Exploring Dental Behaviours of Carers of Adults with Disabilities: Oral Health Literacy and Psycho-social Factors

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List of abbreviations

ABS	Australian Bureau of Statistics
ALLS	Adult Literacy and Life Skills
ARCPOH	Australian Research Centre for Population Oral Health
CAM	Carer activation measure
CDE	Carer dental efficacy
COHC	Carer oral health competence
GA	General anaesthesia
GFI	Gunning Fog Index
GL	General literacy
OHL	Oral health literacy
PHCS	Perceived Health Competence Scale
PID	People with physical and intellectual disabilities
REALM	Rapid Estimate of Adult Literacy Measure
SADS	South Australian Dental Service
SCT	Social Cognitive Theory
TOFHLA	Test of Functional Health Literacy in Adults
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Abstract

Background: People with physical and intellectual disabilities (PID) depend on their carers for daily oral care at home and attending regular preventive dental visits. However, very few carers seem to receive training in oral care for people with PID. Carers‟ oral health literacy, and psycho-social factors (carer dental efficacy, carer oral health competency, and carer activation measure) may be associated with the ability of carers to provide good oral care to their care recipients. The oral health care provided could be further associated with the environment, such as the residential setting of the care recipients where the care is provided. Thus, the aims of the study were to describe and compare oral health literacy and psycho-social factors among carers, and assess any associations with preventive dental behaviours. Favourable associations could then be utilised to make recommendations for the development of appropriate education programmes for carers, that match their oral health literacy and psycho-social preparedness, so that carers can provide more appropriate care for their care recipients.

Methods: The research was a follow-up study of carers of adults with PID living in Adelaide in three residential settings: family home; community housing; and institutions. Data were collected (February 2009 - April 2010) through a structured face-to-face interview of 100 carers. Oral health literacy (OHL) and general literacy (GL) were measured using text passages and prompts with a total of 25 items to assess comprehension and numerical ability of carers, based on five domains: accessing dental care, understanding appointments, completing medical history and consent forms, and following medication instructions. Carer dental efficacy (CDE) was measured using five items on oral care behaviours. Carer perceived oral health competence (COHC) was measured using five items on managing oral health care. Carer activation measure (CAM) was used to determine capability or readiness to engage in desired oral health behaviours. CAM included 13 items on three subscales- Knowledge, Skills and Confidence. The key outcome measures were toothbrushing and dental visiting pattern.

Results: GL score was higher than OHL score among all groups, but neither of the literacy scores were significantly associated with the toothbrushing and dental visit frequency of the care recipients. After adjusting for carer and care recipient characteristics, multivariate analysis showed that twice a day toothbrushing was significantly associated with higher CDE [OR= 4.2 (1.5, 11.6)]. Regular dental visit among the care recipients was significantly associated with

higher CDE [OR= 4.7 (1.3, 17.2)], COHC [OR= 5.7 (1.4, 23.4)], and CAM-Skills [OR= 4.3 (1.1, 15.9].

Conclusions: OHL among carers was not associated with key dental behaviours for care recipients. However, psycho-social factors (carer dental efficacy, carer oral health competence, carer skills) were associated with dental visit frequency. CDE was also associated with toothbrushing frequency. These psycho-social factors may be enhanced by providing encouragement and positive reinforcement to carers, and by specific interventions that match their level of preparedness. Providing such support and guidance to carers may then improve their ability to provide appropriate oral health care for their care recipients.

Signed statement

I Archana Pradhan certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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Date: ……

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Thesis format

This thesis presents an introductory chapter that provides background information that led to this research, and gives an overview of various theories in health behaviour change. It also includes a conceptual framework, thesis rationale, aims and hypothesis. 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", or "residents".

The second chapter reviews available literature on health and oral health literacy and the effectiveness and applicability of various psycho-social theories in health behaviour modification. This includes a review of the associations of oral health literacy and psycho-social factors among carers with dental behaviours- toothbrushing and dental visits. The third chapter describes the study design, sampling frame and data collection methods including details of the structured interview, and a summary of the analytical approaches undertaken. The fourth chapter includes responses from the carers and results from the face-to-face interviews completed by them. The final chapter discusses the major findings of the study, whenever possible, comparing them with previous studies. It also includes the strengths and limitations of this study and the significance and implications of findings. It concludes with recommendations based on the findings of this study.

Tables and figures are presented together with their corresponding text, where possible. References to published work are in the text with the author(s) and date of publication in parenthesis. Where there were three or more authors, the first author is listed, followed by et al., in the text. The complete list of authors is listed in the bibliography at the end. Where there were multiple references for an author, references are listed in the bibliography in alphabetical order of authors and date. The appendices include primary approach letters to the administrators of organisations, contents of information package for the study participants, structured interview, and letter of approval for ethical approval of the study.

CHAPTER 1. INTRODUCTION

This thesis describes the dental practices among carers for adults with disabilities. It also explores various factors that may be associated with the dental behaviours of carers, including oral health literacy and psycho-social factors. This chapter begins with a background that led to this research, and gives an overview of various theories in health behaviour change. The thesis rationale is based on the significant role of carers and the need to explore oral health literacy levels and psycho-social factors in the planning for oral health education programmes for carers. A conceptual framework is proposed to explain factors that may be associated with the dental behaviours of carers. Finally, the aims and hypothesis of this study are presented.

1.1 Background

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). The ABS 2009 Survey of Disability, Ageing and Carers reported four million people in Australia (18.5%) as having a disability in 2009 (ABS, 2010). However, the most recent National Health Survey conducted by the Australian Institute of Health and Welfare (AIHW) included only severe or profound disability conditions like mental health, back problems, arthritis, cardiovascular diseases and asthma, but excluded people in institutions and disability conditions in the Australian population such as Down syndrome, cerebral palsy and dementia (AIHW, 2010). Institutions or family homes had been the main living arrangements for people with disabilities, however, with the Australian deinstitutionalisation initiatives from the 1980s (Wen and Madden, 1998), people with intellectual disability typically have been moved from state institutions to live in state-operated community group homes (Molony and Taplin, 1990).

Due to difficulty in dental treatment, prevention of dental diseases with consistent daily oral care and regular preventive dental visits is particularly important among people with disabilities. These preventive dental behaviours, however, depend on the carers‟ ability to provide daily oral

care, recognise problems, and seek and obtain appropriate dental care. Carers provide informal assistance to persons with disabilities, long-term conditions, or persons who are elderly (ABS, 1999). They may be family carers or non-family carers. However, very few carers seem to receive training in daily oral care for people with disabilities, with most of them trained 'on the job' (Simons et al., 2000) at community and institutional settings and those in family homes receiving virtually no training (Pradhan, 2008). Lack of formal training for carers means that further barriers to care are experienced by people with disabilities (Fiske et al., 2000).

Dental behaviours of carers have been associated with the daily oral hygiene care and dental visit pattern for their care recipients with disabilities (Pradhan, 2008). More carers in family settings were reported to be practising infrequent toothbrushing for themselves and their care recipients, possibly due to lower a priority to oral health and/or carer burden, compared to carers at community and institutional settings. Similarly, there was a significantly higher number of carers from family homes who had never visited the dentist or visited only because of a dental problem compared to carers at community and institutional settings (Pradhan, 2008). Wardh et al. (2000) also noted that personal dental experiences seem to influence the ability of carers to provide good daily oral care to their care recipients. Therefore, attention to factors associated with dental behaviours of carers may offer an insight into addressing the oral health care of those people with disabilities for whom they provide care. Additional factors that need to be further explored are oral health literacy and psycho-social factors among carers and the environment such as the health care system and the residential setting where the care is provided.

1.1.1 Health promotion

Health promotion efforts during the 1970s to 1980s focused on trying to improve oral health by attempting to change knowledge, and in turn, individuals‟ behaviours. The emphasis was on transmission of information, based on the relationship between communication and behaviour change. Recognizing that education is a necessary but not a sufficient component of any health behaviour change intervention, contemporary health promotion and disease prevention are now adopting a broader perspective addressing multiple determinants of oral health (Watt et al., 2001) beyond the individual level (Bandura, 2004a). Research aimed at informing health promotion efforts should therefore consider psycho-social and physical aspects of the individuals‟

environment as well. This calls for a more ambitious, and broader range of health promotion efforts and socially-oriented research.

1.1.2 Health literacy

Health literacy is a relatively new concept in health promotion that emerged in the 1980s. Especially since the 1990s, health literacy has emerged as an independent research field. Health related activities are a part of peoples‟ daily experiences. In health care settings, patients are expected to fill out medical history forms, make health decisions, sign consent forms, and read and follow directions. The Adult Literacy and Life Skills (ALLS) survey by ABS (ABS, 2006) provides information on knowledge and skills in the following domains:

Prose literacy- the ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures;

Document literacy- the knowledge and skills required to locate and use information contained in various formats including job applications, payroll forms, transportation schedules, maps, tables and charts;

Numeracy- the knowledge and skills required to effectively manage and respond to the mathematical demands of diverse situations;

Problem solving- goal-directed thinking and action in situations for which no routine solution is available; and

Health literacy- produced as a by-product of the above domains.

In the ALLS, the ABS defined health literacy as the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy. In The Healthy People 2010 document, health literacy was defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (US Department of Health and Human Services, 2000a). The World Health Organisation (WHO) has adopted a definition of health literacy that reflects a health promotion orientation, and states that health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve

personal and community health by changing personal lifestyles and living conditions (Nutbeam, 2000; 2008) and improved self-efficacy in relation to defined tasks (Nutbeam, 2000).

There are five Skill levels (only four levels for the problem solving scale) with Level 1 being the lowest measured level of literacy. Level 3 is regarded as the "minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy." Approximately 60% of Australians (15 to 74 years) attained scores at Level 1 or 2, 35% were at Level 3 and 6% were at Level 4 or 5 (ABS, 2006). In a developed country like Australia, this was surprising, and indicated that individuals may not be able to consistently apply their general literacy in situations requiring specific content knowledge, or in a new environment. It is possible that for many individuals, as patients and carers, health care settings are unfamiliar and challenging environments.

Although the current definitions imply that health literacy is directly linked to changed health behaviours and practices, evidence is inconclusive as to whether health literacy is a necessary or sufficient condition for accomplishing the ultimate goal of better health, given a wider range of options and opportunities for health (Nutbeam, 2008). With the inbuilt link between knowledge, empowerment and health-promoting actions, Nutbeam does not believe that these definitions consider the possibility that someone may possess and understand health information without using it in health-promoting ways, and questions how we can describe the health literacy of someone who knows and understands the health risks of „binge drinking", but chooses to ignore them. Such an example indicates that the possession of health information does not mean the correct understanding of it, resulting in a failure to use it to promote health. According to Nutbeam, people who have better-developed health literacy will thus have skills and capabilities that enable them to engage in a range of health enhancing actions including personal behaviours, but it is important to accept motivation and activation as inseparable aspects of health literacy. Thus, having information alone is no guarantee that it will be used to promote health (Nutbeam, 2000).

More recently, health literacy is being viewed at both the patient-level and health-care system level. Many of the health disparities associated with health literacy may be due the complexities of the health-care system, the accessibility of the health care workforce for the target population, the preparedness of the health care workforce to engage productively with the patient, and the

features of the health care system and community in which the care-giving and self-management support take place (Paasche-Orlow et al., 2006). Health literacy is believed to affect access and utilization of health care, patient-provider relationship, and self-care activities (Paasche-Orlow and Wolf, 2007). Accordingly, others suggest clinical and public health approaches to health literacy (Pleasant and Kuruvilla, 2008). The clinical approach tends to characterize health literacy as a problem that patients have, and aims to help physicians better communicate, so patients can better understand and comply with treatment regimens. On the other hand, researchers working with a public health approach to health literacy connect health literacy with health promotion and social marketing of public health interventions.

1.1.3 Oral health literacy

Regarding health literacy in dentistry, there have been a few studies limited to assessing the reading level of patient educational materials (Alexander, 1999), and post-operative materials (Chung et al., 2000). The general finding was that many dental instructions and brochures have a level of difficulty beyond the average patient"s reading ability and often contain jargon. Given the increased attention to links between literacy and health, studies of literacy have been added to the oral health research agenda. The definition of oral health literacy has been adapted from the definition of health literacy in The Healthy People 2010 document as the degree to which individuals have the capacity to obtain, process, and understand basic *oral* health information and services needed to make appropriate oral health decisions (NIDCR, 2005). Oral health literacy is thus not simply the ability to read, but requires a complex set of reading, listening, analytical, and decision-making skills. This definition therefore addresses functional oral health literacy, encompassing knowledge as well as the ability to use that knowledge to apply skills in making appropriate oral health-related decisions.

1.1.4 Psycho-social factors

There are many psycho-social models of health behaviour based on the common metatheory that psycho-social factors are strong contributors to health. Their focus is on the social context of behavioural decisions to enable people to develop personal and social skills necessary for positive health behaviour choices. This thesis explores psycho-social factors among carers on the following concepts and theories:

1. Behaviour is mediated by cognitions; that is, what people know and think affects how they act (self-efficacy) (Bandura, 1977).

2. Education and therefore knowledge is necessary for, but not sufficient to produce, most behaviour changes (Nutbeam, 2000; Watt et al., 2001).
3. Beliefs, motivations, skills, and the social environment affect behaviour and outcomes (Bandura, 2004a; Hibbard et al., 2004).

1.2 Research problem

In spite of the availability of a range of preventive measures for oral diseases, carers do not always utilise these measures or seek appropriate dental care for their care recipients. Researchers with a focus on oral health literacy claim the literacy concept may explain to some extent the gaps between what science discovers, health systems deliver and the public uses (NIDCR, 2005). Several instruments have been developed to identify patients with potential literacy problems in an attempt to overcome the adverse effects of low oral health literacy. However, oral health literacy is complex to measure as it involves knowledge, motivation and activation. Another group of researchers have focused on psycho-social factors to explain health behaviours. This current study explores both oral health literacy and psycho-social factors among carers due to their potential influential position in the provision of daily oral hygiene care, diet and regular dental visits for their care recipients.

Therefore, this research attempts to answer the following questions:

- What is the current functional oral health literacy and psycho-social preparedness among carers?
- Do carers at various settings vary in oral health literacy levels and psycho-social preparedness?
- What are the factors that are associated with high or low oral health literacy levels and psycho-social preparedness among carers?
- Is there any association between oral health literacy level, psycho-social factors and oral care provided for care recipients?

1.3 Rationale

The rationale for studying this research problem is broadly based on two issues.

Role of carers

People with disabilities depend on carers for daily care. Carers are responsible for a wide range of issues including health promotion, health protection and disease prevention. They need to ensure a healthy diet and maintain daily oral hygiene care for their care recipients. They need to be able to screen, recognise, monitor and describe changes in signs and symptoms so as to make timely appointments. They need to know where and how to access care and be able to navigate systems and organise appointments. They need to be able to communicate well with health care providers and provide information for assessment and diagnosis, and give consent to an appropriate treatment plan. They are involved in health care and maintenance by scheduling and timing medicines and complying with instructions. However, carers‟ oral health literacy, and psycho-social factors towards the oral health care of their care recipients (carer dental efficacy, carer oral health competency, and carer activation measure) that may be associated with the ability of carers to provide good oral care to their care recipients have not yet been explored.

Oral health intervention programmes for carers

Few studies have focused on patients' and carers' perceptions of their information needs in relation to specific conditions or patient groups (Hagenhoff et al., 1994; Luker et al., 1995). Identifying patients' and carers' perceptions of their information needs has been viewed as important in empowering patients and enabling them to make informed decisions regarding treatment options, and in increasing patient satisfaction (Luker et al., 1995). Likewise, health care professionals have a responsibility to use education materials that will meet the special learning needs of carers. Providers tend to be unaware of their patients limited literacy levels (Bass et al., 2002). A motivating premise for this research is the lack of carer education or training in the oral care of people with disabilities (Pradhan, 2008).

It is intended that this thesis will provide information on carers‟ oral health literacy and psycho-social preparedness towards preventive dental behaviours. This information will be valuable in the development of materials for planning and implementation of oral health intervention programmes of carers in the provision of oral care for people with disabilities so carers can provide the best possible care for their care recipients. This thesis will also assist in building

knowledge in an area of research that needs better understanding and clarity not only in Australia, but worldwide. Also, highlighting the important role of carers could help them be recognised as valuable health care team members and oral health intervention programmes tailored to match their oral health literacy and psycho-social preparedness will hopefully have better outcomes for the people with disabilities for whom they care.

1.4 Aims

The overall aim of the study was to develop and test a brief measure of functional oral health literacy among carers and explore if oral health literacy and psycho-social factors are associated with the behaviours of carers in the provision of oral care for their care recipients. The specific aims were:

1) Among care recipients sampled from three residential settings,

To describe the characteristics of care recipients and preventive dental practices as carried out by their carers;

2) Among carers of the care recipients,

To describe and compare oral health literacy and psycho-social factors (dental-efficacy, oral health competency, and activation levels) among carers;

To determine factors that are associated with higher or lower oral health literacy levels and psycho-social preparedness among carers;

To assess the association of oral health literacy and psycho-social factors with oral care provided (toothbrushing frequency, and dental visit pattern); and

To utilise favourable associations to make recommendations for the development of appropriate intervention programmes for carers, that match their oral health literacy and psycho-social preparedness, so that carers can provide more appropriate care for their care recipients.

1.5 Hypotheses

The hypotheses of the study were:

1) Preventive dental practices among care recipients vary by carer characteristics (carers‟ age, sex, education, income and language most used at home) and socio-structural factors (carer support, and residential settings of the care recipients;

2) Oral health literacy and psycho-social factors (dental-efficacy, oral health competency, and activation levels) among carers are associated with carer characteristics (carers‟ age, sex, education, income and language most used at home);

3) Higher scores for oral health literacy and psycho-social factors among carers are associated with favourable preventive dental behaviours for their care recipients.

1.6 Conceptual framework

The proposed conceptual framework examined in this research is presented in Figure 1.1. Pathways in the framework indicate preventive dental behaviours for care recipients as being associated with several factors. Daily oral hygiene, a healthy diet and regular dental visits are necessary to maintain good oral health. However, most care recipients depend on their carers for these required preventive dental behaviours. Carers‟ oral health literacy and psycho-social preparedness towards the oral health care of their care recipients (carer dental efficacy, carer oral health competency, and carer activation measure) may be associated with the ability of carers to provide good oral care to their care recipients. The oral health care provided could be further associated with the socio-structural factors such as carer support, and how and where the daily home care and regular clinical care is provided. In „socio-structural factors‟, „health care system‟ is mentioned, but not included in this thesis. The „health care system‟ was regarded as beyond the scope of this study. This study focused on carers because the oral health of care recipients depends on the care provided by carers.

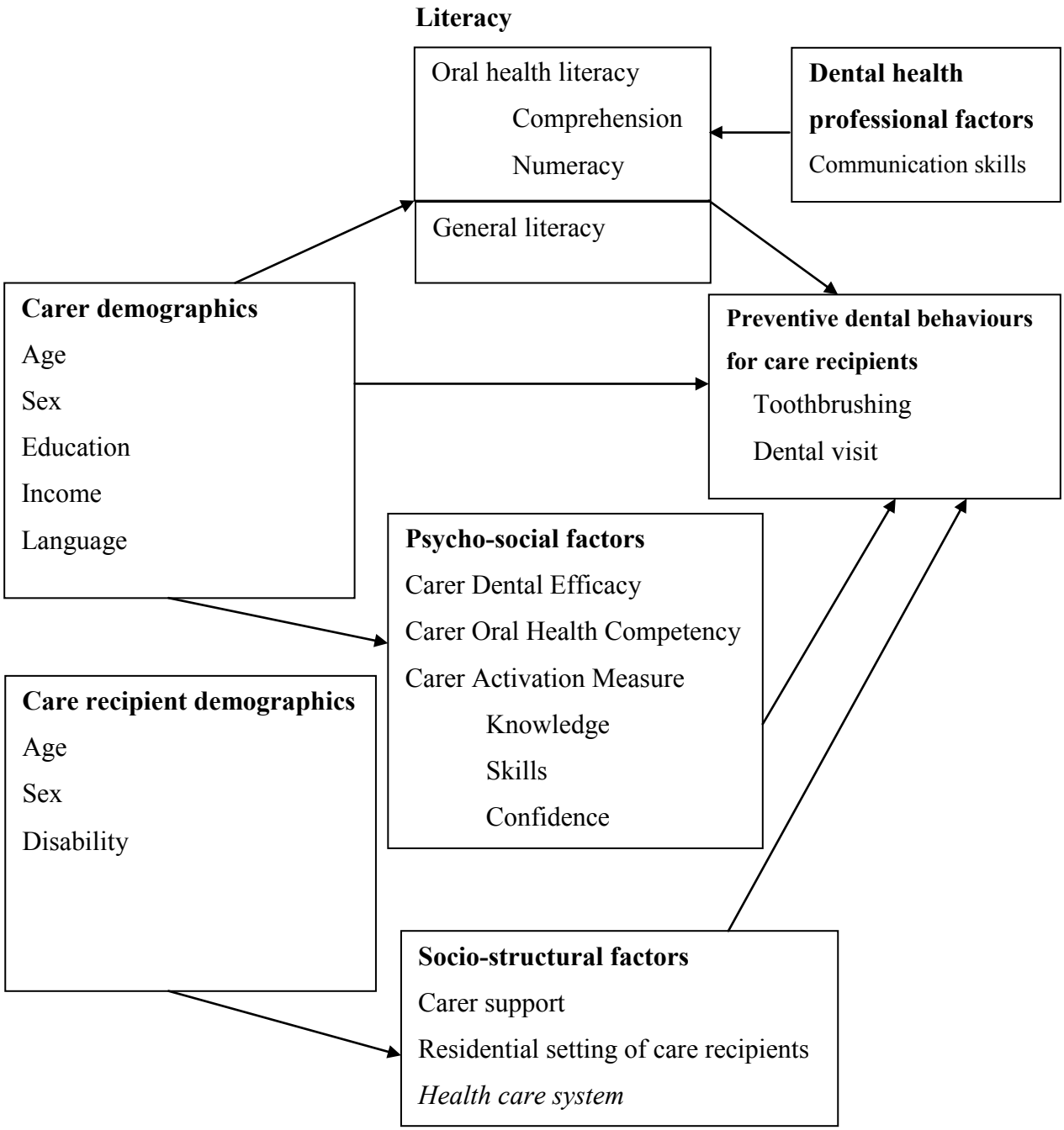

Figure 1.1 Conceptual framework explaining preventive dental behaviours for care recipients

CHAPTER 2. LITERATURE REVIEW

This chapter reviews available literature on health and oral health literacy and the effectiveness and applicability of various psycho-social theories in health behaviour. This includes a review of the associations of oral health literacy and psycho-social factors with dental behaviours-toothbrushing and dental visits.

2.1 Measurement of health literacy and its scope

The field of health literacy has expanded to such scope and depth that the term "health literacy" itself has come to mean different things to various groups, leading to confusion and debate. According to some definitions, health literacy is a set of *individual capacities* that allow the person to acquire and use new information, which are relatively stable over time, but may improve with educational programmes or decline with ageing or pathologic processes that impair cognitive function (Baker, 2006). For others, health literacy is the ability to function in the health care environment, which depends on the characteristics of both the individual and the health care system. It is a *dynamic state* of an individual, which may vary depending upon the health problem being treated, the health care provider, and the system providing the care (Pleasant and Kuruvilla, 2008). Not surprisingly, there is disagreement about how health literacy should be measured and there are several health literacy instruments.

2.1.1 Rapid Estimate of Adult Literacy Measure (REALM)

Rapid Estimate of Adult Literacy Measure (REALM) is a reading recognition literacy screening instrument used widely in health services research and adapted to specific diseases like arthritis and diabetes (Davis et al., 1991). Between one and three minutes, patients read aloud and correctly pronounce from a 66-item list of medical terms arranged in increasing order of difficulty, and one point is scored for each word that is pronounced correctly. The REALM assigns patients to one of four reading grade range estimates: (1) 3rd grade and below, (2) 4th to 6th grade, (3) 7th to 8th grade, and (4) 9th grade and above. However, this is in sharp contrast to the range of skills stated in the definition of health literacy, as it does not address the possession of knowledge or its utilisation, but focuses on pronunciation of clinical and medical terms.

2.1.2 Test of Functional Health Literacy in Adults (TOFHLA)

Test of Functional Health Literacy in Adults (TOFHLA) was designed to measure patients' ability to read and understand the things they commonly encounter in the health care setting using actual materials like pill bottles and appointment slips (Parker et al., 1995). It consists of a 50-item reading comprehension test which has three health-related passages with three degrees of readability. In addition, there is a 17-item numerical ability test which assesses quantitative literacy needed in the health-care setting (i.e. the ability to read and understand numerical information in the form of prescription bottles, appointment slips, or other health-related materials like obtaining financial assistance). Patients are given cue cards or bottles to read (e.g. the directions for taking medication) and then verbally asked questions about the information. The TOFHLA is, therefore, a more accurate indicator of a patient's reading ability because it measures comprehension, including the ability to read and understand both prose passages and numerical information.

2.1.3 Short TOFHLA (S-TOFHLA)

Baker et al. (1999) then developed Short TOFHLA (S-TOFHLA) by reducing the TOFHLA from 17 numeracy items (e.g. prescription bottles, appointment slips) and three prose passages to a version containing four numeracy items and two prose passages. Item selection for the S-TOFHLA was based on data from a large previous study that used the TOFHLA (Williams et al., 1995). For the reading comprehension portion, two passages were included, one at 4th grade level and the other at the 10th grade level. Numeracy items were selected based on the perceived importance and frequency of the task in the health care setting, the proportion of patients who answered items incorrectly, and the perceived ease of administration. The S-TOFHLA has similar reliability and validity to the full TOFHLA, but is more practical because it requires a maximum time of 12 minutes to complete instead of 22 minutes. In addition, the numeracy items selected for the S-TOFHLA are easier to administer than the full battery of questions in the TOFHLA, and scoring correct answers is less subjective.

Links between literacy and health outcomes

Using available health literacy instruments, there have been comparisons between high skills versus low skills in several studies. In a study conducted at two public hospitals using the TOFHLA, one third of English-speaking patients were unable to read the most basic health-

related materials, and the prevalence of inadequate literacy was markedly higher among the elderly (Williams et al., 1995). The most recent national survey of English literacy in the USA included the first-ever assessment of adults‟ ability to perform literacy tasks by using written health-related information (Kutner et al., 2006). This study is important because the skills required to perform a health literacy task are not the same as those required for general literacy tasks, although they are related. Those who experience difficulties are more likely to be men, minorities, elderly and less educated, with worse health, and have public insurance (Kutner et al., 2006).

