Providing Oral Health Care to Patients with Traumatic Brain Injury: The Challenges and Barriers faced by their Caregivers

Salima S. Alibhai

A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Public Health

University of Washington

2013

Program Authorized to Offer Degree:
Public Health and Community Medicine – Health Services

University of Washington

Abstract

Providing Oral Health Care to Patients with Traumatic Brain Injury: The Challenges and Barriers Faced by their Caregivers

Salima S. Alibhai
Chair of the Supervisory Committee:
Research Associate Professor Lloyd Mancl
Oral Health Sciences, School of Dentistry, University of Washington

Background: Access to dental care for the disabled population remains a challenge, and in some cases is almost non-existent within large numbers of the disabled population. The current literature lacks information on perceived challenges, barriers, strategies and enablers encountered by group home caregivers who provide daily oral care for individuals with traumatic brain injury.

Objective: This survey was designed to identify the enablers and barriers caregivers experience in providing daily oral to patients with traumatic brain injury patients and to assess the self-perception of caregivers regarding their own personal oral care.

Subjects: A total of 53 caregivers working at Snohomish Chalet (88% response rate), meeting the inclusion participated in the survey.

Methods: The study used a descriptive, cross-sectional survey to evaluate caregivers' challenges, strategies, barriers and knowledge of the dental needs of their disabled clients. The response format on the survey included fifteen general knowledge questions, seven Likert items and two open-ended questions to gather information on knowledge, attitudes, and practices regarding provision of oral care.

Statistical analyses: Descriptive statistics were the primary analysis for the results from the survey. Frequencies and percentages were used to summarize the responses for qualitative factors, and means, standard deviations, minimum and maximum values were used to summarize the responses for quantitative factors. A thematic approach was taken to organize and explore the responses from the open-ended questions that were collected.

Results: Eighty three percent of the caregivers had received some type of dental training, and 66% of the caregiving staff had received dental training as part of their orientation. Only 4% of the caregivers had received dental training through dental in-service. The most common resident behaviors that may present a barrier to oral care delivery were mild in nature. Sixty six percent of caregivers reported residents not opening their mouth occasionally to very frequently, 51% reported residents being orally defensive or refusing oral care, and 49% reported residents moving their head to avoid oral care. Over 80% of the caregivers reported brushing teeth once or more day for both cooperative (85%) and uncooperative residents (83%), but less than 15% reported flossing teeth once or more a day for either cooperative individuals (13%) or uncooperative individuals (10%). Most caregivers reported brushing their teeth (96%) and tongue (99%) 1 or more times a day, but, only 58% of caregivers reporting flossing their teeth 1 or more times a day, and 17% reported flossing their teeth less than once a week or never.

Conclusions: Although most caregivers had received some type of dental training, more education and routine dental in-services is needed to overcome common barriers and better serve oral care needs of residents. More collaboration with dental health professionals and frequent in-service is critical in providing better care to this population.

TABLE OF CONTENTS

INTRODUCTION

Access to dental care for the disabled population remains a challenge, and in some cases is almost non-existent within large numbers of the disabled population. Caregivers to this population provide key linkages in addressing these issues and facilitating dental care needs. It is well documented that caregivers find the provision of oral care difficult. The reasons include caregivers' attitudes towards dental treatment and oral hygiene,[1] how they see their role in mouth care, undermining of autonomy and independence, fitting the task into an already busy routine, practical skills, concerns about being bitten, finding the task unpleasant, and the possibility of hurting the individual.[2]

A study by Chalmers et al[3], found that nurses' aid provide up to 90% of direct care required for residents in nursing facilities and the majority of residents require assistance from aides with activity of daily living. This emphasizes the dependency on caregivers to provide daily oral hygiene. However, only 44% felt that they could provide appropriate care. Possible reasons why caregivers may feel inadequate in providing oral care include lack of experience [4], lack of training, being uncomfortable with oral hygiene in general [5], and the potential barriers they face while providing this care to individuals with special health care needs[3]. Many of the same attitudes, knowledge, and barriers can be expected to be found amongst staff members in group homes.

There are many reasons why caregivers are apprehensive about providing oral health care. One study[3] has shown that residents do not open their mouth, may bite the toothbrush, and refuse oral care. Encountering these barriers makes providing oral hygiene routines difficult for caregivers. Many of these barriers are thought to be the same among the population with special care health needs. By incorporating strategies to minimize these barriers, more adequate oral hygiene may be performed while helping to increase the health of each individual[6].

Knowledge and importance of oral hygiene is another crucial component in the decisions to provide oral care to individuals with special health care needs. Studies have shown that caregivers have many duties to fulfill and 40% of nurses' aides stated they were busy and would cut out oral care[3]. This emphasizes that oral health care is not a priority in the daily activities of caregivers.

Caring for the mouth requires a certain level of understanding and a certain level of manual dexterity. Functional disabilities can restrict access to dental care and pose limitations on the management of personal hygiene. Oral care is an essential part of personal daily care, affecting communication, dignity, self-esteem, self-confidence, appearance, dietary enjoyment, nutrition, comfort and general health [7]. A survey of nursing personnel, caregivers and dentists regarding priorities for oral healthcare for people with dementia found that although the groups had different priorities, they were all concerned about oral well being.[8] Nursing staff felt that being able to eat was important, relatives were much more concerned about social behavior and

communication, including aesthetics, speech and fresh breathe, whereas dentists' primary concern was freedom from oral pain.

When people are dependent on caregiver as a result of disability or chronic illness, the primary healthcare professional (including members of the dental team) plays a role in motivating and encouraging those individuals and their caregivers in the provision of daily oral care. A prompt, in the form of a reminder or encouragement, or supervision during the task,[9] may be all that is needed for some people, such as those with mild to moderate learning disabilities and early-stage dementia. An oral health program for people with psychiatric disabilities found that whilst the provision of mechanical toothbrushes improved oral hygiene, the combination of mechanical toothbrush, instruction and reminders resulted in additional improvements.[10] However, a person who cannot care for her own oral health will be dependent upon a caregiver for her daily oral hygiene needs.[11]

The value of oral hygiene programs for dependent adults has been demonstrated. For example, Budtz-Jorgenson *et al*.[12] found that an oral health preventive program for residents in a long-term care facility was effective in reducing the colonization of the oral mucosa and dentures by *Candida* and thereby improving the health of the oral mucosa[12]. However, there are mixed reports on the value of oral hygiene training for care staff in care facilities. Simons *et al*[13] conducted a multi-center, cross-sectional study to evaluate caregiver knowledge of oral health by providing high quality, consistent oral health training programs. Thirty-nine caregivers from

seven residential homes participated and 213 elderly residents in 18 homes were examined both at baseline and after 12 months. After 12 months, the program was evaluated by examining both the caregivers' changes in knowledge and any changes in the caregiver's behavior as reported by residents. Residents were also assessed for any changes in their own oral health. Simon et al described caregivers' baseline knowledge about oral health as poor, but high one week after an oral health-training program.[13] Although the program was well received, no changes in oral health practice resulted and there was no measurable improvement in the oral health of residents after caregiver training. They concluded that barriers to practice of oral care by caregiver remained and training (even when including practical skills, evaluation by peers and a high knowledge gain) failed to reduce these barriers.

