			
=<50 (Ref)			
50+	~	~	~
Sex			
Male (Ref)			
Female	↓	~	~
Relationship			
Family carer (Ref)			
Non-family carer	↑	↑	↑
Training of carers			
No training (Ref)			
Had training	↑	↑	↑
Interest in training			
Not interested (Ref)			
Interested	~	~	~
Importance of oral health to carers for care recipients			
Important (Ref)			
Very important	~	~	~
Extremely important	~	~	~
Importance of oral health to carers for themselves			
Important (Ref)			
Very important	~	~	~
Extremely important	~	~	~
Uncomfortable providing oral care			
No (Ref)			
Yes	~	~	~

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.3.5 Relationship between periodontal status and continuity of care

The prevalence of extensive calculus was significantly higher in care recipients for whom carers always provided assistance with self-care activities. This group also had a higher prevalence of extensive plaque and gingivitis than those who never/sometimes received assistance with self-care activities; however the difference was not statistically significant (Table 4.55). Similarly, the prevalence of extensive plaque was significantly higher in care recipients with low and high weekly hours of care. Likewise, the prevalence of extensive plaque, calculus and gingivitis were significantly higher among those care recipients whose carers had more than one care recipient under their charge than those care recipients whose carers had only one care recipient under charge. Similarly, the prevalence of extensive calculus and gingivitis were significantly higher among those care recipients cared by four or more carers compared to those cared by only one carer. In this group, prevalence of extensive plaque was also higher, but the difference was not statistically significant. However, the prevalence of extensive plaque, calculus and gingivitis were significantly lower in care recipients who had been in contact with their carer for over 10 years compared to those who had been with their carers for 10 years or less.

Table 4.55 Relationship between extensive plaque, calculus and gingivitis and continuity of care

	Plaque score ≥ 2 n (%) [95%CI]	Calculus score ≥ 2 n (%) [95%CI]	Gingivitis score ≥ 2 n (%) [95%CI]
Carers provided assistance with self-care activites			
Never/sometimes	33 (36.7) [26.7, 46.6]	26 (28.6) [19.3, 37.9]	26 (28.6) [19.3, 37.9]
Always	72 (42.4) [34.9, 49.8]	82 (48.2) [40.7, 55.8]	70 (41.2) [33.8, 48.6]
Weekly hours of care provided by carer			
≤ 40 hours (low)	44 (49.4) [39.0, 59.8]	44 (50.0) [39.6, 60.5]	36 (40.9) [30.6, 51.2]
40–100 hours (medium)	11 (19.6) [9.2, 30.1]	16 (28.6) [16.7, 40.4]	15 (26.8) [15.2, 38.4]
>100hours (high)	40 (40.8) [31.1, 50.6]	41 (42.3) [32.4, 52.1]	34 (35.1) [25.6, 44.6]
Length of contact between carer and care recipient			
≤ 10 years	57 (55.3) [45.7, 64.9]	61 (58.7) [49.2, 68.1]	57 (55.3) [45.7, 64.9]
>10 years	42 (28.4) [21.1, 35.6]	45 (30.4) [23.0, 37.8]	34 (23.0) [16.2, 29.8]
Number of carers providing care			
1 carer	21 (30.4) [19.6, 41.3]	21 (30.4) [19.6, 41.3]	17 (24.6) [14.5, 34.8]
2–3 carers	40 (41.2) [31.4, 51.0]	39 (39.8) [30.1, 49.5]	32 (33.0) [23.6, 42.4]
4+ carers	34 (44.7) [33.6, 55.9]	42 (56.0) [44.8, 67.2]	38 (50.0) [38.8, 61.2]
Number of care recipients under charge			
1 care recipient	34 (26.4) [18.8, 34.0]	37 (28.5) [20.7, 36.2]	28 (21.5) [14.5, 28.6]
2+ care recipients	71 (54.2) [45.7, 62.7]	73 (56.2) [47.6, 64.7]	67 (51.5) [43.0, 60.1]

4.4.3.5.1 Summary of findings on periodontal status and continuity of care recipients

Care recipients with low and high weekly hours of care and those cared for by carers in charge of 2 or more care recipients were more likely to have a higher prevalence of extensive plaque, while those who had been in contact with their carers for over 10 years were more likely to have lower prevalence of extensive plaque, calculus and gingivitis. Care recipients for whom carers always provided assistance with self-care activities, those with low weekly hours of care, who were cared for by four or more carers and whose carers provided care for two or more care recipients were associated with a higher prevalence of extensive calculus. Care recipients cared for by four or more carers and whose carers provided care for two or more care recipients were also associated with higher prevalence of extensive gingivitis (Table 4.56).

Table 4.56 Summary of findings on periodontal status and continuity of care of care recipients

	Plaque score ≥ 2	Calculus score ≥ 2	Gingivitis score ≥ 2
Carers provided assistance with self-care activites			
Never/sometimes (Ref)			
Always	~	↑	~
Weekly hours of care provided by carer			
< 40 hours (low)	↑	↑	~
40–100 hours (medium)(Ref)			
>100 hours (high)	↑	~	~
Length of contact between carer and care recipient			
≤ 10 years (Ref)			
> 10 years	↓	↓	↓
Number of carers providing care			
1 carer (Ref)			
2–3 carers	~	~	~
4+ carers	~	↑	↑
Number of care recipients under charge			
1 care recipient (Ref)			
2+ care recipients	↑	↑	↑

(Ref): reference group ~ no significant difference ↓ significantly lower ↑ significantly higher

4.4.4 Multivariate models

The primary purpose of multivariate analyses was to estimate the effect of residential setting on oral health while simultaneously adjusting for other factors found in preceding analyses to be associated with oral health. This was done whether or not the unadjusted (bivariate) analysis revealed a significant association between residential setting and oral health status to determine if other variables were confounding the bivariate relationship, either away from the null hypothesis (where the bivariate finding was statistically significant) or towards it (where the bivariate finding was a null effect). Multivariate models were constructed as described in the methods (chapter 3, section 3.3.4). In summary, variables with significant associations in the bivariate analyses were entered in blocks, retaining only individual variables that were statistically significant or that altered one or both parameter estimates for residential setting by 10% or more. The family setting was used as the reference group in these models which therefore estimated effects of institution and community settings, each one relative to the family setting. Age and sex were included in all models. Each model estimated effects for community housing and institution relative to family setting and other significant variables. The effects are expressed as odds ratios for oral health outcomes that are proportions, and parameter estimates of mean differences for DMFT.

4.4.4.1 Multivariate logistic regression models: factors associated with untreated decay among the care recipients

Three logistic regression models were constructed for untreated decay among the care recipients (Table 4.57). Care recipient age, sex and main disabling condition were included in the first model to adjust for care recipients' demographic and disability characteristics. Dental practices (frequency of dental visits) were added to the second model and risk factors (frequency of sweet drinks) to the third model. In the unadjusted analysis, the odds of untreated decay did not differ significantly among the residential settings, and this relationship remained statistically non-significant in models 1 and 2. However, in model 3, care recipients who never visited the dentist or visited only because of a dental problem had 5.2 times greater odds of having untreated decay compared to those who visited the dentist every 1–2 years. A moderate intake of sweet drinks was associated with a 3.7 times greater odds of untreated decay than low intake, while a high intake of sweet drinks was associated with 3.3 times greater odds of untreated decay.

Table 4.57 Binary logistic regression models for factors associated with untreated decay (D>0) among the care recipients

Models	N	Variables	Odds Ratio [95% CI]
Unadjusted	267	Family (Ref)	
Residential setting only		Community	0.8 [0.4, 1.7]
		Institution	0.5 [0.2, 1.2]
Model 1	267	Family (Ref)	
Care recipient characteristics[1]		Community	0.8 [0.3, 2.0]
		Institution	0.5 [0.2, 1.6]
Model 2	262	Family (Ref)	
Model 1 + dental practices[2]		Community	1.9 [0.7, 5.1]
		Institution	1.1 [0.3, 4.0]
Model 3	235	Family (Ref)	
Model 1 + risk factors[3]		Community	1.7 [0.6, 5.2]
		Institution	0.8 [0.2, 3.4]
		Frequency of dental visits	
		Never/problem only	5.2 [1.7, 15.8]
		Every 1–2 years (Ref)	
		Every 6 months	2.4 [0.9, 6.0]
		Frequency of sweet drinks	
		Low (Ref)	
		Moderate	3.7 [1.2, 11.4]
		High	3.3 [1.1, 11.1]

[1] Care recipient age, sex

[2] Frequency of dental visits

[3] Frequency of sweet drinks

Care recipient age and sex were not significant.

4.4.4.2 Multivariate logistic regression models: factors associated with missing teeth among the care recipients

Four logistic regression models were constructed for missing teeth among the care recipients (Table 4.58). Care recipient characteristics (care recipient age, sex and main disabling condition) were added to the first model, dental practices (toothbrushing frequency, frequency of dental visits, dental treatment pattern) to the second model, carer characteristics (relationship to care recipient) to the third model and factors associated with continuity of care (weekly hours of care provided by carer, number of care recipients under charge) to the final fourth model. In the unadjusted analysis, the odds of missing teeth did not differ significantly among the residential settings, and this relationship remained statistically non-significant in models 1, 2, 3 and 4. However, in the fourth model, care recipients requiring a general anaesthetic for usual dental treatment had 3.2 times greater odds of having a missing tooth compared to those who could be treated in the chair without any sedation.

Care recipients with low weekly hours of care had 3.4 times greater odds and those with high weekly hours of care had 4.2 times greater odds of having a missing tooth compared to those with medium weekly hours of care from their carers.

Table 4.58 Binary logistic regression models for factors associated with missing teeth (M>0) among the care recipients

Models	N	Variables	Odds Ratio [95% CI]
Unadjusted	267	Family (Ref)	
Residential setting only		Community	1.2 [0.7, 2.1]
		Institution	3.3 [0.7, 6.4]
Model 1	267	Family (Ref)	
Care recipient characteristics[1]		Community	0.9 [0.4, 1.7]
		Institution	1.6 [0.6, 3.9]
Model 2	238	Family (Ref)	
Model 1 + dental practices[2]		Community	0.5 [0.2, 1.4]
		Institution	1.1 [0.4, 3.2]
Model 3	237	Family (Ref)	
Model 2+ carer characteristics[3]		Community	0.5 [0.1, 1.8]
		Institution	1.0 [0.2, 4.0]
Model 4	202	Family (Ref)	
Model 3 + continuity of care[4]		Community	0.4 [0.1, 2.0]
		Institution	0.4 [0.1, 2.3]
		Treatment pattern	
		Without sedation (Ref)	
		With sedation	2.0 [0.6, 6.2]
		Under GA	3.2 [1.4, 7.2]
		Weekly hours of care	
		≤ 40 hours (low)	3.4 [1.1, 10.3]
		40–100 hours (medium) (Ref)	
		>100 hours (high)	4.2 [1.7, 10.7]

[1] Care recipient age, sex, main disabling condition

[2] Toothbrushing frequency, frequency of dental visits, dental treatment pattern

[3] Relationship to care recipient

[4] Weekly hours of care provided by carer, number of care recipients under charge

Care recipient age, sex, main disabling condition, toothbrushing frequency, frequency of dental visits, relationship to care recipient and number of care recipients under charge were not significant.