Systematic reviews in medicine have confirmed that low literacy is associated with adverse health outcomes such as poor knowledge about medical care and medical conditions, lack of understanding and use of preventive services, poorer self-reported health, poorer compliance rates, increased hospitalizations, and increased health care costs (Andrus and Roth, 2002), poorer morbidity measures, general health status, and the use of health resources (Dewalt et al., 2004). Two recent comprehensive reviews were conclusive in linking low parental health literacy with inadequate health knowledge (DeWalt and Hink, 2009) and poor preventive care behaviours resulting in poor child health outcomes (Sanders et al., 2009).

Further, there has been an interest in the progressive testing of interventions designed to mitigate the effects of low literacy through modified communications, and improved service organisation (Coulter and Ellins, 2007; Pignone et al., 2005). More recently, a small number of studies have also considered the costs of low literacy and a failure to manage the consequences to the health care system (Howard et al., 2005). In combination, this work on the costs and effects on health of low literacy has begun to attract the attention of policy-makers and health service providers. Although developers of brief screening tools have promoted the idea of screening in the clinical setting, the usefulness of screening patients for limited health-literacy skills is now being questioned, noting that the only study examining the effect of a screening programme failed to show benefits for patients (Paasche-Orlow and Wolf, 2008). Currently, such testing could lead to stigma with no obvious benefit. Instead, materials written in plain language, using clear communication techniques and confirming comprehension should be provided as part of health care for all patients regardless of their literacy level, adopting the “universal precautions” approach (Paasche-Orlow et al., 2006). If health service providers take the time to evaluate

patient comprehension, they can target each patient‟s specific clinical needs, rather than a specific group of patients. It must also be noted that health literacy also involves knowledge, motivation and activation, and is therefore complex to measure and to influence. These additional factors will be reviewed later.

2.2 Measurement of oral health literacy and its scope

Given the differences between the oral and general health, instruments should be specifically designed to measure oral health literacy. Accordingly, several instruments have been developed to measure oral health literacy.

2.2.1 Rapid Estimate of Adult Literacy in Dentistry (REALD)

The Rapid Estimate of Adult Literacy in Dentistry (REALD-30) (Lee et al., 2007) is a word recognition test modelled on the REALM. The REALD-30 consists of 30 dental words with various degrees of difficulty taken from the American Dental Association Glossary of Common Dental Terminology and patient education materials. Adding 69 new words representing more components of dental health to the REALD-30, thereby creating the REALD-99 (Richman et al., 2007), did not improve the results enough to justify making the list of dental words longer. Low REALD-30 scores have being associated with poor oral health-related quality of life and poor self-rated oral health (Lee et al., 2007).

2.2.2 Test of Functional Health Literacy in Dentistry (TOFHLiD)

Test of Functional Health Literacy in Dentistry (TOFHLiD) is another instrument to measure functional oral health literacy (Gong et al., 2007), that uses TOFHLA as a template. TOFHLiD consists of a 68-item reading comprehension section and a 12-item numeracy section. The reading comprehension section of the TOFHLiD has three passages; a set of instructions about fluoride varnish applications, a consent form for dental treatment and a Medicaid rights and responsibilities form. The numeracy section has questions on instructions for fluoridated toothpaste use, dental appointment, and prescription labels for fluoride drops and fluoride tablets, with a paediatric focus.

2.2.3 Oral Health Literacy Instrument (OHLI)

Oral Health Literacy Instrument (OHLI) was developed to evaluate the functional oral health literacy of adults (Sabbahi et al., 2009). The OHLI measures the patient‟s ability to perform oral health literacy-related tasks that require reading, comprehension and numeracy skills, applicable to the general adult patient population. For the generation of items, different dental patient educational materials and text types were selected that had reading levels similar to materials used for the TOFHLA. The reading comprehension section is a 38-item test with words omitted from one passage on dental caries and another on periodontal disease. The numeracy section has 19 items to test comprehension of directions for taking common prescriptions associated with dental treatment, post-extraction instructions and dental appointments.

Links between oral health literacy and oral health outcomes

Jones et al. (2007) examined the association of dental care visits and oral health status with oral health literacy in adult dental patients in two private dental offices using REALD-30. About 29% of the sample scored low literacy level (below 22 on the 30-point test). Those with fair-to-poor oral health status were more likely to have a low literacy level than were their reference groups. Not having had a dental care visit in the last year was not associated with literacy. Sabbahi et al. (2009) used OHLI among a convenience sample of 100 patients and reported patients visiting a dentist every 3–6 months had significantly higher levels of oral health literacy than those visiting only for pain. In a study among 468 rural-dwelling Indigenous Australians (Parker and Jamieson, 2010) reported that REALD-30 scores were lower among those who believed teeth should be infrequently brushed, believed cordial was good for teeth, did not own a toothbrush or owned a toothbrush, but brushed irregularly.

More recently researchers have examined mother-child dyads for links between oral health literacy and oral health outcomes. Miller et al. (2010) examined the relationship of primary caregivers' literacy with children's oral health outcomes also using REALD-30 among 106 caregiver-child dyads in the teaching clinics at the University of North Carolina. The study showed a significant relationship between caregiver literacy scores and clinical oral health status. Caregivers of children with mild to moderate treatment needs were more likely to have higher REALD-30 scores than those with severe treatment needs. However, there was no significant relationship between literacy and oral health knowledge and behaviours.

Thus, current literature on oral health literacy is restricted to instruments that deal with word pronunciation as in REALD-30 (Lee et al., 2007) and REALD-99 (Richman et al., 2007) or reading comprehension as in TOFHLiD (Gong et al., 2007) and OHLI (Sabbahi et al., 2009) which probably test proficiency in English language rather than oral health literacy. Research has focused on dental patients and mother-child dyads for links between oral health literacy and oral health outcomes and dental behaviours. This study developed a functional oral health literacy instrument assessing dental terms. This instrument aimed to explore oral health literacy among carers in order to determine whether oral health literacy was the missing link between the available information and expected oral health behaviours for their care recipients.

2.3 Patient-provider interactions

Effective patient-provider interactions for the desired health outcome depends on both patient and provider factors. Obstacles that often hamper patient-provider interaction include the relative infrequency of visits, communication barriers such as language, variation in providers‟ communication content and style, lack of trust in the provider, competing problems that get a higher priority and therefore lack of time per visit (Schillinger, 2001). Patients with low health literacy may not only have difficulties reading and understanding written health instructions, but also be passive and avoid asking questions to their clinicians. In a study of 408 English- and Spanish-speaking diabetes patients, Schillinger et al. (2004) reported that compared to patients with adequate functional health literacy, those with inadequate functional health literacy were more likely to report worse communication in general clarity, explanation of condition and processes of care. Likewise, health care providers may be unaware of their patients‟ limited literacy (Bass et al., 2002). Health care providers must be able to communicate successfully and evaluate the patient‟s comprehension of important action items (Schillinger, 2001; Schillinger et al., 2003). Most suggested communication approaches between health care providers and patients with limited literacy have been shown to benefit all patients and harm none (Pignone et al., 2005). A patient-centered approach of confirming comprehension, known as teach-back is now being considered a new standard of care for clinicians (Paasche-Orlow et al., 2006). Adoption of universal precautions for confirming patient understanding can hopefully lead to improved health outcomes, especially for those with limited literacy (Paasche-Orlow et al., 2006). For this, health care providers should be able to show empathy, promote trust, and encourage dialogue and questions from patients.

2.4 Psycho-social factors

2.4.1 Social Cognitive Theory

Social Cognitive Theory (SCT) specifies a core set of determinants, the mechanism through which they work, and the optimal ways of translating this knowledge into effective health practices. The core determinants include *knowledge* of health risks and benefits of different health practices, *perceived self-efficacy* that one can exercise control over one‟s health habits, *outcome expectations* about the expected costs and benefits for different health habits, the health *goals* people set for themselves and the concrete plans and strategies for realizing them, and the *perceived facilitators* and social and structural *impediments* to the changes they seek (Bandura, 2004a). Whereas most of the models of health behaviour are concerned only with predicting health habits, and not how to change health behaviour, SCT offers both predictors and principles on how to inform, enable, guide, and motivate people to adapt habits that promote health and reduce those that impair it (Bandura, 1997). Therefore, SCT is widely used in health behaviour research.

Theories and research have been essentially confined to personal agency for individuals. However, there are several ways in which people influence events that affect how they live their lives. SCT distinguishes among three different modes of agency: direct personal agency, proxy agency that relies on others to act on one‟s behalf to achieve desired outcomes, and collective agency exercised through socially coordinative and interdependent effort (Bandura, 2001). Proxy agency is relevant to this study as it attempts to explore psycho-social factors among carers not for their individual oral care, but for providing oral care for their care recipients.

2.4.1.1 Self-efficacy

Self-efficacy is a construct of the SCT that refers to an individual's own perceived ability to perform a specified behaviour or set of behaviours (Bandura, 1977; Bandura, 1997). Self-efficacy describes a dynamic, ongoing process in which personal factors (e.g., beliefs, attitudes), environmental and behavioural aspects of learning are constantly interacting (Bandura, 2001). Therefore, a change in one of these factors impacts on the other two. Self-efficacy proposes that patients‟ confidence in their ability to perform health behaviours influences motivation and which behaviours they will engage in (Bandura, 2004a). Unless people believe they can produce the desired effects by their actions, they have little incentive to act or to persevere in difficult times.

Whatever other factors may serve as guides and motivators, the core belief is that one has the power to produce desired changes by one‟s actions (Bandura, 2004a). The stronger the perceived self-efficacy, the higher the goals people set for themselves and the firmer their commitment to them. Bandura (1997) states that people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true. These self-efficacy perceptions help determine what individuals do with the knowledge and skills they have. This helps explain why people's behaviours sometimes differ from their actual capabilities and why their behaviour may differ widely even when they have similar knowledge and skills. Hence, people's achievements are generally better predicted by their self-efficacy beliefs than by their previous attainments, knowledge, or skills.

According to Bandura (1977; 1997), self-efficacy is most appropriately measured at a very specific level corresponding directly to the behaviour being studied. The usual procedure for assessing self-efficacy beliefs is to ask respondents how confident they feel in their ability to perform the behaviour of interest. This process has led the development of many highly specific measures e.g., health-specific self-efficacy, exercise self-efficacy, teacher self-efficacy, and so on. This means that an individual‟s efficacy expectations will vary greatly depending on the particular task and context. It is therefore inappropriate to characterize a person as having “high” or “low” self-efficacy without reference to the specific behaviour and circumstance with which the efficacy judgment is associated. Bandura argues that perceived self-efficacy influences all aspects of behaviour, including the acquisition of new behaviours and inhibition of existing behaviours (for example, commencing or quitting cigarette smoking). Based on this principle, carers not previously involved in the oral care for people with disabilities could be educated on the importance of good oral health and trained to provide daily oral hygiene care and encouraged to maintain regular dental visits.

2.4.1.1.1 Self-efficacy and dental behaviours

Several studies have investigated the relationship between self-efficacy and oral hygiene behaviour such as toothbrushing or flossing. McCaul et al. (1985) analysed the self-efficacy of 131 college students in brushing and flossing to predict their task-related behaviour. They found that self-efficacy is significantly related to both the retrospectively reported and prospective self-monitored frequency of brushing and flossing. Their findings also suggested that educational

programmes intended to increase the frequency of such behaviours should focus on increasing self-efficacy, reducing structural and life-style barriers to adherence, and involving significant others in educational efforts. Stewart et al. (1997) also developed questionnaires to measure the self-efficacy in toothbrushing and flossing. In their cross-sectional study among 103 government employees, they demonstrated that self-efficacy scale scores were significantly associated with brushing frequency, flossing frequency, frequency of dental visits, and dental knowledge. Kiyak (1996) reported self-efficacy regarding oral health has been found to be lower than self-efficacy regarding general health and medication use among older adults, especially among non-Western ethnic minorities. Clarkson et al. (2009) developed oral hygiene self-efficacy asking patients how confident they were on a 7-point scale: following advice from their dentist about brushing their teeth; brushing their teeth as often as they should; for as long as they should; the way that they should. They showed that patients who experienced the intervention (tell-show-do approach) had better behavioural (timing, duration, method), cognitive (confidence, planning), and clinical (decrease in plaque, gingival bleeding) outcomes.

Researchers in Finland have conducted several studies related to self-efficacy beliefs, oral health and diabetes outcomes. Syrjala et al. (1999) developed a self-efficacy scale containing six items concerning toothbrushing self-efficacy, six items concerning interproximal cleaning self-efficacy and five items concerning dental visiting self-efficacy and conducted a cross-sectional survey among 149 insulin-dependent diabetic patients. Their results showed that scores for all the three items in the self-efficacy scale were related to the reported oral health behaviour. The visible plaque index correlated inversely with the toothbrushing self-efficacy and dental visiting self-efficacy. Further, those who reported higher frequency of toothbrushing had higher sum scores for dental visiting self-efficacy. Kneckt et al. (1999) reported dental self-efficacy scale scores correlated with dental caries. Syrjala et al. (2004) reported self-efficacy was associated with both oral health habits and diabetes adherence. This finding has lead the authors to suggest that self-efficacy may be a generalised characteristic in health behaviour, proposing that enhanced self-efficacy in one area of health behaviour may also increase self-efficacy in other areas.

2.4.1.1.2 Carer dental efficacy

Self-efficacy in dental behaviours among carers has been referred to differently in various studies. This study refers to carer dental efficacy (CDE). Resin and Litt (1993) investigated

brushing habits, sugar intake in the diet, social class, stressful life events, dental health locus of control, dental self-efficacy, tooth decay, and bacteria in saliva among 481 children, aged 3 years and carers‟ (parent or guardian) low self-efficacy was found to be associated with higher caries rates in their children. Pine et al. (2004) conducted an international study involving 18 countries with 3–4 year old children and their parents, focusing on cultural differences in parental attitudes about brushing, sugar, and early childhood caries (ECC) and likewise, reported self-efficacy to be the strongest significant predictor of children's brushing habits. Mothers with a high self-efficacy score were more likely to ensure that their children visited the dentist for regular checkups, resulting in appropriate treatment for decayed teeth. Further, the mothers with high self-efficacy scores brushed their children‟s teeth regularly (Kakudate et al., 2010).

Two publications have arisen from a study of mother-child dyads living in Detroit, USA. Finlayson et al. (2005) collected data from 719 low-income African American mothers and their 1–5 year-old children through a series of structured questionnaires on knowledge, attitudes and beliefs about children‟s oral health, feelings of self-efficacy related to brushing children‟s teeth at bed time against a variety of potential barriers, children‟s and mother‟s brushing habits and the caregiver‟s subjective perception of the child‟s oral health status and clinical examinations of mothers and children. Knowledge of children's oral hygiene was significantly associated with mothers' oral health perceptions and children's caries status. Oral health self-efficacy was significantly positively correlated with children's brushing frequency and with mothers' subjective perceptions of children's oral health, which was, in turn, significantly associated with children's caries status.

Finlayson et al. (2007) reported on maternal cognitive, behavioural and psycho-social factors and toothbrushing practices. Maternal self-efficacy was a strong predictor of toothbrushing. Moreover, as anticipated, whether or not the mother brushed, was strongly and significantly associated with children's brushing frequency. The authors concluded that oral health-specific self-efficacy and knowledge measures are potentially modifiable cognitions, suggesting that intervening on these factors could encourage healthy dental habits and increase children's brushing frequency early in life.

In a study investigating the multidimensional causal model of caries in 184 pre-school children from low income families, self-efficacy was an important predictor of sugar intake (Litt et al., 1995). However, the self-efficacy scale used in this study did not seem to follow the same criteria of most self-efficacy measures following SCT concepts, which focus on people‟s confidence in their abilities to perform health-related tasks under varied circumstances, such as when stressed or busy. Instead the authors developed a dental self-efficacy scale specifically for this study. It consisted of eight items describing specific preventive dental and treatment behaviours, asking participants to rank their confidence in their abilities to perform the behaviours.

Just as children are dependent on their mothers, so are people with disabilities dependent on their carers. Similar to the findings from mother-children dyads, CDE could be associated with the dental practices for care recipients and in turn their oral health.

2.4.1.1.3 Sources of self-efficacy

Self-efficacy can be gained by several means (Bandura, 1977; 2001):

(i) Mastery experience or performance accomplishment (practising and experiencing success in achieving goals)

This is the most influential source. As a healthy behaviour produces results, success reinforces success, while repeated failures lower expectations. Individuals may have no intention of changing behaviours, but after experiencing a success, behaviours, knowledge and environments change.

(ii) Vicarious experience (observing others perform activities successfully)

This is often referred to as modelling, as the observer expects to improve his or her own performance as a result of the learning obtained by observing the task being performed by someone else. Individuals do not have to experience the affects of poor health choices if they can learn from others' experiences. Observing the successes of models contributes to the observers' beliefs about their own capabilities. Modelled behaviours presented with clear and rewarding outcomes are more effective than modelling with unclear or unrewarded outcomes.

(iii) Verbal persuasion (receiving positive verbal reinforcement from others)

Verbal persuasion refers to activities in which suggestion is used as a tool to raise people's beliefs in their capabilities while at the same time ensuring that the expected success is achievable. Guidance and providing positive feedback on the individual‟s performance are common forms of

verbal persuasion that lead the individual into believing that he or she can successfully perform specific tasks.

(iv) Self-appraisal (monitoring information about the physical and emotional effects of a specific situation)

Affective states such as pain or fatigue deter self-efficacy (Bandura, 2001). Improving physical and emotional well-being can reduce negative emotional states and raise self-efficacy beliefs. All influence an individual's efficacy-expectations that, in turn, influence behaviour, which predicts a particular outcome (Kiyak, 1996; Syrjala et al., 1999; Syrjala et al., 2001). As Bandura (1997) has observed, people live in psychic environments that are primarily of their own making.

2.4.1.1.4 The role of self-efficacy

Substantial evidence from diverse methodological and analytic strategies verifies that, of the different psychological characteristics, self-efficacy is the best predictor of healthy habits and enhances motivation and performance attainments (Bandura and Locke, 2003). Self-efficacy also plays a major role in the initiation and maintenance of health behaviours (Strecher et al., 1986). Therefore, measurement of self-efficacy is helpful for planning patient education programmes because the identification of areas with low self-efficacy helps targeting self-management education to the individual patient.

Self-efficacy is also useful to detect and predict the behavioural functioning between individuals at different levels of efficacy over time, and even variation within the same individual in the tasks performed or attempted but failed. Such measurement of changes in self-efficacy over time is important to evaluate the impact of patient education programmes.

Self-efficacy beliefs also help determine how much *effort* people will give on an activity, how long they will *persevere* when confronting obstacles, and how *resilient* they will be in under adverse situations (Bandura, 1988). The higher the sense of efficacy, the greater is the effort, persistence, and resilience. People with greater self-efficacy approach difficult tasks as challenges to be mastered rather than as threats to be avoided and maintain strong commitment to them. Moreover, they more quickly recover their sense of efficacy after failures as momentary setbacks, and attribute them to external factors like insufficient effort or deficient knowledge and skills that are acquirable. Conversely, people with low self-efficacy may believe that things are tougher than

they really are, and typically attribute the negative outcomes to their own inability to carry out the task (Maibach and Murphy, 1995). This function of self-beliefs can also create the type of self-fulfilling prophecy in which one accomplishes what one believes one can accomplish. That is, the perseverance associated with high self-efficacy is likely to lead to increased performance, which, in turn, raises one's sense of efficacy and spirit, whereas the giving-in associated with low self-efficacy helps ensure the very failure that further lowers confidence and morale.

Many experiments have been conducted in which people receive true feedback concerning their performance, but their efficacy beliefs are changed by incorrect feedback. Such erroneous feedback can serve as a form of persuasory influence (Litt, 1988). Bouffard-Bouchard (1990) instilled high- or low-efficacy beliefs in students by suggesting that they were of higher or lower standing, irrespective of their actual performance. Students whose perceived efficacy was raised set higher goals for themselves, used more efficient problem-solving strategies, and achieved higher intellectual performances than did students of equal cognitive ability who were led to believe that they lacked such capabilities. Likewise, self-efficacy can be raised to improve the performance of individuals.

In addition to the above mentioned direct effects of self-efficacy on health behaviours, it could also serve as a mediator in the knowledge-behaviour relationship, facilitating the translation of knowledge into behaviour (Rimal, 2000). All of these roles of self-efficacy could be applied to carers providing oral care.

2.4.2 The Perceived Health Competence Scale (PHCS)

There is considerable controversy concerning the level of specificity at which self-efficacy or perceived competence should be measured. Some believe in general self-efficacy which is reflected in an individual‟s general tendency, while others believe in task-specific self-efficacy which is an individual‟s efficacy in relation to a certain task. The Perceived Health Competence Scale (PHCS) is an eight-item scale measuring both health outcome expectancies and health behavioural expectancies, at an intermediate level of specificity (Smith et al., 1995). Each question has a five-point response scale (5: Strongly disagree - 1: Strongly agree).

The role of PHCS

Smith et al. (1995) developed the PHCS expecting that, as an intermediate level health-specific measure, it would be useful in a variety of studies designed to examine diverse health-related behaviours and outcomes across a range of conditions or situations, in a way that more specific or more general measures would not be. It would also be relevant for studies in which individuals have had little experience with the behaviour and have not had a chance to develop more specific expectancies yet. Identification of factors that explain participation in oral health behaviours would be useful for healthcare professionals in all practice settings to design intervention programmes to enhance participation in oral health behaviours. It may be useful in determining who may be better able or motivated to become more involved, or who may need additional encouragement and support in adopting a new oral health care regimen. PHCS has been positively correlated with a positive state of mind and well-being, and healthy behaviours (Smith et al., 1995). In a pilot study, among patients with chronic heart failure who were asked about competency in managing personal oral health care, there was a significant increase in competency scores after the implementation of oral care plan by trained non-dental personnel (Pradhan and Spencer, 2009).

This study used the carer oral health competency (COHC), or the perceived adequacy of an individual‟s performance as a carer in oral health care for their care recipients. Similar to the role of PHCS, COHC can be assessed among carers before and after oral health training programmes.

2.4.3 Patient activation measure (PAM)

Patient activation measure (PAM) was developed to assess an individual‟s knowledge, skills, and confidence for self-management (Hibbard et al., 2004). PAM is considered to be a proxy for "motivation" and includes 13 items on three subscales: Knowledge, Skills and Confidence. The concept of activation is explored as a possible organising construct for informing strategies to increase consumer involvement in health. While there is strong agreement that consumers need to be more engaged and proactive about their care and their health and different strategies employed to stimulate consumer engagement, there is much less agreement about how best to achieve this, and limited evidence for the efficacy of those strategies. The main idea of PAM is that by using reliable and valid measures, consumers can be grouped based on their capability or readiness to engage in productive health behaviours.

Activation is developmental in nature, with the different knowledge, belief, and skill elements constituting activation having a hierarchical order in the progression from low to high activation (Hibbard et al., 2004). Behaviours that are more challenging are unlikely to be adopted among those who are less activated. Findings indicate that when activation changes, behaviours change in the same direction (Hibbard et al., 2007a). For patients in each level, experiencing a series of successes, with the particular challenges they face at that level, will likely build a sense of self-efficacy and increase activation (Bandura, 2004a) and feel more competent to manage their health. Tailoring care based on activation level improves outcomes of disease management and has shown more improvement in clinical indicators (Hibbard et al., 2009).

The role of PAM

The developers of PAM (Hibbard et al., 2004) believe that it can be applied for more targeted and potentially more effective strategies. The PAM may be useful for both designing interventions and in evaluating them. The measure can be used in a clinical setting to assess individual patients and to develop care plans tailored to that patient and integrated into the processes of their care. As the measure is developmental, interventions could be tailored to the individual's stage of activation. For example, those at early stages of activation would need interventions designed to increase knowledge about their condition and their treatments. Patients at later stages would need interventions designed to increase their skills and confidence in the different self-management tasks. As patients advance in activation, the type of interventions that will be helpful to them will also change. The approach is economical because it is targeted to the specific individual and task.

Employers could also use the measure to assess interventions designed to increase engagement and activation among their employees. Such wide use of a precise, valid, and useful measure could be the first step toward the goal of informed and engaged patients and ultimately to more effective and efficient delivery systems (Hibbard et al., 2004). Research shows that PAM scores are predictive of most health behaviours (Hibbard et al., 2007a).

This study used carer activation measure (CAM), to assess carers‟ knowledge, skills, and confidence in providing oral health care for their care recipients. Similar to the role of PAM for patients with medical conditions, CAM can be assessed among carers by clinicians to tailor oral health messages for their care recipients.

2.4.3.1 Knowledge, Skills and Confidence

Knowledge, as defined by SCT, refers to the knowledge and understanding of health, health risks and benefits of particular health behaviours. Therefore, knowledge is considered to be the foundation or precondition for change in attitudes and behaviours that lead to better health. However, it may not be sufficient to produce such health behaviour changes in an individual (Bandura, 2004a; Bandura, 2004b). If people lack knowledge about how their lifestyle habits affect their health, they have little reason to change the unhealthy habits they enjoy. For various and complex reasons, having information is no guarantee that it will be used to promote health (Nutbeam, 2000). Even when means of information are well designed, they still may not always translate into knowledge. When information does translate into knowledge, it still may not translate into action. That is, while information is essential, even well-presented information is likely to be insufficient to stimulate the kind of change that is expected (Hibbard, 2009). Even if people are knowledgeable about lifestyle contributors to health, those with low self-efficacy take no action and perceive themselves to be vulnerable to disease (Rimal, 2000). It may therefore be useful to distinguish between: the possession of information; the understanding of it; and the inclination and ability to act on it in ways consistent with promoting health. Gaining confidence in one's own ability is another important step in becoming activated. When individuals see others experiencing success and experience some success themselves, they begin to feel more capable and confident. Gaining confidence is a self-reinforcing process that can actually lead to more successes (Bandura, 2004a).

The knowledge and skills of carers have an impact not only on the provision of oral care for their care recipients but also their perception of need, and may influence the frequency of contact with dental services. Their knowledge and practice of oral health care has generally been demonstrated to be inadequate (Simons et al., 2000), thus requiring basic oral health care training. Another study of 398 nursing personnel (Wardh et al., 1997) also revealed that there is a gap between knowledge and practice in the oral health care of dependent elderly and severely disabled patients. In a randomised controlled trial among 369 carers (Frenkel et al., 2002) reported that the oral health care education was well received and resulted in improved oral health care knowledge, attitudes and skills, resulting in reductions in plaque, denture stomatitis and improved gingival health of the residents, nevertheless still short of the acceptable level of oral health.

