Exploring Oral Self-Care Practices and Concerns of Community-Dwelling Individuals Living with Dementia and Their Care Partners

by

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Abstract

Background

Dementia is a progressive disorder that affects thinking and memory. One of the most significant day-to-day impacts of dementia is the loss in ability to complete basic activities of daily living (ADLs), such as oral care. Toothbrushing is a multi-step task that individuals living with dementia often experience difficulty completing independently due to forgetting the need or even how to brush their teeth and/or dentures. The objective of this study was to explore the practices and concerns around oral self-care from the perspective of community-dwelling individuals living with dementia (ILDs) and their care partners (CPs).

Methods

A qualitative exploratory design was employed using focus group (FG) sessions. Partnership with the Alzheimer Society of Alberta & Northwest Territories (ASANT) facilitated the recruitment of CP and ILD participants. Twenty CP participants participated in one of three FGs (N=7; 7; 6); seventeen CP participants identified themselves as an ILD's spouse and three as a child of an ILD. These participants were primary care partners to people living with various ASANT-specific classifications of dementia including early-stage, young-onset, and respite. Nine ILD participants were also recruited, all of which had CPs participating in the FG sessions. Early-stage and young-onset ILD participants took part in one of two FGs (N=6; 3). The FG sessions were conducted separately but simultaneously; one group consisting of CP participants, and one group of ILD participants. FGs were guided by a series of semi-structured questions that were asked verbally and provided in-text for reference. Oral care props were used in ILD focus groups as triggers to allow for deeper and more dental-oriented discussions. FG sessions lasted 90-minutes and were audio and video recorded to complement recall. Data were transcribed by a professional; transcripts were reviewed and enhanced with descriptive and nonverbal details obtained from video recordings by the research team. Content analysis of transcript data consisted of open coding, categorization, and abstraction. Two co-supervisors also coded each transcript and discussion resolved any differences in interpretations.

Results

While ILD participants were categorized using clinical diagnostic criteria, there was little correspondence between their reported level of independence and the oral care practices they discussed. CP participants strove to contextualize oral care as one dimension of preserving autonomy and humaneness of their loved one. Oral care practices reflected a continuum of independence ranging from wholly or partially independent to wholly dependent. All ILD participants reported being wholly independent in oral care and stressed the maintenance of their remaining capacities until the time when tasks would be delegated for them. Strategies used to ensure oral care included relying on embodied habits (e.g. toothbrushing), providing supportive aids (e.g. setting out toothbrush), verbal reminders, and physical interventions. Difficulties were encountered when an ILD resisted support because of their claim of independence or when an ILD stressed the simplicity these engrained habits as these behaviours were instilled at a young age.

Conclusion

CP and ILD participants were cognizant that strategies to promote oral care had to change over time, although some CPs realized during the FG sessions, their current practices were insufficient to meet the needs of their loved ones. CP participants struggled to identify key transition points that indicated a different level of assistance was required as oral care was assumed to be an embodied and persistent habit. CPs need support in accurately determining an

ILD’s actual abilities, as well as, strategies to gain cooperation as CPs enter into a more assistive role. Implications of this study include the need for anticipatory guidance in discussing and educating CPs around behavioural indicators to watch for as the ILD progresses through the various levels of independence. In addition, this study will allow for better cognitive assessments to take place in dental clinics by asking direct questions that probe into contextual information that may indicate the ILDs capacity for oral self-care has deteriorated, for example asking whether or not the level of toothpaste and/or floss has changed? Dental hygienists are well-situated to provide appropriate interventions and homecare strategies, which could decrease disjunction between what CPs think, what ILDs report, and what oral self-care practices actually take place. Dental hygienists contribute to maintaining adequate oral health for ILDs, that could, in turn, improve their quality of life in the community.

Preface

This thesis is the original work of Nadia Kobagi. This research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, titled "Oral Health Practices and Concerns of Community-Dwelling Individuals Living with Dementia and Their Care Partners," No. Pro00060323, November 17, 2015.

Dedication

For one of the strongest men, I was blessed to know, my uncle, Nadim.

I miss you.

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Without the skills and guidance of my supervisors, Dr. Minn Yoon and Dr. Jude Spiers, along with their unwavering belief in my abilities, the completion of this research project would not have been possible. Words will never be able to express my wholehearted gratitude.

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grateful for the memories, laughs, and tears we have shared. Thank you for being an ear to listen, a shoulder to cry on, and having an endless supply of candy ready.

Thank you, Lord, for drawing near to me in my times of weakness throughout this journey.

May He grant your heart's desires and make all your plans succeed – Psalm 20:4

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List of Abbreviations

ADLs	activities of daily living
AHS	Alberta Health Services
ASANT	Alzheimer Society of Alberta & Northwest Territories
CDHA	Canadian Dental Hygiene Association
CIHI	Canadian Institute for Health Information
CP	care partner
CRDHA	College of Registered Dental Hygienists of Alberta
FDI	Federation Dentaire Internationale
IADL	instrumental activity of daily living
ILD	community-dwelling individual living with dementia
LTC	long-term care home
MoCA	Montreal Cognitive Assessment
PI	partially independent
RDH	Registered Dental Hygienist
WD	wholly dependent
WHO	World Health Organization
WI	wholly independent

Glossary of Terms

In the context of this thesis, terms are defined as follows:

Activities of daily living (ADLs): Tasks of everyday life including eating, bathing, dressing, toileting, transferring (walking), and continence.

Alzheimer's disease: The most common cause of dementia and may contribute to 60–70% of all diagnosed cases characterized by impairment in memory, thinking, comprehension, and judgment (Kocaelli, Yaltirik, Yargic, & Özbas, 2002).

Alzheimer Society of Alberta & Northwest Territories (ASANT): This organization consists of a provincial office and seven regional organizations across Alberta and Northwest Territories. ASANT works by improving quality of life for those living with dementia. The Alzheimer Society offers a network of educational and support services for those with dementia and their care partners. ASANT builds partnerships with health professionals, the community, and advances research to find effective treatment and potential cure for dementia.

Care partner (CP): An unpaid individual providing support and care to an individual living with dementia in many, if not all, activities of daily living. Other literature commonly refers to these individuals as caregivers. ASANT prefers the use of the term care partner rather than caregiver, and as such we have adopted the same vocabulary.

Community-dwelling individual living with dementia (ILD): A person who has received a medical diagnosis of dementia, regardless of the type of dementia, and is still living independently within the community, either alone or with family.

Dementia: A term for an overall set of symptoms that are caused by disorders affecting the brain. It is progressive, which means that symptoms will gradually get worse as more brain cells become damaged. Dementia is not a specific disease. Many diseases can cause dementia including Alzheimer's disease, vascular dementia (stroke-induced), Lewy Body diseases, Parkinson's disease, Huntington's disease, head trauma, and many more. These conditions can have similar or overlapping symptoms. Symptoms may include memory loss, mood or behavior changes, and difficulties with thinking and problem-solving which can be severe enough to reduce a person's ability to perform everyday tasks.

Early-stage dementia: An ASANT-specific terminology to refer to individuals who are in the early or mild stage of their dementia diagnosis.

Respite dementia: An ASANT-specific terminology used to refer to individuals who have not been placed in a specific diagnostic category and cannot be left at home when care partners are attending support group meetings. Therefore, the Alzheimer Society provides the care partners respite for their loved ones.

Young-onset dementia: An ASANT-specific terminology to refer to individuals who have been diagnosed with dementia before the age of 65 years.

Long-term care home (LTC): These homes provide a variety of services, both medical and social to individuals who are no longer able to manage independently within the community.

Assisted living residence: A housing facility for people with disabilities or for adults who cannot or chose not to live independently.

Model: A construct or diagram that explains the underpinnings of a theory; however, the model itself is not the theory and therefore will not be tested or validated.

Oral health: World Health Organization (WHO) (2012) defines oral health as "essential to general health and quality of life. It is a state of being free from mouth and facial pain, oral and throat cancer, oral infection and sores, periodontal (gum) disease, tooth decay, tooth loss, and other diseases and disorders that limit an individual's capacity in biting, chewing, smiling, speaking, and psychosocial wellbeing" (World Health Organization, 2012).

Oral self-care: The independent practice of keeping the mouth clean and healthy by brushing and flossing to prevent tooth decay and gum disease in dentulous individuals. In edentulous individual's oral self-care involves cleaning, brushing, and soaking dental prosthesis (partial or complete denture) as well as, moistening and removing any build-up of oral secretions from soft tissues.

Registered dental hygienist (RDH): A primary health care professional who works independently or alongside a dentist or other dental professionals to provide oral health care services to achieve and maintain optimal oral health, as an integral part of wellbeing. They have training and education that focus on prevention of oral diseases through theory and evidence-based practice.

Chapter One

Introduction

Background of the Study

Dementia is a collection of symptoms caused by disorders that affect the brain (Chen, Clark, & Naorungroj, 2013). In addition to memory loss, individuals living with dementia may lose their ability to (1) generate coherent speech or understand verbal or written language; (2) recognize or identify objects; (3) perform motor tasks; and (4) plan and carry out complex tasks (Chen et al., 2013). Loss of memory and ability can have a considerable impact on the capability of an individual living with dementia to complete activities of daily living such as oral self-care. Toothbrushing alone is comprised of twenty-five distinct steps, including a sequence of identifying one's personal toothbrush, applying toothpaste onto a toothbrush, and then brushing various surfaces of one's dentition to adequately remove plaque biofilm (Wehman & Kregal, 2017; Wilson, Rochon, Mihailidis, & Leonard, 2013). Due to the complex sequence of a large number of steps required for toothbrushing, individuals living with dementia often have difficulty completing this task independently (Tappen, 1994). Therefore, as dementia progresses, individuals often become dependent on care partners for such care (Ghezzi, Ship, & Mich, 2000).