4.4.4.3 Multivariate logistic regression models: factors associated with filled teeth among the care recipients

Three logistic regression models were constructed for factors associated with filled teeth among the care recipients (Table 4.59). Care recipient characteristics (care recipient age and sex) were added to the first model, dental practice (who cleaned teeth) to the second model and continuity of care (weekly hours of care) to the third model. In the unadjusted analysis, care recipients in institutions had 2.2 times greater odds of having a filled tooth than those in family homes. However, when adjusted for care recipients characteristics, this relationship was not statistically significant in model 1. This relationship remained statistically non-significant in models 2 and 3. However, in the fourth model, care recipients aged 35–44 years old had 5.4 times greater odds of having a filled tooth compared to those aged 18–24 years old. Those who lacked oral hygiene assistance from their carers had 5.1 times greater odds of having a filled tooth compared to those who received complete or partial assistance from their carers. Care recipients with high weekly hours of care had 4.4 times greater odds of having a filled tooth compared to those with medium weekly hours of care.

Table 4.59 Binary logistic regression models for factors associated with filled teeth (F>0) among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	267	Family (Ref)	
Residential setting only		Community	1.0 [0.6, 1.7]
		Institution	2.2 [1.1, 4.4]
Model 1	267	Family (Ref)	
Care recipient characteristics[1]		Community	0.5 [0.2, 1.0]
		Institution	0.9 [0.4, 2.1]
Model 2	266	Family (Ref)	
Model 1 + dental practice[2]		Community	0.4 [0.2, 0.9]
		Institution	0.9 [0.3, 2.2]
Model 3	231	Family (Ref)	
Model 2 + continuity of care[3]		Community	0.8 [0.3, 2.0]
		Institution	1.1 [0.4, 3.3]
		Age	
		18–24 (Ref)	
		25–34	1.2 [0.6, 2.7]
		35–44	5.4 [2.0, 14.9]
		Who cleaned teeth	
		With carer assistance (Ref)	
		Care recipient only	5.1 [2.2, 11.8]
		Weekly hours of care	
		< 40 hours (low)	1.6 [0.7, 3.6]
		40–100 hours (medium) (Ref)	
		>100 hours (high)	4.4 [2.0, 9.5]

[1] Care recipient age, sex
[2] Who cleaned teeth
[3] Weekly hours of care
Care recipient sex was not significant.

4.4.4.4 Multivariate logistic regression models: factors associated with caries prevalence (DMFT>0) among the care recipients

Three logistic regression models were constructed for factors associated with caries prevalence among the care recipients (Table 4.60). Care recipient characteristics (care recipient age, sex and main disabling condition) were added to the first model, dental practices (who cleaned teeth) to the second model and continuity of care (weekly hours of care) to the third model. In the unadjusted analysis, care recipients in institutions had 3.8 times greater odds of caries experience than those in family homes. However, when adjusted for care recipients characteristics, this relationship was not statistically significant in model 1. This relationship remained statistically non-significant in models 2 and 3.

Table 4.60 Binary logistic regression models for factors associated with caries prevalence (DMFT>0) among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	267	Family (Ref)	
Residential setting only		Community	0.8 [0.4, 1.5]
		Institution	3.8 [1.4, 10.6]
Model 1	267	Family (Ref)	
Care recipient characteristics[1]		Community	0.5 [0.2, 1.1]
		Institution	1.6 [0.4, 5.6]
Model 2	266	Family (Ref)	
Model 1 + dental practices[2]		Community	0.4 [0.2, 0.9]
		Institution	1.6 [0.4, 6.1]
Model 3	231	Family (Ref)	
Model 2 + continuity of care[3]		Community	0.8 [0.3, 2.3]
		Institution	2.0 [0.5, 9.0]
		Age	
		18–24 (Ref)	
		25–34	1.1 [0.4, 3.3]
		35–44	7.3 [2.0, 26.3]
		Who cleaned teeth	
		With carer assistance (Ref)	
		Care recipient only	4.0 [1.3, 12.5]
		Weekly hours of care	
		<40 hours (low)	1.6 [0.6, 4.0]
		40–100 hours (medium) (Ref)	
		> 100 hours (high)	6.3 [2.5, 15.9]

[1] Care recipient age, sex, main disabling condition

[2] Who cleaned teeth

[3] Weekly hours of care

Care recipient sex and main disabling condition were not significant.

However, in the third model, care recipients aged 35–44 years old had 7.3 times greater odds of having caries experience compared to those aged 18–24 years old. Those who lacked oral hygiene assistance from their carers had 4.0 times greater odds of having caries experience compared to those who received complete or partial assistance from their carers. Care recipients with high weekly hours of care had 6.3 times greater odds of having caries experience compared to those with medium weekly hours of care.

4.4.4.5 Linear regression models: factors associated with caries experience (mean DMFT) among the care recipients

Five linear regression models were constructed for factors associated with caries experience **(**mean DMFT) among the care recipients (Table 4.61). Unlike previous models, where effects were quantified as odds ratios, the effects in this model represent the net difference in mean DMFT between one group and its corresponding reference group. In these models, the effect is held to be statistically significant if the 95% CI excludes the null value of zero.

Care recipient characteristics (care recipient age, sex and main disabling condition) were added to the first model, dental practices (frequency of dental visits) to the second model, risk factors (frequency of sweet drinks and number of medications) to the third model and carer characteristics (relationship to care recipient) to the fourth model. Relationship to care recipient did not have any effect to the regression coefficient of the residential settings and was therefore removed from the model. Continuity of care (weekly hours of care, number of care recipients under charge) was then added to the third model for the fifth model. The unadjusted analysis showed a significant effect of institutional residency, but that effect became much smaller and non significant in model 1, and it remained small and non-significant in later models. From the final model, the mean DMFT was greater by 3.0 teeth among those in the 35–44 age-group compared to the 18–24 age-group, 3.4 teeth among those with autism, and 2.5 teeth among those with intellectual disability with reference to those with cerebral palsy. The mean DMFT was greater by 3.6 teeth among those with high weekly hours of care compared to those with medium weekly hours of care from their carer.

Table 4.61 Linear regression model: factors associated with caries experience (mean DMFT) among the care recipients

Models	Independent variables	Regression coefficient [95% CI]
Unadjusted	Family (Ref)	
Residential setting only	Community	0.5 [-1.1, 2.0]
	Institution	4.4 [2.7, 6.2]
Model 1	Family (Ref)	
Care recipient characteristics[1]	Community	-1.2 [-3.1, 0.6]
	Institution	1.1 [-1.1, 3.3]
Model 2	Family (Ref)	
Model 1 + dental practices[2]	Community	-1.6 [-3.5, 0.4]
	Institution	0.3 [-2.0, 2.6]
Model 3	Family (Ref)	
Model 2 + risk factors[3]	Community	-1.0 [-3.3, 1.4]
	Institution	0.8 [-2.1, 3.7]
Model 4	Family (Ref)	
Model 3 + carer characteristics[4]	Community	-1.0 [-4.3, 2.3]
(removed)	Institution	0.8 [-3.0, 4.5]
Model 5	Family (Ref)	
Model 3 + continuity of care[5]	Community	0.2 [-3.0, 3.4]
	Institution	0.9 [-3.0, 4.8]
	Age-group	
	18–24 years (Ref)	
	25–34 years	0.4 [-1.9, 2.6]
	35–44 years	3.0 [0.4, 5.6]
	Disabling condition	
	Cerebral palsy (Ref)	
	Autism	3.4 [1.3, 5.8]
	Intellectual disability	2.5 [0.3, 4.8]
	Other	1.0 [-2.0, 4.1]
	(Spina bifida, quadriplegia, head injury)	
	Weekly hours of care	
	<40 hours (low)	1.1 [-1.2, 3.4]
	40–100 hours (medium) (Ref)	
	>100 hours (high)	3.6 [1.6, 5.6]

[1] Care recipient age, sex, main disabling condition
[2] Frequency of dental visits
[3] Frequency of sweet drinks, number of medications
[4] Relationship to care recipient
[5] Weekly hours of care, number of care recipients under charge

Care recipient sex, frequency of dental visits, frequency of sweet drinks, number of medications and number of care recipients under charge were not significant.

4.4.4.6 Multivariate logistic regression model: factors associated with anterior tooth wear among the care recipients

Two logistic regression models were constructed for factors associated with anterior tooth wear among the care recipients (Table 4.62). Care recipient characteristics (care recipient age, sex and main disabling condition) were added to the first model and oral habits (regurgitates, re-chews and re-swallows food and places food/medicine/other products in mouth) were added to the second model. Both community and institutional settings had significant effects in the unadjusted model, but (like DMFT) both became small and non-significant in model 1 and thereafter. From the final model, care recipients aged 25–34 years old had 3.1 times and 35–44 years old had 2.6 times greater odds of having anterior tooth wear compared to those aged 18–24 years old. Those who had the habit of regurgitating, re-chewing and re-swallowing food had 3.4 times greater odds of having anterior tooth wear compared to those who did not have such habits.

Table 4.62 Binary logistic regression models for factors associated with anterior tooth wear among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	263	Family (Ref)	
Residential setting only		Community	2.8 [1.6, 5.0]
		Institution	3.0 [1.6, 5.8]
Model 1	263	Family (Ref)	
Care recipient characteristics[1]		Community	1.4 [0.7, 2.8]
		Institution	1.3 [0.5, 3.0]
Model 2	261	Family (Ref)	
Model 1 + oral habits[2]		Community	1.5 [0.7, 3.1]
		Institution	1.3 [0.5, 3.0]
		Age	
		18–24 (Ref)	
		25–34	3.1 [1.5, 6.5]
		35–44	2.6 [1.1, 6.2]
		Oral habits	
		Regurgitates, re-chews and re-swallows food	
		No (Ref)	
		Yes	3.4 [1.3, 9.2]

[1] Care recipient age, sex, main disabling condition

[2] Regurgitates, re-chews and re-swallows food, places food/medicine/other products in mouth

Care recipient sex, main disabling condition and placing food/medicine/other products in mouth were non-significant.

4.4.4.7 Multivariate logistic regression model: factors associated with posterior tooth wear among the care recipients

One logistic regression model was constructed for factors associated with posterior tooth wear among the care recipients (Table 4.63). Care recipient characteristics (care recipient age, sex and main disabling condition) were added to the model. Community setting was significant and had a sizable effect in unadjusted analysis and, unlike previous outcomes, it persists (just) in Model 1. Care recipients living in the community had 2.3 times greater odds of having posterior tooth wear compared to those living in family homes.

Table 4.63 Binary logistic regression models for factors associated with posterior tooth wear among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	263	Family (Ref)	
Residential setting only		Community	3.0 [1.6, 5.9]
		Institution	1.8 [0.9, 4.0]
Model 1	263	Family (Ref)	
Care recipient characteristics[1]		Community	2.3 [1.02, 5.1]
		Institution	1.3 [0.5, 3.5]

[1] Care recipient age, sex
Care recipient age and sex were not significant.