2.4.4 Socio-structural factors

According to Chen‟s conceptual model explaining oral health status in disadvantaged populations, health beliefs, values and attitudes and behaviour, which are embedded within the oral health system and social and environmental contexts, are influential factors on oral health (Chen, 1995). She notes that there is an „overreliance on individual-level factors and lack of emphasis on system-level factors‟, most studies concluding that individual-level variables directly or indirectly determine the lower oral health status of disadvantaged populations. These studies largely ignore the impact of system-level variables. Emphasising the importance of individual-level variables (e.g., a disadvantaged group‟s health beliefs, attitudes, perceptions, values and oral health behaviours) without placing these variables in the larger context of the oral health system and socio-environment is an approach that tends to blame the individual. This approach fails to take a comprehensive and ecological view of the complex factors influencing oral health and, as a result, provides only a partial understanding of the explanations for the poor health status of disadvantaged groups.

Limitations of educational preventive approaches in improving population health have led public health researchers to focus on exploring the relationship between the social environment and health. Likewise, various theoretical models have been developed to explain how social structure and social environments influence oral health outcomes (Watt, 2002). Oral health is largely determined and conditioned by the social environments in which individuals live and receive care. The US Surgeon General‟s Report on oral health has highlighted the importance of the social and environmental determinants of oral health and the need to adopt a more holistic approach to oral health promotion activities (US Department of Health and Human Services, 2000). However, the relationship between socio-structural factors and oral health is not well understood, not always easy to act upon and therefore, has not received as much attention.

There have been political debates between individualist approaches and structuralist approaches to health, with the former stating that people have control over their health, and therefore should be responsible to maintain it. On the contrary, the structuralist proponents argue that health depends on social, environmental, political, and economic conditions, over which individuals have little control. Bandura (2004a) states health promotion needs both approaches, not contentious debates.

Behaviours and therefore health have been reported to vary by living arrangements of the people with disabilities. 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. Appropriate interventions should accordingly be targeted to address the specific needs of individuals living in different types of residential settings and their carers. While SCT has focused mainly on the individual, Bandura (2004a) has more recently written about the important role of social support in the long-term success of behaviour change, especially when provided during early stages of change and maintenance. Bandura suggests that attention should be given to psycho-social models on how best to enable people to work together to improve their health at local levels and promote community self-help by giving people the necessary resources and enabling guidance to help themselves (Bandura, 2004a). Bandura (1988) explains how personal factors can be modified to improve the level of organisational functioning by the following strategies, which can be applied to role of carers.

Developing competencies through mastery modelling

Modelling is the first step in developing competencies. Complex skills are broken down into subskills. Effective modelling teaches general rules and strategies for dealing with different situations rather than only a specific response. In perfecting their skills, people need informative, constructive feedback on how they are performing. To produce good results, attention should be given to successes and improvements, while correcting deficiencies, in such a way as to build self-assurance in one's capabilities. Effective ways of performing the subskills which have not been adequately learned can be modelled by those who are proficient at it. Trainees then rehearse those subskills until they master them and can perform the skills proficiently and spontaneously.

Strengthening people's self-efficacy

Success requires not only skills but also strong self-belief in one's capabilities to exercise control over events to accomplish the desired goals. People with the same skills may therefore perform poorly, adequately, or extraordinarily, depending on whether their self-beliefs of efficacy enhance or impair their motivation and problem-solving efforts.

Enhancing self-motivation through goal systems

Goals have strong motivational effects and can improve psychological well-being and accomplishments in several ways by providing a sense of purpose and direction. Self-motivation can be enhanced by adopting goals and by evaluating one's progress in relation to those goals. Similar strategies can be adopted by organisations involved with the care of people with disabilities. As carers are responsible for the care of their care recipients, carers should be provided support with adequate training, incentives and time to achieve their goals.

Continuity of care is yet another vital component of social support (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 Heifetz, 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.

This study explores whether the dental practices of adults with disabilities varied by their residential setting and the carer support they received.

2.4.5 Health literacy and patient activation

The relative contribution of health literacy and patient activation has been examined in relation to a number of health-related behaviours and health care choices (Greene et al., 2005). The findings indicate that patient activation and health literacy are distinct concepts, with only a moderately weak association. Both constructs are important, but contribute differently to health, behavioural, and choice outcomes. Those with higher levels of patient activation were more likely to engage in

healthy behaviours (for example, exercised and were on low fat diet), consumeristic behaviours (such as looking up a doctors qualifications before choosing a physician), and had fewer hospital visits than those with lower activation levels. In contrast, respondents with higher literacy were more likely to be skilled at using comparative information for making health plan choices. For almost all the outcomes examined, both health literacy and patient activation were significant contributors. However, the degree to which they contributed depended on the nature of the outcome examined.

From a convenience sample of 303 adults, Hibbard et al. (2007b) indicated that once people have awareness of and access to information, at least three factors determine the use of that information. First, the nature of the information: how it is presented, its complexity, and how significant it is to the user. Second, the skill level of the user, including literacy and numeracy skills, which determines whether the information is understood and whether it is weighted in a choice. The third key factor is the motivation level of the user.

However, the main focus of research so far has been on individual constructs such as health literacy, self-efficacy, perceived health competency and patient activation measure. Efforts to support informed patient choices and promote healthy behaviours would be more successful if the focus is on addressing and simplifying the complex relationship between the numerous constructs.

2.5 Dental practices of carers for care recipients

2.5.1 Toothbrushing frequency

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, the maintenance of optimal oral hygiene in people with disabilities can be difficult due to problems with manual dexterity or cognitive ability and can be a major challenge not only to care recipients and their carers, but also dental professionals. Whether at home, or in community or institutional settings, great demands are placed on carers or parents and plaque control may be an additional burden with a lower priority. In an evaluation of a long-term oral health programme by carers of children and adults (6–50 years) with intellectual disabilities at three French centres, Faulks and Hennequin (2000) noted that carers were able to clean all teeth

for only 24% of care recipients, with 42% of them not co-operating with their carers, and 79% of care recipients having their teeth brushed only once a day.

In a UK study of 60 adults (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. In a South Australian study of 485 adults (18–44 years) with physical and intellectual disability, Pradhan (2008) reported a much higher (72%) carer involvement in toothbrushing. Nearly 40% of the care recipients had their teeth brushed once a day or less, and this was more common among care recipients at family homes compared to community housing and institutional settings.

2.5.2 Diet

A healthy diet plays an important role in the prevention of oral diseases (Moynihan, 2005). A diet high in sugar is a risk factor for dental caries (Peterson, 2003), and frequent consumption of acids are one of the important determinants of dental erosion (Bartlett, 2009). People with disabilities may place food in the mouth for longer periods of time, also increasing the risk of caries (Pradhan, 2008). Sweetened drinks are often used as reinforcers in behaviour modification programmes for people with disabilities to manage disruptive behaviours. Rimmer et al. (1995) suggested that less restrictive settings such as group homes or family settings may provide less supervision and monitoring of diets, exposing care recipients to frequent snacking and therefore putting them at a higher risk for caries and erosion. However, Pradhan (2008) reported 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. The same study reported that care recipients who had a moderate to high intake of sweet drinks were more likely to have untreated decay compared to those who had a low intake of sweet drinks. Although the latter finding is not unexpected, 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.

2.5.3 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). Francis et al. (1991) reported that of the 25–34 year old handicapped adults in Wessex, 69% visited the dentist at least once a year. 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. Likewise, 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. Although a slightly higher percentage (74%) of the South Australian population of adults with disabilities visited the dentist at least once a year, nearly 20% of care recipients either never visited the dentist or visited only because of a dental problem, or had over two years between visits (Pradhan et al., 2009). A more irregular dental visit pattern was greater among care recipients in family homes, while care recipients in institutions were most likely to attend regular recalls. In the same study, about 75% of carers accompanied their main care recipient(s) for their dental visit, with carers from family homes most likely to be present at the dental visit compared to carers at other settings.

2.6 Factors associated with dental practices of carers for care recipients

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 aids used, the ability of the person involved in cleaning (care recipient alone and/or carer) and any associated behavioural problems of the care recipients encountered by carers during the procedure, or even organisational problems like lack of time. Cumella et al. (2000) have highlighted the fact that carers are also instrumental in taking their care recipients to the dentist, supported by the fact that those who reported that they had not been to the dentist, lived with little or no carer support. Dental practices of carers for their care recipients may be associated with several factors.

2.6.1 Socio-demographics and dental practices

Women have been reported to have significantly higher sum scores for brushing self-efficacy and dental visiting self-efficacy than men (Syrjala et al., 1999). Studies show that those with low levels of education also tend to have poor dental behaviours and bad oral health outcomes. On the other hand, those with higher professional education have been reported to have significantly

higher sum scores for dental visiting self-efficacy than the others (Syrjala et al., 1999). Spencer and Harford (2007) also report that recent dental visits are associated with higher levels of schooling. Higher family income and dental insurance coverage both have been positively associated with brushing among 4–5 year olds (Finlayson et al., 2007).

2.6.2 Dental behaviours of carers

Carer knowledge of oral hygiene measures influences the degree of appropriate oral care provided to their care recipients (Shaw and Shaw, 1991). 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 toothbrushing was a widely held misconception by carers on a qualitative exploration of the views of nursing staff (Weeks and Fiske, 1994). Even after an oral health education intervention, Frenkel et al. (2002) reported that carers persisted in believing that they should stop brushing when there was gingival bleeding.

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 contrast, in the South Australian study (Pradhan, 2008) a significantly higher percentage of carers (30%) brushed their own teeth only once a day or less. About 43% of the carers visited the dentist every 1–2 years, while a smaller percentage (24.3%) visited the dentist every 6 months. There were 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 institutional settings. Dental care practices among carers tend to be reflected in the care that they provided for their care recipients (Pradhan, 2008).

2.7 Summary

Most studies reviewed indicate that there may be a missing link between available information given to carers and the expected preventive oral health behaviours for their care recipients. Whilst research has focussed on oral health literacy and psycho-social factors, both of which are diverse in methodological and analytic approaches, meta-analyses have demonstrated that efficacy beliefs consistently influence individual levels of motivation and performance (Bandura and Locke, 2003). This thesis attempts to explore the complex relationship between oral health literacy, and psycho-social factors among carers as the potential missing link that could be modified to obtain better oral health practices for people with 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 the structured interview, and a summary of the analytical approaches undertaken. Data management includes recording of the structured interview and response formats. Ethical implications and approvals are also mentioned.

3.1 Study design

The study design was a cross-sectional survey of oral health literacy and psycho-social factors among carers of people with physical and intellectual disabilities living in South Australia in three settings: family home, community housing, and institutions.

3.1.1 Sampling frame

Target population

The target sample comprised of primary carers of people with physical and intellectual disabilities living in various residential settings in Adelaide, who participated and released their names in a previous study titled "Oral care for adults with physical and intellectual disabilities" in 2005–2007. From a total of 485 valid responses in the 2005–2007 study, only 378 care recipients had adequate contact details. As one carer often responded for multiple care recipients, there were 260 individual carers with adequate contact details for inclusion in this study.

Inclusion criteria

Initially, it was planned that only those carers who remained carers for the care recipients who participated in the previous study would be included in this study, so that oral health literacy and psycho-social factors among carers could be linked to oral health outcomes of care recipients observed in the previous study. However, due to the high turnover of carers in community and institutional settings, current carers were included in this study, even if they had not participated in the previous study.

Exclusion criteria

Some care recipients had moved from family homes to community or institutional settings, and their family carers were no longer the primary carer of the care recipient. Other care recipients were quite independent for self-care activities and did not need much carer support. In other

cases, carers in community and institutional settings had changed to managerial roles. Such carers were excluded from this study.

3.1.2 Sampling carers for structured interview

Beginning in February 2009, carers were approached with a primary approach letter (Appendix 1). They were asked to assist the researchers with this follow-up study to find out what oral health care information is easily understood and what is confusing, with the goal of helping oral health professionals to write and provide information more clearly, so that it is better understood and implemented, so carers can provide best possible care for their care recipients. They were thanked for their participation in the previous study and a summary report of the previous study was included. Carers were requested to complete a form to ascertain their current involvement as a carer and their willingness to participate in the study. A reply-paid envelope was enclosed for the completed form to be returned to the researchers.

3.2 Data collection and management

3.2.1 Structured face-to-face interview of carers

As most care recipients had been examined at Adelaide Dental Hospital (ADH), date of last visit was checked and if they were due for their recall visit. In scope carers willing to participate in the study were then contacted by phone to make an appointment for a structured face-to-face interview, after the recall visit. This arrangement was done because the carers were not willing to come just for an interview. Where care recipients did not attend ADH, interviews were conducted at Strathmont, Highgate and Minda community houses. Where carers could not attend any of the above clinics, interviews were conducted by a second interviewer at their residence, or another mutually convenient location. The second interviewer was experienced in interviewing and the structured face-to-face interview was reviewed by both interviewers to avoid inconsistencies. When the carer had more than one care recipient, he/she was asked to respond to the interview as the primary carer of one care recipient. When necessary, permission was sought from managers for the participation of carers at community and institutional settings in this study.

Prior to the interview, carers were given:

1. An information sheet on the study (Appendix 2)
2. An information sheet on „Contact for information on project and independent complaints procedure" from The University of Adelaide Human Research Ethics Committee (Appendix 3)
3. A consent form (Appendix 4)

At the face-to-face structured interview, information about the carer was updated: age, sex, main language spoken at home, education level, income, relationship to care recipient, attitude regarding oral health, and dental visit pattern. Information was also updated about the care recipient: age, sex, living arrangement, means of communication, oral hygiene practices and dental visit pattern. Socio-structural support was assessed by the care recipients" residential setting, carers" last dental visit, and the length of carer contact.

A functional oral health literacy instrument was based on the following five domains: navigating the health care system, reading appointment slips, completing medical history and consent forms, and following medication instructions. For assessing functional oral health literacy, similar to TOFHLiD, developed by Gong et al., (2007), text passages and prompts were used to assess comprehension, and numerical ability of carers. The text passages and prompts were drawn from appointment cards, recall reminder slips, medical history forms, consent forms, and toothbrushing instruction leaflets and general information routinely used at the Special Needs Unit, Adelaide Dental Hospital. The SMOG and the Gunning Fog Index calculators[1] were used to estimate the educational level required to understand and assess the readability of text passages.

For comprehension of oral health and general literacy sections, words were omitted from the passages and three choices were given, one of which was correct and the other two were similar sounding words, or grammatically correct, but contextually incorrect words. For the choice of words, 30 were from REALD-99 and 15 from TOFHLiD. Prompts on numeracy section were similar to TOFHLiD and OHLI, but more specific to carers.

[1] Accessed at: http://www.online-utility.org/english/readability_test_and_improve.jsp

Psycho-social factors among carers were assessed with additional questions to determine the carer dental-efficacy (CDE), carer oral health competency (COHC) and carer activation measure (CAM) in managing oral health for their care recipients. For this study, a number of slight modifications were made to the original instruments to ensure that items were relevant to a carer. Therefore the items are personal, using the word "I". The five CDE items about oral care behaviours were constructed based on Bandura‟s social cognitive theory (Bandura, 1977) modified by Schwarzer (1992). The key difference with this scale is that it does not ask about the ability to perform under different situations, defined by Bandura as potential impediments (Bandura, 2004a). It included:

(i) brushing teeth

(ii) maintaining regular dental check-up

(iii) giving a high priority for any dental problem

(iv) controlling snacking between meals

(v) following instructions from dental professionals.

Similar to the perceived health competence scale developed by Smith et al. (1995), five COHC items were constructed about competency in managing oral health. It included:

(i) responsibility in caring for oral health

(ii) ability to do things for oral health as well as most other people

(iii) succeeding in the projects undertaken to improve oral health

(iv) achieving goals with respect to oral health

(v) active role in maintaining their oral health.

Further, thirteen CAM items were modified from the patient activation measure (PAM) developed by Hibbard et al. (2004) to determine capability or readiness of carers to engage in productive oral health behaviours for care recipients. Based on the statements, three subscales were formed:

1. Knowledge, with four items on:

(i) prescribed medications

(ii) oral health problems and what causes them

(iii) what treatments are available

(iv) how to prevent further oral health problems.

Table 3.1 Summary of psycho-social factors

Statements	CDE	COHC	CAM-Kowledge	CAM-Skills	CAM-Confidence
I brush his/her teeth at least once a day.	√				
I take him/her for regular dental check-up.	√				
I give a high priority for any dental problem.	√				
I control snacking between meals.	√				
I carefully follow any instructions my dental professional gives me about home-care.	√			√	
I take responsibility in caring for their oral health.		√		√	
I am able to do things for their oral health as well as most other people.		√			
I succeed in the projects I undertake to improve their oral health.		√			
I am generally able to achieve my goals with respect to their oral health.		√			
I take an active role in maintaining their oral health		√		√	
I am confident I can help prevent or reduce their oral health problems.					√
I know what each of their prescribed medications do.			√		
I am confident I can tell whether they need to go to the dentist.					√
I am confident I can tell a dentist about their possible dental concerns.					√
I understand their oral health problems and what causes them.			√		
I know what treatments are available for their oral health problems.			√		
I know how to prevent further oral health problems.			√		
I am confident I can maintain a healthy diet for them.					√
I am confident I can figure out solutions when new problems arise with their oral health condition.					√
I am confident I can maintain a healthy diet for them, even during times of stress.					√

2. Skills, with three items on:

(v) following instructions from dental professionals (also included in CDE)

(vi) responsibility in caring for oral health (also included in COHC)

(vii) active role in maintaining the oral health of care recipients (also included in COHC).

3. Confidence, with six items on:

(viii) preventing or reducing oral health problems

(ix) need to go to the dentist

(x) telling a dentist about possible dental concerns

(xi) maintaining a healthy diet

(xii) maintain a healthy diet, even during times of stress

(xiii) figure out solutions when new problems arise with oral health condition.

Psycho-social factors are summarized in Table 3.1.

After 20 interviews were completed, preliminary findings were discussed with colleagues at the Australian Research Centre for Population Oral Health (ARCPOH) and amendments were made to the text passages. Three choices of words were given for the text passages instead of two to avoid carers simply guessing the words. All words tested were selected from REALD-99 and TOFHLiD. Carers who had completed the first 20 interviews, were re-interviewed. Interviews of 100 carers were completed between February 2009 and April 2010.

Data from the interviews were collected by one of two methods:

a) For carers of care recipients who were patients of South Australian Dental Service (SADS) and who were scheduled for a dental visit during the period February 2009–April 2010, the interview was conducted by AP at the Adelaide Dental Hospital, Strathmont Centre or Highgate Dental Clinic.

b) For other carers, appointments were scheduled with one interviewer (LJ) to record the same information at the residence or work place of the carer, whichever was more convenient.

The questions and response categories for the survey were printed in large font and placed in a bi-fold binder so that the respondent could see them clearly while the interviewer read the questions aloud. Before interviews began, carers were reminded that if they were not sure of an answer, or

if they did not know the correct response to a question, that it was acceptable to answer, “I don't know.” Data from the interview were recorded onto a paper form (Appendix 5).

3.2.2 Data management

Data from the interviews were later keypunched into a Microsoft Access database.

3.2.2.1 Response formats

Responses to most questions were recorded by ticking one pre-coded response. Some questions needed specifying numbers – age of carer and care recipient and length of contact with care recipient as primary carer. 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 ≤29, 30–39 and 40+.
- Three types of communication were analysed – verbal, non-verbal and little or no effective communication.
- Length of contact was entered in months and years and grouped as ≤1 year, 1–5 years and 5+ years for analysis.
- 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 three categories were collapsed as „never/only with a problem/over 12 months‟ and every year and every 6 months collapsed as „within 12 months‟.
- Frequency of dental visits among the carers was also recoded as „never/only with a problem/don‟t know, „within 2 years‟ and „within 6 months‟.

3.2.2.2 Data scaling

In order to quantify constructs that are not directly measurable, multiple-item scales and summated ratings are often used to quantify the constructs of interest. To calculate the literacy scores, each item of the prompts was given a score of one (1), if answered correctly, or zero (0) if they did not know the answer or if answered incorrectly. To enable comparison with scores of other oral health literacy instruments, scores for prompts 2–5, 6a and 6b were added to obtain a comprehension score, and scores for prompts 1a-b, 6c, 6d and 6e were added to obtain a numeracy score. The scores of the comprehension and numeracy sections were then multiplied by 3.3 (50/15) and 10 (50/5), respectively to obtain a scaled score ranging from 0 to 50 for each

section, to give a total of 100 for oral health literacy. The total of prompt 7 was the general literacy score, which was multiplied by 5 to give a scale score of 100 (Table 3.2).

Table 3.2 Summary of scaled scores for literacy

Sections	Items	Scaled score	Total scaled score
1. Comprehension (Com)	15	X 3.33 (50/15)	50
2. Numeracy (Num)	5	X 10 (50/5)	50
3. Oral health literacy (Com + Num = OHL)	20	X5	100
4. General literacy	5		100

For measuring carer dental-efficacy, carer oral health competency and carer activation measure in managing oral health for their care recipients, response options were recorded on a 5-point Likert scale, strongly disagree= 1, disagree = 2, neutral= 3, agree = 4 and strongly agree = 5. Responses were summed to produce a single score, higher scores indicating greater CDE, COHC and CAM.

3.2.3 Statistical approach

The data were then imported into SPSS for Windows (version 17) for analysis.

3.2.3.1 Dependent and independent variables

The main independent variables used in the analyses were OHL, CDE, COHC and CAM. The dependent variables were toothbrushing frequency and dental visits. Additional independent variables were carer characteristics and socio-structural factors.

3.2.3.2 Factor analysis

In this study, three multiple-item scales were developed to measure the psycho-social factors- CDE, COHC and CAM. A factor analysis with Principal components analysis (PCA) and varimax rotation was conducted on all items of CDE, COHC and CAM to determine the underlying composition and dimensionality of each measure.

3.2.3.3 Internal consistency analysis

The internal consistency of the three scales (CDE, COHC and CAM) and their individual items was assessed with Cronbach‟s alpha coefficients, to ensure that items in the scale measured the same construct.

3.3 Analyses

For questions with multiple responses/items (OHL, CDE, COHC and CAM), initially, central tendency and distributions of responses were tabulated. Then they were dichotomised with the median score as the cut-point.

Finally each of the study aims was analysed. For aim 1, contingency table analyses were created to examine the bivariate relationships between dental practices among care recipients (toothbrushing frequency and dental visit pattern) and the following variables:

- carer characteristics – age, sex, main language spoken at the carer‟s home, carer‟s education and income
- socio-structural factors – residential setting of care recipient, carers‟ last dental visit and the length of contact between the carer and the care recipients.

For aim 2, contingency table analyses were created to describe the bivariate relationships between the independent variables (OHL, CDE, COHC and CAM) and dependant variables, oral care provided (toothbrushing frequency, and dental visit pattern). Additional independent variables were carer characteristics and socio-structural factors.

To evaluate overall differences between independent variables and the dependent variables, chi-square statistic was used, with an alpha level of $p=0.05$ as the standard for statistical significance. Analysis of variance (ANOVA) was also used to examine differences in the mean scores of OHL, CDE, COHC and CAM among carers and socio-structural groups.

For aim 3, the analysis sought to estimate the association between the dependent variables oral care provided (toothbrushing frequency, and dental visit pattern) and various literacy and psycho-social factors (OHL, CDE, COHC and CAM), recognising that the crude relationship might be confounded by other independent variables. To adjust for potential confounding by multiple variables, logistic regression models were constructed in which the dependent variables were log

(odds) of regular toothbrushing or dental visit. In the first model examining dental visiting as the outcome variable, regular dental visit was coded as 1, otherwise as 0, and in the second model examining toothbrushing as the outcome variable, twice a day toothbrushing was coded as 1, otherwise as 0. The selection of variables into the models was based on the possibility of those variables having influences on each of the preventive dental practice and whether these variables had a significant association in the bivariate analyses. These variables were entered in blocks, for example, carer characteristics and socio-structural factors. Age and sex were included in all models, even when bivariate relationships showed associations to be non-significant. The results of the logistic regression models are presented as odds ratios with 95% confidence intervals. An odds ratio of 1.0 indicates that the odds of the outcome variable are the same for the explanatory variable in relation to the reference category. Odds ratios greater than 1.0 indicate higher odds of the outcome for the explanatory variable in relation to the reference category, and odds ratios less than 1.0 indicate lower odds of the outcome for the explanatory variable in relation to the reference category. An estimate of R^2 (i.e., the percentage of variance explained) was given by the Nagelkerke pseudo R^2 statistic.

3.4 Ethical implications and approvals

The Human Research Ethics Committee of the University of Adelaide approved the study conducted from February 2009 to April 2010 (Appendix 6). Carers in community and institutional settings sought permission from their managers to participate in the study. All carers signed consent for the participation in the study prior before the commencement of the interview.

CHAPTER 4. RESULTS

This chapter includes responses from the carers and results from the face-to-face interviews completed by them. The characteristics of carers and care recipients are described. The distributions of the key dependent variables (toothbrushing frequency and dental visit of care recipients) are then presented along with their association with the independent variables- carer- and care recipient- characteristics, oral health literacy and psycho-social factors. Internal consistencies and factor analyses of the psycho-social measures are also included.

4.1 Participation

In the 2005–2007 study, of the 485 care recipients, only 378 had adequate contact details. As one carer often responded for multiple care recipients, there were 260 individual carers with adequate contact details. Adjusting for out of scope carers, the number of carers that could be included in this study was 230, of which 105 responded, giving a participation rate of 46%. However, nearly all participants (100) were interviewed between April 2009 and April 2010, giving a final participation rate of 44% (Table 4.1). Contrary to what was initially planned, apart from family carers, most were new carers, who had not participated in the previous study.

Table 4.1 Participation

	Care recipients with contact details		Individual carers
Target (carers of 485 care recipients)		378	260
Out of scope			
Deceased care recipients	8		8
Independent care recipients	2		2
No longer a carer	9		9
Wrong address	14		11
Total out of scope		33	
In scope		345	230
Refusal	38		7
No response	186		
Agreed to interview	121		**(46%) 105**
Interviewed			**(44%) 100**

4.2 Analyses

4.2.1 Characteristics of care recipients

The age of the care recipients ranged from 22 years to 48 years (mean 37 years). A significantly higher proportion of care recipients in family homes were 29 years old or younger (73.9%) compared to those in community and institutions (13.0%) ($p<0.01$, Table 4.2). There was no significant difference in the sex distribution and means of communication among care recipients across the three residential settings (Table 4.2).