Brady *et al* had a more positive finding, finding that provision of oral care training for caregivers' looking after people with neurological conditions (such as stroke) in a nursing home setting improved their knowledge of, and attitudes towards, the provision of oral care.[14] However, this review of three studies involving 470 participants found little evidence of how this care is best delivered. Information on a small number of nursing home residents who had a stroke (67 participants from a larger trial) showed that training nursing staff improved their knowledge of oral care and resulted in improved oral hygiene in their patients. Another trial demonstrated the beneficial impact of a decontamination gel on the incidence of pneumonia amongst patients in a stroke ward. The residents' dentures were cleaner but no other oral hygiene measures changed. Frenkel's findings have been

the most positive.[15] In her study of 22 randomly selected nursing homes with 416 caregivers, the majority of caregivers thought that residents had a right to good oral health, accepted the caregivers' role in helping residents with oral and denture hygiene, but recognized that the provision of oral healthcare was deficient.[15,16,17] Caregivers were critical of the lack of care facilities' arrangements for routine professional dental checks, lack of commitment to staff training, low standards of oral healthcare by colleagues, and lack of provision of oral hygiene aids and cleansing materials for clients. Despite finding that most of the residents who required help with oral health did not receive it, and that residents' plaque levels and associated dental disease were high because staff did not perform effective oral healthcare appropriate to residents' needs,[16] the oral healthcare education program was well received. It resulted in improved oral healthcare knowledge and attitudes as well as improved delivery of oral healthcare,[17] and demonstrated that access to information and training can help reduce the barriers to oral hygiene.

Brain injury, which includes traumatic brain injury (TBI) and stroke, has become a serious public health issue over the past decades for several reasons[18,19,20.] First, there has been an increase in incidence. For example, it is estimated that 1.7 million people experience a TBI every year in the US, of which 275 000 are hospitalized and 52 000 die [18.] Furthermore, 795 000 individuals have a stroke, with an estimated 20% of survivors having another[21]. Brain injury occurs at all ages, although there are differences between TBI and stroke. TBI occurs most often within the age

groups of 0–4 years, 15–19 years and over 65 years of age, with adults over the age of 75 demonstrating the highest incidence of hospitalization and death related to TBI[18]. Strokes occur most often in older adults, with about 75% occurring in individuals over the age of 65[22].

Secondly, the limitations that are caused by brain injury can vary from mild-to-extremely severe because of the uniqueness of the brain and can lead to issues with physical, cognitive and psychosocial functioning [23]. Individuals may experience several associated conditions (e.g. seizures, impaired reasoning, apraxia, aphasia), as well as being at increased risk of secondary conditions[23]. Secondary conditions are health conditions that result from a change in lifestyle caused by the disability (e.g. decreased mobility can lead to an increase in sedentary behaviors and increased risk of obesity). Other examples of secondary conditions include depression, pain, fatigue and increased risk for epilepsy or seizures [24.] Individuals with brain injury are also at greater risk of developing chronic conditions including diabetes, hypertension or cardiovascular disease.

Thirdly, as a result of the complex nature of the damage and conditions experienced post-injury there are high healthcare costs. For example, in 1998 it was estimated that on average TBI costs ranged from $600 000–$1 875 000 per individual across the lifetime [25] and this figure has undoubtedly risen since publication in 1998. Overall annual costs of TBI are estimated to be at $60 billion [19], while stroke is at

$68.9 billion each year in the US [21]. These high costs emphasize the importance and need for interventions to improve health and reduce healthcare costs post-injury.

Dental care and oral hygiene programs for persons with traumatic brain injury have been relatively ignored areas of clinical care and research. Data regarding the need for structured oral hygiene programs with this population are sorely lacking [26]. Historically, the practice of oral hygiene has been relatively overlooked as an ingredient for successful community reintegration following traumatic brain injury. The absence of research in this area ignores the significance of oral health on a person's general appearance and ability to relate with others.

The neurobehavioral sequelae of the brain injury are often diverse, involving changing in physical, cognitive, behavioral, and emotional functioning. Cognitive problems may include compromised memory, concentration, and attention. Behaviorally, increased fatigue and irritability are often seen following brain injury. Furthermore, a range of emotional problems, such as depression and anxiety may accompany TBI[27,28,29,30]

The common sequelae of moderate to severe brain injury have implications for the practice of regular oral hygiene as well as the medical necessity. Engaging in efficient oral health care practices clearly requires a basic level of cognitive understanding, ability and initiative. Also, the neurobehavioral symptoms associated with brain injury may compromise dental hygiene practice. Increased fatigue and/or lack of initiation, for example, can diminish a person's ability to

perform regular dental care. Similarly, one might be able initiate dental care, but concentration problems could interfere with the ability to fully execute a routine. Adequate oral hygiene is also medically necessary to prevent dental decay and disease[26]. Beyond the associated medical risks, the social stigma of having unattractive teeth and or bad breathe diminishes a person's chance of integrating more easily into the community.

In addition to the physical and psychosocial consequences of TBI, oral hygiene problems present unique issues to persons with TBI that are often not seen among the general public. For example, persons with brain injury often experience disorders of oropharyngeal function such as dysarthria, dysphagia, and difficulty in controlling saliva, drooling, oromotor dyspraxia, aspiration, and gingival hyperplasia secondary to Dilantin[26]. In some cases, patients with TBI are at high risk for poor hygiene due to the fact that oral hygiene is often neglected relative to other health care issues.

In1975, the Delta Foundation for Rehabilitation and Research was founded with the mission to identify the needs of people with acquired disability from traumatic brain injury that are not met by present social, medical and government programs. The foundation also develops and implements strategies for responding to those unmet needs with the goal of assuring an individual's ability to make the full transition from coma to community. The Delta Rehabilitation Center facility, also known locally as the Snohomish Chalet, is home for people who struggle every day to

overcome the devastation caused by severe brain injury. The purpose of the Snohomish Chalet has been to provide a residence for people who, as the result of a traumatic injury to their central nervous system, are in need of very specialized services[31].

While there is substantial research with regard to the elderly populations treated in long-term care facilities, there is very little on the traumatic brain injury populations. The current literature lacks information on perceived challenges, barriers, strategies and enablers encountered by group home caregivers who provide daily oral care for individuals with traumatic brain injury. The specific aims of this proposal are to:

1. Identify the enablers and barriers caregivers experience in providing daily oral care to patients at a traumatic brain injury center.

2. Assess the self-perception of caregivers regarding their own personal oral care.

METHODS

Design

Approximately 170 employees work at Snohomish Chalet, with about 60 employees providing direct oral care to patients. Of the 115 patients, only a few patients are able to care for their own mouths under direct supervision. While oral care is provided twice (and sometimes up to four times) a day by caregivers, effective oral care still remains a challenge. The Dental Care and Education for Persons with Disabilities (DECOD) Clinic at the University of Washington is an affiliate of the center. The program provides direct care to individuals who might be in need of advanced restorative care. To date, there has been limited formal education or in-service provided to the staff at the facility by the DECOD Clinic. Affiliate DECOD dentists generally communicate process of care to caregiver coordinators on specific patients by pointing out areas of concern that need to be monitored. The coordinators then relay the message to the patient's caregiver who then follows up with the patient one-on-one.