A significant number of individuals with dementia are community-dwelling (Parsons, Surprenant, Tracey, & Godwin, 2013). Current Canadian literature suggests that 91.7% of individuals diagnosed with mild dementia reside within the community (Government of Canada, 2016). The percentage of individuals living with dementia in institutional care increases as the dementia stages progress from mild or moderate to severe dementia (Government of Canada, 2016). For individuals with dementia who are community dwellers, indicators of functional capacity or one's ability to carry out everyday tasks, becomes important because it identifies areas that may require assistance from care partners (Canadian Institute for Health Information, 2011). Indicators from the Canadian Institute of Health Information (CIHI) (2011) include activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Activities of daily living reflect a person's level of independence related to functional activities including walking, bathing, and dressing (Canadian Institute for Health Information, 2011). Instrumental activities of daily living are those which are not essential for fundamental functioning, but let an individual live independently, such as shopping, completing chores, and making meals (Canadian Institute for Health Information, 2011). Though CIHI does not explicitly include oral care as an indicator to assess a person's level of independence, studies show that daily oral care in individuals living with dementia is important because they are at a greater risk for oral diseases (Dolan, Atchison, & Huynh, 2005; Matthews et al., 2012).

The effects of poor oral care can be considerable for individuals living with dementia. Poor oral care can manifest in oral diseases, including dental caries and periodontal disease, which when left untreated can cause pain and infection. Oral pain may influence food and fluid intake leading to decreased nutritional health (Harding, Gonder, Robinson, Crean, & Singhrao, 2017; Sheiham, Steele, Marcenes, Finch, & Walls, 2008). Poor oral care has also been linked to an increase risk of cardiovascular disease (Lam, Zhang, Samaranayake, Li, & McGrath, 2011; Persson et al., 2002) and respiratory infections (Azarpazhooh & Leake, 2006; Scannapieco, Bush, & Paju, 2003). Furthermore, dental pain and poor oral hygiene can lead to behavioural responses such as aggression, restlessness, and insomnia (Chalmers, Gryst, & Jolly, 2001; Jablonski, Therrien, & Kolanowski, 2011). In general, poor gingival health and maintenance of oral care in individuals living with dementia has been linked to increased severity of dementia (Gil-Montoya et al., 2017).

Significance of the Problem

Though existing research has highlighted the manifestations of poor oral self-care on the oral health and systemic health of individuals living with dementia, research focused on community dwellers living with dementia is limited. Existing literature pertaining to oral health for individuals living with dementia consists primarily of prevalence studies on oral disease (Ellefsen et al., 2008; Hatipoglu, Kabay, & Güven, 2011) and studies that address oral health concerns of individuals living with dementia in the context of long-term care settings (Adam & Preston, 2006; Chalmers & Pearson, 2005b; Pearson & Chalmers, 2004). As current Canadian literature suggests the number of individuals living with dementia is 564,000, research understanding the perspectives of oral self-care in these individuals and their care partners is important to help the dental community better support the oral health needs of these individuals (Alzheimer Society Canada, 2016).

Furthermore, population projections in Canada predict an acceleration of population ageing (Statistics Canada, 2015). As the population ages, an increasing number of people with dementia will require oral and dental care in community settings. However, nearly half (44%) of all seniors have not visited a dental professional in the previous year, compared to over a quarter (27%) of those aged 45 to 64, suggesting that barriers to accessing dental care within the community needs further investigation (Canadian Institute for Health Information, 2011). There is a lack of information on how to best provide accessible dental care to this vulnerable population, and what factors contribute to successful care. This study is timely, as Canada's population ages and dental professionals are seeing an increased number of individuals living with dementia in their practices (Pynn & Kolic, 2014).

Purpose of the Study

The purpose of my study was to explore the experiences, practices, and concerns of oral self-care from the perspective of both individuals living with dementia and their care partners. The main research question guiding the study was:

> What are the oral health practices and concerns among community-dwelling individuals living with dementia and their care partners?

This research question was supported by four secondary research questions:

a. What are the practices of oral self-care in community-dwelling individuals with dementia and their care partners?
b. What are the prevalent oral health concerns of community-dwelling individuals with dementia and their care partners?
c. How do individuals living with dementia and their care partners perceive accessibility of community dental offices?
d. How do oral care practices fit in, and reflect community-dwelling individuals with dementia and their care partners values and expectations around personhood and autonomy?

As common to qualitative research, development of the research questions was an iterative process and was influenced by the understanding I gained related to oral care needs of individuals living with dementia and their care partners through the emic experience of study participants. In addition, the methodology used was important to preserve the sense of autonomy of the individuals living with dementia by allowing them to openly share personal practices and experiences of oral self-care in a safe environment. The notion of personhood, according to Kitson (1999), is when an individual is an active recipient of care to ensure that their overall health needs are met (Kitson, 1999). This notion of personhood also considers the care partners wants and needs, which is often negotiated at encounters between a care partner and the individual receiving care (Kitson, 1997). While this particular definition of personhood is widely accepted in nursing, the current study adopts Kitwood's (1997) theory of personhood, in which an individual living with dementia is still recognized and respected as a social being (Kitwood, 1997). Kitwood's theory of personhood directly aligns with the method of data collection used and enriches the understanding of personhood throughout data analysis.

Findings from my study will provide much-needed information on how to address oral concerns of individuals living with dementia, as well as, assist care partners in identifying transition points in their loved one's oral care practices, which may indicate the need for further support and possible intervention.

Researcher Interest

This research study was inspired by my work as a registered dental hygienist and by volunteer experiences serving individuals living with dementia. Prior to my work as a dental hygienist, I was employed and volunteered for organizations that provided health care support to underserved populations with complex needs, most of whom were older adults. This is when I first witnessed challenges surrounding oral care, either in the individual living with dementia or their care partner. In my practice as a dental hygienist, I became more aware of the oral health care challenges of older adults, especially for persons living with dementia.

During a typical dental hygiene appointment, I would investigate my patients' current oral care practices in an attempt to provide recommendations, education and instruction that best aligned with their values, preferences, and practices. However, once the appointment was over, I was often left wondering about the effectiveness of my teaching. This thought then spiralled a multitude of questions that I wanted to explore. I questioned if my patient's responses were accurate or out of habit, especially in people with apparent cognitive decline. I felt uncertainty in how to best support my patient with their daily oral self-care as they experienced cognitive decline. I reflected on what care partners might feel in assuming the responsibility of daily oral care for their loved one who was once independent. I wondered if their loved one or primary care partner knew about the patient's current oral health status. During the course of my research, I reflected on my practice and wondered how many patients I had treated without knowing about their dementia diagnosis.

All of these unanswered questions led me to seek out current dental health literature surrounding dementia so I could better help support the health of my patients. Through this inquiry, I became more familiar with the gap in knowledge related to daily oral care practices of individuals living with dementia. This was when I began to inquire about daily oral care practices of individuals living in the community that had a diagnosis of dementia. This gap became the inspiration for my study. I wanted to create a study that captured the perspectives of primary care partners and individuals living with dementia to examine if oral care views are consistent between the two perspectives. I knew that care partners are often called upon to help their loved one with oral care, and understanding their perspectives is an important step to help support care partner needs. It was also important to me to include people living with dementia in my study because I wanted to hear directly from them about their practices and concerns with daily oral care. I acknowledge that there are limitations in studying a vulnerable population, such as those living with dementia, as they may not be able to fully recall short-term practices; however, past information regarding oral care is still of value and will assist in addressing a gap amongst clinicians and care partners. I have come to believe that without continual exploration and research, efforts for improving oral care in adults living with dementia are futile.

Thesis Outline

This thesis is organized into five chapters: the introduction, literature review, methodology, findings, and discussion. In chapter one, I provided a brief overview of the subject matter, the context, and significance of my research. In the second chapter, I will provide a comprehensive review of the current literature on Canada's ageing trends, care partner roles, oral-systemic link, dementia and oral care, roles of dental professionals, and barriers to oral health care. In the third chapter, I will outline the methodology I used in this project including the research design, data collection, and analysis. I will also discuss ethical considerations, rigour and mechanisms I used to support credibility, transferability, conformability, dependability, and neutrality. In chapter four, I describe the main themes and categories I developed in my data analysis. Lastly, in the fifth chapter, I will offer a discussion about these key findings in the context of existing literature, implications for practice and policy, study limitations, and future directions of this research.

Chapter Two

Literature Review

In this literature review, I will provide an overview of existing research related to oral care in adults living with dementia. Researchers have acknowledged that general oral and dental health is poorer for those with cognitive decline (Singla, Krishan, & Singla, 2016). However, there are few studies that address oral care concerns in community-dwelling individuals living with dementia, especially from their own personal perspectives. This underdeveloped area of research has potential implications for care partners and dental clinicians in supporting individuals with cognitive decline living in the community. I begin with research on the general Canadian population, sketching out the demographic trends that relate to ageing and dementia, to show an increase in the number of seniors and those living with dementia. I go on to discuss the literature that suggests an increasing number of seniors with dementia live at home, as opposed to long-term care homes, and I present how this creates a unique set of healthcare needs around oral health and the new role of care partners in activities of daily living. In addition, I outline the research demonstrating a link between oral health and systemic health. Finally, I focus on the dental challenges for seniors living with dementia, their families, and dental professionals, and possible barriers to receiving proper oral care. To conclude, I offer a summary of the current literature reviewed in chapter two of this thesis.