Table 4.2 Characteristics of care recipients

Care recipient characteristics	All n	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value
All	100	33(33.0)	38(38.0)	29(29.0)	
Age					<0.01
≤29	23	17(73.9)	3(13.0)	3(13.0)	
30–39	34	12(35.3)	16(47.1)	6(17.6)	
40+	43	4(9.3)	19(44.2)	20(46.5)	
Sex					0. 17
Male	55	14(25.5)	22(40.0)	19(34.5)	
Female	45	19(42.2)	16(35.6)	10(22.2)	
Means of communication					0.17
Verbally	47	17(36.2)	13(27.7)	17(36.2)	
Non-verbally (effective)	20	7(35.0)	7(35.0)	6(30.0)	
Little or no effective communication	33	9(27.3)	18(54.5)	6(18.2)	

4.2.2 Characteristics of carers

4.2.2.1 Carer demographics

The age of the carers ranged from 19 years to 83 years (mean 48.9 years). A significantly higher proportion of family carers were 55+ years old (62.2%) compared to carers in community (21.6%) and institutional settings (16.2%) ($p<0.01$, Table 4.3). There were significantly more female carers in family homes (42.9%) and community houses (40.0%) than male carers, while there were more male carers (56.7%) in institutional settings ($p<0.01$, Table 4.3). There was no difference in the main language spoken at home among carers across the three residential settings. A significantly higher proportion of family carers had the highest qualification as high school or less (54.8%) and received carer allowance (92.3%) ($p<0.01$, Table 4.3).

Table 4.3 Characteristics of carers

Carer characteristics	Family n (%)	Community n (%)	Institution n (%)	Chi-square p value	Present study† %	2005–2007 study‡ Unweighted %	2005–2007 study‡ Weighted %
All	33(33.0)	38(38.0)	29(29.0)				
Age				<0.01			
≤44 years	1(2.9)	18(51.4)	16(45.7)		35.0	30.7	22.5
45–54 years	9(32.1)	12(42.9)	7(25.0)		28.0	39.1	44.3
55+ years	23(62.2)	8(21.6)	6(16.2)		37.0	30.2	33.3
Sex				<0.01			
Male	3(10.0)	10(33.3)	17(56.7)		30.0	19.6	17.7
Female	30(42.9)	28(40.0)	12(17.1)		70.0	80.4	82.3
Income				<0.01			
No pay/carer allowance	24 (92.3)	1(3.8)	1(3.8)		26.0	32.4	58.7
$15/hour or more	9(12.2)	37(50.0)	28(37.8)		74.0	67.6	41.3
Highest qualification				0.01		na	
High school or less	23 (54.8)	9(21.4)	10(23.8)		42.0		
Trade	5(16.7)	14(46.7)	11(36.7)		30.0		
College+	5(17.9)	15(53.6)	8(28.6)		28.0		
Main language				0.20		na	
English	31(35.2)	34(38.6)	23(26.1)		88.0		
Non-English	2(16.7)	4(33.3)	6(50.0)		12.0		

†n=100, ‡n=485

Table 4.3 also compares the carer characteristics of this study with the 2005–2007 South Australian study, the respondents from which formed the sampling frame for the present study. In that study it was possible to weight the data to account for the different probabilities of selection from the various organisations. The present sampling frame reapproached all respondents of the previous study. As all the carers in the sampling frame were approached, they all had the same probability of selection. Further, some carers had moved out from institutions to community care, breaking the link with the strata from the previous study and their known variation in the probability of selection. Therefore, it was not possible to weight the data for this study to produce a dataset more representative of the population of carers. The differences observed in each category (age, sex and income) indicate that the sample for this study was substantially different from the weighted representative sample of the previous study, but more similar to the

unweighted 2005–2007 study sample. Highest qualification and main language spoken at home was not determined in the previous study, and so no comparisons could be made.

4.2.2.2 Dental attitude and behaviour of carers

All carers reported oral health to be important/very important/extremely important for their care recipients and themselves. Therefore, no further analyses were conducted using this variable. A majority (91%) of them took their care recipients to their dental visits. Some 77% of carers had personally visited the dentist within the last two years. However, 18% of them had visited only with a problem, and 5% had never visited the dentist.

4.2.2.3 Dental practices among carers for their care recipients

As care recipients depend on their carers for their daily oral hygiene and dental visits, this section describes the toothbrushing and dental visit pattern of care recipients as practiced and reported by their carers.

4.2.2.3.1 Toothbrushing frequency of care recipients

4.2.2.3.1.1 Carer demographic factors and toothbrushing frequency of care recipients

Some 91.0% of care recipients needed assistance from their carers for toothbrushing and 30.5% of them had their teeth brushed once a day or less. Three of them were edentulous and did not wear any dentures. Two carers did not know how often their care recipient‟s teeth were brushed. There was no difference in toothbrushing frequency of care recipients by carers‟ age, sex, education or income. However, a significantly higher proportion of carers (73.5%) whose main language spoken at home was English reported twice a day toothbrushing compared to carers whose main language spoken at home was non-English (41.7%) ($p<0.05$, Table 4.4).

4.2.2.3.1.2 Socio-structural factors and toothbrushing frequency of care recipients

Toothbrushing frequency did not differ by care recipients‟ residence, the length of contact with the carer, or the carers‟ last dental visits (Table 4.5).

Table 4.4 Carer demographic factors and toothbrushing frequency of care recipients

	Toothbrushing frequency		
	Once a day n (%)	Twice a day n (%)	Chi-square p value
All	29(30.5)	66(69.5)	
Carer age			0.55
≤44 years	12(36.4)	21(63.6)	
45–54 years	6(23.1)	20(76.9)	
55+ years	11(30.6)	25(69.4)	
Carer sex			0.58
Male	10(34.5)	19(65.5)	
Female	19(28.8)	47(71.2)	
Carer's main language			0.03
English	22(26.5)	61(73.5)	
Non-English	7(58.3)	5(41.7)	
Carer's highest qualification			0.13
High school or less	14(34.1)	27(65.9)	
Trade	4(15.4)	22(84.6)	
college+	11(39.3)	17(60.7)	
Carer's income			0.49
No pay/carer allowance	9(36.0)	16(64.0)	
$15/hour or more	20(28.6)	50(71.4)	

Table 4.5 Socio-structural factors and toothbrushing frequency of care recipients

	Toothbrushing frequency		
	Once a day n (%)	Twice a day n (%)	Chi-square p value
Residential setting			0.31
Family-home	12(37.5)	20(62.5)	
Community-house	8(21.6)	29(78.4)	
Institution	9(34.6)	17(65.4)	
Length of contact with carer			0.63
<1year	4(44.4)	5(55.6)	
1–5 years	10(29.4)	24(70.6)	
>5 years	15(28.8)	37(71.2)	
Carer's last dental visit			0.72
Never/problem/don't know	6(27.3)	16(72.7)	
Within 2 years	9(27.3)	24(72.7)	
Within 6 months	14(35.0)	26(65.0)	

4.2.2.3.2 Dental visit pattern of care recipients

4.2.2.3.2.1 Carer demographic factors and dental visit pattern of care recipients

Some 76.0% of care recipients had visited the dentist within the last twelve months. A significantly higher proportion of carers whose main language spoken at home was English (80.7%) reported that their care recipients‟ last dental visit was within the last twelve months compared to carers whose main language spoken at home was non-English ($p<0.01$, Table 4.6). Surprisingly, carers whose highest qualification was high school or less (85.7%) reported more regular dental visit for their care recipients than carers whose highest qualification was college degree or more ($p<0.05$, Table 4.6). However, dental visiting pattern of care recipients was not associated with carers‟ age, sex and income.

Table 4.6 Carer demographic factors and dental visit pattern of care recipients

	Dental visit pattern		
	Don't know/Problem only />12 months n (%)	Within12 months n (%)	Chi-square p value
All	24.0	76.0	
Carer age			0.16
≤44 years	10(28.6)	25(71.4)	
45–54 years	9(32.1)	19(67.9)	
55+ years	5(13.5)	32(86.5)	
Carer sex			0. 15
Male	10(33.3)	20(66.7)	
Female	14(20.0)	56 (80.0)	
Carer's main language			0.01
English	17(19.3)	71(80.7)	
Non-English	7(58.3)	5(41.7)	
Carer's highest qualification			0.02
High school or less	6(14.3)	36(85.7)	
Trade	6(20.0)	24(80.0)	
College+	12(42.9)	16(57.1)	
Carer's income			0.51
No pay/carer allowance	5(19.2)	21(80.8)	
$15/hour or more	19(25.7)	55(74.3)	

4.2.2.3.2.2 Socio-structural factors and dental visit pattern of care recipients

There was no significant difference in the care recipients‟ dental visit pattern across the three residential settings. However, when care recipients in family-homes and community houses were grouped as living in a non-institutional setting and then compared with those living in institutional settings, a significantly higher proportion of the former group (81.7%) was reported to have had a dental visit within the last twelve months. Likewise, a significantly higher proportion of carers (88.1%) whose last dental visit was within six months and had been a carer for over five years (87.0%) reported that their care recipients‟ last dental visit was within the last twelve months compared to those with less regular dental visiting pattern and shorter length of contact with their care recipients ($p<0.05$, Table 4.7).

Table 4.7 Socio-structural factors and dental visit pattern of care recipients

	Dental visit pattern		
	Don't know/Problem only />12 months n (%)	Within12 months n (%)	Chi-square p value
Residential setting			0.11
Family-home	6(18.2)	27(81.8)	
Community-house	7(18.4)	31(81.6)	
Institution	11(37.9)	18(62.1)	
Length of contact with carer			0.02
<1year	5 (45.5)	6(54.5)	
1–5 years	12(34.3)	23(65.7)	
>5 years	7(13.0)	47(87.0)	
Carer's last dental visit			0.02
Never/problem/don't know	10(43.5)	13(56.5)	
Within 2 years	9(25.7)	26(74.3)	
Within 6 months	5(11.9)	37(88.1)	

4.2.3 Oral health literacy

The functional oral health literacy instrument was used to assess comprehension, numeracy and general literacy. The comprehension section included 15 items: one from understanding location of appointment, three from completing medical history form, four from information at a dental visit, five from understanding a consent form, and two from understanding instructions. The numeracy section included five items: two from understanding appointment times, and three from instructions on medication, post extractions, and fluoride application. The general literacy section included five items on general information on accessing dental care (Table 4.8a, Appendix 5 pages 133-135).

4.2.3.1 Readability and correct responses for specific prompts

The readability of the prompts, based on SMOG ranged from 9.2 (Grade Educational Level of some high school) to 19.3 (post-graduate degree). The readability of the prompts, based on the GFI ranged from 9.4 (fairly difficult) to 21.3 (very difficult). The percentage of correct responses did not match the readability of the prompts based on SMOG and GFI (Table 4.8a). For example, though the readability scores for the prompts on instruction was only 9.2 and 9.4 based on SMOG and GFI respectively, the correct response was only 65%. On the other hand, the prompt on appointment with a higher SMOG readability of 12.2, had 100% of correct responses. The poor correlation between SMOG and GFI and the responses from the carers is shown in Table 4.8b. Both correlations are negative, with GFI showing a weak strength of correlation, although not significant.

Table 4.8a Readability and correct responses for specific prompts

Prompts	Items	Literacy measures: Comprehension	Numeracy	General	Readability: SMOG	GFI	Correct responses (%)
Appointment	Time		√		12.2	9.5	100
	Location	√					
Medical history	Surgery	√			19.3	21.3	68
	Bleeding	√					
	Prescription	√					
Dental visit	Recall visit		√		11.2	10.2	54
	Oral	√					
	Teeth	√					
	Caries	√					
	Gingiva	√					
Consent	Anaesthesia	√			13.6	12.9	19
	Calculus	√					
	Cavity	√					
	Infection	√					
	Extracted	√					
Instructions	Toothbrushing	√			9.2	9.4	65
	Pre GA	√					
	Post-extraction		√				
	Medication		√				
	Fluoride		√				
General	Eligible			√	10.3	9.6	80
	Apply			√			
	Emergency			√			
	Referred			√			
	Location			√			
Total	**25**	15	5	5			

Table 4.8b Spearman rank correlations of SMOG and GFI scores with correct response (%)

	Spearman's rho	P-value
SMOG and response	-.086	0.872
GFI and response	-.371	0.468

Table 4.9 shows the list of the dental words and the percentage of incorrect responses. Words like teeth, cavity and fluoride were understood by all carers. The highest number of incorrect response was for „gingiva" (63%), followed by „caries" (61%).

Table 4.9 Words not known or incorrectly used

Words	Incorrect responses (%)
Gingiva	63
Caries	61
Anaesthesia	24
Calculus	21
Bleeding	13
Surgery	12
Prescription	10
Oral	9
Infection	5
Extracted	1

4.2.3.2 Summary of literacy scores

Comprehension score ranged from 16.7–50.0 (mean = 41.7); Numeracy score ranged from 30.0–50.0 (mean = 46.2); and Oral health literacy (OHL) score ranged from 56.7–100.0 (mean = 87.9). General literacy (GL) score ranged from 40.0–100.0 (mean = 94.8) (Table 4.10). Lowest scores (16.7 on the 50-point scale) were obtained for the comprehension section, for which dental words were used. Only eight carers obtained 100% correct responses. Due to the skewed nature of the distributions for each of the literacy measures, a median split was used to dichotomise each of the variables for further analyses (Figures 4.1 to 4.4). Results using mean scores are also presented for comparison.

Table 4.10 Summary of literacy scores

Literacy measures	No. of items	Mean	Median	Minimum	Maximum
Comprehension	15	41.7	43.3	16.7	50.0
Numeracy	5	46.2	50.0	30.0	50.0
Oral health literacy	20	87.9	90.0	56.7	100.00
General literacy	5	94.8	100.00	40.0	100.00

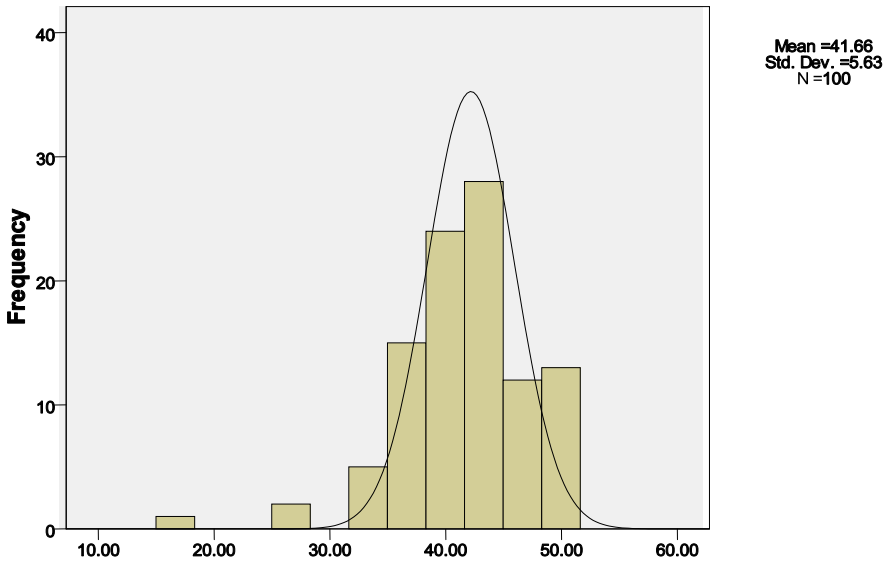

Figure 4.1 Frequency distribution of comprehension scores

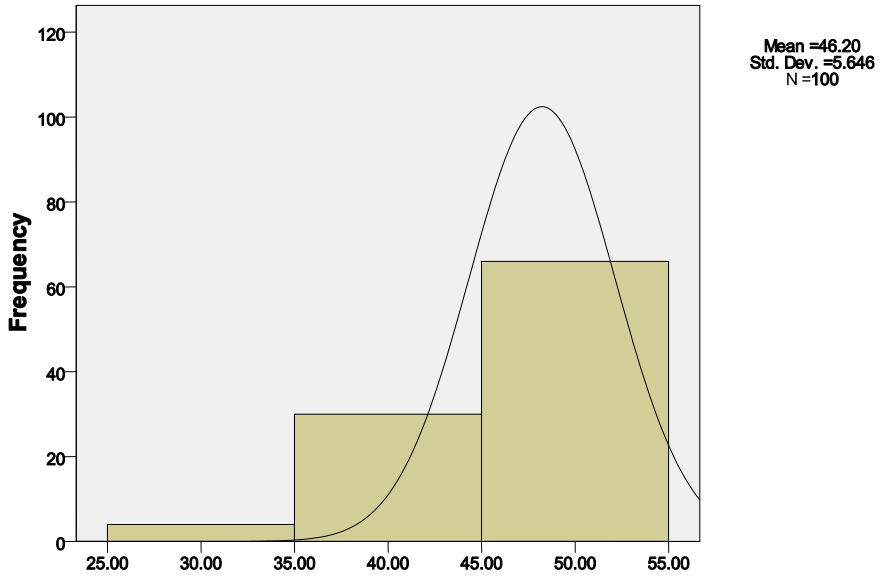

Figure 4.2 Frequency distribution of numeracy scores

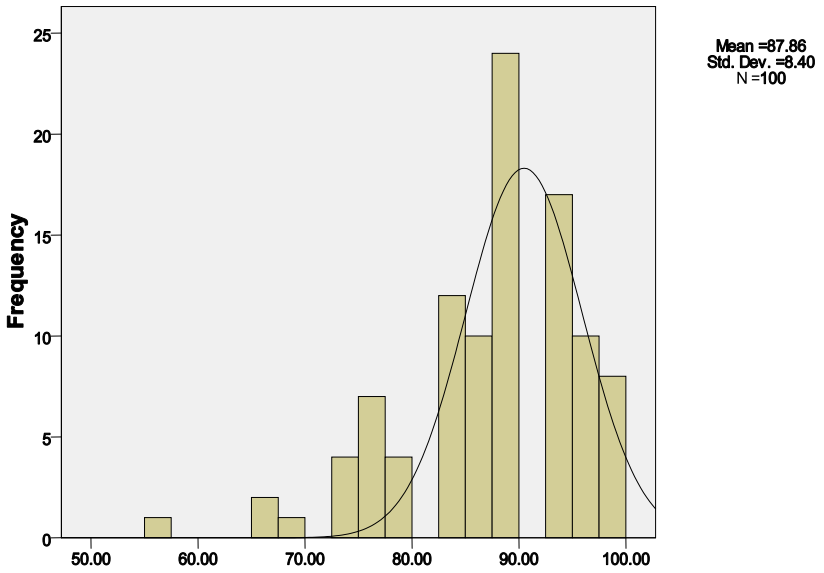

Figure 4.3 Frequency distribution of OHL scores

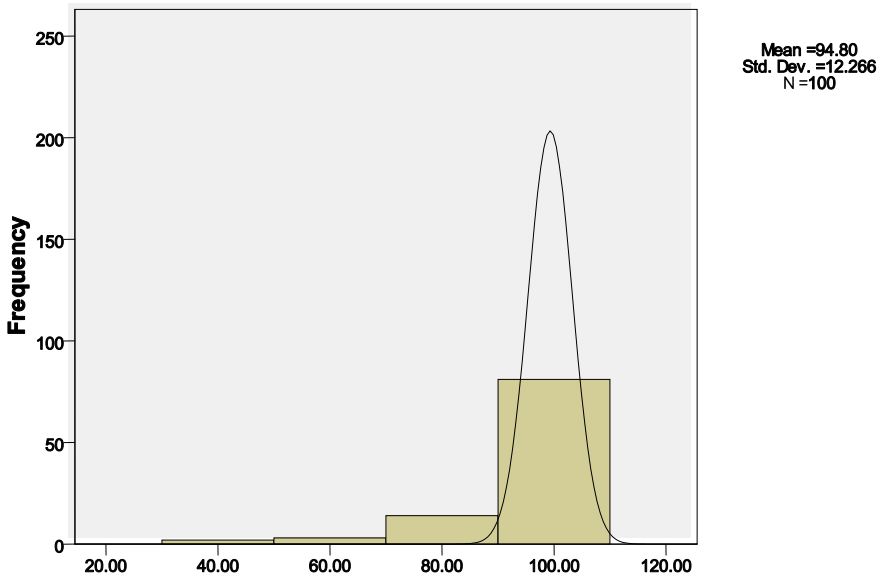

Figure 4.4 Frequency distribution of GL scores

4.2.3.3 Relationship between literacy and carer characteristics

The relationship between literacy and carer characteristics are presented in Tables 4.11a-d. A significantly higher proportion of carers (46.4%) in the 45–54 years had high comprehension scores than carers in other age groups (p<0.01, Table 4.11a). This group also had a high GL score, but the difference was not statistically significant. In fact, GL score was high among most groups, categorised by age, sex, education and income (Table 4.11d). Interestingly, a significantly higher proportion of carers with a trade qualification (40%) had high comprehension scores than carers with qualification of college level or more (28.6%), in addition to those whose education was high school or less (11.9%) (Table 4.11a).

Table 4.11a Relationship between comprehension and carer characteristics

Variables	Comprehension % Low	Comprehension High	Comprehension Mean (sd)
Carer age	***P=0.01**		†P=0.09
≤44 years	88.6	11.4	87.8 (5.9)
45–54 years	53.6	46.4	90.5 (7.4)
55+ years	78.4	21.6	85.9 (10.5)
Carer sex	P=0.21		P=0.87
Male	83.3	16.7	88.1 (7.5)
Female	71.4	28.6	87.8 (8.8)
Main language spoken at home	P=0.16		P=0.10
English	72.7	27.3	88.4 (7.8)
Non-English	91.7	8.3	84.1 (11.6)
Education	**P=0.02**		P=0.20
High school or less	88.1	11.9	86.2 (9.2)
Trade	60.0	40.0	88.6 (8.1)
College+	71.4	28.6	89.6 (7.2)
Income	P=0.43		P=0.29
No pay/carer allowance	69.2	30.8	86.4 (11.1)
$15 /hour or more	77.0	23.0	88.4 (7.2)

*P = Chi-square p value, †ANOVA, n=100

Table 4.11b Relationship between numeracy and carer characteristics

Variables	Numeracy % Low	Numeracy High	Numeracy Mean (sd)
Carer age	*P=0.40		†P=0.23
≤44 years	25.7	74.3	47.4 (4.4)
45–54 years	35.7	64.3	46.1 (5.7)
55+ years	40.5	59.5	45.1 (6.5)
Carer sex	P=0.31		P=0.19
Male	26.7	73.3	47.3 (4.5)
Female	37.1	62.9	45.7 (6.0)
Main language spoken at home	P=0.96		P=0.76
English	34.1	65.9	46.1 (5.8)
Non-English	33.3	66.7	46.7 (5.9)
Education	P=0. 95		P=0.76
High school or less	35.7	64.3	45.7 (6.3)
Trade	33.3	66.7	46.3 (5.6)
College+	32.1	67.9	46.8 (4.8)
Income	P=0.13		P=0. 09
No pay/carer allowance	46.2	53.8	44.6 (6.5)
$15 /hour or more	29.7	70.3	46.8 (5.3)

*P = Chi-square p value, †ANOVA, n=100

Table 4.11c Relationship between Oral Health Literacy and carer characteristics

Variables	Oral Health Literacy % Low	High	Oral Health Literacy Mean (sd)
Carer age	*P=0.14		†P=0.09
≤44 years	77.1	22.9	87.8 (5.9)
45–54 years	53.6	46.4	90.5 (7.4)
55+ years	62.2	37.8	85.9 (10.5)
Carer sex	P=0.49		P=0.87
Male	60.0	40.0	88.1 (7.5)
Female	67.1	32.9	87.8 (8.8)
Main language spoken at home	P=0.16		P=0.10
English	62.5	37.5	88.4 (7.8)
Non-English	83.3	16.7	84.1 (11.6)
Education	P=0.46		P=0.20
High school or less	71.4	28.6	86.2 (9.2)
Trade	63.3	36.7	88.6 (8.1)
College+	57.1	42.9	89.6 (7.2)
Income	P=0.67		P=0.29
No pay/carer allowance	61.5	38.5	86.4 (11.1)
$15 /hour or more	66.2	33.8	88.4 (7.2)

*P = Chi-square p value, †ANOVA, n=100

Table 4.11d Relationship between general literacy and carer characteristics

Variables	General Literacy % Low	General Literacy High	General Literacy Mean (sd)
Carer age	*P=0.42		†P=0.71
≤44 years	22.9	77.1	94.3 (12.4)
45–54 years	10.7	89.3	96.4 (10.9)
55+ years	21.6	78.4	94.1(13.2)
Carer sex	P=0.87		P=0.26
Male	20.0	80.0	92.7 (17.0)
Female	18.6	81.4	95.7 (9.6)
Main language spoken at home	**P<0.01**		**P<0.01**
English	13.6	86.4	96.8 (8.5)
Non-English	58.3	41.7	80.0 (22.6)
Education	P=0.98		P=0.82
High school or less	19.0	81.0	95.7 (9.4)
Trade	20.0	80.0	94.0 (14.0)
College+	17.9	82.1	94.3 (14.3)
Income	P=0.97		P=0.93
No pay/carer allowance	19.2	80.8	94.6 (13.3)
$15 /hour or more	18.91	81.1	94.9 (11.9)

*P = Chi-square p value, †ANOVA, n=100

Literacy scores were not associated with carer sex or income. Analyses using mean scores also did not show any association between literacy and carer characteristics. The exception was carers whose main language spoken at home was non-English and a significantly lower proportion of this group (41.7%) had high GL score with a mean of 80.0, compared to those carers whose main language spoken at home was English (86.4%) with a mean of 96.8 (Table 4.11d).

4.2.3.4 Relationship between literacy and socio-structural factors

The comprehension scores were not associated with the residential setting of care recipients, or the carer‟s last dental visit (Table 4.12a). However, there was a significantly larger proportion of carers with more than five years of contact with care recipients who obtained higher comprehension scores (mean = 42.7) than carers whose contact with care recipients was five years or less (mean = 40.4).