The study used a descriptive, cross-sectional survey to evaluate caregivers' challenges, strategies, barriers and knowledge of the dental needs of their disabled clients. With the permission of Dharamshi et al and Jobman et al, the survey for this study was partly developed with questions taken from the study " Oral Care for Frail Elders: Knowledge, Attitudes, and Practices of Long-Term Care Staff"[32] and "Caregivers' Perceived Comfort Regarding Oral Care in Group Homes: a Pilot

Study"[34] and slightly modified. Dharamshi et al designed the study in order to identify the enablers and barriers that influenced the provision of daily mouth care practices in an elder care facility, as well as assessing the self-perceptions of caregivers regarding their own oral care. While the 2008 study included a survey as well as an interview portion, the current study included a survey only. The response format on the survey included fifteen general knowledge questions, seven Likert items and two open-ended questions to gather information on knowledge, attitudes, and practices regarding provision of oral care. The survey instrument was pilot-tested by seven faculty members at Seattle Central Community College in the Department of Dental Hygiene as well as two caregivers/supervisors from Snohomish Chalet. In September 2012, the primary investigator met with the two supervisors who volunteered to handout the surveys to discuss the various aspects of the survey. A key element of the survey was anonymity and this was emphasized during the meeting. In October 2012, a survey packet including all survey materials including self-addressed envelopes and pens were mailed to Snohomish Chalet. The two supervisors involved in implementing the surveys (dental and meal service) invited all caregivers providing oral care to patients to participate. A cover letter explaining the elements of consent was attached to the survey. Caregivers were asked to place completed surveys in a separate envelope. Two weeks after mailing the surveys, a reminder in the form of a letter as well as a phone call to the administrative staff persons was made to encourage non-respondents to complete the survey. Consent was considered obtained if the respondent returned the survey. All surveys were mailed to the primary investigator in February 2013 in a self-

addressed envelope once the desired sample size was reached. The University of Washington Institutional Review Board approved this study.

Study Population

All caregivers at the Snohomish Chalet, meeting the inclusion were invited to participate in the study. There are 60 caregivers in various capacities that provide care and support during the three shifts. In each shift there are 12 nurse aides and six meal program assistants. The rest of the staff consists of nurses, physical therapist aides, occupational therapy aides and dietitians. The Health Insurance Portability and Accountability Act of 1996 Privacy and Security Rules (HIPPA) and the Institutional Review Board (IRB) guidelines were followed to safeguard confidentiality of subjects.

Inclusion Criteria

The study population is comprised of adult caregivers currently employed at Snohomish Chalet, who met the following inclusion criteria:

1) Male and female
2) All races
3) Over 18 years of age at time of study
4) English speaking
5) Able to write
6) Provide oral hygiene care to clients

Sample Size Determination

There are 60 caregivers at Snohomish Chalet. It was anticipated that 50 to 60 caregivers at the Snohomish Chalet would participate in the survey, which would provide an adequate sample size to estimate prevalence and averages with sufficient precision to identify the relevant enablers and barriers for caregivers in providing daily oral care. With a sample size of 50 to 60 participants, the precision (margin of error) is 8 to 11% for factors with a prevalence of 10 to 20%, and the margin of error is 12 to 14% for factors with a prevalence of 30 to 70% based on a 95% confidence interval for prevalence. Similarly, with a sample size of 50 to 60 participants, the margin of error is ¼ a standard deviation for estimating mean values based on a 95% confidence interval[33].

Data Collection

Data was collected using questionnaires that were prepared by the primary investigator. All eligible caregivers meeting the inclusion criteria for the study were invited to enroll by the clinic supervisors. After all data was complete and scored, it was entered into a database by the investigator.

Data Analysis

Descriptive statistics were the primary analysis for the results from the survey. Frequencies and percentages were used to summarize the responses for qualitative factors, and means, standard deviations, minimum and maximum values were used to summarize the responses for quantitative factors. A thematic approach was taken to organize and explore the responses from the open-ended questions that were

collected. The statistical program SPSS Standard Version 19 was used to analyze the data.

RESULTS

Caregivers and their Work Experience

There were a total of 53 caregivers who participated in the survey (88% response rate). The median age of the study population was 31 years (range of 19 to 69 years) and the majority were females (77%). The majority of the participants were certified nurse assistants or care aids (68%) followed by registered nurses (23%). Total time worked as a caregiver varied from less than a year to 30 years, and the median was 10 years. Hours worked per week varied from 5 to 50 hours, with a median of 29 hours. Caregivers typically provided direct care to 14 residents on a daily basis with about eight residents out of fourteen requiring assistance when brushing their teeth. However, one recreational activity coordinator reported providing care to 54 residents and assisting 44 residents with brushing their teeth. Ninety percent listed oral health care training as part of their job description and 66% had received dental training as part of their orientation. All participants felt qualified to provide oral care to patients and 72% were interested in participating in a program on oral care (Tables 1 and 2).

Table 1. Characteristics of Caregivers

Variable	n (%)
Age (years)	
Mean (SD)	36.8 (15.2)
Median (IQR*)	31 (24-50)
Range	19-69
Gender	
Female	41 (77)
Male	12 (23)
Job Description	
Care Aide/CNA	36 (68)
RN	12 (23)
Meal Program Provider	3 (6)
LPN	1 (2)
Other	1 (2)
Received training on how to provide direct oral health care for patients with TBI	
Training at orientation	35 (66)
One-on-one per specific patient	23 (43)
Did not receive training	9 (17)
Dental in-service	4 (8)
Oral care is part of job description	48 (90)
Interested in participating in an oral health program on how to handle uncooperative patients	37 (70)
Interested in participating in an oral hygiene program on oral health tips	38 (72)
Feel qualified to provide oral care to residents	53 (100)

***IQR: 25th and 75th percentiles**

Table 2. Caregiver Work Experience and Work Load

Variable	Mean (SD)	Median (IQR*)	Min-Max
Total time working as caregiver (years)	10.3 (11.7)	5 (1.5-16)	.10 - 30
Time working at current location (years)	6.6 (7.6)	3 (1-12)	.10 - 30
Hours per week providing care (hours)	29.3 (13.1)	35 (20-40)	5 - 50
Number of residents providing direct care for on a daily basis	19.2 (12.8)	14 (10-27)	6 - 54
Number of residents who are independent and brush their own teeth	6.3 (6.6)	4 (2-8)	0 - 30
Number of residents who require assistance when brushing their teeth	11.3 (8.6)	8 (6-14)	1 - 44

***IQR: 25th and 75th percentiles**

Caregivers' Behavior and Strategies with Uncooperative Patients

Table 3 and 4 summarize caregiver responses in regard to what they did when a resident was uncooperative and the strategies they applied. Two common behaviors and strategies used by the caregivers for treating uncooperative residents were combining oral care with likable activities and asking for help from another aide. Sixty-six to 77% of caregivers reported using these behaviors and strategies occasionally to very frequently. About half of the caregivers had occasionally to very frequently left a resident alone (47%) or continued attempting oral care (53%) when the resident was uncooperative. Bribery had been used by 45% of caregivers, and 35% of caregivers considered it a strategy for delivery of oral care. However, 38% of caregivers had never used bribery nor endorsed bribery as a strategy for treating residents. Force had been used only by 15% of caregivers, and then only

rarely had forced been used. Only 10% of caregivers endorsed it has a strategy for dealing with uncooperative residents.

Table 3. Caregiver Behavior Regarding Oral Care Delivery for Uncooperative Residents.

Behavior	Never	Rarely	Occasionally	Frequently	Very Frequently	N/A
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Leave patient alone	10 (19)	15 (28)	16 (30)	5 (9)	4 (8)	3 (6)
Continue to attempt	1 (2)	11 (21)	13 (25)	13 (25)	7 (13)	8 (15)
Force	37 (70)	8 (15)	0 (0)	0 (0)	0 (0)	8 (15)
Bribery	20 (38)	5 (10)	17 (32)	3 (6)	0 (0)	8 (15)
Combine care with likeable activities	3 (6)	6 (11)	17 (32)	19 (36)	2 (4)	6 (11)
Ask for help from another aide	4 (8)	7 (13)	14 (26)	19 (36)	2 (4)	4 (8)

*** Never = 0% of the time, Rarely = >0% - 25%, Occasionally = >25% - 50%, Frequently = >50%-75%, Very Frequently = >75%, N/A = Caregiver left unanswered or indicated as N/A on survey**

Table 4. Caregiver Strategy Regarding Oral Care Delivery for Uncooperative Residents.