4.4.4.8 Multivariate logistic regression model: factors associated with extensive plaque among the care recipients

Four logistic regression models were constructed for factors associated with extensive plaque among the care recipients (Table 4.64). Care recipient characteristics (care recipient age, sex, main disabling condition and general health) were added to the first model, risk factors (places food/medicine/other products) to the second model, carer characteristics (carer sex, relationship to care recipient) to the third model and factors associated with continuity of care (weekly hours of care) to the fourth model. In unadjusted analysis, the odds of extensive plaque in community and institutional settings was significantly greater than in family homes, but was nullified in models 1, 2 and 3, although it almost returned as a significant effect in model 4 – although with a very wide 95% CI. From the final model, care recipients aged 35–44 years old had 3.9 times greater odds of having extensive plaque compared to those aged 18–24 years old and those with poor-fair health had 3.3 times greater odds of having extensive plaque compared to those with very good-excellent general health. Care recipients who had the habit of placing food/medicine/other products in mouth for lengthy periods of time had 7.8 times greater odds of having extensive plaque compared to those without such a habit.

Care recipients cared for by male carers had 3.9 times greater odds of having extensive plaque compared to those cared for by female carers. Those with high weekly hours of care had 4.0 times greater odds of having extensive plaque compared to those with medium weekly hours of care.

Table 4.64 Binary logistic regression models for factors associated with extensive plaque among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	263	Family (Ref)	
Residential setting only		Community	2.6 [1.5, 4.7]
		Institution	4.1 [2.1, 7.9]
Model 1	248	Family (Ref)	
Care recipient characteristics[1]		Community	1.5 [0.7, 3.3]
		Institution	1.7 [0.7, 4.4]
Model 2	246	Family (Ref)	
Model 1 + risk factors[2]		Community	1.6 [0.7, 3.6]
		Institution	2.2 [0.9, 5.5]
Model 3	220	Family (Ref)	
Model 2 + carer characteristics[3]		Community	1.3 [0.4, 4.3]
		Institution	1.2 [0.6, 8.8]
Model 4	203	Family (Ref)	
Model 3 + continuity of care[4]		Community	2.9 [0.7, 12.7]
		Institution	4.5 [0.8, 23.9]
		Age	
		18–24 (Ref)	
		25–34	2.0 [0.8, 5.0]
		35–44	3.9 [1.4, 11.2]
		General health	
		Very good-Excellent (Ref)	
		Good	1.6 [0.7, 3.4]
		Poor-Fair	3.3 [1.2, 9.0]
		Risk factors	
		Places food/medicine/other products	
		No (Ref)	
		Yes	7.8 [2.7, 22.7]
		Carer sex	
		Female (Ref)	
		Male	3.9 [1.4, 10.8]
		Weekly hours of care	
		<40 hours (low)	1.5 [0.5, 3.9]
		40–100 hours (medium) (Ref)	
		>100 hours (high)	4.0 [1.5, 10.8]

[1] Care recipient age, sex, main disabling condition, general health

[2] Places food food/medicine/other products

[3] Carer sex, relationship to care recipient

[4] Weekly hours of care

Care recipient sex, main disabling condition and relationship to care recipient were not significant.

4.4.4.9 Multivariate logistic regression model: factors associated with extensive calculus among the care recipients

Five logistic regression models were constructed for factors associated with extensive calculus among the care recipients (Table 4.65). Care recipient characteristics (care recipient age, sex, main disabling condition, means of communication, general health and needs help with self-care activities) were added to the first model, dental practices (usual dental treatment pattern) to the second model, carer characteristics (relationship to care recipient) to the third model and factors associated with continuity of care (number of care recipients under charge, length of contact) to the fourth model. In unadjusted analysis, the odds of extensive calculus in community and institutional settings is significantly greater than in family homes, but is nullified by model 1 and retained in subsequent models. From the final model, care recipients aged 25–34 and 35–44 years old had 4.3 and 5.3 times (respectively) greater odds of having extensive calculus compared to those aged 18–24 years old.

Table 4.65 Binary logistic regression models for factors associated with extensive calculus among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	263	Family (Ref)	
Residential setting only		Community	2.7 [1.5, 4.9]
		Institution	3.0 [1.6, 5.7]
Model 1	248	Family (Ref)	
Care recipient characteristics[1]		Community	1.1 [0.5, 2.4]
		Institution	0.9 [0.3, 2.2]
Model 2	231	Family (Ref)	
Model 1 + dental practices[2]		Community	1.1 [0.5, 2.4]
		Institution	0.9 [0.3, 2.6]
Model 3	231	Family (Ref)	
Model 1 + carer characteristics[3]		Community	0.7 [0.2, 2.5]
		Institution	0.7 [0.2, 2.5]
Model 4	209	Family (Ref)	
Model 3 + continuity of care[4]		Community	0.7 [0.2, 2.5]
		Institution	0.7 [0.2, 2.5]
		Age	
		18–24 (Ref)	
		25–34	4.3 [1.8, 10.7]
		35–44	5.3 [1.8, 15.4]

[1] Care recipient age, sex, main disabling condition, means of communication, general health, needs help with self-care activities

[2] Dental treatment pattern

[3] Relationship to care recipient

[4] Number of care recipients under charge, length of contact

Care recipient sex, main disabling condition, means of communication, general health, needs help self-care activities, dental treatment pattern, relationship to care recipient, number of care recipients under charge and length of contact were not significant.

4.4.4.10 Multivariate logistic regression model: factors associated with extensive gingivitis among the care recipients

Five logistic regression models were constructed for factors associated with extensive gingivitis among the care recipients (Table 4.66). Care recipient characteristics (care recipient age, sex, main disabling condition, means of communication, general health and needs help with self-care activities) were added to the first model, dental practices (tooth brushing frequency, dental treatment pattern) to the second model, risk factors (one or more medications) to the third model, and carer characteristics (relationship to care recipient) to the fourth model. Relationship to care recipient did not have any effect to the parameter estimate for the residential settings and was therefore removed from the model. Factors associated with continuity of care (number of care recipients under charge) was then added to the third model for the fifth model.

Table 4.66 Binary logistic regression models for factors associated with extensive gingivitis among the care recipients

Models	N	Variables	Odds ratio [95% CI]
Unadjusted	263	Family (Ref)	
Residential setting only		Community	3.2 [1.7, 5.8]
		Institution	4.1 [2.1, 8.0]
Model 1	247	Family (Ref)	
Care recipient characteristics[1]		Community	1.4 [0.6, 3.3]
		Institution	1.4 [0.5, 3.5]
Model 2	224	Family (Ref)	
Model 1 + dental practices[2]		Community	1.6 [0.6, 4.4]
		Institution	2.4 [0.8, 7.4]
Model 3	201	Family (Ref)	
Model 2 + risk factors[3]		Community	2.2 [0.8, 6.3]
		Institution	2.9 [0.8, 10.3]
Model 4	201	Family (Ref)	
Model 3 + carer characteristics[4]		Community	2.3 [0.6, 9.4]
(removed)		Institution	3.0 [0.6, 14.7]
Model 5	197	Family (Ref)	
Model 4 + continuity of care[5]		Community	2.0 [0.6, 6.7]
		Institution	2.5 [0.6, 10.1]
		Help with self-care activities	
		Never/sometimes (Ref)	
		Always	3.5 [1.2, 10.2]

[1] Care recipient age, sex, main disabling condition, means of communication, general health, needs help with self-care activities

[2] Toothbrushing frequency, dental treatment pattern

[3] Medications

[4] Relationship to care recipient

[5] Number of care recipients under charge

Care recipient age, sex, main disabling condition, means of communication, general health, toothbrushing frequency, dental treatment pattern, medications, relationship to care recipient and number of care recipients under charge were not significant.

In unadjusted analysis, the odds of extensive gingivitis in community and institutional settings was significantly greater than in family homes, but was nullified in subsequent models. From the last model, those who always needed help for self-care activities from carers had 3.5 times greater odds of having extensive gingivitis compared to those who never or only sometimes needed help for self-care activities.

CHAPTER 5. DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

This chapter gives an overview of the major findings of the study, with particular reference to the hypotheses in relevant sections. Whenever possible, comparisons have been made to previous studies and possible explanations for the differences discussed. It also includes the strengths and limitations, the significance, and implications of findings of this study. Finally, conclusions from this study are drawn and recommendations based on them.

5.1 Results and comparison with previous studies

The principal finding from this study was that the type of residential setting is not associated with the oral health status of care recipients, after adjustment was made for the characteristics of people living in those different settings. Several variables were found to confound the crude association between residential setting and oral disease: care recipient's age, which tended to be older, on average in institutional settings than other settings, and care recipient's main disabling condition, which was over-represented by intellectual disability and under-represented by cerebral palsy in institutions. After adjustment for both of these characteristics, there were no significant differences between residential settings in most aspects of oral health, with the exception of care recipients at community housing being more likely to have posterior tooth wear compared to those in family homes. However, certain aspects of care recipients’ demographics and general health, preventive dental practices, oral disease risk behaviours, relationship to care recipient and continuity of care were associated with their oral health. The findings are discussed in details below, with reference to each aim and hypothesis and compared to previous studies whenever possible.

5.1.1 Results from mail questionnaire

5.1.1.1 Care recipient characteristics

The distribution of care recipients across the three residential setting was comparable to the earlier Australian study by Scott et al. (1998) on 101 adults (21–53 years) with developmental disabilities, in which 29% lived in institutional care, 31% in the community and 40% at family homes. The current study's finding that slightly more care recipients (47%) lived in family homes compared with the study by Scott et al. (1998), could have been due to the younger age-group of the care recipients in this study. The majority of the 18–24 years age-group lived in family homes, while the majority of the 35–44 years age-group lived in institutions. This appears logical as the older care recipients would have older parents, who would no longer be able to look after their adult children with disabilities. There were more males than females and intellectual disability was the most reported main disabling condition. These findings are consistent with the report on Disability Support Services

2004–2005 (AIHW, 2006) that provides information on the characteristics of the people who use Commonwealth State/Territory Disability agreement of 2002–07 (CSTDA)-funded services in Australia.

5.1.1.2 Perceived oral health problems and treatment needs of care recipients and impact on quality of life

One hypothesis of this study was that adults with physical and intellectual disabilities, living in various residential settings have varying perceived oral health problems and treatment needs. The results of this study confirmed variation among residential settings in several aspects of oral health, but not all. In the bivariate analyses, carers at institutions reported significantly more oral health problems compared to those at family homes and community housing, but more carers at family homes reported not knowing if their care recipients had an oral health problem or not. The most frequent oral health problem reported was bad breath followed by decay and bleeding gums. Compared to the French study by Faulks and Hennequin (2000) on adults with intellectual disabilities, the prevalence of bad breath reported in this study was similar (45% versus 49%), but the prevalence of bleeding gums reported was less than half (33% versus 67%).

A significantly higher proportion of carers in community housing and institutions reported bad breath among care recipients compared to those in family homes, while carers in family homes more frequently reported other problems. Family carers also reported more perceived treatment needs than carers at other settings, but there was no statistically significant difference across the three settings with respect to specific treatment needs like scaling and filling.