Canadian Demographic Trends in Ageing and Dementia

Throughout history, children have tended to outnumber the senior population. For the first time in Canada, the number of seniors aged 65 years and over has surpassed the number of children aged 14 years and under (Statistics Canada, 2015). This means that nearly one in six Canadians, approximately 16.1% of the population, are at least 65 years of age (Statistics

Canada, 2015). The number of seniors aged 85 and older is growing rapidly, in comparison to seniors in the lower age bracket (Canadian Institutes of Health Information, 2011). It is estimated that by 2052, these proportions will nearly double, meaning seniors age 85 and older will account for 24% of all seniors and 6% of the total population (Canadian Institutes of Health Information, 2011). Moreover, most seniors are women, especially among the older age groups, accounting for 52% of seniors age 65 to 74 and 60% of seniors age 75 and older (Canadian Institutes of Health Information, 2011). Women will continue to outnumber men in the future; however, this gender gap will become narrow as life expectancy for men approaches that of women (Statistics Canada, 2015).

Canadian seniors are now living longer on average than they did a decade ago (Statistics Canada, 2015). This statistic is important when determining if these added years are lived in good health. Life expectancy is an indicator to quantify years of life lived; however, this metric does not consider the quality of life. Other measures are used to give a more holistic understanding of health during the later years of life. The two indicators currently used in Canada are functional capacity and multiple morbidities. Functional capacity measures independence, specifically one's ability to carry out everyday tasks (Canadian Institutes of Health Information, 2011). Functional capacity is designed to take into account both basic activities of daily living (ADLs) such as walking and eating, as well as instrumental activities of daily living (IADLs) such as shopping and housekeeping (Canadian Institutes of Health Information, 2011). Assessing functional capacity is important in seniors' health and quality of life because as age increases, especially in older seniors, independence may decrease. A report by the Canadian Institute of Health Information (2011), indicated that while the majority of surveyed Canadians 45 to 84 years did not report any functional limitations, 57% of Canadians

85 years and older reported at least one functional limitation. Moreover, one-quarter of seniors 85 years and older indicated that impairment of their functional capacity was moderate (15%), severe (5%) or involved total limitations (5%) (Canadian Institutes of Health Information, 2011). These statistics signify the need for added support in some seniors' later years to ensure optimal quality of life.

Furthermore, seniors suffer disproportionately from chronic health conditions, and multiple morbidities are a second indicator considered in assessing seniors' health status. Nearly three in four Canadian seniors reported having at least one of eleven chronic health conditions. Additionally, nearly one-quarter (24%) of seniors have been diagnosed with multi-morbidities of three or more chronic conditions (Canadian Institutes of Health Information, 2011). The risk of multiple morbidities also increases with age. However, it is noteworthy that this correlation between an increase in age and multiple morbidities did not hold true for seniors 85 years and older (Canadian Institutes of Health Information, 2011). There are several additional factors that can affect health status beyond functional capacity and chronic health conditions, such as lifestyle choices and socio-economic status. However, the cumulative effect of dealing with chronic health conditions and limitations in functional capacity place Canadian seniors at risk for further health complications and often lead to the need for assistance to help maintain independence and preserve the quality of life (Canadian Institute for Health Information, 2011).

While Canada's seniors are generally healthy, the incidence and prevalence of dementia increases as people age (Canadian Institute for Health Information, 2010). Dementia refers to a class of disorders characterized by the progressive deterioration of thinking and memory (Canadian Nurses Association, 2016). Other dementia symptoms include changes in the ability to perform activities of daily living, as well as, varying mood and behaviour. As of 2016, there was an estimated 564,000 Canadians living with dementia, plus about 25,000 new cases are diagnosed every year (Alzheimer Society Canada, 2016). By 2031, this number is expected to rise to 937,000 cases, an increase of 66% from 2014 (Government of Canada, 2016). Of the current number of Canadians living with dementia, more than 65% are women (Government of Canada, 2016). The financial impact of dementia takes a tremendous toll not only on those living with dementia, but to their families, care partners, employers, and the healthcare system. As of 2016, the combined health care system and out-of-pocket care partner costs were estimated at $10.4 billion per year (Canadian Nurses Association, 2016). By 2031, this figure is expected to increase by 60% to $16.6 billion (Government of Canada, 2016). Generally, costs for people with dementia are approximately five and a half times greater than those who do not have this condition (Government of Canada, 2016). Home care and long-term care are the largest contributors to direct costs (Government of Canada, 2016). In 2011, family care partners provided 19.2 million unpaid hours of care, which is projected to double by 2031 (Government of Canada, 2016). Recognizing anticipated rising costs associated with the care of individuals living with dementia, some reports have suggested mitigating the economic burden on the health care system by encouraging these individuals to remain at home, with support from a care partner, to prevent or delay institutionalization.

Living with Dementia in Long-term Care Homes (LTC) or Community

Depending on the availability of family support and the level of care required, an individual may be able to remain at home with home care services or may require admission to a long-term care home. However, as the dementia progresses, an individual’s need for support and care increases. In fact, dementia is currently the main cause of institutionalization among the elderly (Canadian Institutes of Health Information, 2011). It is anticipated the need for LTC will increase ten-fold, and the cost of providing care for those with dementia is expected to surpass $153 billion by 2038 (Canadian Nurses Association, 2016). Costs associated with LTC were greatest for people living with dementia, at approximately $14,000 a year (Government of Canada, 2016). One problem with LTC is a shortage of beds, but another problem is the lack of funding to have adequate levels of regulated nurses working in this setting (Canadian Nurses Association, 2016; Government of Canada, 2016). While some hospitalizations and long-term care stays may be unavoidable, changes to health care in Canada have included a shift towards more community services to allow for individuals to live at home longer (Canadian Institute for Health Information, 2010).

While long-term care homes have traditionally been the main housing option for older adults who were partially or fully dependent on others for their activities of daily living, in recent years, many older adults have chosen to remain in their homes and age in place (Delgado et al., 2016). Ageing in place is the ability to live in one’s own home and community regardless of factors such as age or ability level (Chen et al., 2013). A considerable number of older adults with some form of cognitive decline are living independently within the community, either alone or with family (Parsons et al., 2013). Forecasts indicate that the 55% of persons with dementia (65 and over) living in their own homes in 2008 will grow to 62% by 2038 (Canadian Nurses Association, 2016). This growth represents over half a million people who will need community and home-based care in 2038, with a projected shortfall of 157,000 LTC beds by that time (Canadian Nurses Association, 2016). A very high number of individuals with a mild form of dementia (92%) choose to live within their communities; however, only 50% remain when the dementia has progressed to a moderate stage (Government of Canada, 2016). Community care must, therefore, be prepared to meet this demand.

Due to an increase in the number of dependent seniors choosing to age in place, the need for care partners to assist with ADLs has proportionately increased (Constanza, Fernando, Iris, & Darinka, 2012). Non-professional, in-home care partners are an alternative to LTC. Alternatively, in some cases, care partners can be used to extend the period of time some seniors live at home before transitioning into long-term care. Care partners are usually family members, who provide all care independently or with some assistance from home care services.

Canadians' preferences for ageing in place presents an opportunity to improve outcomes for persons with dementia. Seniors living at home can be diagnosed sooner and managed for longer periods of time (Canadian Nurses Association, 2016). In fact, early diagnosis and management are essential for relieving the burden on the senior, the care partners, and the healthcare system (Canadian Nurses Association, 2016). In order to achieve this goal, the capacity of community care must be enhanced through proper training of homecare workers or family care partners.

To date, research with regards to oral health concerns for individuals living with dementia has largely focused on populations residing in long-term care homes (Chalmers & Pearson, 2005a). The literature has consistently indicated that the oral health status of residents in LTC is poorer than the general population of older adults (Matthews et al., 2012; Porter et al., 2015). Despite this link in the research, oral health experiences of adults with dementia, particularly those living in the community, have not been adequately explored. The studies that do exist on the topic are mainly prevalence studies on oral diseases using indices such as decayed, missed, or filled teeth (DMFT index) to assess the oral health status of a resident (Hatipoglu et al., 2011). Reliance on this data means the voices of individuals living with dementia are excluded from research (Wilkinson, 2002). One other limitation of the data is perspective. Research studies are typically conducted from the perspective of either frontline staff employed in facilities or from loved ones and/or care partners (Adam & Preston, 2006; Chalmers & Pearson, 2005b). There are compelling reasons from an ethical standpoint to consider the experiences of individuals with dementia who choose to live at home. The inclusion of their experiences and perspectives can help to supplement the existing research in reports done by health care professionals and other proxies such as, paid home care workers or family members who do not live with the individual living with dementia.

Care Partner (CP) Roles

Institutionalized adults living with dementia are typically cared for by informal caregivers and paid caregivers. Community-dwelling individuals living with dementia could be supported by formal caregivers, but are more likely cared for by informal care partners who are generally family members (Constanza et al., 2012). Most older adults with dementia receive assistance from their spouse, but when the spouse is no longer alive or is unavailable to provide assistance, adult children usually step in to help (Schulz & Martire, 2004). Adult daughters and daughters-in-law are more likely than sons and sons-in-law to provide routine assistance with household chores and personal care over long periods of time, and they also spend more hours per week in providing assistance (Schulz & Martire, 2004). Although caregiving tasks are sometimes divided among several family members or friends, the more common scenario is that most care is provided by one individual (Takahashi, Tanaka, & Miyaoka, 2005).

Although family caregivers perform an important service for society and their relatives, they often do so at a considerable cost to their own well-being (Butcher, Holkup, & Kathleen, 2001). Caring for seniors with disabilities has been associated with higher rates of anxiety and depression (Butcher et al., 2001; Etters, Goodall, & Harrison, 2008). The term caregiver burden is most often used to describe this phenomenon and is defined as the extent to which caregivers perceived their emotional or physical health, social life and financial status as being compromised as a result of caring for their relatives (Takahashi et al., 2005). Caregiver burden increases as dementia of the persons being cared for progress and as they become more and more dependent on caregivers in their activities of daily living (Etters et al., 2008). This can result in poor outcomes for individuals living with dementia, such as decreased quality of life and early nursing home placement as the caregiver feels unable to cope with these demands (Etters et al., 2008). Therefore, efforts to identify, understand, and reduce caregiver burden are important and need to be addressed.