Strategy	Never	Rarely	Occasionally	Frequently	Very Frequently	N/A
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Leave patient alone	14 (26)	8 (15)	17 (32)	7 (13)	0 (0)	7 (13)
Continue to attempt	0 (0)	9 (17)	22 (42)	11 (21)	1 (2)	10 (19)
Force	37 (70)	3 (6)	2 (4)	0 (0)	0 (0)	11 (21)
Bribery	20 (38)	3 (6)	14 (26)	7 (1)	1 (2)	8 (15)
Combine care with likeable activities	2 (4)	8 (15)	15 (28)	13 (25)	8 (15)	7 (13)
Ask for help from another aide	3 (6)	5 (9)	15 (28)	16 (30)	10 (19)	4 (8)

*** Never = 0% of the time, Rarely = >0% - 25%, Occasionally = >25% - 50%, Frequently = >50%-75%, Very Frequently = >75%, N/A = Caregiver left unanswered or indicated as N/A on survey**

Oral Regimen with Cooperative and Uncooperative Residents

To assess for oral hygiene regimens between cooperative and uncooperative patients, caregivers were asked how often they rendered care (Tables 5 and 6). Caregivers typically reported brushing resident's teeth 1 or more times a day for both cooperative (85%) and uncooperative (83%) residents. Similarly, they reported brushing the resident's tongue 1 or more times a day 85% of the time for cooperative residents and 80% of the time for uncooperative residents. Interestingly, caregivers reported flossing a resident's teeth 1 or more times a day only 13% of time for cooperative residents and 10% of the time for uncooperative residents. Over a third reported flossing a resident's teeth less than once a week for both cooperative (38%) and uncooperative (40%) residents. In addition, caregivers frequently did not answer the question about flossing frequency or wrote 'N/A' on the survey (32% for cooperative and 34% for uncooperative residents), which may indicate the low frequency or lack of flossing is even higher than reported in Tables 5 and 6.

Table 5. Caregiver Oral Care Regimen With Cooperative Residents:

Oral Care	1 or More Times a Day	1 to 3 Times a Week	Less Than Once a Week	N/A
	n (%)	n (%)	n (%)	n (%)
Brush resident's teeth with a fluoridated toothpaste?	45 (85)	3 (6)	2 (4)	3 (6)
Brush resident's tongue?	45 (85)	3 (6)	2 (4)	3 (6)
Floss (or help floss) the resident's teeth?	7 (13)	6 (12)	20 (38)	17 (32)
Use (or help use) mouth rinse (e.g., Peridex) for the residents?	39 (74)	4 (8)	6 (11)	3 (6)

*** N/A = Caregiver left unanswered or indicated as N/A on survey**

Table 6. Caregiver Oral Care Regimen With Uncooperative Residents:

Oral Care	1 or More Times a Day	1 to 3 Times a Week	Less Than Once a Week	N/A
	n (%)	n (%)	n (%)	n (%)
Brush resident's teeth with a fluoridated toothpaste?	44 (83)	3 (6)	2 (4)	4 (8)
Brush resident's tongue?	42 (80)	4 (8)	2 (4)	5 (9)
Floss (or help floss) the resident's teeth?	5 (10)	5 (10)	21 (40)	18 (34)
Use (or help use) mouth rinse (e.g., Peridex) for the residents?	35 (66)	5 (10)	6 (11)	7 (13)

*** N/A = Caregiver left unanswered or indicated as N/A on survey**

Barriers to Oral Care Delivery

Resident behavior, while the caregivers were providing oral care, is summarized in Table 7. The most common resident behaviors that may present a barrier to oral care delivery were mild in nature. Sixty six percent of caregivers reported residents not opening their mouth occasionally to very frequently, 51% reported residents being orally defensive or refusing oral care, and 49% reported residents moving

their head to avoid oral care. Ninety percent of caregivers reported residents never or rarely trying to bite them and 87% reported residents never or rarely spitting. However, 28% of caregivers reported that residents occasionally or frequently hit them. A thematic approach was taken to organize and explore the responses from an open-ended question about the caregivers' experiences and challenges providing oral care to residents (Table 8). Most barriers expressed by caregivers reflected resistance or refusal to oral care. Some common challenges reported were swinging of the head, and clenching, clamping or biting on the toothbrush (Theme 1). One caregiver noted that the resident's was resistance to oral care was likely due to poor oral health (bleeding gums). There were also challenges due to physical (e.g., dysphagia) and cognitive limitations (e.g., memory loss) of the residents (Theme 2). A few caregivers indicated residents biting or hitting (Theme 3). Caregivers also reported being rushed (lack of time) along with lack of knowledge and confidence in delivering oral care as challenges (Theme 4).

Table 7. Caregiver Barriers to Oral Care Delivery

Barrier	Never	Rarely	Occasionally	Frequently	Very Frequently	N/A
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Patient not opening his/her mouth	3 (6)	15 (28)	26 (49)	8 (15)	1 (2)	0 (0)
Patient is orally defensive and refuses oral care	1 (2)	24 (45)	22 (42)	5 (9)	0 (0)	1 (2)
Patient moves head uncontrollably	4 (8)	22 (42)	18 (34)	7 (13)	1 (2)	1 (2)
Patient bites	25 (47)	23 (43)	3 (6)	1 (2)	0 (0)	1 (2)
Patient spits	21 (40)	25 (47)	5 (10)	1 (2)	0 (0)	1 (2)
Patient hits	11 (21)	26 (49)	14 (26)	1 (2)	0 (0)	1 (2)

*** Never = 0% of the time, Rarely = >0% - 25%, Occasionally = >25% - 50%, Frequently = >50%-75%, Very Frequently = >75%, N/A = Caregiver left unanswered or indicated as N/A on survey**

Table 8. Caregiver Experiences and Challenges to Providing Oral Care

Theme 1: Resistance or refusal to oral care (e.g., swinging head, clamping mouth, biting toothbrush)
1. They were swinging their head around refusing oral care. I gently put my palm on their forehead and brushed their teeth as fast as I could before they pushed me away. 2. The resident would not open their mouth. 3. Providing care to a resident who would not open her mouth and constantly moving her head. 4. I needed to swab a resident's mouth. He had no teeth but he refused to open his mouth so I changed the subject. He started talking and then asked again to swab and open his mouth. 5. He wouldn't let me clean the inside of his teeth. He kept his jaws tight, mouth closed and kept moving his head away from the toothbrush 6. Shaking of head and resisting by closing mouth. 7. When a resident absolutely refuses to open their mouth. 8. One of my residents is resistant and clamps her mouth shut when giving oral care. Revisiting later is usually successful. 9. Sometimes a resident does not want their teeth brushed. I will usually wait a few minutes and ask again. 10. A new resident would not let me brush his teeth so I let supervisor know. 11. When a pt. or resident does not open their mouth to have myself assist them with brushing, I would do 3 attempts then ask another CAN to try. 12. Res kept clenching mouth and would move head around clenching teeth closed. 13. Did not want his teeth brushed, so I explained if he didn't than eventually he'd have to go to the dentist and a tooth pulled or drilled on and he let me brush his teeth. 14. Residents at times will want to refuse brush their teeth and leave the room on their own. Explaining why it is important to brush usually will get them to return. 15. Have had residents refuse to open mouth generally leave them bee (?) 16. The resident wouldn't open their mouth to allow me to brush. 17. One of my residents refused teeth being brushed at get-ups in the morning and after meals and snacks. So instead I approached slower tone to conversation, build trust and gave praise when task was complete. 18. Physically resistive patients severe cognitive defects 19. Person was combative pulling his face in his lap and yelling – NO! Was told he was complaining of sore gums. Used a swab instead until gums cleared. He co-operated with the swab and rinsed with a mouthwash. 20. One guy I usually care for is a real brat when it comes to brushing his teeth and he has real bad breath. I have to be stern with him. Sometimes I have to hold his head still and sometimes I have to get someone else to help hold him still. I don't like doing this and I don't think he likes it either. 21. One resident who always let's me help him didn't open his mouth. He was (being?) mean. Then I noticed he was in sittin on his seat belt! After I fixed it he let me brush his teeth like normal. 22. Just didn't want me doing his teeth so I let him do it. 23. The resident bit the toothbrush and kicked the table. 24. When I worked in meal program residents would bite toothbrush while trying to brush. 25. I had a resident who likes to bite the toothbrush; I learned to brush before he bit. 26. I brush my tube feeder's teeth everyday. We had a new guy who was always biting the toothbrush. He likes stuffed animals so I started giving him one to hold. This made it a lot easier and if I go slow I can get his mouth nice and clean. 27. Bites down on toothbrush. I wait until patient releases. 28. I have helped a resident brush their teeth and their gums bled very bad – a sign of not brushing well. I have also helped a resident who refuses and I was able to brush just a bit which was NOT enough.