In spite of the fairly high prevalence of perceived oral health problems and treatment needs, prevalence of negative impact from a dental problem on individual items was low with one or more negative impacts reported by only 13.5% of care recipients, with family carers reporting more negative impacts compared to carers from other settings. The marked discrepancy in the proportion of carers reporting a negative impact on quality of life and the presence of a clinically-defined oral health problem, indicates an underestimation by carers of pain and suffering among their care recipients. This may be due to lack of effective communication and expression of pain and discomfort by the care recipients. In fact, reported negative impacts were significantly more for those who could communicate verbally, than for those with non-verbal and little or no communication. Also, carers may not be aware of signs of oral pain like crying or altered facial expression and lack of interest in surroundings or a refusal to communicate as described by Guisiano et al. (1995) and obvious facial swelling, increased halitosis or drooling and changes in behaviour particularly at mealtimes, and aspiration of food and/or liquids as described by Hennequin et al. (2000), simply due to lack of training in the recognition of such manifestations.

To the author's knowledge, this is the first published study that has attempted to estimate the impact of oral health on the quality of life in this population. The closest comparison can be made to the study by Henneqin et al., 2000 in which patient discomfort from perceived dental treatment need was evaluated by the carer using visual analogue pain scores, in which average pain rating expressed by the carer was much lower compared to the quantity of treatment ultimately undertaken. This is consistent with the findings of Andresen et al. (2001) who compared health related quality of life responses of people with disability to proxies and reported that proxies over-estimated impairment but under-estimated pain.

It must be noted that items in a questionnaire concerning the psychological and certain symptomatic aspects of oral health status (e.g. degree of pain, as opposed to presence or absence of pain) may not be accurate as they require a level of interpretation by a proxy respondent, the validity of which is highly questionable. However, observable domains like function (problem eating) or social issues (irritability) are more likely to be validly assessed. This study, therefore, included four questions on trouble sleeping, pain and discomfort, unsatisfactory diet and irritable behaviour due to a dental problem. However, the more frequently reported oral health problems like bad breath and gum problems were not included in this study on the questions on quality of life. It can be argued that bad breath and gum problems may not have a negative impact on quality of life. At the same time, it must also be noted that gum problems in this population would be more on the extreme end of the scale compared to the general population and could be causing pain and discomfort. Bad breath could be putting off the carers from cleaning their care recipient’s teeth and the problem could worsen with time and have additional negative impacts on social life. One recommendation for future research is that studies endeavor to evaluate carers' perceptions of both conditions. Precedents exist in the literature, including two questions from the Oral Health Impact Profile:

How often during the last year, has your main care recipient…

Had stale breath (functional limitation)

Had painful gums (physical pain)…because of a dental problem?

However, additional work would be needed to evaluate if those questions are appropriate and specific in assessing such problems among adults with disabilities.

5.1.1.3 Dental practices

Another hypothesis of this study was that dental practices (toothbrushing and dental visit patterns) among care recipients vary among residential settings.

Toothbrushing pattern

In this study, a higher proportion of care recipients at institutions received assistance for toothbrushing from their carers than other settings. Compared to the UK study of adults with intellectual disability by Cumella et al. (2000), which reported 22% of subjects with intellectual disability needed assistance from their carers for oral care, carer involvement was much higher in this study at 72%, suggesting care recipients in this study were comparatively more dependent.

In this study, infrequent toothbrushing was more common among care recipients at family homes compared to community housing and institutions, with more carers at family homes reporting inadequate time to clean compared to carers at other settings. This may reflect greater carer burden in family settings, and suggests that parents require additional support (eg. financial, physical and respite) in the provision of oral hygiene care at home.

The use of cleaning aids such as toothbrushes, toothpaste and gels was similar across the three settings. Less than 10% used gels or mouth rinse and although asked in the questionnaire, very few of them specified they used fluoride or chlorhexidine. Of the few care recipients who used mouthrinses, it was more commonly used among those at community housing compared to those at family homes and institutions. The low use of mouthrinses could be due to the inability of the care recipients to rinse. Where provision of daily oral hygiene by carers is inadequate or not possible due to behavioural problems, use of fluoride to prevent decay and chlorhexidine to maintain gingival health has been encouraged (Glassman and Miller, 2003). For care recipients who can not rinse or spit out the solution, swabs (Siefel et al., 1992) or sprays (Burtner et al., 1991) can be used.

Compared to the French study by Faulks and Hennequin (2000) of children and adults with physical and intellectual disabilities aged 6–50 years, infrequent toothbrushing among the care recipients in this study was half as low (39% versus 79%) and the use of toothpaste with toothbrush for cleaning their teeth was much higher (93% versus 71%). Cleaning ability of carers was also better, with carers in this study able to clean all teeth for 46% compared to only 24% of care recipients in the same study. Cleaning ability among carers for their care recipients was similar across the three settings.

There were several organisational barriers to providing oral hygiene care, such as lack of time in usual routine for all carers and lack of staff and lack of communication among staff between shifts for non-family carers. Family carers should therefore be provided with some assistance at home. Among non-family members, effective communication among staff between shifts should be encouraged using communication books or logs of personal hygiene including oral hygiene, so that oral hygiene care for their care recipients is not compromised.

Some behavioural difficulties were also reported by carers when providing oral hygiene care, the most frequent being inability to rinse with mouthwash. Similar problems were reported by Faulks and Hennequin (2000), which included constant movement, chewing tooth brush, refusing to open mouth and gag reflex.

Toothbrushing is a basic yet important marker of good oral health and is considered the most reliable means of controlling plaque, provided cleaning is adequate and performed daily (Loe, 2000). However, people with disabilities depend greatly on their carers for their daily oral care. For some care recipients, it is not realistic to provide oral hygiene care on a regular, daily basis as ideally needed due to behavioural problems. It may only be possible to provide oral hygiene care ‘as best as possible’ at ‘unpredictable times’. Whether this was the reason for infrequent toothbrushing could not be confirmed by the results of this study.

Family carers and managers of community housing and institutions should be made aware of this high prevalence of infrequent toothbrushing and the low use of preventative aids among the care recipients. These findings highlight the need for oral health promotion, training and assistance among carers to improve oral care for people with disabilities.

Dental visit pattern

Care recipients in institutions visited the dentist more frequently (six-monthly recalls) compared to care recipients at other settings. This was possible due to formal arrangements between the institutions and SADS, whereby a dentist and a hygienist visit the institution every week. Overall, 74% of the South Australian population represented in this study visited the dentist at least once a year which was comparable to the earlier Australian survey of adults with developmental disabilities by Scott et al. (1998) and the UK study of handicapped adults by Francis et al. (1991) which reported the dental visit in the last 12 months as 65%

and 69% respectively. However, in this study, nearly 19% of care recipients had never visited the dentist or not after turning 18 years of age or visited only because of a dental problem, of which 78% of them were from family homes. Some of the reasons were no dental problem, appointments for check-ups unavailable, unable to find a dentist who will see people with disabilities, care recipients can not tolerate dental procedures, cost and transportation difficulties.

A general anaesthetic was required more often for care recipients from family homes, while oral sedation was required more often for care recipients from institutions mainly for behaviour management, rather than the complexity of the dental treatment. Overall, fewer care recipients (18% versus 25%) needed a general anaesthetic than that reported by Francis et al. (1991). Due to the risks, cost and long waiting periods associated with dental treatment under a general anaesthetic, greater emphasis should be placed on preventive measures.

Carer involvement at dental visits occurred in over 76% of cases compared to 61% of cases in the UK survey by Cumella et al. (2000). It was a practical necessity in making and keeping appointments as most care recipients were unable to do so, on their own. Carers from family settings were most likely to be present at the dental visit compared to carers at other settings. Most frequent reason for carers from other settings not taking their care recipients for dental visits was not being rostered. Whenever possible, the same carers should accompany the care recipients so that the carer can provide additional information and support, whenever needed. Also, they can see for themselves the problems if any, how they were managed by the dentist and learn how the problem can be prevented in the future.

The frequency of usual services received by care recipients in this study was also higher than in the earlier Australian survey by Scott et al. (1998), which examined 101 adults with developmental disabilities between 21–53 years. Despite the younger age-group in the current study, the percent reporting dental examination was much higher (73% versus 39%) in the study by Scott et al. (1998). Similarly, the percentage with fillings was higher in this study (39% versus 30%). Scott et al. (1998) reported that 46% of the study participants had received teeth cleaning and polishing while 8% had received periodontal treatment. When added together, those two percentages were lower than the 59% of care recipients in this study who reported receiving scaling and cleaning. Surprisingly, extractions were not reported in that study. Care recipients at institutions received significantly more scaling, fillings and extractions as they visited the dentist more frequently than care recipients at other settings.

Cumella et al. (2000) reported only four carers with problems obtaining dental care, which was attributed to dentists' unwillingness to treat people with intellectual disability. In contrast, in this study there were over 43% of carers who reported one or more problems in obtaining dental care, the most frequent being lack of dentists with adequate skills in managing people with disabilities. Carers at family homes experienced the most number of problems, while those at institutions reported minimal problems in obtaining dental care for their care recipients. Again, this was possible due to the formal arrangement with the institutions and SADS, whereby care recipients had access to care for relief of pain on the same day or at least within a week and for routine dental check-up every 6 months. However, some carers at institutions acknowledged that there were too many patients to be seen by one dentist in one morning every week. In Australia and overseas, there is a lack of clinical training for undergraduate and postgraduate students in the management of people with disabilities. In fact, Special Needs Dentistry was recognised as a speciality in Australia only in 2006.

Cost was yet another problem mentioned by some carers. Although eligible to be treated at a concession rate at government clinics, with the introduction of co-payments, the cost of a general course of dental treatment could reach Aus $178.00, which may not be affordable to all.

Lack of suitable transportation, especially for wheel-chair bound care recipients and inadequate disabled parking outside dental clinics resulting in late arrivals for appointments were problems exclusive to those living at family homes and community housing. As services are provided within the institution, care recipients at institutions have no transportation and parking problems.

Other problems included carers not being aware of services available for people with disabilities and not knowing where to take their care recipients, or having the impression that there was a long waiting list to be seen at government clinics. There is a need to raise awareness about the importance of oral health and clinical services available for people with disabilities among relevant organisations and family carers via formal and informal meetings and discussions. Perhaps, organisations associated with people with disabilities should have a referral directory that includes dental services for this sub-group of the population. Also, formal arrangements could be made for appropriate referrals from the SADS School Dental Service and the Women's and Children's Hospital to the Special Needs Unit at the Adelaide Dental Hospital, after care recipients are no longer eligible for services under their care, to ensure continuity of care into adulthood. Where care recipients are compliant, government clinics should arrange priority recall visits to this disadvantaged sub-group of the population as most of them would not understand the concept of a waiting list and would not be asking to be put on such lists and even if they were, would still depend on their carers for arranging the appointment and making the visit.