Table 4.12a Relationship between comprehension and socio-structural factors

Variables	Comprehension % Low	High	Comprehension Mean (sd)
Residential setting	*P=0.48		†P=0.37
Family-home	69.7	30.3	42.3 (7.6)
Community-house	73.7	26.3	42.1 (4.3)
Institution	82.8	17.2	40.4 (4.3)
Carer-care recipient contact	**P=0.04**		**P=0.04**
≤5 years	84.8	15.2	40.4 (4.2)
>5 years	66.7	33.3	42.7 (6.5)
Carer's last dental visit	P=0.82		P=0.74
Never/problem/don't know	78.3	21.7	40.9(6.9)
Within 2 years	71.4	28.6	42.1(4.9)
Within 6 months	76.2	23.8	41.6(5.4)

*P = Chi-square p value, †ANOVA, n=100

Table 4.12b Relationship between numeracy and socio-structural factors

Variables	Numeracy % Low	High	Numeracy Mean (sd)
Residential setting	*P=0.09		†P=0.09
Family-home	48.5	51.5	44.5 (6.2)
Community-house	28.9	71.1	46. 6 (5.8)
Institution	24.1	75.9	47. 6 (4.4)
Carer-care recipient contact	P=0.48		P=0.43
<1year	18.2	81.8	48.2 (4.0)
1–5 years	34.3	65.7	46.3 (5.5)
>5 years	37.0	63.0	45.7 (6.0)
Carer's last dental visit	P=0.27		P=0.37
Never/problem/don't know	47.8	52.2	44.8(5.9)
Within 2 years	28.6	71.4	46.9(5.3)
Within 6 months	31.0	69.0	46.4(5.8)

*P = Chi-square p value, †ANOVA, n=100

The remaining literacy measures (numeracy, oral health literacy and general literacy), were not significantly associated the socio-structural factors. Analyses using mean scores also did not show any association between these literacy measures and socio-structural factors (Table 4.12b-d).

Table 4.12c Relationship between Oral Health Literacy and socio-structural factors

Variables	Oral Health Literacy % Low	High	Oral Health Literacy Mean (sd)
Residential setting	*P=0.87		†P=0.66
Family-home	63.6	36.4	86.8 (10.4)
Community-house	63.2	36.8	88.6 (7.8)
Institution	69.0	31.0	88.0 (6.5)
Carer-care recipient contact	P=0.31		P=0.73
<1year	81.8	18.2	86.9 (7.1)
1–5 years	68.6	31.4	87.2 (7.2)
>5 years	59.3	40.7	
Carer's last dental visit	P=0.25		P=0.35
Never/problem/don't know	78.3	21.27	85.8(9.1)
Within 2 years	57.1	42.9	89.0(7.9)
Within 6 months	64.3	35.7	88.1(8.4)

*P = Chi-square p value, †ANOVA, n=100

Table 4.12d Relationship between General Literacy and socio-structural factors

Variables	General Literacy % Low	High	General Literacy Mean (sd)
Residential setting	*P=0.92		†P=0.96
Family-home	18.2	81.8	94.5 (13.5)
Community-house	21.1	78.9	95.3 (9.8)
Institution	17.2	82.8	94.5 (14.0)
Carer-care recipient contact	P=0.70		P=0.94
<1year	27.3	72.7	94.5 (9.3)
1–5 years	20.0	80.0	94.3 (13.3)
>5 years	16.7	83.3	95.2 (12.2)
Carer's last dental visit	P=0.27		P=0.53
Never/problem/don't know	30.4	69.6	93.0(11.5)
Within 2 years	14.3	85.7	96.6(9.1)
Within 6 months	16.7	83.3	94.3(14.8)

*P = Chi-square p value, †ANOVA, n=100

4.2.4 Psycho-social factors

Principal components extraction was performed on all psycho-social measures. Internal consistency of each psycho-social measure was then assessed with Cronbach's alpha. Relationship between psycho-social measures and literacy scores was assessed by Spearman‟s correlation. The association between the dependent variables oral care provided (toothbrushing frequency, and dental visit pattern) and psycho-social factors (CDE, COHC and CAM), was assessed by multivariate regression analyses, adjusting for potential confounding variables.

4.2.4.1 Carer dental efficacy

The Carer dental efficacy **(**CDE) included five measurement items that were designed to capture the carers‟ beliefs in providing care for their care recipients. Principal components extraction of the CDE scale indicated the extraction of a single component. This component accounted for 45.4% of variance in the data. Rotation was not necessary given the existence of a single component. All items were good measures of the component; component loadings ranging from 0.502 to 0.783 (Table 4.13).

Table 4.13 Factor analysis for items measuring carer dental efficacy

Component	Eigenvalues	% of Variance	Items	Factor loadings
1	2.271	45.423	I brush his/her teeth at least once a day.	.502
2	.942	18.831	I take him/her for regular dental check-up.	.720
3	.748	14.952	I give a high priority for any dental problem.	.736
4	.586	11.721	I control snacking between meals.	.588
5	.454	9.073	I carefully follow any instructions my dental professional gives me about home-care.	.783

Extraction Method: Principal Component Analysis.
1 component extracted

The CDE scale also demonstrated a moderate level of item internal consistency. The five measurement items had item-scale correlations ranging from 0.279–0.563 (Table 4.14), where a correlation score of 0.40 is generally accepted as the minimum standard for acceptable internal consistency. The internal consistency of the CDE was also shown to be borderline with an alpha coefficient of 0.607, which is slightly lower than the 0.70 deemed minimally reliable. Deleting the item on brushing teeth, which had the lowest item-scale correlation had minimal change to the scale‟s alpha level, confirming the „fit‟ of that item to its conceptualised scale. Therefore, the item on brushing teeth was retained.

Table 4.14 Internal consistency analysis for carer dental efficacy

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1. I brush his/her teeth at least once a day.	.279	.635
2. I take him/her for regular dental check-up.	.472	.491
3. I give a high priority for any dental problem.	.468	.539
4. I control snacking between meals.	.301	.596
5. I carefully follow any instructions my dental professional gives me about home-care.	.563	.515

Alpha coefficient = 0.607

Response for carer dental efficacy

Over 65% of the carers strongly agreed that for their care recipients, they brush their teeth at least once a day, take them for regular dental check-up, give a high priority for any dental problem, and carefully follow any instructions from their dental professional about home-care (Table 4.15). However, only 37% of the carers strongly agreed that they controlled snacking between meals, and almost a quarter of them were neutral for this statement.

Table 4.15 Carer dental efficacy: frequency distribution of responses

For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I brush his/her teeth at least once a day.	3	11	4	7	**75**
2. I take him/her for regular dental check-up.	0	8	3	19	**70**
3. I give a high priority for any dental problem.	0	0	2	33	**65**
4. I control snacking between meals.	1	8	24	30	**37**
5. I carefully follow any instructions my dental professional gives me about home-care.	0	0	2	26	**72**

4.2.4.2 Carer oral health competency

The carer oral health competency (COHC) scale included five measurement items that were designed to capture the carers‟ beliefs in providing care for their care recipients. Principal components extraction of the COHC scale indicated the extraction of a single component.

Table 4.16 Factor analysis for items measuring carer oral health competency

Component	Eigenvalues	% of Variance	Items	Factor Loadings
1	2.863	57.257	I take responsibility in caring for their oral health.	.713
2	.727	14.549	I am able to do things for their oral health as well as most other people.	.683
3	.575	11.499	I succeed in the projects I undertake to improve their oral health.	.785
4	.475	9.502	I am generally able to achieve my goals with respect to their oral health.	.773
5	.360	7.194	I take an active role in maintaining their oral health	.822

Extraction Method: Principal Component Analysis.
1 components extracted.

This component accounted for 57.3% of variance in the data. Rotation was not necessary given the existence of a single component. All items were good measures of the component; component loadings ranging from 0.683 to 0.822 (Table 4.16).

The COHC scale also demonstrated a good level of item internal consistency. The five measurement items had item-scale correlations ranging from 0.522–0.680. The internal consistency of the COHC was high with an alpha coefficient of 0.809 (Table 4.17). The COHC scale therefore retained the five measurement items.

Table 4.17 Internal consistency analysis for carer oral health competency

		Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1.	I take responsibility in caring for their oral health.	.551	.786
2.	I am able to do things for their oral health as well as most other people.	.522	.794
3.	I succeed in the projects I undertake to improve their oral health.	.627	.763
4.	I am generally able to achieve my goals with respect to their oral health.	.619	.768
5.	I take an active role in maintaining their oral health	.680	.750

Alpha coefficient = 0.809

Response for carer oral health competency

About 60% of the carers strongly agreed that they take responsibility in caring for their care recipients‟ oral health and are able to do things as well as most other people. Furthermore, only 55% of the carers strongly agreed that they take an active role in maintaining their care recipients‟ oral health. A much lower 40% of the carers strongly agreed that they are generally able to achieve their goals and succeed in the projects they undertake to improve the oral health of their care recipients (Table 4.18).

Table 4.18 Carer oral health competency: frequency distribution of responses

For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I take responsibility in caring for their oral health.	0	2	2	37	**59**
2. I am able to do things for their oral health as well as most other people.	0	1	6	35	**58**
3. I succeed in the projects I undertake to improve their oral health.	0	0	11	49	**40**
4. I am generally able to achieve my goals with respect to their oral health.	0	2	15	43	**40**
5. I take an active role in maintaining their oral health	0	0	6	39	**55**

4.2.4.3 Carer activation measure

Carer activation measure (CAM) was tested with a principal components factor analysis with varimax rotation. The analysis yielded a three-factor solution, the first component accounting for 45.3% of variance, the second 12.4% and the third 9.1% of variance in the data. Generally, factors with eigenvalues greater than 1.0 are retained, but selecting the number of factors also involves consideration of the reasonableness of the subject matter, which was not the case in this analysis (Table 4.19). Therefore, the three theoretically driven subscales: Knowledge, Skills and Confidence were used for further analyses. The items “I am confident I can help prevent or reduce their oral health problems”, “I am confident I can tell whether they need to go to the dentist and “I am confident I can figure out solutions when new problems arise with their oral health condition” loaded reasonably well with the subscale CAM-Confidence.

Table 4.19 Factor analysis for items measuring carer activation measure

Component	Eigenvalues	% of Variance	Items	Factor Loadings 1	2	3
1	5.887	45.286	I carefully follow any instructions my dental professional gives me about home-care.	-.002	.811	.208
2	1.609	12.374	I take responsibility in caring for their oral health.	.308	.666	-.361
3	1.184	9.108	I take an active role in maintaining their oral health.	.262	.847	.161
4	.953	7.329	I am confident I can help prevent or reduce their oral health problems.	.254	.697	.355
5	.689	5.304	I know what each of their prescribed medications do.	.630	-.038	.199
6	.537	4.128	I am confident I can tell whether they need to go to the dentist.	.605	.191	.340
7	.471	3.625	I am confident I can tell a dentist about their possible dental concerns.	.524	.351	.275
8	.413	3.181	I understand their oral health problems and what causes them.	.840	.186	.057
9	.374	2.880	I know what treatments are available for their oral health problems.	.795	.178	.098
10	.314	2.414	I know how to prevent further oral health problems	.722	.320	.180
11	.149	1.145	I am confident I can figure out solutions when new problems arise with their oral health condition.	.660	.231	.403
12	.230	1.769	I am confident I can maintain a healthy diet for them.	.246	.215	.844
13	.189	1.457	I am confident I can maintain a healthy diet for them, even during times of stress.	.421	.116	.812

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization

The CAM scale demonstrated a good level of item internal consistency. The 13 measurement items had item-scale correlations ranging from 0.327–0.724. The internal consistency of the CAM was high with an alpha coefficient of 0.894 (Table 4.20).

Table 4.20 Internal consistency analysis for CAM

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
Knowledge		
1. I understand their oral health problems and what causes them.	.684	.881
2. I know what each of their prescribed medications do.	.472	.893
3. I know what treatments are available for their oral health problems.	.655	.883
4. I know how to prevent further oral health problems.	.713	.881
Skills		
5. I carefully follow any instructions my dental professional gives me about home-care.	.423	.893
6. I take responsibility in caring for their oral health.	.327	.896
7. I take an active role in maintaining their oral health.	.613	.886
Confidence		
8. I am confident I can tell whether they need to go to the dentist.	.627	.884
9. I am confident I can tell a dentist about their possible dental concerns.	.614	.885
10. I am confident I can help prevent or reduce their oral health problems.	.617	.885
11. I am confident I can maintain a healthy diet for them.	.591	.886
12. I am confident I can maintain a healthy diet for them, even during times of stress.	.665	.882
13. I am confident I can figure out solutions when new problems arise with their oral health condition.	.724	.879

Alpha coefficient = 0.894

4.2.4.3.1 CAM-Knowledge

Measurement items for subscale CAM-Knowledge were designed to capture the carer‟s knowledge in providing care for their care recipients. The subscale also demonstrated a high level of item internal consistency. The four measurement items had item-scale correlations ranging from 0.464–0.740. The internal consistency of the subscale CAM-Knowledge was high with an alpha coefficient of 0.806 (Table 4.21).

Table 4.21 Internal consistency analysis for subscale CAM-Knowledge

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1. I understand their oral health problems and what causes them.	.740	.699
2. I know what treatments are available for their oral health problems.	.671	.734
3. I know what each of their prescribed medications do.	.464	.834
4. I know how to prevent further oral health problems.	.657	.750

Alpha coefficient = 0.806

4.2.4.3.2 CAM-Skills

Measurement items for subscale CAM-Skills were designed to capture the carer‟s skills in providing care for their care recipients. The subscale demonstrated a good level of item internal consistency. The three measurement items had item-scale correlations ranging from 0.465–0.655. The internal consistency of the subscale CAM-Skills was moderate with an alpha coefficient of 0.736 (Table 4.22).

Table 4.22 Internal consistency analysis for subscale CAM-Skills

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1. I carefully follow any instructions my dental professional gives me about home-care.	.592	.633
2. I take responsibility in caring for their oral health.	.465	.777
3. I take an active role in maintaining their oral health.	.655	.531

Alpha coefficient = 0.736

4.2.4.3.3 CAM-Confidence

The subscale CAM-Confidence contained six measurement items that were designed to capture the carer‟s confidence in providing care for their care recipients. The subscale demonstrated a high level of item internal consistency. The six measurement items had item-scale correlations ranging from 0.549–0.737. The internal consistency of the subscale CAM-Confidence was high with an alpha coefficient of 0.850 (Table 4.23).

Table 4.23 Internal consistency analysis for subscale CAM-Confidence

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1. I am confident I can tell whether they need to go to the dentist.	.605	.832
2. I am confident I can tell a dentist about their possible dental concerns.	.568	.838
3. I am confident I can help prevent or reduce their oral health problems.	.549	.841
4. I am confident I can maintain a healthy diet for them.	.668	.819
5. I am confident I can maintain a healthy diet for them, even during times of stress.	.737	.805
6. I am confident I can figure out solutions when new problems arise with their oral health condition.	.689	.816

Alpha coefficient = 0.850

Response for carer activation measure

The Carer activation measure (CAM) therefore retained the 13 measurement items that were designed to capture the carer‟s level of activation in providing care for their care recipients, with three subscales- Knowledge, Skills and Confidence. Of the four items assessing CAM-Knowledge, only 22–39% of carers strongly agreed that they knew or understood oral health problems, causes, available treatments, prescribed medications and how to prevent further oral health problems. The three items assessing CAM-Skills, for which there was a higher proportion of carers (55–72%) in strong agreement, were also included in the CDE and COHC scales. Of the six items assessing CAM-Confidence, 32–45% of carers strongly agreed that they are confident about the need to go the dentist, tell about the possible dental concerns, help prevent or reduce the oral health problems, maintain a healthy diet, even during times of stress, and figure out solutions when new problems arise with the oral health condition for their care recipients (Table 4.24).

Table 4.24 Carer activation measure: frequency distribution of responses

For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Knowledge					
1. I understand their oral health problems and what causes them.	0	7	17	44	**32**
2. I know what each of their prescribed medications do.	1	7	13	40	**39**
3. I know what treatments are available for their oral health problems.	4	6	25	43	**22**
4. I know how to prevent further oral health problems.	0	1	19	48	**32**
Skills					
5. I carefully follow any instructions my dental professional gives me about home-care.	0	0	2	26	**72**
6. I take responsibility in caring for their oral health.	0	2	2	37	**59**
7. I take an active role in maintaining their oral health	0	0	6	39	**55**
Confidence					
8. I am confident I can tell whether they need to go to the dentist.	0	7	24	37	**32**
9. I am confident I can tell a dentist about their possible dental concerns.	1	4	9	45	**41**
10. I am confident I can help prevent or reduce their oral health problems.	0	2	11	44	**43**
11. I am confident I can maintain a healthy diet for them.	0	3	15	36	**45**
12. I am confident I can maintain a healthy diet for them, even during times of stress.	0	7	14	35	**43**
13. I am confident I can figure out solutions when new problems arise with their oral health condition.	0	4	22	42	**32**

4.2.4.4 Summary of psycho-social factors

CDE and COHC scores ranged from 15.0–25.0 (mean = 22.2 for CDE and 22.0 for COHC) (Table 4.25). CAM scores ranged from 31.0–65.0 (mean = 54.4). The median scores of 23.0, 22.0 and 54.0 for CDE, COHC, and CAM respectively, indicated that the data were skewed towards the higher scores (Figures 4.5, 4.6 and 4.7).

Carers‟ CAM-Knowledge, CAM-Skills and CAM-Confidence scores ranged from 7.0–20.0 (mean = 15.9), 9.0–15.0 (mean = 13.7), 12.0–30.0 (mean = 24.8) respectively (Table 4.25). The median scores of 16.0, 14.0 and 25.0 for CAM-Knowledge, CAM-Skills and CAM-Confidence

indicated that the data were skewed towards the higher scores (Figures 4.8, 4.9 and 4.10). Due to the skewed nature of the distributions for each of the psycho-social measures, a median split was used to dichotomise each of the variables for further analyses. Results using mean scores are also presented for comparison.

Table 4.25 Summary of scores for psycho-social factors

Factors	No of Items	Mean	Median	Minimum	Maximum
CDE	5	22.2	23.0	15.0	25.0
COHC	5	22.0	22.0	15.0	25.0
CAM	13	54.4	54.0	31.0	65.00
Knowledge	4	15.9	16.0	7.0	20.0
Skills	3	13.7	14.0	9.0	15.0
Confidence	6	24.8	25.0	12.0	30.0

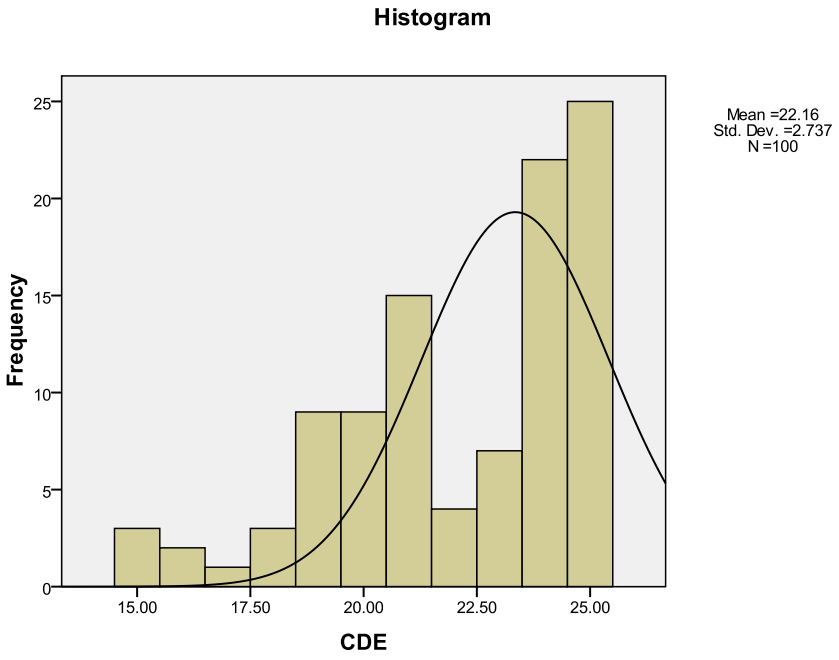

Figure 4.5 Frequency distribution of CDE scores

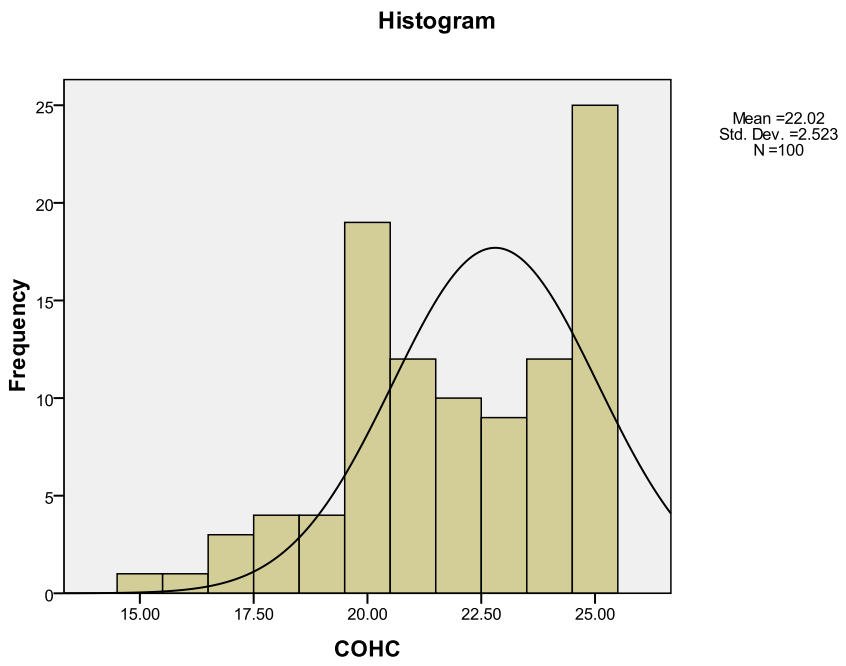

Figure 4.6 Frequency distribution of COHC scores

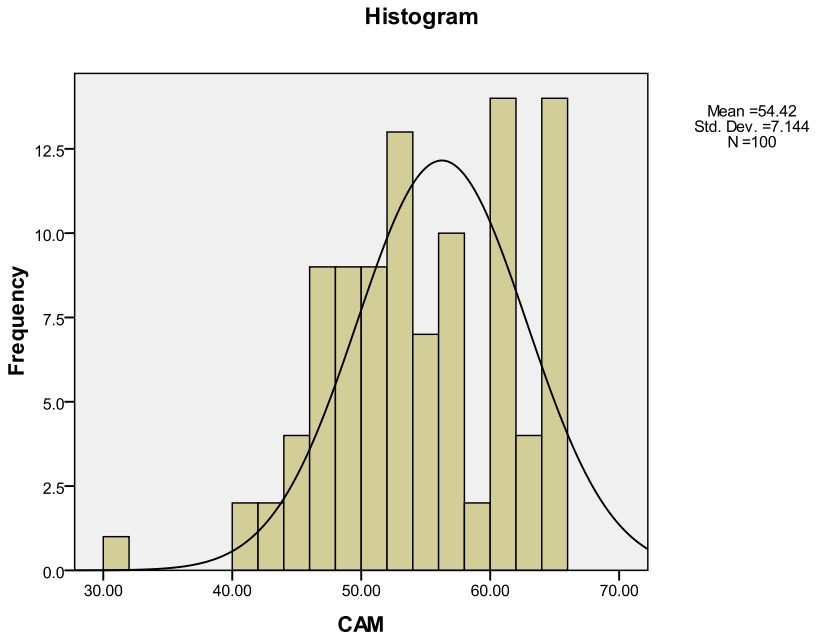

Figure 4.7 Frequency distribution of CAM scores

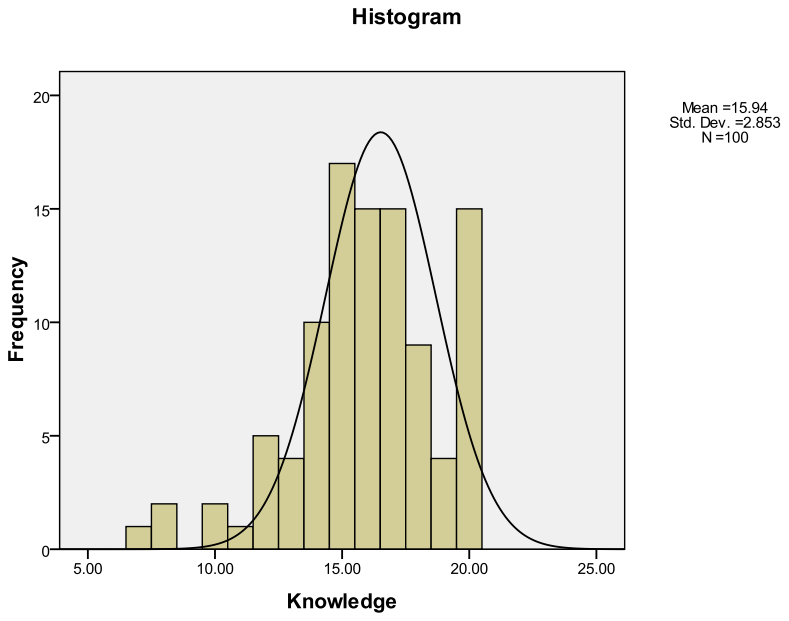

Figure 4.8 Frequency distribution of CAM-Knowledge scores

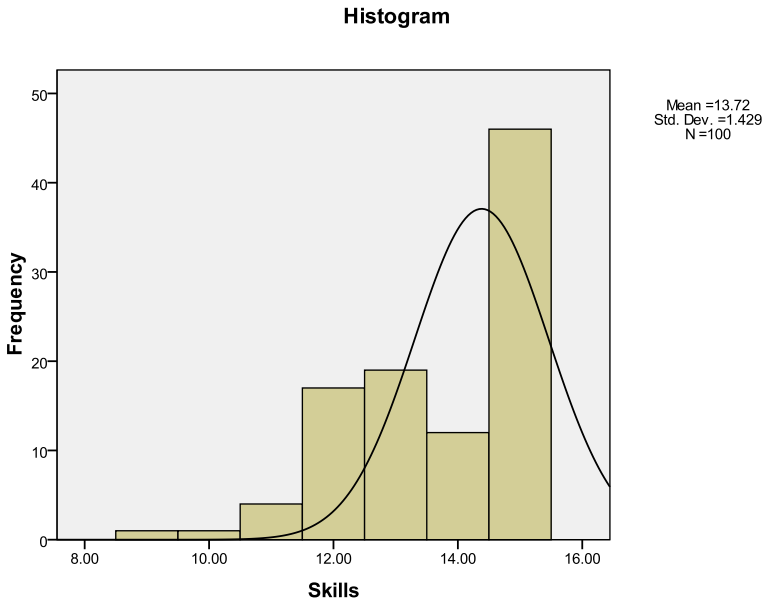

Figure 4.9 Frequency distribution of CAM-Skills scores

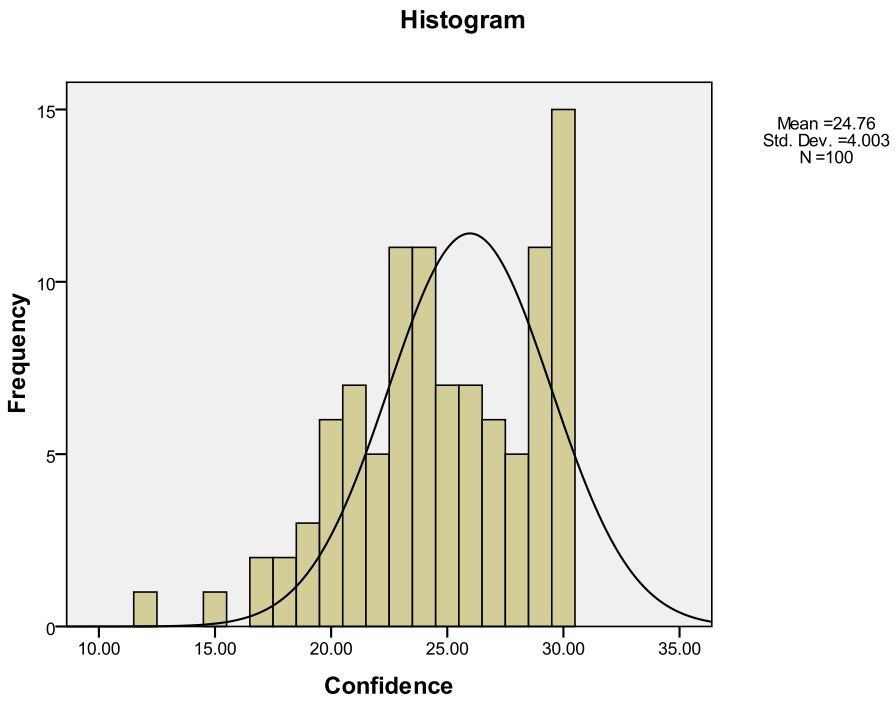

Figure 4.10 Frequency distribution of CAM-Confidence scores

4.2.5.1 Relationship between psycho-social factors and carer characteristics

The relationship between psycho-social factors and carer characteristics are presented in Tables 4.26a-c. There was a significantly higher proportion of 55+ year old carers (64.9%) who reported high COHC compared to carers in the younger age groups ($p<0.05$, Table 4.23b). A significantly higher proportion of female carers also had higher COHC (52.9%) and CAM (57.1%) than male carers. Likewise, significantly higher proportion of carers speaking English as the main language spoken at home reported high CDE (51.1%), COHC (50%) and CAM (53.4%) than carers whose main language spoken at home was non-English. Interestingly, a significantly higher proportion of carers whose highest level of education was college or more reported lower COHC (82.1%) with a mean of 20.8 and CAM (71.4%) with a mean of 51.1 than carers whose highest level of education was high school or less or trade. On the other hand, carers‟ income was not associated with CDE or COHC. However, carers with no pay/carer allowance had higher mean score for CAM than paid carers.