Theme 2: Physical and cognitive limitations (e.g., dysphagia, limited comprehension, memory loss)
1. Resident is unable to swallow properly, had to be careful to not get too much water/mouth rinse in mouth. 2. Knowing the person you are caring for has no grasp of language therefore cannot understand explanations and fears your approach, 3. Many times reapproaching resistant clients or forgetful clients can assist in meeting oral care needs. 4. Routinely resident refuses due to short - term memory. Can return later and may be successful in her cooperating.
Theme 3: Combative behavior (biting or hitting)
1. A resident hit me but I just went and got a different aid to try and it worked. 2. Resident was trying to bite me. 3. They attempted to bite me so I backed off and gave them a minute to relax.
Theme 4: Lack of time or knowledge, and other challenges
1. Time not enough for employee to keep up with oral care. 2. I very rarely do oral care in my daily work routine. My stomach gets upset if I do it. 3. I was afraid to brush one ladies teeth for a long time. Then my boss showed me how to brush her teeth and that it wasn't hurting her. It made me much more confident at doing my job. 4. One resident doesn't like his Listerine treatment, so I started singing a song to him while I do it. Now he lets me do it every time. 5. The resident not talking through his meal until it came to brush his teeth then he wouldn't let me near his mouth for like 5 mins. I was running behind. Because of knowledge I required through training I was able to get it done.

*** 12 caregivers left the question unanswered or indicated as N/A on survey**

Caregivers' Personal Oral Care and Oral Health Knowledge

Most caregivers reported brushing their teeth (96%) and tongue (99%) 1 or more times a day (Table 9). However, only 58% of caregivers reported flossing their teeth 1 or more times a day, and 17% reported flossing their teeth less than once a week or never. Sixty eight percent used mouth rinse 1 or more times a day.

Table 10 summarizes the caregivers' dental knowledge and the provisions of dental care. In general, caregivers were highly knowledgeable about the importance of oral hygiene on quality life, the impact of oral pain and the need for daily oral care. Ninety-four to 100% of caregivers agreed or strongly agreed to statements about these aspects of oral care (Questions 1 to 3). The majority of caregivers were also knowledgeable about the use of tooth brushing and flossing for oral care (70 to 81%

agreed or strongly agreed to Questions 4 to 7). However, there was a lack of knowledge about specific aspects of oral care, as indicated by 11 to 17% of the caregivers being unsure about the use of tooth brushing and flossing for oral care. Although 93% of caregivers disagree or strongly disagreed that bleeding gums are not a oral hygiene concern (Question 8), only 59% disagreed or strongly disagreed that tooth loss is a natural process of aging (Question 9) and only 67% disagreed or strongly disagreed that one should use your fingers to open a resident's mouth, if the resident is unable to his mouth (Question 10). In addition, 29% of caregivers agreed to strongly agreed that tooth loss was a natural process of aging, and 19% were unsure about the whether it is proper to use one's fingers to open a resident's mouth. Caregiver's comfort and confidence with delivery of oral care was high, with 90 to 96% agreeing to strongly agreeing with statements about the caregiver's comfort and training about mouth care (Questions 11 to 15).

Table 9. Caregivers' Personal Oral Care

Oral care	**1 or More Times a Day**	**1 to 3 Times a Week**	**Less Than Once a Week**	**N/A**
	n (%)	n (%)	n (%)	n (%)
Brush teeth	51 (96)	1 (2)	0 (0)	1 (2)
Brush tongue	52 (99)	1 (2)	0 (0)	0 (0)
Floss teeth	31 (58)	10 (20)	9 (17)	3 (6)
Use mouth rinse	36 (68)	5 (10)	10 (19)	2 (4)

*** N/A = Caregiver left unanswered or indicated as N/A on survey**

Table 10. Caregiver Knowledge About Oral Health Issues

Knowledge	Strongly Agree	Agree	Disagree	Strongly Disagree	I am Not Sure*
	n (%)	n (%)	n (%)	n (%)	n (%)
Oral health measures					
1) Care aides should provide daily mouth care for all residents.	27 (51)	24 (45)	1 (2)	0 (0)	1 (2)
2) Daily oral hygiene improves the quality of life.	24 (45)	26 (49)	2 (4)	0 (0)	1 (2)
3) Oral pain can impact a patient's eating pattern.	38 (72)	15 (28)	0 (0)	0 (0)	0 (0)
4) A little cleaning at a time helps the resident to be less anxious.	9 (17)	30 (57)	5 (10)	1 (2)	8 (15)
5) A soft to very soft toothbrush should be used for residents.	10 (19)	33 (62)	1 (2)	0 (0)	9 (17)
6) Dental floss should be used to clean between the teeth.	9 (17)	33 (62)	2 (4)	0 (0)	9 (17)
7) Plaque can only be removed by mechanical forces such as brushing and flossing.	11 (21)	26 (49)	9 (17)	1 (2)	6 (11)
8) Bleeding gums are a normal process and not an oral hygiene concern.	2 (4)	2 (4)	30 (57)	19 (36)	0 (0)
9) If a resident is unable to open their mouth, the caregiver should place her finger between the upper and lower teeth to keep the resident's mouth open.	3 (6)	5 (10)	22 (42)	13 (25)	10 (19)
10) Tooth loss and oral diseases are natural processes of aging.	5 (10)	10 (19)	26 (49)	5 (10)	7 (13)
Delivery of care					
11) I am comfortable providing daily mouth care for the residents.	28 (53)	23 (43)	1 (2)	0 (0)	1 (2)
12) I have sufficient knowledge about mouth care.	12 (23)	37 (70)	1 (2)	0 (0)	3 (6)
13) I have the skills to provide daily mouth care to the residents.	17 (32)	34 (64)	0 (0)	0 (0)	2 (4)
14) I am aware of the current protocol for daily mouth care.	20 (38)	29 (55)	2 (4)	0 (0)	2 (4)
15) How do you feel about receiving instructions in providing oral hygiene care for residents?	17 (32)	30 (57)	0 (0)	0 (0)	6 (11)

*** Includes questions left unanswered or indicated as N/A on survey**

Improving Oral Hygiene for Residents

Caregivers provided valuable suggestions in improving oral hygiene care for their residents (Table 11). Many voiced the need for more frequent dental visits, as well as ongoing dental care (Theme 1). Providing better tasting products and the use of daily mouthwash to all residents was commonly suggested (Theme 2). One caregiver recommended the use of bite blocks and proper infection control. Caregivers eloquently described taking time to educate and explain procedures, being kind and re-assuring and involving the resident in oral care activities in order to enhance care (Theme 3). Other suggestions included increasing dental in-service and staff (Themes 4 and 5).