Location of services received by care recipients was not queried as it was assumed that most people with disabilities are eligible for public dental service and are seen at SADS clinics. However, on contacting carers for an appointment for an oral examination, there were 22 care recipients who saw private practitioners on a regular basis, of which only 9 agreed to participate in the study. Most of them had private health insurance.

Most carers reported that the dentist/hygienist showed sensitivity to the special needs of their care recipients, conducted a proper dental examination, diagnosis and treatment, fully explained treatment choices, offered clear oral hygiene instructions to them and care recipients, and arranged recall visits for their care recipients. Generally, most carers had positive reports, however, family carers were either more neutral or negative about their reports compared to carers from other settings, problems with cost, transportation and lack of services available, as discussed above, being the probable reasons.

This is the first study that has attempted to compare dental practices in this population across the three residential settings. Managers of institutions should note the regular oral health care that their care recipients are receiving at the institutions and ensure that level of care is continued when they are moved into the community. Carers at community housing and family homes should have access to information on services available through support organisations with which they are associated, and subsequently access to regular dental visits.

5.1.1.4 Frequency of risk factors and behaviours

Diet

In this study, sweetened tea/coffee and soft drinks/cordials were the most frequently consumed foods in a day. Though there was no difference in the frequency of acidic drinks and sweet solids, it was rather surprising to note that within the residential settings, a higher proportion of care recipients at institutions had a high intake of sweet drinks compared to care recipients at other settings. It was expected that meals and snacking would be more restricted in institutions and therefore less frequent than in family homes and community housing.

Medication usage

Considering the presence of at least one main disabling condition and possibly one or more other disabling conditions, it was not surprising that 78% of care recipients took one or more medications. The higher proportion of care recipients taking one or more medications and medications with potential adverse effects on oral health at institutions than those at family homes and community housing suggests that care recipients at institutions may be more medically compromised than care recipients at other settings. Potential oral effects of medications like dry mouth, candidiasis and hyperplasia were observed but not recorded during the oral examination.

Other risk habits

Other risk habits included smoking and adverse oral habits. Although the prevalence of smoking in this population was a low 3%, it was rather disappointing that it still exists. In fact, this was slightly higher than that reported by Gabre et al. (2001).

The prevalence of clenching, grinding or tapping teeth was quite high at 32%. If signs of tooth wear are noted, where appropriate, night guards could be considered, including taking dental impressions during a general anaesthetic session for other dental treatment. Although much less prevalent, carers should be made aware of the risk habits like placing food/medicine/other products in mouth for lengthy periods of time, regurgitating, re-chewing and re-swallowing food, and eating non-edible substances like cigarette butts. Carers should take extra care to ensure that food/medicine is properly swallowed by care recipients, checking the mouth after each meal or dose of medicine, inform their doctors about regurgitation and seek appropriate medical care and provide close supervision so that non-edible substances are avoided as much as possible.

5.1.1.5 Socio-demographics of carers

There was a wide age range among carers, with the average age of carers at family homes being the highest at 53 years and over 30% of carers over the age of 55 years. The older carers in community and institutions were parents who continued to be the primary carer for their care recipients, even if the carer did not live with the care recipient. They commented that being unable to care due to practical difficulties caused significant anxiety for the future of their children with disabilities. The increasing number of such ageing carers is yet another looming problem in the near future.

For the majority of carers at family homes, the source of income was carer allowance/payment, with one commenting that “care allowance is insulting!” A significantly lower proportion of carers at family homes received wages as they spent most of their time providing unpaid hours of care to their care recipients. There is an urgent need to develop innovative strategies of supporting carers at family homes.

Knowledge of carers

It is of concern to note that so few carers had received any training in oral care for people with disabilities, with virtually none of the carers at family homes. For the few that had any training, the training was outdated and short. Rather disappointing was the lack of interest in any training, with carers at family homes showing the least interest compared to paid carers at community and institutional settings. Possible reason was reported in a qualitative study by Weeks and Fiske (1994) on the views of nursing staff on oral care of people with a disability, where respondents did not perceive a need for further knowledge and skills as they thought mouth care was “common sense”. Older carers in this study commented that it was rather too late for them to undergo training. Inadequate time would be yet another reason, especially for family carers. However, there were a few interested in learning new techniques in oral hygiene and managing uncooperative behaviour. Participating organisations should be made aware of these findings, especially of the new approaches to managing oral hygiene care among people with disabilities and new preventive strategies. Appropriate training and support should then be organised to improve daily oral care of their care recipients.

Attitude of carers

The majority of the carers reported that they took on the caring role to provide better care. Most carers had a positive attitude to oral health, stating it was important, very important or extremely important for themselves and their care recipients. In contrast to the randomised clinical trial in the UK by Frenkel et al. (2002) on oral health care education and its effect on carers’ knowledge and attitudes, which reported that only 16% of carers agreed strongly that they felt comfortable brushing teeth for their care recipients and about 50% felt fairly or very uncomfortable, in this study a much higher 72% reported that they were not uncomfortable providing oral care and only 13% were uncomfortable providing oral care.

Dental behaviours of carers

In this study, a significantly higher number of carers at family homes brushed their own teeth only once a day or less, compared to carers at community and institutional settings. This behaviour of infrequent toothbrushing was reflected in the toothbrushing frequency of their care recipients.

Most carers visited the dentist once every year or every two years, while a smaller percentage visited the dentist every 6 months. A much higher proportion of carers at family homes had never visited the dentist or visited only because of a dental problem compared to carers from other settings. This behaviour of infrequent dental visit was also reflected in the dental visit pattern of their care recipients.

In summary, people with disabilities depend greatly on their carers for their daily oral care and preventive dental practices, which in turn is influenced by the personal dental behaviour of their carers. Frenkel et al. (2002) report encouraging results that oral health care education among carers of institutionalised elderly people can lead to significant improvements in oral health care knowledge, attitudes and skills that eventually result in better oral health outcomes. Such approaches could be replicated among people with disabilities in Australia and tested in randomised clinical trials.

5.1.1.6 Care provided, continuity of care and effects of caring role

Most of the carers in all three settings always or sometimes provided assistance with self-care activities, with some carers providing over 100 hours of weekly care, most of them providing continuous care at family homes. Over 54% of the carers had been the primary carer for over 10 years. A higher proportion of the carers at family homes had spent significantly longer time as the main carer compared to the carers at community and institutional settings. Most carers were satisfied with their caring role, but many were also stressed, frustrated, angry, were weary/lack of energy, and suffered muscle pain. The demanding nature and negative effects of caring roles should be recognised with provision of adequate support strategies for carers.

Carer burden

A carer burden scale for the carers of people with disabilities was not included in this study. However, several variables were used to estimate carer burden: absence of a fall-back carer, carers who reported need for more support (respite, financial, physical, emotional and other) and negative effects of caring. Carers at family homes were the most affected, with nearly 50% of them not having a fall-back carer, most of them needing significantly more support to assist in their caring role and reporting negative effects of caring.

In its 2007–08 budget, the Australian Government announced that:
“A further 1,000 carers of young people with a severe or profound disability will have access to respite support as part of a $6 million Federal Budget 2007–08 initiative”,
“$12 Million to Support National Disability Advocacy Programme” and
“Carers to receive $394 million Budget Bonus” (FaCSIA, 2007).
If and how these funds will help carers in their provision of health and oral health care to their care recipients is yet to be seen.

5.1.2 Results from oral epidemiological examination

In this study, the DMFT was based on 28 teeth, excluding third molars because neither the carers nor the care recipients could confirm the reason for missing third molars. Only a German study by Pieper et al. (1986) of 250 handicapped adults aged 17–64 years, reported caries experience based on 28 teeth. Recently, Fung and Allison (2005) compared caries rate in non-institutionalised individuals with and without Down syndrome in France and suggested that a more appropriate method of comparing caries rate between people with and without Down syndrome would be through a proportional indicator, where the number of decayed and filled teeth is divided by the total number of teeth present. This method would avoid the inclusion of congenitally missing teeth (third molars, lateral incisors and mandibular second premolars) which is highly prevalent in people with Down syndrome or missing teeth due to reasons other than caries (teeth removed for orthodontic reasons as malocclusion is common in people with Down syndrome, cerebral palsy and in intellectual disability).

In contrast to the other studies that have reported a high prevalence of untreated dental caries, this study found that 17% of care recipients had untreated decay. The figure was lower than the prevalence of 26% in the general Australian population aged 15 years or more

(Roberts-Thomson and Do, 2007). It was much lower than the English studies by Cumella et al. (2000) on 25–44 years old people with intellectual disability and by Francis et al. (1991) on handicapped adults, which reported a prevalence of 58% and 61% respectively. Also, the ratio of missing to filled teeth was not as high as reported by Cumella et al. (2000). When compared to the Australian study of 21–53 years old developmentally disabled adults by Scott et al. (1998), mean DMFT among 25–29, 30–34 and 35–44 year olds, was lower in each age-group. Also, the mean DMFT of the present sample of 5.2 teeth [95% CI= 4.5, 5.6] was significantly lower than that of the general Australian population of 12.8 [95% CI= 12.4, 13.8] (Roberts-Thomson and Do, 2007) and of the study carried out by Cumella et al. (2000) which reported a mean DMFT of 16.3 teeth.

In contrast to about 50% of carers reporting oral health problems and treatment need for their care recipients, the much lower prevalence of negative impact, 13.5% was closer to the observed untreated decay, 17%. Prevalence of untreated decay in the population also reflects access to dental care for treatment. The low prevalence of untreated decay could be a result of regular dental care provided to the care recipients in this study.

Due to lack of previous studies, comparisons of tooth wear from this study were not possible. Due to methodological reasons, comparisons of periodontal status from this study with previous studies were also not possible.

5.1.2.1 Influence of residential setting on oral health of care recipients

One hypothesis of this study was that oral health status of care reccipients would differ among residential settings. Bivariate analysis showed that the prevalence of untreated decay and filled teeth did not vary across the three residential settings, but the prevalence of missing teeth and caries experience and mean DMFT were significantly higher among the care recipients at institutions than those at family homes. When stratified by significant variables in bivariate relationship between mean DMFT and the three residential settings, care recipient age, main disabling condition, frequency of sweet drinks, relationship to care recipient, weekly hours of care and number of care recipients under charge were found to be confounders. Furthermore, after adjusting for the confounding variables in the multivariate analysis, there was no significant difference in dental status across the three residential settings.

There were similar results for periodontal conditions. That is, bivariate analysis showed that the prevalence of extensive plaque, calculus and gingivitis were significantly higher among the care recipients at institutions and community housing than those at family homes. However, multivariate analysis did not support the difference. In contrast, bivariate analysis showed that the prevalence of anterior and posterior tooth wear was higher among care recipients at community housing compared to those in family homes and institutions. However, multivariate analysis found a difference in the three residential settings only for posterior tooth wear. No other explanatory variable was associated with posterior tooth wear. The high prevalence of posterior tooth wear among care recipients at community housing needs further exploration, perhaps by looking into the aetiology of different types of tooth wear like erosion, attrition and abrasion.