Table 4.26a Relationship between CDE and carer characteristics

Variables	CDE (%) Low	High	CDE Mean (sd)
Carer age	*P=0.32		†P=0.25
≤44 years	60.0	40.0	22.2 (2.0)
45–54 years	57.1	42.9	21.5 (3.1)
55+ years	43.2	56.8	22.6 (2.9)
Carer sex	P=0.18		P=0.39
Male	63.3	36.7	21.8 (2.5)
Female	48.6	51.4	22.3 (2.8)
Main language spoken at home	**P=0.03**		P=0.27
English	48.9	51.1	22.3 (2.8)
Non-English	83.3	16.7	21.3 (1.9)
Education	P=0.18		P=0.05
High school or less	47.6	52.4	22.5 (2.8)
Trade	46.7	53.3	22.7 (2.4)
College+	67.9	32.1	21.1 (2.8)
Income	P=0.69		P=0.45
No pay/carer allowance	46.2	53.8	21.8 (3.7)
$15/hour or more	55.4	44.6	22.3 (2.3)

*P = Chi-square p value, †ANOVA, n=100

Table 4.26b Relationship between COHC and carer characteristics

Variables	CDE (%) Low	High	CDE Mean (sd)
Carer age	***P=0.01**		†P=0. 22
≤44 years	68.6	31.4	2.5 (2.3)
45–54 years	60.7	39.3	2.9 (2.5)
55+ years	35.1	64.9	2.6 (2.8)
Carer sex	**P=0.04**		P=0.21
Male	70.0	30.0	21.5 (2.4)
Female	47.1	52.9	22.2 (2.6)
Main language spoken at home	**P=0.03**		P=0. 172
English	50.0	50.0	22.1 (2.6)
Non-English	83.3	16.7	21.1 (2.1)
Education	**P<0.01**		**P<0.01**
High school or less	38.1	61.9	22.6 (2.5)
Trade	50.0	50.0	22.3 (2.5)
College+	82.1	17.9	20.8 (2.1)
Income	P=0.07		P=0.26
No pay/carer allowance	38.5	61.5	22.5 (2.9)
$15/hour or more	59.5	40.5	21.9 (2.4)

*P = Chi-square p value, †ANOVA, n=100

Table 4.26c Relationship between CAM and carer characteristics

Variables	CAM (%) Low	High	CAM Mean (sd)
Carer age	*P=0.09		**† P<0.01**
≤44 years	65.7	34.3	51.4 (7.4)
45–54 years	46.4	53.6	54.9 (6.3)
55+ years	40.5	59.5	56.8 (6.6)
Carer sex	**P=0.01**		**P<0.01**
Male	70.0	30.0	50.8 (7.5)
Female	42.9	57.1	55.9 (6.4)
Main language spoken at home	**P=0.02**		**P<0.01**
English	46.6	53.4	55.1 (6.6)
Non-English	83.3	16.7	49.3 (8.9)
Education	**P=0.03**		**P=0.02**
High school or less	47.6	52.4	55.5 (6.9)
Trade	36.7	63.3	55.9 (6.7)
College+	71.4	28.6	51.1 (7.2)
Income	P=0.14		**P=0.04**
No pay/carer allowance	38.5	61.5	56.9 (7.3)
$15/hour or more	55.4	44.6	53.5 (6.9)

*P = Chi-square p value, †ANOVA, n=100

The relationship between CAM subscales and carer characteristics are presented in Tables 4.26d-f. There was a significantly higher proportion of 55+ year old carers who reported high CAM-Knowledge (56.8%) and Skills (62.2%) scores. This group also had higher CAM-Confidence scores, but the difference was not statistically significant. A significantly higher proportion of female carers had higher CAM-Knowledge scores (50%) with a mean of 16.7 and CAM-Confidence scores (51.4%) with a mean of 25.5 than male carers. Likewise, a significantly higher proportion of carers speaking English as the main language spoken at home reported high CAM-Knowledge (46.6%) scores with a mean of 16.3 than carers whose main language spoken at home was non-English. This group also had significantly higher mean scores for CAM-Confidence. Interestingly, a significantly higher proportion of carers whose highest level of education was college or more reported lower CAM-Skills (75.0%) and CAM-Confidence (75.0%) scores than carers whose highest level of education was high school or less or trade. Likewise, a significantly higher proportion of carers with no pay or on carer allowance (65.4%) had higher CAM-Knowledge scores with a mean of 17.3 than paid carers.

Table 4.26d Relationship between subscale CAM-Knowledge and characteristics of carers

Variables	Knowledge (%) Low	High	Knowledge Mean (sd)
Carer age	***P=0.03**		**†P<0.01**
≤44 years	74.3	25.7	14.4 (3.2)
45–54 years	53.6	46.4	16.3 (2.2)
55+ years	43.2	56.8	17.1 (2.3)
Carer sex	**P=0.03**		**P<0.01**
Male	73.3	26.7	14.2 (3.3)
Female	50.0	50.0	16.7 (2.3)
Main language spoken at home	**P=0.05**		**P<0.01**
English	53.4	46.6	16.3 (2.6)
Non-English	83.3	16.7	13.5 (3.2)
Education	P=0.18		P=0.18
High school or less	50.0	50.0	16.5 (2.6)
Trade	53.3	46.7	16.1 (2.7)
College+	71.4	28.6	14.9 (3.2)
Income	**P=0.01**		**P<0.01**
No pay/carer allowance	34.6	65.4	17.3 (2.4)
$15/hour or more	64.9	35.1	15.4 (2.8)

*P = Chi-square p value, †ANOVA, n=100

Table 4.26e Relationship between subscale CAM-Skills and characteristics of carers

Variables	Skills (%) Low	High	Skills Mean (sd)
Carer age	***P=0.04**		†P=0.35
≤44 years	65.7	34.3	13.5 (1.3)
45–54 years	60.7	39.3	13.7 (1.3)
55+ years	37.8	62.2	13.9 (1.6)
Carer sex	P=0.22		P=0.19
Male	63.3	36.7	13.4 (1.4)
Female	50.0	50.0	13.9 (1.4)
Main language spoken at home	P=0.120		P=0.23
English	51.1	48.9	13.8 (1.4)
Non-English	75.0	25.0	13.3 (1.4)
Education	**P=0.03**		P=0.06
High school or less	42.9	57.1	13.9 (1.4)
Trade	50.0	50.0	13.9 (1.3)
College+	75.0	25.0	13.2 (1.5)
Income	P=0.164		P=0.603
No pay/carer allowance	42.3	57.7	13.8 (1.7)
$15/hour or more	58.1	41.9	13.7 (1.3)

*P = Chi-square p value, †ANOVA, n=100

Table 4.26f Relationship between subscale CAM-Confidence and characteristics of carers

Variables	Confidence (%) Low	High	Confidence Mean (sd)
Carer age	*P=0.24		†P=0.05
≤44 years	65.7	34.3	23.5 (4.2)
45–54 years	57.1	42.9	24.9 (3.7)
55+ years	45.9	54.1	25.5 (3.8)
Carer sex	**P=0.02**		**P<0.01**
Male	73.3	26.7	23.1 (4.1)
Female	48.6	51.4	25.5 (3.8)
Main language spoken at home	P=0.16		**P=0.04**
English	53.4	46.6	25.1 (3.8)
Non-English	75.0	25.0	22.5 (4.9)
Education	**P=0.03**		**P=0.02**
High school or less	54.8	45.2	25.1 (3.9)
Trade	40.0	60.0	25.9 (3.7)
College+	75.0	25.0	23.0 (4.2)
Income	P=0.10		P=0.15
No pay/carer allowance	42.3	57.7	25.7 (4.2)
$15/hour or more	60.8	39.2	24.4 (3.9)

*P = Chi-square p value, †ANOVA, n=100

4.2.5.2 Relationship between psycho-social and socio-structural factors

The relationship between psycho-social factors and socio-structural factors are presented in Tables 4.27a-c. CDE was not significantly associated with any of the socio-structural factors. There was a significantly higher proportion of carers providing care at family-homes (63.6%) who reported higher COHC than those at community-house (28.9%) and institutional settings (48.3%). Carers providing care at family homes and those who had over five years of contact with their care recipients had significantly higher mean scores for CAM, compared to carers in other residential settings and with less contact with their care recipients.

Table 4.27a Relationship between CDE and socio-structural factors

Variables	CDE (%) Low	High	CDE Mean (sd)
Residential setting	*P=0.50		†P=0.83
Family-home	48.5	51.5	21.9 (3.4)
Community-house	50.0	50.0	22.3 (2.5)
Institution	62.1	37.9	22.2 (2.1)
Carer-care recipient contact	P=0.09		P=0.41
<1year	81.8	18.2	21.2 (2.4)
1–5 years	54.3	45.7	22.5 (2.2)
>5 years	46.3	53.7	22.2 (3.1)
Carer's last dental visit	P=0.18		P=0.11
Never/problem/don't know	69.6	30.4	21.1(2.8)
Within 2 years	45.7	543	22.6 (2.7)
Within 6 months	50.0	50.0	22.4 (2.6)

*P = Chi-square p value, †ANOVA, n=100

Table 4.27b Relationship between COHC and socio-structural factors

Variables	COHC (%) Low	High	COHC Mean (sd)
Residential setting	***P=0.01**		†P=0.26
Family-home	36.4	63.6	22.5 (2.9)
Community-house	71.1	28.9	21.5 (2.1)
Institution	51.7	48.3	22.2 (2.5)
Carer-care recipient contact	P=0.25		P=0.38
<1year	63.6	36.4	21.9 (2.2)
1–5 years	62.9	37.1	21.6 (2.4)
>5 years	46.3	53.7	22.3 (2.7)
Carer's last dental visit	P=0.29		P=0.16
Never/problem/don't know	65.2	34.8	21.1(2.6)
Within 2 years	45.7	54.3	22.3 (2.3)
Within 6 months	47.6	52.4	22.3(2.6)

*P = Chi-square p value, †ANOVA, n=100

Table 4.27c Relationship between CAM and socio-structural support of care recipients

Variables	CAM (%) Low	High	CAM Mean (sd)
Residential setting	*P=0.10		**† P<0.01**
Family-home	36.4	63.6	57.3 (6.6)
Community-house	55.3	44.7	53.7 (6.2)
Institution	62.1	37.9	52.0 (7.9)
Carer-care recipient contact	P=0.13		**P=0.02**
<1year	72.7	27.3	50.5 (5.7)
1–5 years	57.1	42.9	52.9 (7.0)
>5 years	42.6	57.4	56.1 (7.1)
Carer's last dental visit	P=0.29		P=0.21
Never/problem/don't know	65.2	34.8	52.1(5.9)
Within 2 years	48.6	51.4	54.9(6.5)
Within 6 months	45.2	54.8	55.3(8.1)

*P = Chi-square p value, †ANOVA, n=100

The relationship between CAM subscales and socio-structural factors are presented in Tables 4.27d-f. A significantly higher proportion of carers providing care at family-homes, those caring for their care recipients for five years or more and those whose last dental visit was within six months had high CAM-Knowledge scores than those at other settings, those with less contact with their care recipients and those whose dental visits were less frequent. These groups also had significantly higher mean scores.

Table 4.27d Relationship between subscale CAM-Knowledge and socio-structural factors

Variables	CAM-Knowledge (%) Low	High	CAM-Knowledge Mean (sd)
Residential setting	*** P<0.01**		**† P<0.01**
Family-home	30.3	69.7	17.4 (2.1)
Community-house	65.8	34.2	15.9 (2.2)
Institution	75.9	24.1	14.3 (3.4)
Carer-care recipient contact	**P=0.02**		**P<0.01**
<1year	90.9	9.1	13.7 (2.8)
1–5 years	62.9	37.1	15.2 (2.9)
>5 years	46.3	67.4	16.9 (2.5)
Carer's last dental visit	**P=0.02**		**P=0.03**
Never/problem/don't know	78.3	21.7	14.6(2.9)
Within 2 years	60.0	40.0	16.1(2.5)
Within 6 months	42.9	57.1	16.5(2.9)

*P = Chi-square p value, †ANOVA, n=100

Table 4.27e Relationship between subscale CAM-Skills and socio-structural factors

	CAM-Skills (%)		CAM-Skills
Variables	**Low**	**High**	**Mean (sd)**
Residential setting	* **P=0.04**		†P=0.33
Family-home	39.4	60.6	13.9 (1.7)
Community-house	68.4	31.6	13.4 (1.3)
Institution	51.7	48.3	13.9 (1.3)
Carer-care recipient contact	P=0.19		P=0.51
<1year	54.5	45.5	13.6 (1.4)
1–5 years	65.7	34.3	13.5 (1.3)
>5 years	46.3	53.7	13.9 (1.5)
Carer's last dental visit	P=0.11		P=0.18
Never/problem/don't know	69.6	30.4	13.3(1.4)
Within 2 years	57.1	42.9	13.7(1.5)
Within 6 months	42.9	57.1	13.9(1.4)

*P = Chi-square p value, †ANOVA, n=100

Similarly, there was a significantly higher proportion of carers providing care at family-homes who had high CAM-Skills and CAM-Confidence scores.

Table 4.27f Relationship between subscale CAM-Confidence and socio-structural factors

	CAM-Confidence (%)		CAM-Confidence
Variables	**Low**	**High**	**Mean (sd)**
Residential setting	* **P=0.05**		†P=0.09
Family-home	39.4	60.6	25.9 (3.8)
Community-house	60.5	39.5	24.4 (3.7)
Institution	69.0	31.0	23.8 (4.4)
Carer-care recipient contact	P=0.10		P=0.16
<1year	81.8	18.2	23.2 (3.3)
1–5 years	60.0	40.0	24.3 (4.1)
>5 years	48.1	51.9	25.4 (4.0)
Carer's last dental visit	P=0.31		P=0.72
Never/problem/don't know	69.6	30.4	24.2(3.3)
Within 2 years	54.3	45.7	25.1(3.6)
Within 6 months	50.0	50.0	24.8(4.6)

*P = Chi-square p value, †ANOVA, n=100

4.2.6 Relationship between carers‟ literacy and dental behaviours for care recipients

Carers‟ preventive dental behaviours for their care recipients included toothbrushing frequency and dental visiting pattern of their care recipients.

4.2.6.1 Relationship between carers‟ literacy and toothbrushing frequency among care recipients

There was no significant difference between carers‟ oral health literacy scores and toothbrushing frequency among care recipients. Although more carers with high general literacy scores tended to have their care recipients‟ teeth brushed twice a day compared to those with low general literacy scores, the difference was not statistically significant (Table 4.28).

Table 4.28 Relationship between carers‟ literacy and toothbrushing frequency among care recipients

	Toothbrushing frequency among care recipients		Chi-square
Carers' literacy	**Once a day (%)**	**Twice a day (%)**	**p value**
Comprehension			P=0.87
Low	31.0	69.0	
High	29.2	70.8	
Numeracy			P=0. 08
Low	18.8	81.2	
High	36.5	63.5	
Oral health literacy			P=0.88
Low	30.0	70.0	
High	31.4	68.6	
General literacy			P=0.08
Low	47.4	52.6	
High	26.3	73.7	

n=100

4.2.6.2 Relationship between carers' literacy and dental visit pattern of care recipients

Dental visit pattern of care recipients was not associated with carers' oral health or general literacy (Table 4.29).

Table 4.29 Relationship between carers' literacy and dental visit pattern of care recipients

	Dental visit pattern		
Carers' literacy	**Don't know/ Problem only / >12 months (%)**	**Within 12 months (%)**	**Chi-square p value**
Comprehension			0.59
Low	25.3	74.7	
High	20.0	80.0	
Numeracy			0.36
Low	29.4	70.6	
High	21.2	78.8	
Oral health literacy			0.84
Low	24.6	75.4	
High	22.9	77.1	
General literacy			0.79
Low	26.3	73.7	
High	23.5	76.5	

n=100

4.2.7.1 Relationship between carers" psycho-social factors and toothbrushing frequency among care recipients

Not surprisingly, a significantly higher proportion of carers (84.8%) with higher CDE scores reported twice a day toothbrushing than those with lower CDE scores (p<0.01, Table 4.30). Other psycho-social factors (COHC, CAM, CAM-Knowledge, CAM-Skills and CAM-Confidence) were not associated with toothbrushing frequency among care recipients.

Table 4.30 Relationship between carers" psycho-social factors and toothbrushing frequency among care recipients

Carers' psycho-social factors	Toothbrushing frequency among care recipients		Chi-square p value
	Once a day (%)	Twice a day (%)	
CDE			P<0.01
Low	44.9	55.1	
High	15.2	84.8	
COHC			0. 28
Low	35.3	64.7	
High	25.0	75.0	
CAM			0.29
Low	35.4	64.6	
High	25.5	74.5	
Knowledge			0.61
Low	32.7	67.3	
High	27.9	72.1	
Skills			0. 28
Low	35.3	64.7	
High	25.0	75.0	
Confidence			0.16
Low	36.5	63.5	
High	23.3	76.7	

n=100

4.2.7.2 Relationship between carers‟ psycho-social factors and dental visit pattern among care recipients

A significantly higher proportion of carers who had higher CDE, COHC, CAM, CAM-Knowledge, and CAM-Skills scores reported their care recipients‟ last dental visit as being within the last 12 months than carers with lower psycho-social scores (Table 4.31). Although carers‟ Confidence showed a similar tendency, it was not significantly associated with dental visit pattern among care recipients.

Table 4.31 Relationship between carers‟ psycho-social factors and dental visit pattern among care recipients

	Dental visit pattern		
Carers' psycho-social factors	**Don't know/ Problem only / >12 months (%)**	**Within 12 months (%)**	**Chi-square p value**
CDE			P<0.01
Low	37.7	62.3	
High	8.5	91.5	
COHC			P<0.01
Low	37.0	63.0	
High	8.7	91.3	
CAM			0.03
Low	33.3	66.7	
High	14.3	85.7	
Knowledge			P<0.01
Low	35.1	64.9	
High	9.3	90.7	
Skills			P<0.01
Low	35.2	64.8	
High	10.9	89.1	
Confidence			0.09
Low	30.4	69.6	
High	15.9	84.1	

n=100

4.2.8 Bivariate correlations

Bivariate correlations were used to investigate the relationship between literacy and psycho-social variables (Table 4.32). There was a low correlation between general and oral health literacy. There was a moderate correlation between CDE and COHC, CAM and its subscales Knowledge, Skills and Confidence. As two items in CAM-Skills were also included in COHC, there was a high correlation between COHC and CAM-Skills.

Table 4.32 Bivariate correlations between each of the independent variables

Correlations

		Comprehension	Numeracy	OHL	General	CDE	COHC	CAM	Knowledge	Skills	Confidence
Spearman's rho	Comprehension	1.000									
	Numeracy	.080	1.000								
	OHL	.657**	.776**	1.000							
	General	.303**	.059	.219*	1.000						
	CDE	.057	-.173	-.040	.074	1.000					
	COHC	.017	-.142	-.089	.077	.647**	1.000				
	CAM	.212*	-.212*	-.023	.088	.570**	.659**	1.000			
	Knowledge	.276**	-.203*	.019	.126	.432**	.507**	.876**	1.000		
	Skills	.041	-.123	-.055	.108	.657**	.892**	.654**	.488**	1.000	
	Confidence	.171	-.211*	-.047	.064	.484**	.541**	.938**	.718**	.512**	1.000

**Spearman's Correlation is significant at the 0.01 level (2-tailed).
*Spearman's Correlation is significant at the 0.05 level (2-tailed).

4.2.9 Multivariate models

Binary logistic regression analyses were used to model the relationship between the dependent variables (toothbrushing frequency and dental visiting behaviour) and the independent variables (psycho-social factors) with a median split. The main purpose of the multivariate analyses was to estimate the effect of psycho-social factors CDE, COHC, CAM, CAM-Knowledge and CAM-Skills on dental behaviours, while simultaneously adjusting for other factors found in preceding analyses to be associated with the dental behaviours. Multivariate models were constructed as described in the methods (Chapter 3). 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 psycho-social factors by 10% or more. The group with the lower score was used as the reference group in these models which therefore estimated effects of the group with the higher score. Age and sex were included in all models. Each model estimated effects for the higher score group relative to lower score group and other significant variables. The effects are expressed as odds ratios. CAM-Knowledge did not have any significant associations with toothbrushing and dental visit in the bivariate analyses, and therefore no multivariate models were constructed.

4.2.9.1 Binary logistic regression models for factors associated with twice a day toothbrushing among the care recipients and CDE

One logistic regression model was constructed for toothbrushing frequency among the care recipients and CDE (Table 4.33). Carer age, sex and main language spoken at home were included in the model to adjust for carers‟ demographic characteristics. In the unadjusted analysis, the odds of twice a day toothbrushing was higher among carers with high CDE, and this relationship remained statistically significant in model 1. Carers with high CDE had 4.2 times greater odds of having care recipients‟ teeth brushed twice a day. The R square shows that 18.7% of the variation in the toothbrushing behaviour was explained in this logistic regression model.

Table 4.33 Binary logistic regression models for factors associated with twice a day toothbrushing among care recipients and CDE

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted	CDE – low (Ref)		
CDE only	CDE – high	4.5 [1.7, 12.1]	14.4
Model 1	CDE – low (Ref)		
Carer characteristics[1]	CDE– high	4.2 [1.5, 11.6]	18.7

[1] Carer age, sex, main language spoken at home
Carer age, sex, and main language spoken at home were not significant.

4.2.9.2 Binary logistic regression models for factors associated with regular dental visit among care recipients and CDE

Two logistic regression models were constructed for regular dental visit among the care recipients and CDE (Table 4.34). Carer age, sex and main language spoken at home and education were included in the first model to adjust for carers‟ demographic characteristics. Socio-structural factors (care recipients‟ residence, carers‟ last dental visit, and length of contact with carer) were then added to the first model, to form the second model.

Table 4.34 Binary logistic regression models for factors associated with regular dental visit among the care recipients and CDE

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted CDE only	CDE – low (Ref) CDE – high	6.5 [2.0, 20.9]	17.7
Model 1 Carer characteristics[1]	CDE – low (Ref) CDE – high	5.1 [1.5, 17.4]	27.9
Model 2 Model 1 + Socio-structural factors [2]	CDE– low (Ref) CDE – high	4.7 [1.3, 17.2]	37.6

[1] Carer age, sex, main language spoken at home, education
[2] Care recipients' residence, carers' last dental visit, length of contact with carer
Carer age, sex, main language spoken at home and education, and care recipients' residence, carers' last dental visit, and length of contact with carer were not significant.

In the unadjusted analysis, the odds of regular dental visit was higher among carers with high CDE, and this relationship remained statistically significant in models 1 and 2. Carers with high CDE had 4.7 times greater odds of having their care recipients visit the dentist within the last twelve months. The R square shows that 37.6% of the variation in the dental visiting behaviour was explained by this logistic model.

4.2.9.3 Binary logistic regression models for factors associated with regular dental visit among care recipients and COHC

Two logistic regression models were constructed for regular dental visit among the care recipients and COHC (Table 4.35). Carer age, sex and main language spoken at home and education were included in the first model to adjust for carers‟ demographic characteristics. Socio-structural factors were then added to the first model, to form the second model. In the unadjusted analysis, the odds of regular dental visit was higher among carers with high COHC, and this relationship remained statistically significant in models 1 and 2. Carers with high COHC had 5.7 times greater odds of having their care recipients visit the dentist within the last twelve months. The R square shows that 38.0% of the variation in the dental visiting behaviour is explained by this logistic model.

Table 4.35 Binary logistic regression models for factors associated with regular dental visit among the care recipients and COHC

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted COHC only	COHC – low (Ref) COHC – high	6.2 [1.9, 19.8]	16.7
Model 1 Carer characteristics[1]	COHC – low (Ref) COHC – high	4.5 [1.3, 15.9]	25.3
Model 2 Model 1 + Socio-structural factors [2]	COHC – low (Ref) COHC – high	5.7 [1.4, 23.4]	38.0

[1] Carer age, sex, main language spoken at home, education
[2] Care recipients' residence, carers' last dental visit, length of contact with carer
Carer age, sex, main language spoken at home and education, and care recipients' residence, carers' last dental visit, and length of contact with carer were not significant.