Table 11. Caregiver's Suggestions for Improving Oral Hygiene for Residents

Theme 1: Increase Dental Visits and Continued Care
1. Increase dental visits. Many clients who are resistant to oral care have PRN Rx for dental/MD visits. More frequent dental visits could assist maintain dentition, along with daily efforts by care staff.
2. Increased dental visits.
3. Staff needs to acknowledge that residents do need ongoing dental care for their well-being and may need help.
4. More dentist appointments for residents should be made for people with sensitive teeth.
5. Brush their teeth 3 times a day instead of 2.
6. Everyone should try harder to get residents to brush teeth better
7. Making sure their teeth are fully brushed and rinsed.
8. Keep trying
9. Make sure they get everyday.
10. More often

Theme 2: Provide Improved Dental Products
1. Give them mouthwash with toothbrush at least daily. 2. Use mouthwash with all residents. 3. Better tasting toothpaste. 4. Using mouthwash with all the residents and not just the ones that swab 5. Sometimes use more than one toothbrush for residents with messy mouths 6. Better toothbrushes, ours are kinda hard. 7. We don't use bite blocks here, I think it would help with some patients. 8. Residents do not do a good job brushing (95% don't). At least once per day the aid should brush their teeth before bed including flossing with long "Reach Flosser". Aid should wear eyewear protection along with other safety equipment like gloves. This would be time consuming and would probably need to add another staff member to the floor at bedtime.
Theme 3: Educate, Praise and Involve the Resident
1. Be patient and allow resident to be highly involved in activity. Be kind and reassuring to their feelings or needs. 2. Ask them may I brush your teeth and if not let the Blg (?) know. 3. Tell the resident what you are doing. 2) Have them help if they can. 4. Explain the importance of oral care and explain consequences of not properly brushing. 5. If it's possible, have them brush their own teeth so it makes them feel more independent. 6. Explain the procedure, brush teeth or all surfaces for a minute or so, brush tongue, offer spit and rinse cups, wipe face. 7. By asking then nicely and seeing of they will let me. 8. I think this facility already does a good job with oral care
Theme 4: Increase Education and In-Service
1. Educate staff. PS: Al these questions would vary depending on the resident. Each resident is unique. You have to balance resident needs with resident rights and diagnosis. Due to these variables, how to handle the resident varies from each individual. 2. Educate staff in improved techniques 3. Meal program staff could use more training 4. Brief in-service during the year to keep staff reminded on the importance of care to residents. 5. I think we do a really good job with difficult residents. I think more in-service would be helpful. Also better staffing so we don't feel rushed 6. I think it would be good to have more training. Maybe the dentist who comes here to see our residents could do it.
Theme 5: Increase Staff
1. In meal service here, we provide oral care after breakfast and dinner. We do not have extra personnel available at these meals. I think extra staff would allow caregivers to take more time and do a more thorough job with oral care. 2. Given the current SNF/DSHS system of care, physical plant providing care after meals in D.R is about the best that can be provided. 3. Have the nurses do it

*** 18 caregivers left the question unanswered or indicated as N/A on survey**

DISCUSSION

Group home caregivers are vital to individuals with traumatic brain injury as most of them are dependent on the caregivers requiring assistance with activities of daily living including oral care. Most caregivers reported brushing teeth once or more a day for both cooperative individuals (85%) and uncooperative individuals (83%). However, only a small number of caregivers reported flossing teeth once or more a day for either cooperative individuals (13%) or uncooperative individuals (10%). In addition, over 30% of caregivers wrote 'N/A' in response to the frequency of flossing, which may indicate that flossing is not part of their normal oral hygiene care.

Although all caregivers felt qualified to provide oral care to residents and 90% of the caregivers reported that oral care was part of their job description, flossing may not be an activity identified as an integral part of oral care. It is possible that group homes catering to traumatic brain injury patients may not emphasize flossing as part of their oral care routine due to safety concerns to the resident. Because resident behaviors can range from swinging their head and clamping the toothbrush to hitting and biting the caregivers, providing routine flossing may present as an even more complex task than tooth brushing. Flossing may also be considered as a task that is too time consuming in an environment where both time and staff is scarce. Lastly, even though flossing was not a consistent practice, it was not due to lack of knowledge because most caregivers agreed that floss should be used to clean between the teeth, but may be due to the caregivers own personal flossing practices.

Only fifty eight percent of caregivers flossed their teeth once or more than once a day.

In the current study, over 90% of caregivers reported experiencing difficult behaviors, such as residents not opening their mouth, refusing oral care and moving their head, when delivering oral care. Seventy seven percent of caregivers had experienced patient hitting, 59% patient spitting and 51% patient biting. These results supports what Chalmers et al[3] have reported; that approximately 80% of nursing aides experienced individuals not opening their mouths, biting the toothbrush, and refusing oral care. Both studies reported similar barriers, which indicate a need for incorporating new strategies to overcome these common barriers and improve oral hygiene of the residents. One strategy suggested by a caregiver is the use of bite blocks. There are many different types of dental bite blocks available. The one used at the University of Washington's DECOD Clinic is fabricated in the clinic using a stack of tongue blades, gauze and masking tape and works well with nearly all types of disabilities. This bite block is soft in texture and provides a handle so that the caregiver can slowly work their way into the oral cavity. The bite block not only helps with propping the mouth open to gain access, but it also helps in facilitating any clenching or clamping reflexes the patient might experience. The use of bite blocks, along with other techniques on how to manage common barriers to oral care delivery, can be taught to the caregivers during informal in-services by (DECOD) trained dental professionals.

Only two-thirds of caregivers reported using mouth rinse once or more a day as part of a resident's oral care. Use of mouth rinse should be nearly universal, as it is a safe and simple method to use as an antimicrobial to treat and prevent infections. One caregiver suggested that mouthwash should be used with all residents and not just ones that swab. It would be worthwhile to investigate the reasons why the use of mouth rinse is not more common, as well as the type of mouth rinses and swabs being used. There is some concern with the use of swabs (toothettes), which are soft sponge-tipped mouth cleaners, because they have been contraindicated due to the risk of aspirating small pieces of sponge in the disabled population.[32] However, most mouth rinses can be applied with a toothbrush, which is standard protocol of the DECOD clinic. The use and application of mouth rinse is another oral care technique that could easily be taught to the caregivers during informal in-services by (DECOD) trained dental professionals.

The study in general found that caregivers were highly knowledgeable about the importance of oral hygiene on quality life, the impact of oral pain and the need for daily oral care. Nearly a 100% of caregivers agreed or strongly agreed to statements about these aspects of oral care. The majority of caregivers were also knowledgeable about the use of tooth brushing and flossing for oral care. However, there was also some lack of knowledge about tooth brushing and flossing, as indicated by 11 to 17% of the caregivers being unsure about the use of tooth brushing and flossing for oral care. There was also a lack of knowledge or training

about the use of fingers to open a resident's mouth, with only two thirds of the caregivers knowing that this was not an appropriate method of care.