In a pilot study of residents with mental retardation in the US, Thornton et al. (1989) compared “oral hygiene levels and periodontal disease prevalence among residents with mental retardation at various residential settings”; however, the 20 subjects from a large state institution, 20 subjects from a small regional facility and 22 subjects from group home settings, were selected according to convenience and availability. In a study by Gabre and Gahnberg (1994) that compared dental health status of mentally retarded adults in three settings, decayed and filled surfaces and loss of alveolar bone were reported, neither of which were recorded in this study and therefore these results can not be compared. Also, the subjects were selected from a hospital dental clinic and therefore were not a representative sample and the possibility of other influences on oral health was not tested. To date, this is the first study that has estimated population prevalence using weighted data to compare the oral health of adults with physical and intellectual disabilities in various living arrangements. The findings therefore are representative of the South Australian disabled population. In addition, multivariate analyses have allowed the assessment of potential confounding effects on each oral health outcome.

In summary, residential settings did not influence the oral health of care recipients, with the exception that care recipients at community housing were associated with 2.3 times greater odds of having posterior tooth wear compared to those in family homes. The significant associations between residential settings and dental and periodontal status observed in bivariate analyses were found to be confounded by other factors described below.

5.1.2.2 Other factors influencing oral health

Other factors influencing oral health includes care recipient characteristics, their preventive dental practices, oral disease risk behaviours, including medication usage and carer characteristics, their knowledge, attitudes and provision of care including continuity of care.

5.1.2.2.1 Care recipient characteristics

Care recipient age was significantly associated with most oral health outcomes, in bivariate analysis. Multivariate analysis confirmed its association with filled teeth, caries experience, anterior tooth wear and extensive plaque and calculus. Care recipients aged 35–44 years old were 5.4 times more likely to have a filled tooth and 7.3 times more likely to have caries experience compared to those aged 18–24 years old. Mean DMFT was greater by 3.0 teeth among those in the 35–44 age-group compared to the 18–24 age-group. Care recipients aged 25–34 years old were 3.1 times and 35–44 years old were 2.6 times more likely to have anterior tooth wear compared to those aged 18–24 years old. Care recipients aged 35–44 years old were 3.9 times more likely to have extensive plaque and care recipients aged 25–34 and 35–44 years old were 4.3 and 5.3 times (respectively) more likely to have extensive calculus compared to those aged 18–24 years old.

Bivariate analysis showed that care recipients' main disabling condition was significantly associated with missing teeth, caries experience, anterior tooth wear and extensive plaque, calculus and gingivitis. Mean DMFT was greater by 3.4 teeth among those with autism and 2.5 teeth among those with intellectual disability with reference to those with cerebral palsy as shown by the linear regression model. All remaining associations did not survive the multivariate analysis.

The way care recipients communicated and how often they needed help with self-care activities were significantly associated with a higher prevalence of extensive calculus and gingivitis in bivariate analysis, but not in multivariate analysis.

Bivariate analysis showed that care recipients' general health was significantly associated extensive plaque, calculus and gingivitis. In multivariate analysis, the only confirmation was that care recipients with fair-poor health were 3.3 times more likely to have extensive plaque compared to those with very good-excellent general health indicating that those with the worst general health also have the worst oral hygiene.

5.1.2.2.2 Dental practices

Toothbrusing pattern of care recipients was not significantly associated with untreated decay. Surprisingly twice a day toothbrushing was associated with a higher prevalence of missing teeth and extensive gingivitis. However, congenitally missing teeth and missing teeth due to reasons other than decay and periodontal problems were included in the count of missing teeth in this study. Also, there is a possibility of reporting bias on the toothbrushing frequency by carers. Even when reporting of toothbrushing frequency was true, it may not have been adequate. However, both associations did not remain as statistically significant in the multivariate analysis. Fung and Allison (2005) also reported that daily toothbrushing was not associated with caries.

Care recipients who did not receive any assistance from their carers for cleaning their teeth had significantly higher number of filled teeth and caries experience than those who received assistance from their carers. This finding was confirmed by the multivariate analysis, which showed that care recipients who cleaned their teeth themselves without any assistance from their carers were 5.1 times more likely to have a filled tooth and 4.0 times more likely to have caries experience compared to those who received complete or partial assistance from their carers. Care recipients who think they are capable of adequate tooth cleaning by themselves and believed so by their carers, should be encouraged to brush their own teeth. However, carers must still ensure that adequate cleaning has been performed.

Although bivariate analyses showed that one or more behavioural problems during oral hygiene care were associated with more caries experience and frequent dental visits were associated with a higher prevalence of missing teeth and mean DMFT, these associations were not confirmed in the multivariate analyses.

Bivariate analyses also showed that care recipients who usually required a general anaesthetic for routine dental treatment had a higher prevalence of missing teeth and extensive calculus and gingivitis, but only the former association was confirmed in the multivariate analysis. Care recipients requiring a general anaesthetic for routine dental treatment were 3.2 times more likely to have a missing tooth compared to those who could be treated in the chair, without any sedation. Treatment planning by dentists for people with disabilities under a general anaesthetic is often less conservative than one would prefer and teeth with any doubts of survival are extracted due to time constraints, inherent difficulties in performing endodontics or crown and bridgework in a single session in an intubated patient and to avoid any problems in the near future. Also, regardless of symptoms, wisdom teeth are often extracted. To prevent further loss of teeth, adequate daily oral hygiene and a tooth friendly diet are therefore extremely important.

5.1.2.2.3 Oral disease risk behaviours

Bivariate analysis showed that there was no untreated decay for those who were tube-fed and did not eat anything by mouth. Multivariate logistic regression model showed that care recipients who had a moderate intake of sweet drinks were 3.7 times and those who had a high intake of sweet drinks were 3.3 times more likely to have untreated decay compared to those who had a low intake of sweet drinks. These findings are not unexpected, but it should be noted that of the many factors that influence oral health, diet is perhaps one factor that can be modified by carers, without much resistance from their care recipients, as opposed to daily oral hygiene care.

Medication usage

Although many care recipients took medications that reportedly have been associated with dry mouth, caries experience was significantly associated with the intake of one or more medications but not with the type of medications. The number of medications was also significantly associated with increased extensive gingivitis in the bivariate analysis, but neither remained statistically significant in the multivariate analysis, demonstrating that confounding by other characteristics may have been responsible for the apparent association. This is consistent with the findings of Gabre et al. (2001) which also found no correlation between use of medication and dental caries.

5.1.2.2.4 Carer characteristics, their knowledge, attitude and behaviour

Carer characteristics

Bivariate analyses showed that the prevalence of missing teeth, mean DMFT and extensive plaque, calculus and gingivitis were elevated among care recipients cared for by non-family carers compared with those cared for by family carers. However, none of them were significant in the multivariate analyses.

Interestingly, extensive plaque was also more frequent among care recipients cared for by male carers, which was further confirmed in multivariate analysis. Care recipients cared for by male carers were 3.9 times more likely to have extensive plaque compared to those cared for by female carers. Initially it was thought that perhaps males were assigned care recipients that had more difficult behavioural problems and therefore plaque removal was not as expected, however, no significant association was observed between carer sex and care recipient with one or more behaviour problems or carer attitudes. It could be that male carers are not as persistent or thorough in cleaning their care recipient’s teeth as their female colleagues. If a care recipient does have behavioural issues and has a male as a carer, there should be consideration given to having a male and a female carer working together when providing oral hygiene care.

Contrary to what was expected, bivariate analyses showed experience of carers on training in oral care was significantly associated with extensive plaque, calculus and gingivitis. However, this apparent inconsistent finding could have been because the training reported by carers in this study was too short and outdated. For the same reason, it was not included in the multivariate analysis. Training programmes for carers should be current and appropriate for favourable outcomes and followed up at regular intervals to ensure that expected results are maintained.

5.1.2.2.5 Care provided, continuity of care and effects of caring role

Dental status was not significantly associated with how often carers provided assistance with self-care activities and the length of contact between carer and care recipient. Although the prevalence of extensive plaque, calculus and gingivitis were significantly lower in care recipients who had been in contact with their carer for over 10 years in bivariate analysis, there was no difference in multivariate analyses.

High weekly hours of care provided by carers was associated with a high prevalence of missing and filled teeth, caries experience and oral hygiene, but not with untreated decay and gingival status in bivariate analyses. This association was confirmed in the multivariate analyses for all except extensive calculus. Low and high weekly hours of care provided by carer were also significantly associated with a higher prevalence of missing teeth. Care recipients with low weekly hours of care were 3.4 times more likely and those with high weekly hours of care were 4.2 times more likely to have a missing tooth compared to those with medium weekly hours of care provided by their carers. Care recipients with high weekly hours of care were 4.4 times more likely to have a filled tooth and 6.3 times more likely to have caries experience compared to those with medium weekly hours of care. Mean DMFT was greater by 3.6 teeth among those with high weekly hours of care hours compared to those with medium weekly hours of care. Those with high weekly hours of care were 4.0 times more likely to have extensive plaque compared to those with medium weekly hours of care.

The higher odds of missing teeth in care recipients with low weekly hours of care may be a reflection of inadequate time to build good rapport between carer and care recipients to provide better care. The higher odds of missing teeth, filled teeth and extensive plaque among care recipients with high weekly hours of care with carers may be a reflection of carer burden. Increased work load, coupled with low pay can result in high turnover of paid staff, which in turn may affect the rapport built with the care recipient and adversely affect the quality of care provided. However family carers may be left with no choice. To summarise, managers should ensure that carers have adequate time with their care recipients to build trust and rapport, but should take caution that they are not overworked, so that optimal care is provided to their care recipients. Respite should be available for parents at regular intervals.

5.2 Methodological strengths and limitations of this study

5.2.1 Study design and sampling

Only a few oral epidemiological studies have been conducted among people with physical and intellectual disabilities, due in part to the challenges of selecting a representative sample of this population. As a sampling frame of people with physical and intellectual disabilities is not available in South Australia, many possible sources were considered – Centrelink[1], carers' associations, and patients attending Special Needs Unit at various SADS locations. Eventually, information on all known disability organisations in Adelaide that provide accommodation and/or support services to adults with disabilities was obtained from the Disability Information and Resource Centre and Community Information Strategies Australia Inc. This sampling frame allowed access to carers from all three residential settings, via a two stage sampling procedure: first, by approaching administrators of organisations, and second, approaching people who provided care to people with disabilities registered with each organisation. Thus, one strength of this study lies in its sound sampling strategy. Further, all analyses (except description of organisation participation and yield of participants) were undertaken using weighted data which population estimates. To date, this is the first study that has estimated population prevalence using weighted data to compare the oral health of adults with physical and intellectual disabilities in various living arrangements. The findings therefore are representative of the South Australian disabled population.

Age was limited to 18–44 years of age in order to represent the adult population and to provide access to a wide range of carers, including siblings, parents, partners and other carers. The sampling design also permitted selection of care recipients living in different

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[1] Centrelink is an Australian Government Statutory Agency, assisting people to become self-sufficient and supporting those in need.

residential settings which formed the basis for the primary aim of this study, namely to investigate whether different residential settings were associated with variation in oral health.