The ability of a care partner to manage the care needs of a loved one living with dementia largely relies on their ability to assume, master, and maintain caregiving roles. Family caregivers continually undergo a process of role change (Hepburn, Tornatore, Center, & Ostwald, 2001). There are simultaneous role evolutions as dementia affects the primary relationship (e.g. as a spouse, child, relative), and as CPs gradually assume the work in the new role as caregiver. Family caregivers may have no training and may have little understanding or appreciation of the disease, and its progression, as well as how to support the care needs of their loved one living with dementia (Hepburn et al., 2001). As caregivers come to terms with their loved one's condition, many seek additional information about the disease (Butcher et al., 2001). Research highlighted that information sought focused primarily on reducing adverse stress by developing or strengthening the knowledge and skills family members needed to perform in the caregiving role thereby increasing their own capacity of CP's to support care needs (Hepburn et al., 2001). Research with respect to informal care partner/family member attitudes is quite limited.

Oral-Systemic Link

Oral cavities are host to a plethora of microorganisms, with the majority of them being commensal flora. Normally, the body's host response and natural defence mechanisms, along with good oral care, such as brushing and flossing, can keep pathogenic bacteria under control. However, without proper oral hygiene, pathogenic bacteria can reach levels that might lead to oral infections, such as tooth decay and gum disease (Scannapieco et al., 2003). Moreover, poor oral hygiene may increase the risk of serious health problems such as heart attack, stroke, and poorly controlled diabetes (Dougall & Fiske, 2008; Persson et al., 2002; Taylor, Loesche, & Terpenning, 2000). Oral care and its link to total body health are especially important in persons living with dementia as their host response may be suppressed , and therefore they may not be able to overcome certain oral flora that are potentially harmful to both their oral and systemic health (Chen, Clark, Chen, & Naorungroj, 2015; Taylor et al., 2000).

Mouths have been said to be the window to the rest of the body, often serving as a vantage point for detecting the early signs and symptoms of systemic diseases. Systemic diseases affect or pertain to one's entire body, not just one of its parts (Noble, Scarmeas, & Papapnou, 2013). For example, a disease like diabetes often first becomes apparent as mouth lesions, ulcerations, or oral problems (Taylor et al., 2000). In fact, more than 90% of all systemic diseases produce oral problems or manifestations (Taylor et al., 2000).

Typically, saliva helps protect against oral pathogens, however with more than 500 species of bacteria in one's mouth at any given time, saliva cannot always do its job, particularly in those with reduced salivary flow (Fade & Swift, 2011; Ritchie, Joshipura, Hung, & Douglass, 2002). Existing literature reports impairment in submandibular saliva output in individuals living with dementia (Ghezzi et al., 2000). This is especially true in persons living with dementia who are on multiple medications (Kocaelli et al., 2002; Ritchie et al., 2002). Consequently, oral bacteria in the form of dental plaque, cling to the teeth surfaces more easily and are not as readily flushed away by saliva. Without routine brushing and flossing, dental plaque builds up along the gum line creating an environment for additional bacteria to accumulate in the space between the tooth and the gums. This gum infection is known as gingivitis. If left unchecked, gingivitis can lead to a more serious gingival infection known as periodontal disease (Persson et al., 2002; Scannapieco et al., 2003).

Bacteria from the mouth typically does not enter the bloodstream. However dental treatments or routine brushing and flossing can provide a portal to the bloodstream for these microbes. Medications and antibiotics can either reduce the saliva flow or disrupt the normal flora which can compromise the mouth's defences, allowing bacteria to enter the bloodstream (Haumschild & Haumschild, 2009). In an individual with an active and healthy immune system, a small amount of oral bacteria in the bloodstream is not typically problematic. However, if an immune system is weakened, oral bacteria (bacteremia) may cause an infection to develop in another part of the body. Infective endocarditis is an example of bacteria entering the bloodstream and travelling to the heart valves (MacEntee, 2011).

Prolonged active periodontal disease can also result in tooth loss, as well as other systemic conditions such as cardiovascular disease, type 2 diabetes mellitus, and osteoporosis. However, the consequences may not end there. An individual with diabetes is at an increased risk of developing gum diseases, and conversely, chronic gum disease may make diabetes more difficult to control (Taylor et al., 2000). Oral inflammation due to bacteria may also play a role in blocking arteries and forming blood clots (Persson et al., 2002). Inflammation within the mouth has been attributed to inflammation throughout the body, including arterial edema (Persson et al., 2002). Clearly, oral health is a critical concern both to monitor for manifestations of systemic disease but also to ensure the individual can maintain adequate nutrition and hydration and overall physical health. Oral health is crucial for quality of life in that it plays a role in nutrition, socialization, emotional state, daily functioning, and life satisfaction (MacEntee, 2011).

Unfortunately, frequently, oral health is not a priority in relation to other health concerns (MacEntee, Thorne, & Kazanjian, 1999). More importantly, oral problems including tooth sensitivity, toothaches, bleeding gums, dry mouth, and loose natural teeth among the dentate and loose or ill-fitting dentures among the edentate, were strongly associated with worse oral health-related quality of life (Porter et al., 2015). Oral problems and poor oral health have been shown to have a considerable impact on the quality of life and the ability of an individual to go about their daily routines (Hatipoglu et al., 2011; Locker & Slade, 1993). The impacts of oral health on one's quality of life highlight~~s~~ the importance of health promotion that is geared toward helping care partners and individuals living with dementia maintain an acceptable level of oral health and oral functioning (Porter et al., 2015). Therefore, assessing clinical oral health conditions, through tools like oral health-related quality of life, provides a holistic understanding of health, as these indices go beyond the historical disease-based clinical measures and highlight the psychological and social consequences of oral diseases (Chen et al., 2015; Locker & Slade, 1993; Porter et al., 2015).

Dementia and Oral Health

Individuals with cognitive decline or impairment may be inattentive to oral care or may have limited access to routine dental care and consequently have worse dental health (Noble et al., 2013). In the earlier stages of dementia, dental appointments and oral health instructions are frequently forgotten (Noble et al., 2013). As the dementia progresses, an individual's perception of pain may become distorted making dental pain very difficult to diagnose and treat (Kocaelli et al., 2002). Existing research also suggests that poor oral health could potentially be a precursor condition affecting cognitive impairment (Noble et al., 2013).

It has been demonstrated that individuals living with dementia have impaired oral health as a result of poor oral hygiene (Chalmers, Carter, & Spencer, 2003). Furthermore, oral diseases and conditions were present in community-dwelling adults living with dementia before entry into LTC and these oral diseases and conditions continue to occur at high levels over time while in LTC homes (Chalmers & Pearson, 2005a). Individuals living with Alzheimer's disease have more gingival plaque, bleeding, and calculus compared to age and gender-matched adults (Chalmers et al., 2003; Riberio, Costa, Ambrosano, & Garcia, 2012; Ship, 1992). There is also a notable decline in salivary gland function, particularly the submandibular salivary gland, in otherwise healthy and un-medicated adults with Alzheimer's disease (Chalmers & Pearson, 2005a). Salivary output is also reported to be impaired in individual's living with dementia who are taking multiple medications (Ship, 1992). The reduction in salivary flow negatively impacts the oral mucosa as reduced salivary flow can lead to difficulty swallowing, chewing, speaking, and oral discomfort (Delwel et al., 2017; Wu, Plassman, Liang, & Wei, 2007). In addition to its effect on daily functioning, hypo-salivation increases the risk of developing oral diseases, such as candidiasis, periodontal diseases and caries, especially in older adults living with dementia (Chalmers et al., 2003; Ghezzi et al., 2000).

There is an increased prevalence of edentulism in seniors with dementia of up to approximately 65% (Chalmers & Pearson, 2005a). For those wearing partial or complete dentures, the dentures are frequently lost, broken, or unworn (Chalmers et al., 2003). Nearly one-quarter of individuals living with dementia that own dentures do not wear them (Chalmers & Pearson, 2005a). For those that do wear them, there is a greater prevalence of denture-related oral mucosal lesions (Chalmers et al., 2003; Pearson & Chalmers, 2004). Similarly, for individuals with dementia who are dentate, the deterioration of oral care may lead to the destruction of the dentition by caries and periodontal disease (Kocaelli et al., 2002). Caries and periodontitis are two predominant causes of tooth loss that often co-occur in an individual living with dementia (Noble et al., 2013). The pattern of dental caries differs between older adults with and without dementia, with more coronal caries and retained tooth roots in individuals with dementia (Chalmers & Pearson, 2005a). Also, tooth roots are more likely to be decayed in individuals with dementia compared to older adults without (Chalmers & Pearson, 2005a). These oral changes create challenges when eating, which in turn can potentially affect swallowing and nutritional intake (Kimura et al., 2013).

Oral health and its impact on the ability to bite and chew is considered to be particularly important in seniors as it can influence their nutritional status and quality of life (Gil-Montoya, Sánchez-Lara, Barrios, Llodra, & Bravo, 2013; Sheiham et al., 2008). Intact dentition has significantly better masticatory function than removable partial or complete dentures (Ritchie et al., 2002). Edentulous individuals are particularly prone to inadequate dietary intake by ingesting too few nutrient-rich foods and consuming too many calorie-rich and high fatty foods (Ritchie et al., 2002). Studies suggest that edentulous men consume fewer fruits and vegetables while edentulous women consume higher amounts of fat than dentate women (Fade & Swift, 2011; Harding et al., 2017; Ritchie et al., 2002). Therefore, community-dwelling seniors that have retained their natural dentition confer a benefit in terms of eating and chewing ability, overall nutritional intake, and improved oral health-related quality of life (Gil-Montoya et al., 2013; Sheiham et al., 2008).