In addition, nearly one third of caregivers believed that tooth loss was a natural process of aging, reflecting a common misconception among caregivers. The rate was even higher, 51% of caregivers, in the study by Dharmashi et al[32].

Oral health care training is an important factor in the outcome of the oral care being provided for individuals with traumatic brain injury. Results of this study showed that the majority of caregivers had received some form of training in oral health care. Even though most had received training at orientation or as needed on a one-on-one per specific patient, the quality, consistency and effectiveness of these training sessions remains unclear. As one caregiver stated: "I was afraid to brush one ladies teeth for a long time. Then my boss showed me how to brush her teeth and that it wasn't hurting her. It made me much more confident at doing my job". While instant feedback and a hands-on demonstration worked in this instance, it may not be the best format to educate an entire caregiving staff. Having a more formal, qualitative and consistent process of training may eliminate some of the stresses and questions encountered by the caregiver. It may also provide additional strategies and techniques to handle uncooperative patients. Of interest, one caregiver stated: " I think we do a really good job with difficult residents. I think more in-service would be helpful. Also, better staffing so that we don't feel rushed." This type of feedback supports a confident perspective and outlook – a quality that should be harnessed and embraced by the facility. Because there is already ongoing

restorative care that is provided monthly by the DECOD clinic and its dentists, extending care by educating staff and collaborating with administrators at the site would greatly improve provision of oral care. These brief in-services could not only enhance care but also provide caregivers with additional knowledge on current techniques as well as infection control.

Study Limitations

One limitation of this study was the small sample size so it may not be representative of the entire caregiving population. In the Seattle area, Snohomish Chalet remains to be one of the few long-term residency institutions serving the traumatic brain injury population. Another limitation was the large number of 'N/A' or unanswered responses, which were hard to interpret. Although all survey questions were constructed to avoid leading answers, data collected was self-reported by the caregivers so it may not represent the actual behavior or action on the part of the caregiver at the time of the survey.

CONCLUSION

The study indicates that most caregivers at Snohomish Chalet are comfortable in providing oral care to their patients. Most caregivers have received some type of dental training, although more education and routine dental in-services may help caregivers better handle common and frequent barriers to delivery of oral care and improve the oral health of residents. More collaboration with dental health

professionals is critical in providing the oral health care of this population. Literature and research in the area of dental needs of the traumatic brain injured patient as well as other developmental disabilities are lacking. Future research should include a larger and more representative sample of this population.

REFERENCES

1. Fiske J, Frenkel H, Griffiths J, Jones V. Guidelines for the development of local standards of oral health care for people with dementia. *Gerodontology* 2006; 23(Suppl 2): 5–32.

2. Fiske J, Weeks J. Oral care of people with disability: a qualitative exploration of the views of nursing staff. *Gerodontology* 1994; 11: 13–17.

3. Chalmers JM, Levy SM, Buckwalter KC, Ettinger RL, Kambhu PP. Factors influencing nurses'aides' provision of oral care for nursing facility residents. *Spec Care Dentist* 1996;16:71–9.

4. Weeks JC, Fiske J. Oral care of people with disability: a qualitative exploration of the views of nursing staff. *Gerodontology* 1994;11:13–7.

5. Thole K, Chalmers J, Ettinger RL, Warren JJ. Iowa intermediate care facilities: an evaluation of care providers' attitudes toward oral hygiene care. *Spec Care Dentist* 2010;30:99–105

6. American Academy of Pediatric Dentistry. Guideline on Management of Dental Patients with Special Health Care Needs. *Pediatr Dent* 2011;33:142–6.

7. Griffiths J, Boyle S. *Holistic oral care – a guide for health professionals*. Sections 2–3. London: Stephen Hancocks Ltd, 2005.

8. Hicks R. *Dyspraxia*. BBC Health website 'Conditions' section, 2008. http://www.bbc.co.uk.offcampus.lib.washington.edu/health/conditions/dyspraxia2.shtm

9. Department of Health. *Care homes for older people. National minimum standards and the care homes regulations 2001*. 3rd ed. London: The Stationery Office, 2003.

10. Almomani F, Brown C, Williams K. The effect of an oral health promotion program for people with psychiatric disabilities. *J Psychiatr Rehabil* 2006; 29: 274–281.

11. *Dougall A, Fiske J. British Dental Journal* 205, 119 - 130 (2008)

12. Budtz-Jørgensen E, Mojon P, Rentsch A, Deslauriers N. Effects of an oral health program on the occurrence of oral candidosis in a long-term care facility. *Community Dent Oral Epidemiol* 2000; 28: 141–149.

13. Simons D, Baker P, Jones B, Kidd E, Beighton D. An evaluation of an oral health training programme for carers of the elderly in residential homes. *Br Dent J* 2000; 188: 206–210.

14. Brady M, Furlanetto D, Hunter R, Lewin S, Milne V. Staff-led interventions for improving oral hygiene in patients following stroke. *Cochrane Database Syst Rev* 2006; 4: CD003864. DOI: doi: 10.1002/14651858.CD003864.pub2.

15. Frenkel H. Behind the screens: care staff observations on delivery of oral health care in nursing homes. *Gerodontology* 1999; 16: 75–8

16. Frenkel H, Harvey I, Newcome R. Oral health care among nursing home residents in Avon. *Gerodontology* 2000; 1: 33–38.

17. Frenkel H, Harvey I, Needs K. Oral health care education and its effect on caregivers' knowledge and attitudes: a randomised controlled trial. *Community Dent Oral Epidemiol* 2002; 30: 91–100.

18. Faul MXL, Wald MM, Coronado VG, Traumatic brain injury in the United States: Emergency department visits, hospitalizations, and deaths. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010

19. Finkelstein E, Corso P, Miller T. *The incidence and economic burden of injuries in the United States*. Oxford University Press, New York 2006

20. Kalpakjian CZ, Lam CS, Toussaint LL, Hansen Merbitz NK. Describing quality of life and psychosocial outcomes after traumatic brain injury. *American Journal of Physical Medicine & Rehabilitation* 2004; 83: 255–265

21. Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson TB, Flegal K, Ford E, Furie K, Go A, Greenlund K, Haase N, Hailpern S, Ho M, Howard V, Kissela B, Kittner S, Lackland D, Lisabeth L, Marelli A, McDermott M, Meigs J, Mozaffarian D, Nichol G, O'Donnell C, Roger V, Rosamond W, Sacco R, Sorlie P, Stafford R, Steinberger J, Thom T, Wasserthiel-Smoller S, Wong N, Wylie-Rosett J, Hong Y. Heart disease and stroke statistics – 2009 update. A report from the American heart association statistics committee and stroke statistics subcommittee. Circulation 2009; 119:21–181.