The disabling conditions selected were autism, cerebral palsy, intellectual disability, spina bifida and quadriplegia on the basis that most people with these conditions would be receiving partial or complete assistance for oral care from their carers. This selection included most conditions under the larger category of people with physical and intellectual disabilities, in contrast to previous studies where certain groups of disability were excluded. For example, the US study of residents with mental retardation by Thornton et al. (1989) excluded people with Down syndrome due to a high incidence of periodontal disease associated with the syndrome. In this study, Down syndrome was included in the intellectual disability category.

However, this was a cross-sectional study limited to South Australian population. The sampling method excluded people who are not registered with a disability organisation, for example, people with disabilities who are cared for by a parent who is not a member of any of the listed organisations. Only primary or key carers were included in this study. In the real situation, care recipients are often cared for by more than one carer. Also, one carer may have been the primary carer for two or more care recipients and therefore responded on behalf of all of them.

One organisation was identified as interacting with non-English-speaking care recipients and carers. Several phone calls were exchanged to discuss the possibility of participation in this study, with options for translation of the questionnaires, but the offer to participate was declined. Therefore, the study was limited to English-speaking carers. In a multicultural country like Australia, care recipients from non-English-speaking backgrounds should not be disadvantaged and further efforts should be made for their inclusion in future research among this population.

5.2.2 Response

5.2.2.1 Questionnaire

From a total of 1280 invitations to participate in the study, responses were obtained from carers of 485 care recipients. Consistent with the recommended methods for mail surveys, a reminder card and final follow up letter was sent to the sampled people who did not initially respond. A few sampled carers were upset on receiving the reminder card itself and requested to be removed from the mailing list. Some returned blank questionnaires or with short comments like ‘thanks but no thanks’ and ‘happy with private practice’. This may be an indication of the low priority to oral health research by carers, or of oral health itself. Some called to say they were not willing to participate, giving reasons like they were sick of surveys that did not help them and that research is done only to get a degree. On the other hand, a few wrote encouraging comments like “congratulations, on doing this study as teeth are a very important issue, that effect many health issues” and requested they be sent the results of the study. One 75 year old lady called to say she was unable to fill the form and there was no one else to help her, highlighting yet another problem for elderly carers. Such comments are noteworthy and should not be ignored when considering how best to support carers in an effort to improve care recipients' oral health.

Due to the nature of the sampling frame, which merely listed care recipients' names, little was known about the characterisitcs of non-respondents, and hence there was virtually no capacity to undertake analysis of potential non-response bias. According to the chief administrators of the participating organisations, the response to the questionnaire had been much better than previous studies that their organisations had participated in, with a total yield of 38%. Yet, even among those who responded, there were only a few that responded to all questions. Most questions relating to care recipients were answered, but carers were reluctant to answer questions relating to them. It is interesting to note that over 38% of carers did not state their age and over 30% their country of birth. Some of them wrote comments that the study was for care recipients and their information was none of our business!

5.2.2.2 Oral examination

All respondents who indicated in the questionnaire that they were willing to participate in the examination were contacted by phone. The intention was to create a personal contact and to reassure carers of the legitimacy of the study. Every effort was made to reach the maximum number of subjects from each residential setting. This included calls at different times of the day and follow-up calls when they failed to attend, with as many as five re-appointments.

Carers who did agree to their care recipient being examined offered numerous explanations: ‘will not co-operate’, need for sedation/GA, seeing private practitioner or attending other SADS clinics and ill-health. Again, every effort was made to overcome these barriers, explaining the examining dentists were the few experts in the area of special needs and experienced in the dental management of people with disabilities. If sedation/GA was necessary, information was obtained at the time of the next scheduled sedation/GA session. No GA was conducted exclusively for the purpose of the study. If the private practitioner or SADS clinics were known, the treating dentist was contacted and consent and examination forms sent to record information from the routine dental examination, avoiding the need to re-examine the care recipient. If illness was the reason for not attending an oral examination, they were contacted again after a few weeks.

For other carers, transportation was an additional problem. To overcome this, reimbursement or vouchers should be taken into consideration for future research in special needs population. However, this was beyond the resources available for this study.

The number of participants for oral examinations of care recipients reduced further, as some carers who had responded for their care recipients had left their jobs and could no longer be contacted. In spite of all efforts, complete examinations were possible for only 267 care recipients, a total yield of 55%, of those care recipients identified through the mail survey of carers, which was still better than other similar studies like that conducted by Cumella et al. (2000) on adults with intellectual disability in the UK, which had a response rate of only 43%. Examinations could not be completed on 17 care recipients due to behavioural problems. Information on response rates in studies as this may help other researchers researching other special needs populations.

5.2.3 Non-response bias

The low response rate may have compromised the quality of the data obtained. Only the enthusiastic carers may have responded. Response rate from family carers was the lowest and among those who responded, they had more problems obtaining dental care and negative effects of caring role than carers at other settings. It can only be postulated that the non-responding carers may be as likely as or even more disadvantaged than those represented in this study.

Also, the majority of the care recipients examined were already receiving regular dental services from SADS dentists at Adelaide Dental Hospital, Strathmont Centre and Julia Farr Services. Some of them who were receiving services at School Dental Service or Women's and Children's Hospital and initially not participating in the oral examination part of the study later requested to be seen, after their carers realised they were no longer eligible after turning 18 years old. To summarise, the non-participants may not have been in contact with any dental services and therefore, this study may have produced results that have underestimated the problems of access to clinical care and the prevalence of oral diseases.

5.2.4 Proxy-reported data

In this study less than half the sample could communicate verbally. Therefore, results from the questionnaire are mainly proxy-reported data. While there are concerns in the literature about the reliability and validity of proxy-reported data on behalf of people with cognitive limitations, it can be justified as addressed by Freedman and Chassler, 2004 as follows:

1. The health and behavioural data obtained from proxies are primarily fact-oriented, e.g., types of medications used, evidence of specific behavioural problems. Recent research indicates that proxies may be considered reliable sources of objective data about adults with mental retardation, but not as appropriate in providing subjective data related to consumer satisfaction or quality of life (Perry and Felce, 2002).
2. The health and behavioural data were obtained from proxies for all respondents in this study, which avoided potential discrepancies between proxy data collected for some respondents and self-report data for others.
3. The questionnaire in this study was too lengthy and complex to be asked directly to care recipients with significant cognitive limitations.

Also, it is likely that carers could have given what they considered to be acceptable responses rather than reporting actual behaviours for example toothbrushing frequency and dental visit patterns.

5.2.5 Recording of oral examination

Oral examinations of care recipients were limited to visual examination. The three examiners were experienced in the management of people with disabilities and used standardised approaches but they were not calibrated, and hence some systematic bias in examination findings may have been introduced. All examinations were conducted at the time of routine dental examination of the care recipients. Hence, it was not possible to conduct replicate examinations needed to compute inter-examiner reliability due to various locations and to avoid undue stress to the care recipients. Therefore, the degree of any such bias remains unknown.

The majority of the examinations (216) were done by AP who examined care recipients from all three residential settings. Less than 20% of the examinations were conducted by MG and SC (Table 5.1). Therefore, the lack of calibration would not have made much difference to the results.

Table 5.1 Number of care recipients examined at the three residential settings

	Residential settings			
Dentists	**Family home**	**Community housing**	**Institution**	**Total**
AP	58	70	88	216
MG	14	18	4	36
SC	4	5	6	15

For this population, accurate measure of indices is extremely difficult. Dental caries and fillings may have been underestimated as only a visual examination was carried out without the use of dental probes or radiographs. The plaque, calculus and gingivitis indices were derived by averaging the scores recorded for the plaque status, calculus status and gingival status of only six index teeth. This method of averaging categorical variables could have compromised the accuracy of the results. Also, the plaque levels measured on the day of the examination may not necessarily reflect actual plaque levels on other days. The periodontal assessment did not include tooth mobility, as it was assumed that it would not be possible to measure mobility for all subjects due to behavioural problems.

5.3 Implications of the study

In Australia, there has been limited dental research on people with disabilities. Although the findings of this study are not definitive (given the study limitations discussed above), they do suggest several implications for public health, health care and research. Thus the findings of this study:

- Have demonstrated the extent of the oral health problems, impacts of oral heath on quality of life, shortcomings in preventive dental practices and barriers to accessing clinical care and identified disability-associated oral disease risk factors.
- Have highlighted the important role of carers as valuable health care team members and that they need additional support in terms of training and incentives regarding oral health care.
- Challenge the dental profession to train adequate number of dentists and hygienists in special needs dentistry to meet the needs of this growing population of people with disabilities.
- Call for the government to establish dental fee assistance/waivers programmes to assist this very disadvantaged population.

5.4 Future Research

While the findings of this study have contributed to the knowledge of the relationship between residential settings and oral health of care recipients, future research could address some of the limitations as well as explore new research questions raised from this study. The Healthy People 2010 chapter on oral health highlights the lack of data for monitoring the oral health of this group of the population (US Department of Health and Human Services, 2000). There is a need to develop and validate standardised data collection methods for people with disabilities to allow for comparisons with different studies. Also, most of the information available is based on cross-sectional studies. Therefore, there is a need for sound longitudinal studies to broaden our current understanding of changes and transitions in oral health outcomes over time and across various living arrangements.

A good evidence base is also lacking in the area of oral health and oral-systemic health interactions of people with disabilities. The complexity increases as more and newer medications and technologies become available every day. Changing oral health care needs of people with disabilities can be addressed via health services research that aims to improve health and health care systems through research on the structure, processes, and effects of health services. Health services research examines the use, costs, quality, accessibility, delivery, organisation, financing, and outcomes of health care services (Hadley, 2000).

Considering the current issues with the increasing numbers of people with disabilities in accessing oral health care and clinical management of oral disease, one of the strongest mandates for such populations are oral health promotion and disease prevention. However, most care recipients are dependent on the carers for their daily oral hygiene care, diet and dental visits. Carers are also responsible for communicating with health care providers, organising appointments and medications and making treatment decisions and providing consent on behalf of their care recipients. Oral health literacy among carers could be the contributing factor to their knowledge, attitude and behaviours on which their care recipients are so highly dependent on and this is another area that could be explored to explain variations in the oral health of people with disabilities.

5.5 Conclusions

Based on the main findings of the study, with reference to the three specific aims, the following conclusions were drawn.

Characteristics of care recipients

In addition to the main disabling conditions like intellectual disability, autism and cerebral palsy, nearly 50% of the care recipients had other disabling conditions like epilepsy, diabetes, and hearing and visual impairments. Almost a third of the care recipients had little or no effective communication and one fifth of them communicated non-verbally. Over 62% of the care recipients always needed help with one or more self-care activities. A disability support pension was the main source of income for the majority of the care recipients. All of these factors make this population dependent on their carers for their general well-being and health care.

Perceived oral health and treatment needs and impacts on quality of life

About 50% of carers thought that their care recipients presently had an oral health problem and needed dental treatment. The most frequent oral health problem reported was bad breath followed by tooth problems and bleeding gums.

The most frequent perceived treatment need reported was scaling, followed by fillings. In spite of the fairly high prevalences of perceived oral health problems and treatment needs, the prevalence of negative impacts reported from a dental problem was low. However, carers at family homes reported more negative impacts compared to carers from other settings. The marked discrepancy in the proportion of carers reporting a negative impact on quality of life and the presence of a clinically-defined oral health problem may be an indication of an underestimation by carers of pain and suffering among their care recipients or carers not being aware of signs of oral pain due to lack of training in the recognition of such manifestations.