4.2.9.4 Binary logistic regression models for factors associated with regular dental visit among care recipients and CAM

Two logistic regression models were constructed for regular dental visit among the care recipients and CAM (Table 4.36). Carer age, sex, main language spoken at home, education and income were included in the first model to adjust for carers‟ demographic characteristics. Socio-structural factors were then added to the first model, to form the second model. In the unadjusted analysis, the odds of regular dental visit was higher among carers with high CAM, but this relationship was no longer statistically significant in models 1 and 2.

Table 4.36 Binary logistic regression models for factors associated with regular dental visit among the care recipients and CAM

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted	CAM – low (Ref)		
CAM only	CAM – high	3.0 [1.1,8.1]	7.4
Model 1	CAM – low (Ref)		
Carer characteristics[1]	CAM – high	2.2 [0.7, 6.5]	20.0
Model 2	CAM – low (Ref)		
Model 1 + Socio-structural factors [2]	CAM – high	1.8 [0.5, 5.7]	31.4

[1] Carer age, sex, main language spoken at home, education, income
[2] Care recipients' residence, carers' last dental visit, length of contact with carer
CAM, carer age, sex, main language spoken at home and education, and care recipients' residence, carers' last dental visit, and length of contact with carer were not significant.

4.2.9.5 Binary logistic regression models for factors associated with regular dental visit among care recipients and CAM-Knowledge

Two logistic regression models were constructed for regular dental visit among the care recipients and Knowledge (Table 4.37). Carer age, sex, main language spoken at home, education and income were included in the first model to adjust for carers‟ demographic characteristics. Socio-structural factors were then added to the first model to form the second model. In the unadjusted analysis, the odds of regular dental visit was higher among carers with high Knowledge, and this relationship remained statistically significant in model 1, but not model 2.

Table 4.37 Binary logistic regression models for factors associated with regular dental visit among the care recipients and Knowledge

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted Knowledge only	Knowledge – low (Ref)		
	Knowledge – high	5.3 [1.7, 16.9]	13.9
Model 1 Carer characteristics[1]	Knowledge – low		
	Knowledge – high	4.6 [1.3, 16.5]	25.9
Model 2 Model 1 + Socio-structural factors[2]	Knowledge – low	3.3 [0.87, 12.7]	34.2
	Knowledge – high		

[1] Carer age, sex, main language spoken at home, education

[2] Care recipients' residence, carers' last dental visit, length of contact with carer

Knowledge, carer age, sex, main language spoken at home and education, and care recipients' residence, carers' last dental visit, and length of contact with carer were not significant.

4.2.9.6 Binary logistic regression models for factors associated with regular dental visit among care recipients and CAM-Skills

Two logistic regression models were constructed for regular dental visit among the care recipients and Skills (Table 4.38). Carer age, sex and main language spoken at home and education were included in the first model to adjust for carers‟ demographic characteristics. Socio-structural factors were then added to the first model, to form the second model. In the unadjusted analysis, the odds of regular dental visit was higher among carers with high Skills, and this relationship remained statistically significant in models 1 and 2. Carers with high Skills had 4.3 times greater odds of having their care recipients visit the dentist within the last twelve months. The R square shows that 36.4% of the variation in the dental visiting behaviour is explained by this logistic model.

Table 4.38 Binary logistic regression models for factors associated with regular dental visit among the care recipients and Skills

Models	Variables	Odds Ratio [95% CI]	R^2
Unadjusted	Skills – low (Ref)		
Skills only	Skills – high	4.5 [1.5, 13.2]	12.3
Model 1	Skills – low (Ref)		
Carer characteristics[1]	Skills – high	3.7 [1.1, 12.1]	24.1
Model 2	Skills – low (Ref)		
Model 1 + Socio-structural factors[2]	Skills – high	4.3 [1.1, 15.9]	36.4

[1] Carer age, sex, main language spoken at home, education

[2] Care recipients' residence, carers' last dental visit, length of contact with carer

Carer age, sex, education, and care recipients' residence, carers' last dental visit, and length of contact with carer were not significant.

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. Where possible, comparisons have been made to previous studies and possible explanations for the differences discussed. This chapter also includes the strengths and limitations, 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 after adjusting for carer characteristics and socio-structural factors, multivariate analysis showed that twice a day toothbrushing among the care recipients was significantly associated with higher carer dental efficacy (CDE). Regular dental visit among the care recipients was significantly associated with higher CDE, carer oral health competency (COHC) and CAM-Skills. The general literacy score was higher than oral health literacy score among all groups, but neither of the literacy scores was significantly associated with the toothbrushing and dental visit frequency of the care recipients. Other findings are discussed in details below, with reference to each aim and hypothesis and compared to previous studies whenever possible.

5.1.1 Care recipient characteristics

The distribution of care recipients across the three residential setting was comparable to the 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 less care recipients (33%) lived in family homes compared with the previous South Australian study (Pradhan, 2008) could have been due to the older cohort of care recipients in this follow-up study. The majority of the younger care recipients (<29 years) lived in family homes, while the majority of the older age-groups lived in community and institutional settings. 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 at their family homes. Almost a third of the care recipients had little or no effective communication and one fifth of them communicated non-verbally making this population dependant on their carers for their general well-being and oral health care.

5.1.2 Carer characteristics

5.1.2.1 Socio-demographics of carers

There was a wide age range among carers (19 – 83 years), with a significantly higher proportion of family carers being 55+ years old. There were significantly more female carers in family homes and community houses than male carers. On the other hand, there were more male carers in institutions, most likely due to them being able to manage care recipients with behavioural problems. A significantly higher proportion of family carers were older, with the highest qualification as high school or less, and received carer allowance.

Although English is the official language in Australia, more than three million Australians speak a language other than English at home and more than one million people with disability are from non-English speaking backgrounds (Cooper and Wadiwel, 2010). In this study, 12% of carers had non-English as the main language spoken at home. However, they were all proficient in English and no problems were encountered with the interview. It should be noted that all people with disabilities face barriers to social inclusion, such as access to work, technology, and social activity. However, people from non-English speaking backgrounds are likely to face greater obstacles, especially if their carers have a low English proficiency that might affect access to information, services and social networks. Ironically, it is this very group that are generally excluded from participation in research in many English speaking countries (Lee et al., 2007; Miller et al., 2010), including Australia. In the earlier South Australian study (Pradhan, 2008), one of the organisations who had agreed to participate initially, did not take part because the majority of its care recipients were from a non-English speaking background whilst the survey materials were offered only in English.

5.1.2.2 Dental behaviours of carers

All carers reported oral health to be important/very important/extremely important for their care recipients and themselves, similar to other studies (Frenkel et al., 2002). In the South Australian study (Pradhan, 2008), 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 less frequent toothbrushing was reflected in the toothbrushing frequency of their care recipients. As the initial focus of this study was on oral health literacy among carers, information on toothbrushing frequency among carers was not obtained.

Although most carers took their care recipients to their dental visits, a lower percentage (77%) of carers had personally visited the dentist within the last two years, with 18% of them visiting only with a problem. Some 5% of carers had never visited the dentist. Dental visiting among the carers was less frequent in the earlier South Australian study (Pradhan, 2008), in which 68% of the carers visited the dentist within the last two years.

5.1.3 Dental practices among carers for their care recipients

As care recipients depend on their carers for their daily oral hygiene and dental visits, information on the toothbrushing and dental visit pattern of care recipients was obtained from their carers.

5.1.3.1 Toothbrushing frequency

In this study, almost every care recipient received assistance for toothbrushing from their carer, suggesting they were comparatively more dependent than in the UK study of adults with intellectual disability by (Cumella et al., 2000), and the South Australian study (Pradhan, 2008) which reported 22% and 72% of their study subjects needing assistance from their carers for oral care, respectively. In fact, care recipients who were quite independent for self-care activities and did not need much carer support were not included in this follow-up study, as this study had a focus on carers actively involved in the care of dependent care recipients.

About 31% of the care recipients had their teeth brushed once a day or less, which was not much different to the finding in the earlier South Australian study (Pradhan, 2008). There was no difference in toothbrushing frequency of care recipients by carers‟ age, sex, education, income, residential setting, carers‟ last dental visit, or length of contact with carers. However, a significantly higher proportion of carers whose main language spoken at home was English reported twice a day toothbrushing compared to carers whose main language spoken at home was non-English, indicating possible cultural difference in toothbrushing practices. In the earlier South Australian study (Pradhan, 2008), 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.

CDE also assessed if carers brushed their care recipients‟ teeth at least once a day, to which 82% of carers were in agreement. The remaining 18% stated they did not do so because of rosters or behaviour problems. In fact, for some care recipients, it is not realistic to provide oral hygiene care on a regular, daily basis as ideally needed due to poor or no compliance. It may only be possible to provide oral hygiene care „as best as possible‟ at „unpredictable times‟. Moreover, some carers have persisted in feeling that they should stop brushing when there is gingival bleeding, even when the logic behind brushing more effectively in these cases has been explained (Fiske, 2000). Also, carers are reported to feel more comfortable with dentures cleaned outside the mouth than with inserting toothbrush and fingers inside a client's mouth (Frenkel et al., 2002). Lack of familiarity with brushing teeth for another person may account for the reluctance. Whether these were the reasons 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 among the care recipients. These findings highlight the need for oral health promotion, training and support for carers to improve oral care for people with disabilities.

5.1.3.2 Diet

This study did not include specific questions on the diet of care recipients *per se*. Instead, one question related to diet (I control snacking between meals) was included in CDE and two questions (I am confident I can maintain a healthy diet for them, and I am confident I can maintain a healthy diet for them, even during times of stress) were included in CAM. When assessing CDE, only 67% of the carers agreed that they controlled snacking between meals for their care recipients. The remaining carers stated they did not have any control over the snacking habits of their care recipients, either because the care recipients were independent enough to make their own choices for food and drinks, or they were given to them by visiting family and friends. When assessing CAM, less than 50% of the carers strongly agreed that they were confident they could maintain a healthy diet for them, including during times of stress. Carers in institutions mentioned that they have little control over the diet of care recipients. It is the management who plan the meals and carers simply serve what is provided at that institution. Management and family and friends should be informed about the adverse effects of snacking and high sugar diet, not only for dental health, but also general health.

5.1.3.3 Dental visit pattern

Similar to the earlier South Australian study (Pradhan, 2008), in this study, 76% of the South Australian population represented visited the dentist at least once a year which was also comparable to the earlier Australian survey of adults with developmental disabilities (Scott et al., 1998) and the UK study of handicapped adults (Francis et al., 1991) which reported the dental visit in the last 12 months as 65% and 69% respectively. However, in contrast to the earlier study (Pradhan, 2008), in which care recipients in institutions visited the dentist more frequently (six-monthly recalls) compared to care recipients at other settings, in this study, there was no difference in dental practices in this population across the three residential settings. It appears that, as anticipated, oral care has been continued when care recipients have moved into the community. Carers at family homes also have had access to information on services available and maintained access to regular dental visits. In fact, when care recipients at family-homes and community settings were regrouped as being care recipients in non-institutional setting, a higher proportion of this group visited the dentist within 12 months compared to care recipients in institutional settings. The participating carers therefore appear to be more interested in oral health.

Carers‟ age, sex and income were not associated the dental visit pattern of their care recipients. However, more carers whose main language spoken at home was English, whose last dental visit was within six months and had been a carer for over five years reported that their care recipients‟ last dental visit was within the last twelve months compared to those carers whose main language spoken at home was non-English, had less regular dental visiting pattern and shorter length of contact with their care recipients. Surprisingly, carers whose highest qualification was college degree or more reported less regular dental visits for their care recipients than carers whose highest qualification was high school or less or trade. It is possible that their higher levels of qualification did not match their roles as carers, or they were providing care to a different category of care recipients.

In this study, carers accompanied their care recipients to their dental visits in 91% of cases compared to 61% of cases in the UK survey by Cumella et al. (2000). Such carer involvement is a practical necessity in making and keeping appointments as most care recipients are unable to do so, on their own. The most frequent reason for the remaining carers for 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.

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 trials. More attention should be given to carers whose main language spoken at home is non-English, to ensure the information is clearly understood and the recommended task(s) appropriately carried out.

5.1.4 Oral health literacy among carers

Although the concept of oral health literacy is broad, current literature is restricted to instruments that deal with word pronunciation as in REALD-30 (Lee et al., 2007) and REALD-99 (Richman et al., 2007) or reading comprehension and numeracy as in TOFHLiD (Gong et al., 2007) and OHLI (Sabbahi et al., 2009). The focus of these instruments appears to be the development of a reliable and valid instrument to identify people with low oral health literacy for use in clinical or public health practices. However, this study developed a functional oral health literacy instrument to explore oral health literacy among carers by testing whether the information routinely used at the Special Needs Unit, Adelaide Dental Hospital was understood by the carers, to determine if oral health literacy was the missing link between the available information and expected oral health behaviours. It assessed carers on accessing the dental care system, understanding appointment slips, completing medical history and consent forms, and following professional instructions, using text passages and prompts. Prompts on numeracy section were similar to TOFHLiD and OHLI, but more specific to carers. However, for comprehension of the oral health section in this study, three choices for „dental" words were given, unlike TOFHLiD and OHLI, in which „non-dental" words were omitted from the passages, which probably tested proficiency in English language rather than oral health literacy. For the general literacy section, „non-dental" words were selected from REALD-99 and TOFHLiD.

The scores of the comprehension and numeracy sections were scaled to obtain scores ranging from 0 to 50 for each section, to give a total of 100 for oral health literacy. OHL score was very similar to OHLI (Sabbahi et al., 2009), ranging from 56.7–100 (mean=87.9). Comprehension score ranged from 16.7–50 (mean=41.7), which was slightly lower than OHLI (mean=43.3), possibly due to the use of „dental" words. Numeracy score ranged from 30–50 (mean=46.2), which was slightly higher than OHLI (mean=44.0).

Only eight carers obtained 100% correct responses. Of the twenty-five items assessed, only the two items with the appointment card as a prompt were correctly answered by all carers. Familiarity with the appointment card could be contributing factor. Lowest scores (16.7 on the 50-point scale) were obtained for the comprehension section, for which dental words were used. More commonly used words like teeth, cavity and fluoride were understood by all carers. However, the highest number of incorrect responses was for less commonly used words like „gingiva" (63%), followed by „caries" (61%), which can be replaced with more familiar, alternate words like „gums", and „cavity", more easily understood by all carers. This indicates there is a need to ensure information given to carers on dental visits, completing medical history and consent forms, home care instructions and general information on accessing dental care is clearly communicated verbally and in writing.

The National Assessment of Adult Literacy measured health literacy of US adults, and reported that both literacy and health literacy are highly correlated (Kutner et al., 2006). Likewise, in an Australian study, inadequate functional health literacy was significantly associated with older age, lower education, lower income, being born outside Australia, New Zealand, the United Kingdom or Ireland, and poorer health status (Adams et al., 2009). In this study, general literacy score was high among all groups, except for carers whose main language spoken at home was non-English. However, OHL score was lower among all groups, indicating differences in general literacy and oral health literacy. A significantly higher proportion of carers in the 45–54 years had high comprehension scores than carers in other age groups, perhaps from personal and work associated dental experience.

Traditionally, researchers and clinicians used the patient"s level of education as an indicator of literacy skills (Davis et al., 1998). However, it is now understood that educational level cannot be used as a proxy for literacy because it is not an accurate predictor of health literacy with patients

often reading several grade levels lower than the highest grade achieved in school (Baker et al., 1996). Jones et al. (2007) reported that those with incorrect oral health knowledge were more likely to have a lower oral health literacy level than their reference groups. However, Sabbahi et al. (2009) found no association between OHLI and education level. Interestingly, in this study, a significantly higher proportion of carers with a trade qualification had high comprehension scores than carers whose education was high school or less or college level or more, as their trade qualification would have had some training in oral care more relevant to their jobs, compared to the other two groups. This could have been confounded by carer age as well.

Similar to the study among 106 mother-child dyads, by Miller et al. (2010), this study did not find any relationship between oral health literacy and dental behaviours. This finding prompted the search for additional factors that may be associated with dental behaviours.

5.1.5 Psycho-social factors

Several psycho-social factors among carers were assessed to determine if they could explain the dental behaviours of carers for their care recipients. They included carer‟s dental-efficacy (CDE), carer oral health competency (COHC) and carer activation measure (CAM) in managing oral health for their care recipients. However, some modifications were made to the original instruments for this study to ensure that items were relevant to carers. Therefore the items used for CDE, COHC and CAM were personalised, using the word "I". Each measure consisted of several items describing specific preventive dental and treatment behaviours, asking carers to indicate their level of agreement/disagreement with each statement.

5.1.5.1 Carer dental efficacy

There are many different self-efficacy instrument versions. The development and validation process of many self-efficacy instruments utilised to evaluate an individual‟s self-efficacy in relation to management of a chronic disease have been criticized and a systematic approach to development and validation of self-efficacy instruments recommended (Frei et al., 2009). The five CDE items about oral care behaviours, were constructed based on Bandura‟s social cognitive theory (Bandura, 1977) modified by Schwarzer (1992), with a clear aim to measure carers‟ behaviour-specific judgments. The key difference with this scale is that it does not ask about the

ability to perform under different situations, defined by Bandura as potential impediments (Bandura, 2004a).

Oral health is determined by a healthy diet, daily oral hygiene care and regular dental visits. A comprehensive efficacy assessment would be linked to the behavioural factors over which people can exercise some control. Therefore, in this study, CDE assessment included whether the carer controlled snacking habits, brushed the teeth at least once a day and maintained regular dental visits for their care recipients. Brushing teeth „at least once a day" was asked in preference to „twice daily" so as to include carers in different shifts, who may not have the opportunity to be involved in twice daily toothbrushing for their care recipients. Whether carers gave a high priority for any dental problem or followed professional instructions at home were also considered dental behaviour-specific judgment and accordingly included in the assessment.

The majority of carers strongly agreed that for their care recipients, they brush their teeth at least once a day, take them for regular dental check-ups, give a high priority for any dental problem, and carefully follow any instructions from their dental professional about home-care. The few that did not brush their care recipients" teeth at least once a day or take them for regular dental check-ups was due to them not being rostered for those activities. However, only 37% of carers strongly agreed that they controlled snacking between meals, and almost a quarter of them were neutral for this statement. Carers at community and institutional settings stated they had no control over their care recipients" snacking. The more independent care recipients ate what they liked, whenever they wanted. The others were brought treats when family members visited them.

After adjusting for carer and care recipient characteristics, multivariate analysis showed that twice a day toothbrushing and regular dental visits among the care recipients were significantly associated with higher CDE. Measurement of CDE could be used to evaluate the impact of carer education programmes. CDE can also be raised via positive reinforcements to further improve the performance of carers.

5.1.5.2 Carer oral health competency

COHC measured carers" perceived oral health competency at a more general level. About 60% of the carers strongly agreed that they take responsibility in caring for their care recipients" oral

health and are able to do things as well as most other people. However, only 40% of carers strongly agreed that they succeed in the projects they undertake to improve the oral health of their care recipients. This indicates there are differences in the level of agreement between their behaviours and the outcomes. Although the possible reasons for the differences were not queried at the interview, some carers acknowledged the differences and mentioned that the "success" or "achievement" did not depend on an individual carer alone, but on all carers for that care recipient.

There was a significantly higher proportion of carers aged 55+ years old, female carers, carers providing care at family homes and carers speaking English as the main language spoken at home who reported higher COHC scores than carers in other age groups, male carers, carers at community houses and institutional settings and carers whose main language spoken at home was non-English. Interestingly, significantly higher proportion of carers whose highest level of education was college or more reported lower COHC scores than carers whose highest level of education was high school or less or trade. Employers need to ensure that the level of education and training is relevant to the job.

After adjusting for carer and care recipient characteristics, multivariate analysis showed that regular dental visit among the care recipients was significantly associated with higher COHC. COHC could thus be used to examine oral health behaviours among new and old carers and the information applied to design intervention programmes to enhance participation in healthy oral health behaviours.

5.1.5.3 Carer activation measure

CAM measured the carer"s level of activation in providing care for their care recipients, based on three subscales: Knowledge, Skills and Confidence. Assessing CAM-Knowledge, only 22–39% of carers strongly agreed that they knew or understood oral health problems, causes, available treatments, prescribed medications and how to prevent further oral health problems. Assessing CAM-Skills, there was a higher proportion of carers (55–72%) in strong agreement, but one item was already included in the CDE and two items were already included in the COHC scales. Assessing CAM-Confidence, only 32–45% of carers strongly agreed that they are confident about the need to go to the dentist, tell about the possible dental concerns, help prevent or reduce

oral health problems, maintain a healthy diet, even during times of stress, and figure out solutions when new problems arise with the oral health condition of their care recipients.

There was a significantly higher proportion of carers aged 55+ year old who reported high CAM-Knowledge and CAM-Skills scores. A significantly higher proportion of female carers had higher Knowledge and Confidence scores than males. Likewise, a significantly higher proportion of carers speaking English as the main language spoken at home reported high CAM and CAM-Knowledge scores than carers whose main language spoken at home was non-English. Interestingly, a significantly higher proportion of carers whose highest level of education was college or more reported lower CAM, CAM-Skills and CAM-Confidence scores than carers whose highest level of education was high school or less or trade. On the other hand, a significantly higher proportion of carers whose income was $15/hour or more had lower Knowledge scores compared to carers on carer allowance or no pay. There was a significantly higher proportion of carers providing care at family homes who reported high Knowledge, Skills and Confidence than those at community house and institutional settings. Similarly, a significantly higher proportion of carers who had higher CAM, CAM-Knowledge, and CAM-Skills scores reported their care recipients‟ last dental visit as being within the last 12 months than carers with lower psycho-social scores. After adjusting for carer and care recipient characteristics, multivariate analysis showed that regular dental visit among the care recipients was significantly associated with higher CAM-Skills.

An individual‟s ability to act in knowledge-consistent ways depends on their perceived abilities and as long as the perceived barriers to a healthy lifestyle changes are high, it is unlikely that being knowledgeable about health issues will bring about corresponding behaviours (Rimal, 2000). Barriers may include a lack of training, time constraints associated with workload (Pradhan, 2008), poor understanding of the processes causing dental disease (Weeks and Fiske, 1994), low priority for oral care (Wardh et al., 2000), revulsion and lack of materials (Frenkel et al., 2002). By focusing on the characteristics of individual carers that predict dental behaviours, there may be a tendency to blame the carer for the oral health of their care recipients. Rather, the focus should also be on the socio-structural barriers to the improvement of dental behaviours and oral health outcomes (i.e., a multifactorial approach to what is recognised as a multi-factorial problem).

5.2 Methodological strengths and limitations of the study

5.2.1 Study design and sampling

Only a few oral epidemiological studies have been conducted among carers of people with physical and intellectual disabilities, due in part to the challenges of selecting a representative sample of this population and due to the high turnover of non-family carers. This sampling frame allowed access to carers from all three residential settings. However, this was a cross-sectional study limited to Adelaide, comprising of a non-randomised and therefore non-representative sample of carers.

The sampling frame for the present study was the respondents in a previous probability sample of carers. However, the group of respondents in the previous study was biased because the sampling method excluded people who were not registered or not in contact with a disability organisation. Moreover, analyses in the previous study were undertaken using weighted data to account for the different probabilities of selection from the various organisations and make inferences about the associations within the population of people with disabilities in South Australia. The present sampling frame used the unweighted respondents of the previous study. Substantial numbers (11.5%) moved out of scope. In addition, the low response rate in this present study has introduced further uncertainty about representativeness. Therefore, caution needs to be exercised in generalising from the results and associations in this study to the broader population of carers.

The present study is one of the first to investigate the association between carers‟ dental behaviours and literacy and psycho-social factors. Toothbrushing frequency was selected as one of the outcome measures because it is a positive oral health promoting behaviour, and a more immediate outcome. However, as a self-reported measure, toothbrushing frequency is highly subject to socially desirable response bias. It is possible the associations found in this study may be distortions of the real underlying relationships if the self-reported data are misrepresentations of actual behaviours. It is also worthwhile to note that higher reported rates of toothbrushing may not necessarily reflect more effective plaque removal or better hygiene habits than those reporting less frequent toothbrushing, as the quality of toothbrushing was not assessed in this study. Careful cleaning, and not just frequent brushing, is more relevant for oral health.

The second outcome measure was dental visit pattern. However, this could also be subject to recall and socially desirable response biases. In addition, with a high turnover of paid carers, new carers may not have been aware of the dental visit pattern for their care recipients. In fact 15 non-family carers responded "don‟t know" to their care recipient‟s last dental visit. Due to the small sample size, dental visiting was categorised into „within 12 months‟ and „never/only with a problem/over 12 months‟.

In order to quantify constructs that are not directly measurable, multiple-item scales and summated ratings are often used to quantify the constructs of interest. Therefore, for this research, constructs (CDE, COHC and CAM) were measured using multi-item measures as opposed to using single-item measures. A measure constructed from multiple questionnaire items usually has several advantages over a score estimated from a response to a single item. These advantages include better representation of the concept (content validity) and gains in internal consistency from replication across items. Individual items may have considerable random measurement error (i.e. may be unreliable). However, measurement error averages out when individual scores are summed to obtain a total score (Nunnally and Bernstein, 1994).

The median values of the literacy and psycho-social measures were used as the cut-off point for the coding of dichotomous indicator variables to test differences between the two groups. The use of median splits compensates for skewed distributions that can bring about small cell sizes. Results using the scales as continuous measures and the mean scores were also presented for comparison. Significant associations in bivariate analyses could have confounders, but stratified analyses were not possible due to the small sample size.

5.2.2 Response for interview

From a total of 230 carers, 100 were interviewed, giving a final participation rate of 44%, slightly highter than the previous South Australian study (Pradhan, 2008) in which 38% of carers responded to the mail questionnaire. In fact, the participation rate in this study was not much different to the 49% participation rate in the National Oral Health Survey interviews (Mejia et al., 2007). It is likely that the seven carers who refused to participate and the carers of the 186 care recipients who did not respond introduced bias into the study results. Together the limited sampling frame and low participation have resulted in a reduced power to detect differences

between groups. However, it was still possible to test for associations as hypothesised. Even with such a small sample as in this study, significant differences were noted between groups when tested for psycho-social factors.

Contrary to what was initially planned, apart from family carers, most were new carers, who had not participated in the previous study, indicating the high turnover of carers. When necessary, permission was sought from the managers for the participation of carers at community and institutional settings in this study. Every effort was made to interview the carers at their most convenient time. Most of them were interviewed after the care recipients‟ dental visit at the Adelaide Dental Hospital. Both the interviewer and the carer had to be conscious of the safety of the care recipient during the interview. Where care recipients do not attend the Adelaide Dental Hospital, interviews were conducted at Strathmont, Highgate and Minda community houses. Even when a separate interview room was arranged, often there would often be interferences from care recipients present in that house. Where carers could not attend any of the above clinics, interviews were conducted by a second interviewer at their residence, or another mutually convenient location. No problems were encountered during the interviews with this arrangement. Information on response rates in studies as this may help other researchers conducting similar studies.