22. Heron MP, Hoyert DL, Murphy SL, Xu JQ, Kochanek KD, Tejada-Vera B. Deaths: Final data for 2006. *National Vital Statistics Reports* 2009; 57: 1–15

23. National Institute of Neurological Disorders and Stroke. Traumatic brain injury: Hope through research. *National Institutes of Health* 2002; NIH Publication No.: 02–158

24. Rimmer JH, Rowland JL. Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine* 2008; 2: 409–420

25. National Institute of Health. Rehabilitation of person's with traumatic brain injury. *NIH Consensus Statement* 1998; 16: 1–41

26. Nathan D. Zasler, Catherine W. Devany, Amy L. Jarman, Richard Friedman, Ann Dinius. Oral hygiene following traumatic brain injury: A programme to promote dental health. Brain Injury 1993, Vol. 7, No. 4: 339–345

27. Kreutzer J. S., Zasler N. D., Wehman P., Devany C. Neuromedical and psychosocial aspects of rehabilitation following traumatic brain injury. *Rehabilitation Medicine: State of the Art*, G. Fletcher, B. Jann, S. Wolf, J. Banja. Lea & Febiger, New York 1992; 63–102

28. Brooks N., Campsie L., Symington C., et al. The effects of head injury on patient and relative within seven years of injury. *Journal of Head Trauma Rehabilitation* 1987; 2: 1–13

29. Oddy M., Coughlan T., Tyerman A., Jenkins D. Social adjustment after closed head injury: A further follow-up seven years after injury. *Journal of Neurology, Neurosurgery and Psychiatry* 1985; 48: 564–568

30. Rutherford W. H. Postconcussion symptoms: Relationship to acute neurological indices, individual differences, and circumstances of injury. *Mild Head Injury*, H. S. Levin, H. M. Eisenberg, A. L. Benton. Oxford University Press, New York 1989; 217–222

31. Delta foundation: Snohomish Chalet. www.deltafoundation.com

32. Dharamsi S, Jivani K, Dean C, Wyatt C. Oral care for frail elders; knowledge, attitudes, and practices of long-term care staff. Journal of Dental Education 2009; 73: 581 – 588

33. Lenth, R. V. (2009). Java Applets for Power and Sample Size [Computer Software]. Retrieved July 31, 2012 from http://www.stat.uiowa.edu/~rlenth/Power.

34. Jobman, K. J., Weber-Gasparoni, K., Ettinger, R. L. and Qian, F. (2012), Caregivers' perceived comfort regarding oral care delivery in group homes: A

pilot study. Special Care in Dentistry, 32: 90–98. doi: 10.1111/j.1754-4505.2012.00250.x

APPENDIX A: SURVEY COVER LETTER

October 1st, 2012

Dear Caregiver,

I am inviting you to help dental professionals by taking a few minutes to share your opinions and experiences about caregiving practices within the traumatic brain injury population. As a dental hygienist currently enrolled in the University of Washington's Master of Public Health Executive Degree Program, I am contacting all caregivers at Snohomish Chalet for their candid response about their knowledge, attitudes and experiences about oral health care among their patients. Some questions may feel uncomfortable while answering however; your responses and recommendations will be anonymous and valuable in guiding future oral care programs.

This survey is voluntary and will take 5-10 minutes to complete. Your answers are completely anonymous and will not be shared with any caregivers, administrative staff or management. No individual answers will be shared or identified. All caregiving staff providing oral care will be invited to respond. By completing this survey, you are consenting to have your anonymous responses used in this study.

If you have any questions about the survey, please let me know I will be happy to talk to you. If you have any questions regarding your rights as a research subject, please contact the University of Washington Human Subjects Division at (206) 543-0098.

Thank you very much for your time and input towards this study.

Sincerely,

Salima Alibhai, RDH
Salima24@gmail.com
Master of Public Health Candidate
University of Washington

APPENDIX B: SURVEY QUESTIONS

1) I am a: [] Care aide/CNA [] LPN [] RN [] Meal program provider

   [] Other: _____

2) Gender: [] Male [] Female

3) Age: _____years

4) How long have you been in this profession? _____Years

5) How long have you been working at Snohomish Chalet? _____Years

6) In a typical week how many hours do you provide direct care? _____ Hours

7) Do you provide oral hygiene care to patients? [] Yes [] No

8) How many residents do you take care of in a typical shift? _____

9) In a typical shift, how many residents are independent and brush their own teeth?

   _____

10) In a typical shift, how many residents require assistance with brushing their own teeth and oral care? _____

11) What oral health care training have you received while working for Snohomish Chalet? Check all that apply.

    [] Dental in-service [] Training at orientation [] One-on-one per specific patient

    [] Did not receive training

12) Is oral care part of your job description? [] Yes [] No

13) Are you interested in participating in an oral health care program on how to handle uncooperative patients? [] Yes [] No

14) Are you interested in participating in an oral hygiene program on oral health tips?

[] Yes [] No

15) Do you feel qualified to provide oral care to residents? [] Yes [] No

16) What do you do when a resident is not cooperative (aggressive and retaliates) while you try to provide oral care?

	Never (0%)	**Rarely (>0% to 25% of the time)**	**Occasionally (>25% to 50% of the time)**	**Frequently (>50% to 75% of the time)**	**Very Frequently (>75% of the time)**
Leave patient alone					
Continue to attempt					
Force					
Bribery					
Combine care with likeable activities					
Ask for help from another aide					

17) In your experience and practice, what strategies have worked best in the past while providing mouth care to a non-cooperative (aggressive and retaliates) resident?

	Never (0%)	**Rarely (>0% to 25% of the time)**	**Occasionally (>25% to 50% of the time)**	**Frequently (>50% to 75% of the time)**	**Very Frequently (>75% of the time)**
Leave patient alone					
Continue to attempt					
Force					
Bribery					

Combine care with likeable activities					
Ask for help from another aide					

18) Please check one box for each of the statements below. With cooperative residents, how often do you:

	Once a Day	**More Than Once a Day**	**Once a Week**	**Less Than Once a Week**	**2 to 3 Times a Week**
Brush resident's teeth with fluoridated toothpaste?					
Brush resident's tongue?					
Floss (or help floss) the resident's teeth?					
Use (or help use) mouth rinse (e.g., Peridex) for the residents?					

19) Please check one box for each of the statements below. With un-cooperative residents, how often do you:

	Once a Day	**More Than Once a Day**	**Once a Week**	**Less Than Once a Week**	**2 to 3 Times a Week**
Brush resident's teeth with fluoridated toothpaste?					
Brush resident's tongue?					
Floss (or help floss) the resident's teeth?					
Use (or help use) mouth					

rinse (e.g., Peridex) for the residents?					

20) As caregiver, how frequently do you experience the following while providing oral care:

	Never (0%)	**Rarely (>0% to 25% of the time)**	**Occasionally (>25% to 50% of the time)**	**Frequently (>50% to 75% of the time)**	**Very Frequently (>75% of the time)**
Patient not opening his/her mouth					
Patient is orally defensive and refuses oral care					
Patient moves head uncontrollably					
Patient bites caregiver					
Patient spits at caregiver					
Patient hits caregiver					

21) Please check one box for each of the statements below regarding your own oral health, how often do you:

	Once a Day	**More Than Once a Day**	**Once a Week**	**Less Than Once a Week**	**2 to 3 Times a Week**
Brush your own teeth?					
Brush your own tongue?					
Floss your own teeth?					

Use mouth rinse?					

22) What is your opinion about the following statements?

	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**	**I am Not Sure**
Daily oral hygiene improves the quality of life.					
Care aides should provide daily mouth care for all residents.					
I am comfortable providing daily mouth care for the residents.					
I have sufficient knowledge about mouth care.					
I have the skills to provide daily mouth care to the residents.					
I am aware of the current protocol for daily mouth care.					
Oral pain can impact a patient's eating pattern.					
A little cleaning at a time helps the resident to be less anxious.					
A soft to very soft toothbrush should be used for residents.					
Dental floss should be used to clean between the teeth.					
Plaque can only be removed by mechanical forces such as brushing and flossing.					
Tooth loss and oral diseases are natural processes of aging.					
If a resident is unable to open their mouth, the caregiver should					

place her finger between the upper and lower teeth to keep the resident's mouth open.					
Bleeding gums are a normal process and not an oral hygiene concern.					
How do you feel about receiving instructions on providing oral hygiene care for residents?					

23) Please relate an experience when you had a difficult time providing oral care to a resident? What challenges did you encounter?

_____
_____

24) How would you improve oral hygiene care for residents?

_____
_____