Preventive dental practices and barriers

The predominant method of oral hygiene care was toothbrushing, with very few care recipients using preventive measures like fluoride/chlorhexidine gels or mouth rinses. The majority of the care recipients needed partial or complete assistance from their carers for cleaning their teeth, with care recipients at institutions being most likely to need such assistance. Nearly 40% of the care recipients had their teeth brushed once a day or less, which was more common among care recipients at family homes who also reported inadequate time to clean compared to those in community housing and institutions.

Most residents at institutions visited the on-campus dentist every six months. A much lower percentage of care recipients from community housing and family homes received six monthly dental visits. Many parents were not even aware of dental services available for their care recipients after 18 years of age. Other carers reported problems of accessing dental care due to lack of dentists with adequate skills in managing people with disabilities followed by cost, location of dental clinic, lack of dentists willing to treat people with disabilities and transportation problems. Nearly 19% of the care recipients required a general anaesthetic for examination and treatment, while 13% were treated in the chair under sedation.

Oral disease risk behaviours

Sweetened tea/coffee was the most frequently consumed food. Nearly 50% of them drank soft drinks/cordials more than once a day. A higher proportion of care recipients at institutions took a high intake of sweet drinks compared to care recipients at other settings.

The majority of the care recipients took one or more medications, most of which have been associated with dry mouth and candidiasis, or gingival hyperplasia or mucosal problems. The proportion of care recipients taking such medications with potential adverse effects was higher at institutions than those at family homes and community housing.

Very few care recipients were reported to be current smokers or past smokers. However, clenching, grinding or tapping teeth was present in almost a third of the care recipients. Nearly 10% placed food/medicine/other products in the mouth for lengthy periods of time, 8% regurgitated, re-chewed and re-swallowed food, while 5% craved for and ate non-edible substances like cigarette butts.

Carer characteristics

There was almost equal representation of family and non-family carers. Over 82% of them were females and just over 33% above 55 years of age.

Knowledge and attitudes of carers

Only a few carers had received training in oral care and less than 50% of them wanted training in oral hygiene care for people with disabilities. The training received was short and not current. However, most of the carers thought oral health care is important for them and their care recipients and were comfortable providing care.

Care provided to care recipients, including continuity of care and its effects

Most of the carers in all three settings always/sometimes provided assistance with self-care activities, with over 50% of them being the primary carer for over 10 years. Less than 49% of carers were able to clean all teeth for their care recipients, possibly due to one or more behavioural difficulties among the care recipients. Time spent per cleaning session ranged from less than a minute to over 6 minutes, which was adequate for most of them, but more family carers reported inadequate time to clean teeth compared to carers at other residential settings. Lack of staff and lack of communication among staff were additional difficulties for paid carers in providing oral hygiene care for their care recipients.

In spite of many carers working over 100 hours a week, the majority of them reported being satisfied with their caring role. However, they also reported to have been stressed, weary and experienced muscle pain in neck/back/limbs.

Over 50% of the care recipients were cared for by two to four carers, with more care recipients at community and institutional settings cared for by more than five carers on a daily basis, compared to those at home, most of whom were cared for by one or two to four carers. Most carers at family homes had only one care recipient under their charge, while most carers at community and institutional settings cared for two or more care recipients.

Oral health status and factors influencing the oral health status of care recipients

The prevalence of untreated decay among the care recipients in South Australia was 17% and 76% had past and present caries experience. None of the examined subjects wore a removable prosthesis, although nearly 50% had one or more missing teeth.

After adjusting for all potential confounders, there was no statistically significant difference in untreated decay, missing teeth, filled teeth, caries prevalence or mean DMFT between care recipients at the three residential settings. This finding therefore failed to support the alternate hypothesis that oral health would be poorer among care recipients in institutions. However, untreated decay was significantly associated with moderate and high intake of sweet drinks and never visiting the dentist or visiting only because of a problem. Missing teeth were significantly associated with requirement for a general anaesthetic for dental treatment and having low and high weekly hours of care. Filled teeth were significantly associated with 35–44 age-group**,** lack of oral hygiene assistance from carers and high weekly hours of care. Caries prevalence was significantly associated with 35–44 age-group, lack of oral hygiene assistance from carers and high weekly hours of care. Mean DMFT was significantly associated with 35–44 age-group, autism, intellectual disability, and high weekly hours of care.

Anterior tooth wear was found in 45% and posterior tooth wear in 24% of care recipients. Care recipients in the community were more likely to have posterior tooth wear compared to those in family homes. Anterior tooth wear was significantly associated with older age-group and rumination.

Oral hygiene and gingival status were poor with the prevalence of extensive plaque at 40%, extensive calculus at 42% and extensive gingivitis at 36%. Residential setting was not associated with oral hygiene and gingival status. However, extensive plaque was significantly associated with 35–44 age-group, poor to fair general health, habit of placing food/medicine/other products in mouth for lengthy periods of time, care recipients cared for by male carers, and care recipients with high weekly hours of care. Extensive calculus was significantly associated with older age-group, while extensive gingivitis was significantly associated with always needing help for self-care activities from carers.

5.6 Recommendations

Based on the conclusions drawn from this study, the following recommendations have been made.

Advocacy

People with diminished competency, such as the participants in this study share an important characteristic with children: an inability to advocate for themselves. This vulnerability places a responsibility on others, not just family members and carers, but also professionals to be advocates to ensure adequate health care is available to meet their needs. Awareness about the importance of oral health, everyday preventive measures and clinical services available for people with disabilities among relevant organisations and family carers, should be raised via formal and informal meetings, and discussions.

Contrary to the widely held belief, oral health and dental practices of care recipients at institutions were not poorer than at family homes and community housing. In view of the ageing of special needs population and their carers, institutional care remains an important living arrangement for people with disabilities. The current organised system of dental care delivery should be supported and maintained at these institutions.

Modification of identified risk factors

Although the basic problem – inadequate oral health may be the same in different populations, the contributing factors may be different. This study showed that there are several factors that influence the oral health of people with disabilities. However, factors like age and disabling conditions can not be modified. Therefore, more attention should be drawn to factors which can be modified:

Reducing frequency of sweet drinks; regular dental visits; ensuring adequate contact between carers and care recipients but avoiding carer burden; and involving adequate carer supervision and assistance in daily oral hygiene care.

Modifiable factors like diet and provision of oral hygiene assistance from carers should be emphasised to prevent caries and maintain good oral hygiene and gingival health. Regular dental visits should be arranged to detect problems at an earlier stage and avoid the need for a GA for routine dental treatment. Managers should ensure that the carers have adequate time with their care recipients to build trust and rapport, but should take caution that they are not overworked, so that that optimal care is provided to their care recipients. Respite should be available for family carers at regular intervals.

Overcoming identified barriers to dental care

Information on barriers is essential for planning appropriate and effective strategies to improve access to oral health services. Several barriers identified in this study were lack of dentists with adequate skills to treat people with disabilities, cost, location of dental clinic, lack of dentists willing to treat people with disabilities and transportation problems, especially for carers at family homes. Lack of training among carers was an additional barrier, with only a few interested in new techniques in oral hygiene and management of uncooperative behaviour.

University education of dentists/hygienists can be improved via career promotion. Training of dentists (undergraduate and postgraduate) and hygienists in providing oral health care to people with special needs at a professional level should include interdisciplinary and inter-professional team experiences, with an emphasis on oral health promotion and disease prevention, so they are competent, willing and motivated to provide preventive services and if necessary treat people with disabilities. Given the difficulty and suffering involved in routine dental treatment in the chair, and risks, expense, and long waiting times in the public sector involved in dental treatment under a general anaesthetic, prevention is far better than treatment strategies. For the more frequent type of preventive care needed, there should be more involvement of hygienists.

There were few care recipients identified, who saw private practitioners on a regular basis. Otherwise, many parents were not even aware of dental services available for their children after 18 years of age. Establishment of a database of dentists willing to treat people with disabilities should help carers in finding dentists and obtaining necessary dental care for their care recipients.

One way to overcome the barrier of cost, is if dental care could be included in Medicare to cover dental care for people with disabilities. Reimbursement for transportation costs, and adequate disabled parking areas close to the dental clinic should help overcome problems of transportation and location of dental clinics.

Training of carers in providing oral health care to people with special needs at residential settings should focus on behaviour management skills and recognition of possible oral health problems by noting changes in behaviour. To overcome the high rate of staff turnover, and the need to train and re-train staff, a pyramid training programme as suggested by Glassman et al., (1994) could be adopted in which the manager/administrator of a residential care facility/agency is trained who then subsequently trains other carers. Alternately, carers who have been trained could train new staff as suggested by Faulks and Hennequin (2000).

Continuity of clinical care

Appropriate referrals should be arranged from the SADS School Dental Service and the Women's and Children's Hospital to the Special Needs Unit at the Adelaide Dental Hospital after care recipients are no longer eligible for services under their care, to ensure continuity of care into adulthood. At the Special Needs Unit, regular recall visits are arranged for the patients. This allows preventive measures to be reinforced and any treatment needed (if any) to be detected at an early stage, which can be managed in the chair and therefore avoid the need for a GA.

Provision of on-campus dental services should be continued at institutions to maintain accessibility of clinical care for people with disabilities who move out into the community. There is growing concern that many of those who leave institutional care and move into community housing lose readily available access to certain regular health care services that are provided at institutions, including dental care. Of greater concern is the loss of daily oral hygiene care by carers.

Use of local resources

In an area of need but an acute shortage of skilled labourforce, the best possible use of local resources should be made. This should include the use of dental students, dental hygiene students and dental hygienists in the provision of oral hygiene to care recipients and oral health education to carers and care recipients.

Interdisciplinary collaboration

Oral health care for people with disabilities involves multiple disciplines. Therefore, innovative programmes need to be established for greater collaboration between dentistry, medicine, educational institutions and social services to achieve a successful outcome. This study showed that a significant number of care recipients need oral sedation or a general anaesthetic for routine dental treatment. Partnerships can be formed with the medical team so that a dental examination and any treatment needed can be conducted when the patient is under a general anaesthesia for other medical problems. Likewise, simple medical procedures like examining ear, nose throat or even taking blood samples could be performed when the care recipient is orally sedated for a dental procedure in the chair. Medical and dental professionals as well as care recipients and their carers will benefit from such collaboration.

Incentives

It must be acknowledged that extra time and patience is needed to manage people with disabilities. Therefore, there should be incentives for enthusiastic students in the form of scholarships to attract them to this new and challenging profession. Likewise, there should be appropriate incentives for the retention of well trained dentists, hygienists and carers who work with them.

Dissemination and sharing of information

Methods for improving the oral health of special needs populations should be shared locally and internationally so as to prevent reinventing of the wheel. The findings from this study can be disseminated to all organisations involved with people with physical and intellectual disabilities and used to improve provision of oral care by carers in residential settings and the oral health of their care recipients.