Overall, oral infections especially periodontitis may affect the course of a number of systemic diseases, such as cardiovascular disease, bacterial pneumonia, and diabetes mellitus (Kocaelli et al., 2002). Several epidemiological studies have suggested associations between heart disease and periodontitis. Epidemiological studies also show that in older adult's periodontal disease is more prevalent compared to other diseases amongst them high blood pressure and osteoarthritis (Persson et al., 2002).

Diabetes mellitus is characterized by hyperglycemia due to defects in insulin secretion, insulin action or both (Taylor et al., 2000). With advancing ageing, the likelihood of cardiovascular disease, diabetes, and dementia increase, and the risk of these diseases is further exacerbated in individuals living with dementia (Government of Canada, 2016). Substantial evidence supports considering diabetes as a risk factor for poor periodontal health (Taylor et al., 2000). There is also evidence of periodontal disease adversely affecting glycemic control in diabetes, although this has been less extensively studied (Taylor et al., 2000). This is significant, in that, a modifiable risk factor such as type 2 diabetes may not only worsen ones' cognitive health but also impose challenges to maintaining the health of one's mouth and teeth (Canadian Nurses Association, 2016)

Poor oral hygiene and periodontal disease may also be associated with other respiratory diseases such as COPD, which includes emphysema and chronic bronchitis (Scannapieco et al., 2003). In a study examining community-dwelling older adults, the analysis revealed that poor oral hygiene and smoking status are statistically associated with chronic respiratory disease (Scannapieco et al., 2003). Additionally, studies are now showing a potential association between periodontal disease and COPD (Azarpazhooh & Leake, 2006). Oral hygiene and frequent professional oral care are useful for reducing the occurrence of pneumonia among high-risk seniors living in LTC and especially those in intensive care units (ICUs) (Azarpazhooh & Leake, 2006). Medically compromised patients in hospital/ICUs or LTC, especially if they are dentate, are at risk of pneumonia, which can be mitigated/reduced by oral hygiene intervention (Azarpazhooh & Leake, 2006). One study noted that 27% of dentate patients and 19% of LTC patients developed aspiration pneumonia, in comparison to 5% of edentulous patients who developed pneumonia (Scannapieco et al., 2003).

Poor gingival and oral health have been found to increase with the severity of dementia. Therefore, dental professionals and care partners need to be vigilant with monitoring and managing daily oral care. Existing research typically investigates how individuals living with dementia in LTC can improve daily oral care through the support and intervention of nursing staff. As the dementia progresses, individuals living with dementia often become dependent on care partners for additional support (Chalmers et al., 2003; Ghezzi et al., 2000). However, oral care may be given low priority due to limited knowledge about the importance and implications of oral hygiene on general health (MacEntee et al., 1999).

Role of Dental Professionals

Although the need for dental care among seniors is greater than for the general population, their use of dental services is less. Utilization statistics vary considerably among studies because of differing eligibility criteria of study participants, but all are low (Fereshtehnejada et al., 2017). One positive trend is that the proportion of Canadian seniors reporting an annual dental visit has increased significantly from 60.3% in 2001 to over 75% in 2012 (Canadian Dental Association, 2009). Current literature indicates that older adult patients presenting to a dental practice may have undiagnosed dementia, which brings to bear considerable practice implications for dental professionals. For example, Ghezzi et al. (2000), found that some patients with dementia who presented to a dental office had never undergone a cognitive diagnostic evaluation. Patients in this cohort may not even self-identify as having dementia (Ghezzi et al., 2000). Individuals living with dementia and their family members or care partners may not recognize their oral health deficits which may lead them to believe that any oral or dental changes are a normal part of the ageing process. Ideally, if a patient presents at a dental clinic with potential signs and symptoms of cognitive decline, a medical consultation should be suggested. Dental professionals therefore should be adequately trained and educated to recognize the signs and symptoms associated with dementia (Chiappelli et al., 2006).

However, for individuals that are aware of their dementia diagnosis, management and treatment of these patients can be challenging for the dental professional (Ghezzi et al., 2000). Dental professionals face challenges with verbal communication as patients may not be able to express how they feel, if they have pain, and/or may be unable to identify the cause of the pain (Chiappelli et al., 2006). This means that dental providers must rely on the knowledge, history, and interpretations of family members or care partners of the individual living with dementia to provide adequate dental and medical histories (Adegbembo, Leake, Main, Lawrence, & Chipman, 2002; Chiappelli et al., 2006; Ghezzi et al., 2000; Warren, Chalmers, Levy, Blanco, & Ettinger, 1997). The need to rely on care partners for dental and medical history information for the ILD is of particular importance because dental professionals are responsible for keeping up-to-date medical and medication records for these patients to avoid any possible complications during a dental appointment (Kocaelli et al., 2002).

Conducting a comprehensive dental assessment on an individual living with dementia is essential to be able to provide appropriate oral health interventions in a safe environment. Developing and fostering rapport with an individual living with dementia and their family and/or care partners can allow dental treatment plans to be established together, which will ease possible tension and anxiety around the dental experience for the practitioner, patient, and their care partners (Kocaelli et al., 2002). Studies report that family members and care partners feel considerably reassured when the dental professional treating the patient living with dementia is aware of and able to manage typical problems associated with the diagnosis of dementia and is familiar with signs and symptoms associated with it. (Chiappelli et al., 2006; Kocaelli et al., 2002; Sugimura et al., 2015). Additionally, the dental professional has an important role in ensuring that informal care partners are able to complete daily oral care tasks for their dependent loved ones or at least provide them with the knowledge and resources to seek assistance if required (Kocaelli et al., 2002).

A comprehensive team approach to a patient's dental treatment plan can help ensure the desires, the needs, and the safety of the individual living with dementia are met. Collaborative and interdisciplinary methods with other health care professions can help to ensure the best outcome for patients living with dementia (Warren et al., 1997, Dougall, 2008 #21). Ideally, these qualities encompass the patient-centred care model of practice in dental healthcare, which is essentially caring for patients and their families in a way that is meaningful and valuable to that patient (Edvardsson & Innes, 2010; Sloane et al., 2013). The key focus of person or patient-centred care is respecting the individual living with dementia (Edvardsson & Innes, 2010; Kitwood, 1997). The benefit of this approach is giving a voice to a person living with dementia, as well as looking at their health from a holistic standpoint of view (Edvardsson & Innes, 2010; Wilkinson, 2002). Perhaps of utmost importance is the role of the dental professional in advocating that patients with dementia access care early in their dementia diagnosis, so as any outstanding dental treatment can be completed prior to the progression of the dementia. This involves the completion of any outstanding dental treatment prior to the progression of dementia into its later stages (Hatipoglu et al., 2011).

Barriers to Oral Self-Care Practices

To avoid oral and dental infections, proper daily removal of plaque biofilm and regular dental and dental hygiene appointments are essential (Willumsen, Karlsen, Naess, & Bjorntvedt, 2012). However, for individuals living with dementia, adequate daily oral care presents several barriers to ideal daily oral self-care. These barriers may include cost, care partner support and availability, geographic location, local transportation services, time considerations, and experience of the dental team (Adam & Preston, 2006; Goins, Williams, Carter, Spencer, & Soloviena, 2005). Those living within rural community settings encounter larger barriers with regards to transportation difficulties, lack of quality healthcare, social isolation, and financial constraints (Goins et al., 2005). As discussed, the consequences of poor oral care are severe and include an increase in health care costs, reduced residents' quality of life, and elevated risk of malnutrition, aspiration pneumonia, atherosclerosis, and premature death (Mlinac & Feng, 2016). Impacts of poor oral health also include psychological and social consequences, amongst them altered self-image and self-esteem, halitosis, and change in dental aesthetics (Chalmers et al., 2003; Dougall & Fiske, 2008).

While the negative outcomes of poor oral care are well-known, the presence of a large number of decayed teeth and the presence of periodontal disease does not necessarily mean that an individual will seek dental care (Kiyak & Reichmuth, 2005). Poor systemic health paired with multiple chronic conditions can actually prevent one from obtaining dental care, especially in seniors who make frequent medical visits and are taking multiple medications (Kiyak & Reichmuth, 2005). This may be attributed to the time, energy, and impact on ADLs associated with the chronic condition (Kiyak & Reichmuth, 2005). Regardless of the history of dental service use prior to having dementia, the more ADL limitations seniors report, the less likely they are to seek dental care (Kiyak & Reichmuth, 2005). Seniors also accept chronic disease as an inevitable and normal part of ageing (Kiyak & Reichmuth, 2005). The acceptance of natural ageing includes the misconceptions surrounding poor oral health such as living without natural dentition or ill-fitting dentures, or even the existence of oral pain from caries. Many seniors will attribute these dental problems to ageing and therefore not seek dental care (Kiyak & Reichmuth, 2005).