5.3 Implications of the study

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

- Have demonstrated the level of oral health literacy and psycho-social preparedness among carers.
- Have highlighted the important role of carers as valuable oral health care team members and that additional focus in terms of training and support regarding oral health care for their care recipients is needed to gain a continuity of care and better oral health outcomes.
- Challenge the dental profession to involve „non-dental‟ carers to meet the daily oral care needs of this growing population of people with disabilities at their residence.

- Can be utilized in a range of adaptations to traditional oral health education methods in print, broadcast and electronic communication, as well as improved interpersonal communication between the carers and oral health care providers and for the development of tailored oral health training and support programmes for carers.

5.4 Future research

While the findings of this study have contributed to the knowledge of the relationship between oral health literacy and psycho-social factors among of carers and their dental behaviours, future research could address some of the limitations as well as explore new research questions raised from this study.

Considering the current issues with the increasing numbers of people with disabilities in accessing oral health care and clinical management of oral disease, 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. Studies involving carer factors and dental behaviours could be explored further to explain variations in the oral health of people with disabilities.

Although behaviour is the most consequential concept in understanding and improving individuals‟ long-term health, theoretical models also need to consider the relation between behavioural precursors and behaviours. Valente et al. (1998) not only asks questions about the conditions under which knowledge predicts behaviour, but also provides evidence that behaviours themselves can act as independent variables to predict knowledge and attitudes. A better understanding of the underlying reciprocal processes among these variables could help us develop more effective health promotion programmes.

Studies of cost/benefit associated with the oral health of people with disabilities and oral health care system related to direct and indirect impacts of carers‟ dental behaviours could attract the attention of disability organizations and policy makers.

5.5 Recommendations

The final aim of the study was to make recommendations based on the findings, for the development of appropriate intervention programmes for carers, that match their oral health literacy and psycho-social preparedness, so that carers can provide more appropriate care for their care recipients.

Training of carers on providing oral care for people with disabilities

A lack of relevant vocational qualifications and high staff turnover have implications for staff training (Felce et al., 1993) providing a major challenge for the provision of oral health education and oral health care for people with disabilities. Improvements in oral health have been demonstrated through training of direct care staff (Nicolai and Tesini, 1982). Oral health input to staff induction programmes can overcome some difficulties in releasing staff for training (Davies and Whittle, 1990). Therefore, training could be initiated at the time of staff induction and repeated regularly to ensure that all staff are included.

Intervention programmes need to continue imparting knowledge and raising awareness about oral health to provide an adequate knowledge base. However, sharing of oral health information must be optimized to improve the quality of communication, and thus improve oral health outcomes. To achieve this, the content and the method of traditional oral health education and communication should be revised. Health care systems should minimise the burden of paperwork. People across all levels of literacy benefit from health materials that are easier to read and are not too difficult to understand. If information products are well designed they can reduce the effort required to use them, and even users with less skills are more likely to use the information. Information products that require less effort to use may also increase some users‟ motivation to use them and those who are more activated are better able to understand and use comparative information, even when they have lower skill levels (Hibbard et al., 2007b). That is, activation may help compensate for numeracy and literacy skill deficits. By helping carers to better understand what is at stake when they make health care choices, their motivation to understand and use that information may be increased.

Oral health care providers should consider how to convey important oral health care information in ways that do not require high reading skills by communicating without jargon and confirming

the message has been understood. They can use the „„teach-back‟‟ method as recommended by Schillinger et al. (2003) to check to see that carers understand health information. Written materials on consent and oral health education can be revised from "professional language" to "plain language" format to foster increased and generalised understanding among carers. Key written information should be translated into different languages. Experienced dental interpreters can be used for patients with non-English speaking background. The principle of universal precautions that presume limited health literacy for all healthcare users, as recommended by Volandes and Paasche-Orlow (2007) can be adopted.

Oral health education should also raise awareness of the social determinants of oral health, and be directed towards the promotion of actions which may lead to modification of these determinants. As suggested by Nutbeam (2000, 2008), emphasis should be given to more personal forms of communication, and community-based educational outreach, focussed on better equipping people to overcome structural barriers to health. Furthermore, educational content could be broadened to include the development of skills that enable confident interactions with oral health care providers, and the ability to navigate effectively in the oral health care system.

Raising psycho-social preparedness

Providing oral health education and training alone is not sufficient to promote behaviour change and the attitudes and values of carers also need to be addressed (Frenkel, 1999). Concurrently, self-efficacy should also be promoted to change health behaviours. Enhancement of self-efficacy not only has a direct impact on behaviour, but it also facilitates the translation of knowledge into behaviours. Those who gain knowledge about health also need to have realistic appraisals of their abilities. Further, it is likely that once individuals‟‟ knowledge is enhanced, they will be more open to learning about behaviour modification techniques.

Carers have some power to control or change behaviours. Bandura (2004a) provides some useful strategies and direction for enhancing self-efficacy. Each of the four principal sources of self-efficacy (Bandura, 1977): verbal persuasion, performance accomplishment, vicarious performance, and physiological arousal, can be used in intervention programmes to boost carers‟‟ dental-efficacy. For example, while increasing carers‟‟ knowledge of oral health care, carers can

role-play and model appropriate behaviours, making one another aware of the benefits of health-promotive actions and supporting one another.

Carers need to be engaged as a part of the oral health care team in providing oral care for people with disabilities. However, there is a need to provide guidance on how to support greater activation as recommended by Hibbard and Mahoney (2010). As carers begin at different places along the activation continuum and have different needs, tailoring support and education to the carers's current level of activation will likely yield more positive outcomes than a generalized approach. This implies measuring individual activation levels and tailoring approaches to initiate the process of taking ownership and building a sense of competence. Tailoring can occur with educational content, communications strategies, and in supporting change at the individual level. Especially for those carers lower in activation, approaches that are specifically designed to lessen feelings of being overwhelmed should be used. Those who are low in activation will do poorly if they are given a long list of changes to make, or given too much information to absorb. Therefore, carers should be encouraged to take small steps in which they are comfortable while working toward a larger goal. Allowing them to only focus on one small thing at a time may help to reduce their feelings of being overwhelmed. The chances for success and efficacy of efforts are improved on encouraging behaviours that are more realistic. Having experienced success in one area, the carer may be ready for the next level of challenge, which still may be small, but is one more step closer to the desired outcome. Specific behaviours could then be arranged in a series so that they may be consecutively mastered, with initial tasks being easier than subsequent tasks. As accomplishments leading to the overall target behaviour progress in this sequential manner, encouragement should be given to demonstrate the carer"s relative progress toward the target behaviour and attribute previous accomplishments to his/her own abilities. Shortcomings in behaviour should be treated as opportunities to analyse and subsequently control the causes.

Socio-structural factors

Attempting to change beliefs, behaviours, and access to services are not likely to influence health outcomes or reduce oral health disparities if the „fundamental" social determinants of disease such as socioeconomic status and social support are not considered as well (Link and Phelan, 1995). Programmes need to ensure meaningful, collaborative communication at both the patient–provider interface *and* the patient-system interface to improve the healthcare system (Schillinger,

2001). In fact, many believe that the "problem of health literacy" is as much a problem of insufficient dedication of the staff within the healthcare system to the issue of reducing unnecessary complexity and communicating more effectively as it is a problem of limited literacy skills (Paasche-Orlow and Wolf, 2007). Instead of overreliance on individual-level factors, attention should be given to system-level factors as well. For example, if the carers are constantly being shifted from one area to another, there is inadequate time given for a good relationship of trust and confidence to be formed between the carer and care recipients. People with disabilities prefer consistency and constant change of carers only confuses them and does not help with their behavioural issues.

Collaborative partnerships

Oral health problems have risk factors in common with a number of important chronic diseases and conditions such as cardiovascular disease, cancers and injuries. Therefore, oral health professionals should work in collaborative partnerships applying the common risk factor approach with other relevant professionals and agencies to avoid duplication of efforts, increase effectiveness and efficiency and achieve sustained long-term improvements in oral health (Sheiham and Watt, 2000). Such collaborative partnerships should be considered even for the training of carers, so oral health care training is integrated in general health care training.

Strategies for retention of carers

Carers are valuable oral health care team members and continuity of care is essential for effective performance. While poor managerial and peer support, poor communication, poor pay, poor promotion prospects, anti-social shift duties, the routine nature of the work, high contact with residents, perceived lack of resident progress and the occurrence of challenging behaviours have been associated with staff dissatisfaction and turnover, opportunities to use their abilities, relationships with other staff, variety within the job, time spent with residents, resident progress, the service's approach to people with disabilities, opportunities to participate in decisions, the receipt of constructive feedback as well as recognition for their achievements have been reported as the reasons for job satisfaction (Felce et al., 1993). Managers need to be aware of these and provide adequate support to retain carers so they continue to provide care with the best outcome for their care recipients.

5.6 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

The age of the care recipients ranged from 22 years to 48 years, with a significantly higher proportion of care recipients in family homes being 29 years old or younger compared to those in community and institutions. Almost a third of the care recipients had little or no effective communication and one fifth of them communicated non-verbally.

Carer characteristics

A significantly higher proportion of family carers were 55+ years old had the highest qualification as high school or less and received carer allowance compared to carers in community and institutional settings. There were significantly more female carers than male carers in family homes and community houses, while there were more male carers in institutions. All carers reported oral health to be important for their care recipients and themselves, and most of them took their care recipients to their dental visits.

Dental practices among carers for their care recipients

Almost all care recipients needed assistance from their carers for toothbrushing, yet 29% of them had their teeth brushed once a day or less. Twice a day toothbrushing was significantly associated with carers whose main language spoken at home was English. Regular dental visit among the care recipients was significantly associated with carers whose main language spoken at home was English and whose highest qualification was high school or less, carers whose last dental visit was within six months and had been a carer for over five years.

Literacy

Oral health literacy score was lower among all groups than general literacy scores, with the lowest scores obtained for the comprehension section, for which dental words were used, which can be replaced with simpler, alternate words, more easily understood by all carers.

Relationship between literacy, carer characteristics and dental behaviours

Carers in the 45–54 years old group had significantly higher comprehension scores than carers in other age groups, most likely from personal and work associated dental experience. Carers with a trade qualification had significantly higher comprehension scores than carers with qualification of college level or more, and those whose education was high school or less, most likely having more relevant training in oral care compared to the other groups. Oral health literacy was not associated with tooth brushing frequency, or dental visit pattern of care recipients.

Psycho-social factors

All psycho-social factors assessed (Carer dental efficacy, Carer oral health competency and Carer activation measure) were skewed towards the higher scales.

Relationship between psycho-social factors, carer characteristics and dental behaviours

After adjusting for carer and care recipient characteristics, multivariate analysis showed that twice a day toothbrushing was significantly associated with higher carer dental efficacy. Regular dental visit among the care recipients was significantly associated with higher carer dental efficacy, carer oral health competency and carer skills.

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Appendix 1: Primary approach letter

Dear

Firstly, we would like to thank you for your participation in the study titled "Oral care for young adults with physical and intellectual disabilities" in 2005–2007. Please find attached a summary report of the study results.
We now would like your help with a follow-up study, "Oral health literacy among carers". Your participation would be greatly appreciated. It will assist us in developing materials to help carers to improve the oral health of their care recipients. Participation in this study is voluntary and all information collected will be kept strictly confidential.

Before we begin this new study, we need to know your current involvement as a carer. To assist us, please complete the form attached about your current activity and return it to the researchers in the enclosed reply-paid envelope by the 9th of April 2009.

Information on completing the form:

1. **If you have remained the primary carer for** ……. and are willing to participate in the study, complete the form attached, and we will contact you shortly with further information about this new study.
2. **If you are no longer the primary carer for the care recipient named above**, kindly forward this letter and the form attached to his/her current primary carer.
3. **If you are no longer the primary carer for the care recipient named above, but care for another care recipient (s),** please list the names of people for whom you are the primary carer. They may have been participants in the previous study, and again, if you are willing to participate in the study, we will contact you shortly with further information about this new study.
4. **If you are no longer a carer**, please indicate on the attached form. We will not be contacting you again.

If you have any queries, please do not hesitate to contact me by phone or email.
Yours sincerely,
Archana Pradhan

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A summary report on:

"Oral care for young adults with physical and intellectual disabilities"

In 2005–2007, the study titled "Oral care for young adults with physical and intellectual disabilities" was conducted by Dr Archana Pradhan under the supervision of Professor AJ Spencer (Professor of Social and Preventive Dentistry) and Professor GD Slade (Professor of Oral Epidemiology) from The University of Adelaide. The research was on oral care for adults with physical and intellectual disabilities (18-44 years of age), living in different living arrangements. The study aimed to investigate how carers can contribute to improved oral health of the people with disabilities.

Contrary to the general assumption, there was no difference in the oral health of people with disabilities across the three residential settings- family home, community housing, and institutions. However, most residents at institutions (62%) visited the on-campus dentist every six months. A much lower percentage of care recipients from community (38%) and family (33.5%) received six monthly dental visits. Therefore, it is recommended to continue provision of an on-campus dental service at institutions to maintain accessibility of clinical care for people with disabilities who move out into the community.

Nearly 40% of care recipients had their teeth brushed once a day or less. 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 preventive 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. Although carers are responsible for their care recipients" daily oral care, seeking appropriate dental treatment, making informed treatment choices and complying with instructions, very few carers had any training in the oral care for the people with disabilities.

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 older age-group, lack of oral hygiene assistance from 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.

These results show that emphasis should be placed on modifiable factors like carer assistance with daily oral hygiene care, diet and regular dental visits, whilst ensuring that carers are not overburdened. It also 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. 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.

Appendix 2: Information sheet on the study

Oral health literacy among carers
Information sheet

The study is being conducted by Dr Archana Pradhan (postgraduate student of Doctorate of Clinical Dentistry) under the supervision of Professor AJ Spencer (Professor of Social and Preventive Dentistry) from The University of Adelaide. This study is on oral health literacy among you as carers for adults with disabilities, living in different living arrangements. It is a follow-up research of the study titled "Oral care for young adults with physical and intellectual disabilities" conducted in 2005–2007.

We are asking you to assist us in finding out what oral health care information is easily understood and what is confusing, with the goal of helping oral health professionals to write and provide information more clearly, so that it is better understood and hopefully implemented, so carers can provide best possible care for their care recipients. Your participation is voluntary and you may withdraw from the study at any time without any prejudice to future treatment of your care recipient.

The study will consist of a short face-to-face interview. We would like to update information about your care-recipients‟ living arrangement and oral health problems, and his/her as well as your recent dental visit pattern and oral hygiene practices.

We will use prompt cards to explore whether oral health information/educational/materials, appointment cards, medical history forms, consent forms for treatment, and instructions for giving/applying medications are easily understood. It will take approximately 30 minutes to complete.

Confidentiality of your responses to the questionnaires and interview will be maintained by secure storage of the data collected. Its use will be restricted to the research team for the purpose of the study only. No identifiable data will be reported.

If you have further queries on this study, please feel free to contact Dr Archana Pradhan on (08) 8303 6427 or Professor John Spencer on (08) 8303 5438. If you like to speak to someone independent, please refer to the attached document on „Contacts for Information on Project and Independent Complaints Procedure‟.

A John Spencer
Professor of Social and Preventive Dentistry
The University of Adelaide

Appendix 3: An information sheet on „Contact for information on project and independent complaints procedure" from The University of Adelaide Human Research Ethics Committee

THE UNIVERSITY OF ADELAIDE
HUMAN RESEARCH ETHICS COMMITTEE

Document for people who are participants in a research project

CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE

The Human Research Ethics Committee is obliged to monitor approved research projects. In conjunction with other forms of monitoring it is necessary to provide an independent and confidential reporting mechanism to assure quality assurance of the institutional ethics committee system. This is done by providing research participants with an additional avenue for raising concerns regarding the conduct of any research in which they are involved.

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

Project title: **Oral health literacy among carers**

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

   Name: …….

   telephone: …….

2. If you wish to discuss with an independent person matters related to
   - making a complaint, or
   - raising concerns on the conduct of the project, or
   - the University policy on research involving human participants, or
   - your rights as a participant

contact the Human Research Ethics Committee's Secretary on phone (08) 8303 6028

Appendix 4: Consent form

CONSENT FORM

I, ……..*(please print name)*
consent to participate in the research project entitled: Oral health literacy among carers .
I acknowledge that I have read the attached Information Sheet on the study and that I may retain a copy of this Consent Form, when completed, and the attached Information Sheet. I have had the study, so far as it affects me, fully explained to my satisfaction by the researcher.

- I understand that the purpose of this research project is to assess oral health literacy among carers to enable oral health professionals to develop materials to assist carers in providing better care to their care recipients, and that my involvement may not be of any direct benefit to me.
- I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be disclosed.
- I understand that I am free to withdraw from the project at any time.
- My consent to participate in the study is given freely.

Name: ……..….

……

(signature) *(date)*

Appendix 5: Structured interview

Structured Interview

QUESTION	A. Your details	B. Your main care recipient's details
1. Age	☐☐ Years	☐☐ Years
2. Sex	☐1 Male ☐2 Female	☐1 Male ☐2 Female
3. Usual living arrangement (Usual refers to four or more days per week on average)	☐1 Do not live with any care recipient ☐2 Live with one or more care recipients	☐1 With family ☐2 In community housing ☐3 In institution

4. How does he/she communicate with you?

☐1 Verbally- English language ☐2 Verbally- non-English language (Please specify):

☐3 Non-verbal communication- effective ☐4 Little or no effective communication

5. Relationship to your main care recipient

a. ☐1 Family ☐2 Non-family

b. Length of contact as a carer……

6. What is the main language you speak at home? ☐1 English ☐2 Non-English

7. Compared with the other tasks that you provide, how important do you think oral health care is for your main care recipient?

Not important	Somewhat important	Important	Very important	Extremely important
☐1	☐2	☐3	☐4	☐5

8. Does your main care recipient clean his/her own teeth?

☐1 No, needs full assistance

☐2 Yes, with some assistance

☐3 Yes, without any assistance

9. How often are his/her natural teeth/dentures cleaned? (by the care recipient or another person)	
☐1 Not applicable (has no natural teeth/dentures)	☐3 Once a day
☐2 Twice a day	☐4 Don‟t know

10. Do you take your main care recipient for his/her dental visit?	☐1 Yes ☐2 No

11. When was his/her last dental visit?	
☐1 Never had a dental visit	☐2 Only with a dental problem
☐3 Within 2 years	☐4 Within a year
☐5 Within 6 months	☐6 Don‟t know

12. How important do you think oral health is for you?				
Not important ☐1	Somewhat important ☐2	Important ☐3	Very important ☐4	Extremely important ☐5

I3. When was your last dental visit?				
Within 6 months ☐1	Within a year ☐2	Within 2 years ☐3	Only with a problem ☐4	Never ☐5

14. Have you had any training in oral care for people with disabilities?	☐1 Yes ☐2 No

15. Would you be interested in attending a training session in oral care for people with disabilities?	☐1 Yes ☐2 No

16. Highest qualification?				
☐1 Less than grade 11	☐2 High school	☐3 Trade or TAFE	☐4 Some college	☐5 University

17. Your pay rate (before tax)		
☐1 No pay (family/friend relative/Volunteer)	☐2 carer allowance	☐3 $15-$24 an hour
☐4 $25–$40 an hour	☐5 More than $40 an hour	

18. How often are the following difficult to read and understand?	Never	Occasionally	Sometimes	Often	Always
a. Appointment slips	☐1	☐2	☐3	☐4	☐5
b. Medical history forms	☐1	☐2	☐3	☐4	☐5
c. Consent forms	☐1	☐2	☐3	☐4	☐5
d. Patient educational materials	☐1	☐2	☐3	☐4	☐5
e. Medication labels	☐1	☐2	☐3	☐4	☐5

19. How often do you have problems because of difficulty in reading and understanding written information for the following?	Never	Occasionally	Sometimes	Often	Always
a. Getting to clinic appointments at the right time	☐1	☐2	☐3	☐4	☐5
b. Completing medical history forms	☐1	☐2	☐3	☐4	☐5
c. Completing consent forms	☐1	☐2	☐3	☐4	☐5
d. Giving/applying medications	☐1	☐2	☐3	☐4	☐5

20. How often do you have someone help you read hospital materials?"

☐1 All of the time ☐2 Most of the time ☐3 Some of the time ☐4 A little of the time
☐5 None of the time

21. How confident are you filling out forms by yourself?

☐1 Very confident ☐2 Fairly confident ☐3 Occasionally confident
☐4 Hardly ever confident ☐5 Never confident

22. Each of the following statements is about your beliefs for your care recipient‟s oral health. *Please state one number only to indicate your level of agreement/disagreement with EACH statement.*

For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I brush his/her teeth at least once a day.	1	2	3	4	5
2. I take him/her for regular dental check-up.	1	2	3	4	5
3. I give a high priority for any dental problem.	1	2	3	4	5
4. I control snacking between meals.	1	2	3	4	5
5. I carefully follow any instructions my dental professional gives me about home-care.	1	2	3	4	5

23. Each of the following statements is about managing your care recipient‟s oral health. *Please state one number only to indicate your level of agreement/disagreement with EACH statement.*

For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I take responsibility in caring for their oral health.	1	2	3	4	5
2. I am able to do things for their oral health as well as most other people.	1	2	3	4	5
3. I succeed in the projects I undertake to improve their oral health.	1	2	3	4	5
4. I am generally able to achieve my goals with respect to their oral health.	1	2	3	4	5
5. I take an active role in maintaining their oral health	1	2	3	4	5

24. Each of the following statements is about level of activation. *Please state one number only to indicate your level of agreement/disagreement with EACH statement.*

	For my care recipients…	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1.	I am confident I can help prevent or reduce their oral health problems.	1	2	3	4	5
2.	I know what each of their prescribed medications do.	1	2	3	4	5
3.	I am confident I can tell whether they need to go to the dentist.	1	2	3	4	5
4.	I am confident I can tell a dentist about their possible dental concerns.	1	2	3	4	5
5.	I understand their oral health problems and what causes them.	1	2	3	4	5
6.	I know what treatments are available for their oral health problems.	1	2	3	4	5
7.	I know how to prevent further oral health problems.	1	2	3	4	5
8.	I am confident I can maintain a healthy diet for them.	1	2	3	4	5
9.	I am confident I can figure out solutions when new problems arise with their oral health condition.	1	2	3	4	5
10.	I am confident I can maintain a healthy diet for them, even during times of stress.	1	2	3	4	5

ARCPOH OFFICE USE ONLY **Carer ID: ……**

Prompts

I will show you some prompts that you often see at dental visits, and then ask you a few questions.

1. Understanding appointment card: Time and location.
   Have a look at the appointment card for the dental hospital.
   Adelaide Dental Hospital
   Special Needs Unit, First floor
   Day: Monday
   Date: 14/12/09
   Time: 10:00 am
   When and where is your next appointment?

2. Understanding recall visit:
   Have a look at the recall reminder slip.
   Please contact the dental clinic in October, 2009 for a recall examination appointment in December, 2009.
   When will you contact the clinic for the next dental visit?

Here are some sentences with some words missing. Read the sentence and decide which word fits best in the sentence.

3. When completing medical history forms, you will be asked if your care recipient has:

a) Any ……	b) ……problems	c) allergy to…..……medicines.
1) surgery	1. bleeding	1. prescription
2) suture	2. using	2. evaluation
3) surface	3. asking	3. dentition

4. At the ……...examination, the dentist will check your ……... for ……..

1. operative	1. tint	1. charges
2. oral	2. teeth	2. caries
3. analgesia	3. fibre	3. splint

and ……. .....to see if they are healthy.

1. gingiva
2. whole
3. bacteria

5. Completing consent forms

The dentist has explained to me the nature and effects of the following procedures needed:

Examination under general……....

1. anaesthesia
2. aesthetic
3. neuralgia

The teeth will be scaled and cleaned, if there is build-up of……..

1. floss
2. calculus
3. bridge

If the……....is small, the tooth may only need a filling. If there is .....…….....,

1. cavity
2. canine
3. molar

1. instrument
2. infection
3. sterilization

or if the tooth is loose, it will need to be.....

1. weighed
2. discoloured
3. extracted

6. Understanding patient educational/information materials

a) To clean the teeth, a small soft toothbrush must be used, with pea-sized amount of fluoride toothpaste, every morning and before bed at night.

What type of toothpaste should you use?

i) With fluoride
ii) With no fluoride

b) The day before the general anaesthetic, do not give any food or liquids after midnight.

You can give: i) One fruit ii) Nothing iii) Usual medication iv) Water

c) Your care recipient has had a tooth taken out. He/she must not rinse the mouth for 24 hours after extraction. Starting tomorrow, he/she needs to rinse mouth after meals for 5 days.

It is now Monday, 11:00am. This means, you will ensure he/she rinses the mouth starting:

i) Monday, after lunch iii) Tuesday, after lunch
ii) Monday, after dinner iv) Tuesday, after dinner

d) You are asked to give one tablet to your care recipient an hour before the dental appointment.

It takes you an hour and a half to travel to the dental clinic.

If the appointment is at 10:00am, when should you give the tablet?

e) Your care recipient has had fluoride applied to his/her teeth. He/she should not eat or drink anything for 30 minutes. The time is now 12 noon. When can you give him/her a drink?

7. General information

SA Dental service provides a range of dental services for eligible children and adults.

a) You must have a current pensioner concession card or health care card to be.....

1. eligible
2. effective
3. member

b) Waiting times and co-payments .....to all.

1. await
2. reply
3. apply

c) In case of.....…, please contact Adelaide Dental Hospital on 82228222.

1. emergency
2. agency
3. function

d) You will be.....to the Special Needs Unit. The clinic is on the first floor.

1. requested
2. referred
3. treated

e) Based on the information above, where will you be seen?

Any comments

……
……
…….....…….....
……..

ARCPOH OFFICE USE ONLY **Carer ID: ……**

Appendix 6: Ethical clearance

THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

RESEARCH BRANCH
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER
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CRICOS Provider Number 00123M

5 February 2009

Professor AJ Spencer
School of Dentistry

Dear Professor Spencer

PROJECT NO: *Oral health literacy among carers*
H-005-2009

I write to advise you that I have approved the above project on behalf of the the Human Research Ethics Committee. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.

Approval is current for one year. The expiry date for this project is: 28 February 2010

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

Professor Garrett Cullity
Convenor
Human Research Ethics Committee