Individuals living with dementia are sometimes unable to express their wishes or make rational decisions regarding their oral care. Consequently, treatment priorities are often guided by the care partner and dental team (Compilation, 2006). One study reported families and care partners priorities for their loved ones were centred around social behaviours and communication, including aesthetics, speech and halitosis (Compilation, 2006). Another study reported 96% of care partners considered oral care to be important, but most were reluctant to use dental services for their loved one as they perceived the dental team to be ill-equipped to deal with individuals living with dementia (Whittle, Sarll, Grant, & Worthington, 1988). Additionally, some care partners questioned the dentist’s expertise and ability to manage an appointment with an individual living with dementia, who may show signs of resistant behaviours. Therefore care partners typically avoided scheduling dental appointments for the ILD (Goins et al., 2005). Care partners believed lack of dental professionals’ expertise in caring for ILD to be the greatest barrier to accessing dental care for their loved ones (Goins et al., 2005). Further substantiating barriers related to access to professional oral health care for ILDs, a study by Kiyak and Reichmuth (2005) reported dentists’ negative views on ageing, limited disability training, and a lack of understanding and awareness surrounding the limitations and effects of dementia that can hinder care partners' comfort in seeking dental care for their loved one. Care partners also indicated that ILDs who had a past fear of dental care was an important factor that influenced the care partners' decision as to whether or not they would access dental care for their loved one (Kiyak & Reichmuth, 2005). It is understandable that for these reasons care partners are hesitant about taking their loved ones to see a dental professional. However, this also signifies how care partners' attitudes towards the provision of oral care can act as a barrier for their loved one to receive proper dental attention.

Despite the number of literature sources discussing the need and treatment planning of oral care for individuals living with dementia, professional barriers to care still exist (Compilation, 2006). One study found that dentists had much lower expectations than nursing and care partners regarding the importance of various aspects of oral care in people with cognitive impairment (Nordenram, Ryd-kjellen, Ericsson, & Winbald, 1997). In addition, there are issues surrounding the principles of obtaining consent prior to dental treatment, the ability to address poor compliance with daily oral care and accessing appropriate training for all dental professionals (Compilation, 2006; Dougall & Fiske, 2008). The ability of the dental professional to determine and deliver realistic dental treatment while balancing cognitive and physical impairment could potentially be limited, and thus reducing access to appropriate care (Kiyak & Reichmuth, 2005).

Many seniors experience limited access to health care, including dental health care. Seniors living in the community and who have a dementia diagnosis have even more barriers to overcome. For example, accessing dental services, the delivery of dental care, and the development of a realistic treatment goal for individuals living with dementia needs to be flexible and be able to adapt to take into account each individual person's needs, medical status, current stage of dementia, as well as their family's needs (Dougall & Fiske, 2008). Much of the existing literature on health care access focuses on the availability of services, and consequently, there is a paucity of research exploring factors such as needs (Goins et al., 2005). Thus, research is necessary to better understand the diverse experiences of accessing dental care within a community-dwelling senior population living with dementia (Compilation, 2006; Goins et al., 2005).

Summary

Poor oral health, including periodontitis, caries, edentulism, and infrequent dental hygiene care, are more prevalent in seniors living with dementia (Chen et al., 2013; Noble et al., 2013). Existing literature in regards to oral health for individuals living with dementia are predominantly prevalence studies of oral diseases or situated in the context of long-term care homes (Ellefsen et al., 2008; Pearson & Chalmers, 2004). The perspectives of individuals living with dementia and their primary care partners and/or family members have not been adequately explored (Karlsson et al., 2015; Wilkinson, 2002).

Due to the implications of poor oral health on total body health, especially in persons living with dementia, and the current gaps in the literature, the goal of my study was to address current practice and concerns of oral self-care from community-dwelling seniors living with dementia. The aim is to improve the oral health of the ageing population and contribute to the overall understanding of the specific needs of patients with dementia, as well as their care partners, which will hopefully translate into improved resources to optimize oral health service provision. This outcome has the potential to lead to less morbidity and better quality of life for individuals with dementia living in the community. Additionally, my study will contribute further knowledge to the methodological understanding of how best to include older adults with dementia in research.

Chapter Three

Methodology

In this chapter, I will outline the main research question that guided the selection of a qualitative research method in this study. I describe the strategies I used for sample recruitment, data collection, and data analysis. Lastly, I will discuss ethical considerations and the approach I used to ensure rigour of my study.

Research Purpose

The purpose of this exploratory qualitative study was to identify practices, including tasks and processes, of daily oral care from the perspective of the individuals living with dementia (ILDs) and their care partners (CPs). I was particularly interested in identifying any prevalent oral health concerns, perceived accessibility issues of community dental clinics, and possible barriers to daily and routine oral care. The main research question guiding the study was: what are the oral health practices and concerns among community-dwelling individuals living with dementia and their care partners?

Methods

As little is known about the specifics of oral care practices of community-dwelling individuals living with dementia, a qualitative approach was appropriate because it allowed me to freely explore my topic of interest. I needed a method that would allow me to follow interesting leads and to understand the emic perspective of my participants, rather than being restrained by a rigid theoretical or data collection structure. I needed an approach that would be flexible and allow me to probe and inquire into people's normal daily practices. Qualitative methods, in which the researcher engages in conversation and people relay stories explaining how they do things, are valuable. Additionally, I did not assume a theoretical framework for this study. The advantage of this methodological decision was that it helped me to enter the research field inductively, which was important in conducting a broad exploratory study (Loiselle & Profetto-McGrath, 2007). I also wanted a way to help people encourage each other's recall and to stimulate thinking when listening to someone else's experiences. I felt this interaction would enhance the richness of the data and therefore I used a focus group method.

The vast majority of the studies in the area of oral health and dementia are primarily prevalence studies of oral disease (Ellefsen et al., 2008; Hatipoglu et al., 2011; Matthews et al., 2012; Philip, Rogers, Kruger, & Tennant, 2012). There is a need to research descriptive experiences from the perspective of individuals living with dementia and their families to create a richer understanding surrounding oral health in this population. Moreover, as the nature of the research question did not require the quantification of data, qualitative inquiry, as a naturalistic approach, allowed me to explore, interpret, and obtain a deeper understanding of the phenomenon of interest within a community context (Richards & Morse, 2007).

Exploratory qualitative inquiry. A key to conducting an exploratory qualitative study is the willingness to change directions as a result of new insights gathered from the data (Braun & Clarke, 2013). Typically, with this form of inquiry, a researcher has an idea or has observed something and seeks to understand more about it. Exploratory research is ideal for defining and clarifying a problem (Richards & Morse, 2007).

Focus group (FG). Focus group is a research strategy developed in the late 1930s and used by social scientists to investigate alternative ways of conducting interviews (Krueger & Casey, 2015). In the 1950's, market researchers embraced this technique as a method to discover how to make their company's products more attractive to consumers (Krueger & Casey, 2015). Focus groups are considered to be an effective, time-efficient way of collecting specific and well-delineated information (Morgan, 1996). A FG is a special type of group in terms of purpose, size, composition, and procedures. The purpose of conducting a FG is to better understand how people feel or think about an issue, idea, product, or service (Krueger & Casey, 2015). Participants are selected because they have certain characteristics in common that relate to the topic of the focus group. The researchers create a permissive environment that encourages participants to share perceptions and points of view without pressuring participants to reach consensus (Krueger & Casey, 2015). Additionally, this exploratory strategy allows the researcher to take a less directive and dominating role by placing considerable emphasis on understanding the reality and perspectives of the interviewees. This method works when participants feel comfortable, respected, and free to give opinions without worry of judgment. The ultimate intent is to promote self-disclosure, which comes easily for some but is more difficult for others requiring trust, effort, and courage (Krueger & Casey, 2015).

The ability to generate data is based on the assumption that the synergistic effect of interactions within the group will enhance the quality of data (Jamieson & Williams, 2003). An example of this synergistic effect occurred during one of my focus group sessions, where a CP participant had assumptions about her husband’s oral care practices. This CP participant was adamant that her husband was completely independent in all activities of daily living, claiming that even after he was diagnosed with dementia, his oral care practices did not change. However, as discussions amongst other participants continued around the use of dental floss, this CP participant realized that she had not purchased this product for a while, and at that moment in the focus group session she gathered that her assumptions about her husband’s oral care practices might be wrong:

> CP 17: He claims to floss but the floss I haven't had to buy for quite a few weeks, so right this minute I just am realizing that he's probably not flossing and I haven't really noticed that till right now…

The use of focus groups to explore the views and experiences of people with dementia has received little attention. Literature suggests that focus group sessions are an especially appropriate qualitative research method for people with limited power and influence, such as those living with dementia. (Wilkinson, 2002). Focus groups hold potential advantages that include: increased control over level of participation since there is less pressure to contribute than in an individual interview; increased sense of support or empowerment for participants in a group with others who share similar experiences/diagnoses; enhanced quality and quantity of interaction in a group context, and; increased access to memories outside the current context, since sharing experiences might trigger recall of similar events or feelings (Wilkinson, 2002).

Situating the study. This study was conducted at the Alzheimer Society of Alberta & Northwest Territories office located in Edmonton, Alberta. Data were collected between July 2016 and September 2016.

Sample

The inclusion criteria for ILD participants to partake in the study included a diagnosis of early dementia made by a physician, being a fluent speaker of English, living at a personal place of residence (not long-term care), and obtaining a Montreal Cognitive Assessment (MoCA) score of 26 and lower. Cognitive assessments (MoCA 7.1 Original Version) were administered by Dr. Minn Yoon and me to potential ILD participants to verify the level of cognitive function was within the early stage ranges of dementia, as suggested by the MoCA assessment tool (Memoria, Yassuda, Nakano, & Forlenza, 2013). Inclusion criteria for CP participants were: the primary care partner of the individual living with dementia and being a fluent speaker of English.

We purposively recruited a total of twenty-nine CP and ILD participants to participate in this study (N=20 CPs; N= 9 ILDs). Purposive sampling is a mode of selecting participants on the basis that they have certain characteristics which will provide information-rich data to analyze (Braun & Clarke, 2013). According to Alzheimer Society of Alberta & Northwest Territories (ASANT) dementia classifications, the ILD participants selected for this study had either young-onset dementia or early-stage dementia. Young-onset dementia refers to a diagnosis of dementia before the age of 65 years. Early-stage dementia, commonly known as mild dementia, is designated when a physician has diagnosed an individual with cognitive decline in memory and thinking in conjunction with ASANT employees selecting the support group that aligns best with the individual's current health status and needs. Employees of ASANT made the final decision of support group placement and dementia category after a few questions are considered. Some examples of ASANT assessment questions include: Is the ILD contributing and/or following the conversation? Is the ILD speaking about the here and now or only reminiscing? Is the ILD bored in the group or are they enjoying it? Is the ILD repetitive in their discussion and conversation or are they able to change topics of conversation? These selected groups were dynamic, meaning that individuals living with dementia transition between them if ASANT employees re-examine the questions above and note significant changes.

Upon reviewing the literature regarding the use of focus groups on persons living with dementia, sample sizes in existing research vary greatly, however, most studies include 20 to 30 participants. For example, (Sutcliffe, Roe, Jasper, Jolley, & Challis, 2015) used a total of three focus groups with 6 to 10 participants each comprised of both carers and individuals living with dementia for a total of 27 participants. For the current study, we considered the recommendations within existing literature to help approximate initial sampling. Most importantly, we recognized the importance of having heterogeneity between the individual focus groups to help capture different stages of dementia diagnosis. This included focus groups of ILDs with young-onset dementia and early-stage dementia and their CPs, and also a group of CPs who cared for ILDs within the respite ASANT dementia classification. We achieved analytic saturation after completion of five focus groups, which included 29 participants. Analytical redundancy or saturation occurred when no new categories emerged in an ongoing focus group, and we were certain all dimensions of our categories were richly described (Morse, 2015a, 2015b).

Participant recruitment. Recruiting the study participants began two months prior to the actual data collection phase. Dr. Minn Yoon and I met with the manager of Alzheimer Society to explain the study and obtain feedback on feasibility and logistics. Study participants were recruited through the partnership with ASANT. This organization provided study information sheets to members attending monthly support group sessions (Appendix A, Appendix B). Caution was exercised in recruiting the participants due to the vulnerability of individuals living with dementia. Coordinators at ASANTs identified individuals who might be suitable and interested in participating by extending invitations via telephone calls and emails. When participants expressed an interest in the study, the organization passed their contact information to the research team. I then contacted each potential participant and primary care partner via email or telephone and provided additional information regarding the FG sessions. We faced some obstacles in reaching the potential participants and finding a common time to run each focus group, due to busy schedules of some working care partners and having limitations on transportation (i.e. no longer holds an active driver’s license).

Individuals living with dementia (ILD) participant characteristics. The ILDs who participated in the FG sessions ranged in age from 51 to 79 years old. The respite CP participants reported their loved ones, who did not participate in the FGs, ranged in age up to 90 years. A FG with ILDs from the respite CP group was not held, and therefore CP participants reported information about their loved ones. ILD participant's ages were not of primary significance; however, our analysis indicated generation might be linked to oral care practices as well as current medical conditions that could affect oral hygiene. The ILD participants consisted of six males and three females (Table 1). All of the ILD participants identified their spouses as their primary care partners.

Table 1

Focus Group Participant Gender Breakdown

Sample	Focus Group	Male Participants	Female Participants
CPs	Respite CP 1	2	5
	Early-stage CP 2*	2	5
	Young-onset CP 3#	1	5
ILDs	Early-stage ILD 1*	4	2
	Young-onset ILD 2#	2	1

Note. *, # separate yet simultaneous focus group sessions

Seven ILD participants retained their natural dentition, one ILD was partially edentulous with some additional prosthesis such as complete or partial dentures, and one ILD was fully edentulous and wore a complete upper and lower denture. Seventeen CP participants reported that their ILD routinely utilized professional dental services, with the remaining three only going to a dental clinic if symptoms from the oral cavity developed. Of the seventeen routine dental care users, thirteen had a personal dental clinic within the community, whereas the remaining four sought treatment at either the University of Alberta Dental Clinic or the Glenrose Rehabilitation Hospital Dental Clinic. We defined routine users as those who sought professional mouth care at least once annually.

Care partner (CP) participant characteristics. The CP participants were caregivers for ILD in both young-onset and early-stage dementia groups as well as a respite dementia group. The respite dementia group consisted of CP participants whose loved one was no longer in the early-stage of dementia and who could not be left alone at home when care partners attended support group meetings at the Alzheimer Society in Edmonton. Therefore, reprieve care of the ILD was provided to allow care partners to partake in support group meetings. Of the twenty CP participants, fifteen were female, seventeen were spouses to an ILD and three were a child of an ILD. In the young-onset CP focus group, all six of the participants either worked full-time or part-time. The employment status of the respite and early-stage dementia categories were not collected as it was later incorporated into the focus group questions.

Data Collection

We collected experiential and observational data through three CP participant focus groups and two ILD participant focus groups. We conducted FG interviews using a semi-structured interview guide. We developed the interview guide based on current literature and research, professional experience, and by consulting with a speech-language pathologist, who has experience in qualitative research with individuals living with dementia and who assisted in finalizing sentence structure (Appendix C). Semi-structured interview guides are a qualitative method of inquiry that combines a predetermined set of open questions with the opportunity for the researcher to explore particular responses further (Jamieson & Williams, 2003). A semi-structured interview guide does not limit participants to a set of predetermined answers; rather it allows them to discuss and raise issues that the researcher may not have considered (Krueger & Casey, 2015). An example of an open-ended question that I posed during the FG session was, “Describe how you typically care for your teeth?” Accompanying these broad questions, I prepared a few follow-up prompt questions to elicit further discussion and enrich the depth of participant responses. An example of a prompt question was, “Are there particular steps that are difficult in daily oral care?” Previous literature was considered in helping to make the interview questions concise and coherent. As we learnt more, we fine-tuned the wording of the questions to reflect our new understanding and what we needed to explore further. The protocol that guided the FG meetings were similar in both ILD sessions and CP sessions. To respect the privacy of the participants and maintain confidentiality, participants were assigned a code number to be used in place of their real names, which are used in presenting data from this study.

Research setting. All FG sessions took place at the Alzheimer Society of Alberta & Northwest Territories office. This facility was chosen for the study as all participants attend monthly support group meetings at this location. The facility typically runs an informational session for care partners in a boardroom-style office, while the individuals living with dementia complete memory activities and games in a cosier family-style room. This location was chosen because it was already familiar and comfortable for ILD and CP participants. Additionally, the boardroom provided seating arrangements for CP participants and was convenient for audio and video recording of the sessions. It was important that ILD participant focus groups were in a setting that was familiar to participants, to help them feel safe and comfortable to encourage their ease in speaking about their oral care practices and to help mitigate confusion that could come from being in an unfamiliar setting. While all FG interactions took place without conflict, participants sometimes held opposing views regarding the same topics. The differences expressed enhanced the richness of our data and analysis while the moderators played an important role in facilitating these interactions.

Focus group facilitators. I was the primary facilitator for three of the five focus groups, in that I asked the semi-structured interview questions. The three FGs that I conducted included the respite CP participant group and both ILD participant groups. Dr. Minn Yoon supported me in all three FGs by adding in questions and comments where more probing was required. Dr. Yoon also took down observational notes throughout the 90-minute FG sessions. Dr. Yoon has facilitated numerous focus groups sessions and is very familiar with the participant population. I have worked closely, both professionally and through voluntary efforts, with the populations of interest, therefore I was able to use this knowledge while conducting each session. Since FG sessions were held separately yet simultaneously (Table 1), I required assistance for the remaining two CP participant focus groups. Ms. Carla Ickert, a sociologist and research assistant, was the primary facilitator for both the early-stage CP participants and young-onset CP participants focus group meetings. She worked alongside Ms. Arlynn Brodie and Ms. Alix Clarke, who are registered dental hygienists who were present during the FG interviews to assist Ms. Ickert with any oral health comments that might need to be further explored or elaborated.

Assessing Cognitive Impairment. A validated tool for assessing cognitive dysfunction is the Montreal Cognitive Assessment tool (MoCA). In the current study, this tool was administered to help determine the ILD participants level of cognitive impairment.

Mild cognitive impairment (MCI) is an intermediate clinical state between normal cognitive ageing and dementia. Although several screening instruments are available for detecting dementia, the Mini-Mental State Examination (MMSE) is the most widely used by frontline physicians (Nasreddine et al., 2005). Most individuals meeting clinical criteria for MCI score above 26 on the MMSE, which is also the range for normal elderly individuals. Physicians are left with no clearly accepted and easily administered tool to evaluate MCI. To address this problem, the Montreal Cognitive Assessment (MoCA) was developed as a tool to screen individuals who present with mild cognitive complaints and usually perform in the normal range on the MMSE.

The MoCA is designed to rapidly screen for mild cognitive dysfunction (Appendix D). It assesses various cognitive domains including attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculation, and orientation (Memoria et al., 2013). I administered this assessment to seven of the nine ILD participants, Dr. Yoon completed one assessment, and one participant declined to participate in this screening. I invited the ILD participant into a private room and each assessment took roughly ten minutes to complete. The total possible score was 30 points. A score of 26 or higher indicated normal cognitive function. I tallied the MoCA scores and the results produced a range between 12 to 26 (Table 2). One male young-onset ILD participant scored 26 out of a total of 30 points. However, after the FG session, his wife revealed that he would find similar screening tools online and complete them daily so that he could present better in front of clinicians. Including the male participant noted above, a total of three ILD participants were assessed as having a mild cognitive impairment (MCI) whereas the remaining five ILD participants scored lower than 22 indicating dementia.

Table 2

MoCA Scores of ILD Participants

ILD #	MoCA Score	M/F
01	13/30	M
02	12/30	F
03	21/30	M
04	22/30	F
05	REFUSED	M
06	19/30	M
07	23/30	M
08	26/30	M
09	16/30	F

Audio/video data. Each FG was both audio and video recorded after receiving consent or assent from all participants. We used video recording to help capture participants' body language and comments and to provide a backup for the audio recording (Krueger & Casey, 2015). Prior to the FG sessions, one stationary video camera was mounted on a tripod in each room.

Facilitators had nametags for participants which made communication throughout FG sessions much easier to follow and allowed for clarifying any disputes in recordings. Our original intent was to provide dental tools as prompts (i.e. toothbrushes and interdental aids) for the discussion; however, we found that some participants decided to provide physical oral care demonstrations. We encouraged the participants to fully describe their own or their family member's routines, practices, and concerns about oral care. As the sessions progressed, we deliberately focused on key points that stood out in the discussions and asked for further elaboration. This allowed for refinement of the concepts under study and breadth of details required to formulate codes into categories. Finally, we used questions such as, "Is there anything else you would like to share with us?" at the end of our interview to give participants the opportunity to add in their final thoughts and bring the conversation to a close. Participants in the ILD and CP focus groups gave general thanks for the session and mentioned how they found it to be an interesting experience:

CP 14: Well, I learned a lot. I don't know if I like everything that I heard. [Laughter]
CP 08: I found it very interesting

Other CP participants from the young-onset focus groups made comments around being more vigilant with their loved one's oral care by monitoring the use of dental tools:

CP 17: We're all going home to monitor the floss now. [Laughter]
CP 15: Exactly.

Whereas in the ILD participant focus group comments about the structure of the focus group enforced the need for more focus group methods to be used in working with vulnerable populations such as individuals living with dementia:

Interviewer 2: Do you have any questions for Nadia and I or concerns that you'd like to share?
ILD 08: No. Just that I found this very not stressful.
ILD 07: Yeah.
ILD 08: It was very relaxed. So it was easy.
ILD 07: Like how many groups do you get in asking these questions, that you've heard that much laughter. As we've had this evening.

Reactivity, also known as the observer effect, takes place when the act of conducting research changes the behaviours of the participants, thereby possibly distorting or undermining the quality of the data (Paterson, 1994). This is potentially present in any research activity but is considered more likely in the presence of a video camera. Throughout data analysis, I looked for indicators of reactivity such as participants orientation to the camera or unusual changes in emotional valence during the FG sessions (Paterson, 1994). However, there were no explicit instances in our video data. Similarly, studies have mentioned that reactivity is often exaggerated and that within a short period of time of the FG starting the camera is rarely noticed (Jewitt, 2012).

Field notes. I recorded observational notes of the process and the content, in particular, noting any information that would help us remember and interpret the intent of the conversation. This was also completed by the second facilitator in the FG sessions. In the field notes, I included reflections on how the FG felt during its facilitation, observations of participants that might offer additional insight into their data, and some main ideas that emerged. After the FG session ended, I then elaborated on some of the notes that I had already taken and added additional thoughts to assist in the analysis process. According to (Mayan, 2009), a researcher cannot take down everything, but the words chosen to describe the setting are already a representation and interpretation of what was actually happening.

Memos. Memoing is a process of recording analytic insight that provides more depth and complexity than codes (Braun & Clarke, 2013). As I continued to go through data collection and analysis, I started writing memos, which were reflections of what I was seeing and struggling to understand. I used memos to describe ideas, for reflexivity, and to note moments of confusion. Since I am a practicing registered dental hygienist, my reflections throughout the research journey were a way to understand how my professional assumptions and values were influencing my data analysis.

Data Analysis

The five FG sessions that were conducted in-person with audio and video recordings were transcribed verbatim by a professional transcriptionist. I then reviewed the transcripts while listening to the audio recordings to ensure the accuracy of transcripts and to address any discrepancies the professional transcriptionist may have been uncertain about. Para-speech characteristics such as repetitions, incoherent or incomplete utterances were included. Once all the transcripts had been reviewed, notations regarding behavioural changes and body language were made to the transcript margins while watching the video recordings.

To assist in early phases of data analysis, I attended bi-weekly meetings with my supervisors to discuss ideas and concepts that might be reflected in the codes, categories, and how categories and concepts might be related to each other. Data was collected and analyzed through a recursive process which helped identify emerging themes. Transcripts were always concurrently examined while listening to audio or watching the video recording of the FG sessions, in order to fully comprehend and understand the contextual nature of the data.

Content analysis. Content analysis is a research method for making replicable and valid inferences from data with the purpose of providing knowledge, representing facts, creating new insights and a practical guide to action (Elo & Kyngas, 2008). Content analysis has an established position in nursing and health research and offers several major benefits such as flexibility in research design and content sensitivity (Elo & Kyngas, 2008). Content analysis is particularly suitable to our study because it is person-centred and allows for an open starting point (Holloway & Todres, 2003) to examine behaviours, practices, and attitudes of our participants (Vaismoradi, Turunen, & Bondas, 2013).

This form of analysis is essentially a set of techniques used to analyze textual data and reveal themes (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Its main characteristic is the systematic process of coding, examining the meaning and establishing descriptions of social reality through the creation of themes. Qualitative content analysis is suitable when viewing the data as its implied interpretations. Thus, the focus is on the explicit description of the content of communication in our FG sessions (Vaismoradi et al., 2016).

Content analysis approach may range from summarizing and quantifying to a more interpretative approach. I used the content analysis approach suggested by Vaismoradi (Vaismoradi et al., 2013). I read and re-read the transcripts labelling anything that looked relevant. This could include a word, phrase, stories, interaction with other participants, behaviours, or anything else that emerged. As I continued to read the transcripts, I started to consider code labels. The kinds of codes I included were: in vivo, descriptive, and conceptual codes. An in vivo code means that exact word or terms used by the interviewees were taken as codes (Braun & Clarke, 2013). One such example was when CP 19 was validating her loved one's oral hygiene practices by stating she was a "creature of habit." These exact words used by the CP participant then became the code I used. A descriptive code summarizes the basic topic of a passage from transcript data in either a word or short phrase (Braun & Clarke, 2013). An example from the ILD focus group was when we were discussing whether or not their dementia diagnosis was disclosed to their dental providers. ILD 08 told us that his dental practitioners were kept in the dark about his medical diagnosis, but that his family doctor was aware and up-to-date about his health:

> ILD 08: My dentist doesn't know. My doctor knows, but the girl that cleans my teeth doesn't know. Because I can – unless you know me, you wouldn't know I have some issues.

This passage was summarized into a descriptive code we labelled "keeping dental professionals in the dark." Lastly, a conceptual code is when we move towards a more general and higher-level of abstractions (Vaismoradi et al., 2016). This information allowed us to formulate conceptual codes. Conceptual codes were then utilized to develop potential implications of this research for dental hygiene practice. As I re-read the transcripts, I compared codes and began to make decisions to collapse the codes into larger categories. I began to draw a diagram of a model and started placing these larger categories into an interwoven theme. This allowed me to enhance my level of understanding and concurrently develop higher levels of abstraction as data collection and analysis progressed. For example, within our early-stage CP participant focus group, CP 08 spoke to us about how she attempts to keep her husband living independently by using strategies suggested by their doctor. Therefore, autonomy emerged as my conceptual code:

> CP 08: So maybe once they start to forget to do the oral care, doing something as simple as that, not having to remind your wife, but being able to write down the steps that she could then maybe read and still be independent, but you're helping by sort of nudging it a bit.

In our initial descriptive coding, we looked primarily at practices and examined who could perform daily oral self-care. Once this was established, we probed to understand what was being done, how this task was being completed, and how frequently it was occurring. This was when we discovered that these daily oral practices are linked to the ILDs level of independence. While these terms were not blatantly stated in the FG sessions, care partners would allude to varying levels of assistance the ILDs would require.

Ethical Considerations

We obtained ethics approval from the University of Alberta Review Ethics Board prior to the start of the project (HREB PRO number 0006023: Appendix E). We worked with the Alzheimer Society of Alberta & the Northwest Territories to recruit and collect data. We informed participants about the voluntary nature of their participation and provided the ASANT office with additional information sheets to participants who seemed interested. Participants were free to leave the focus group at any time or refuse to answer any questions they found disagreeable, however, no participants did so.

For ILD participants, we obtained written consent from their care partners prior to their participation in the focus group session (Appendix F). Verbal assent was also obtained individually from ILD participants prior to beginning focus group sessions. Care partners provided written consent for themselves. The known risks of this study were that it would take approximately 90-minutes for both the individual living with dementia and the care partner. Some individuals might have felt uncomfortable sharing their experience in a group with others they were unfamiliar with. It was evident from the participants' behaviours that some individuals were more reserved, however, as the FG continued, people relaxed and there did not appear to be any reluctance to participate. In fact, one CP participant was quite verbal in describing her dismay with what she had to do for her spouse's daily oral care routine, which we took as an indicator that people were willing to disclose personal activities of daily living. CP 16 spoke candidly stating:

> CP 16: So I clean it out as good as I can, and it really bothers me doing it. Like he's got his tongue going, pushing things out of the way all the time…I find him very frustrating, but I do it, so it's getting easier for me because I've sort of built up my tolerance.

I informed participants that there were no direct benefits but they would contribute to a body of knowledge geared towards improving oral care for adults living in the community that have dementia and that by providing their opinions they might help guide the development of future research. Following each focus group, a number of participants said they learnt a lot from the session and that they wished they had information about how to care for their loved one's oral health prior to the dementia diagnosis.

CP and ILD participants received a twenty-five-dollar gift card for taking part in the focus group. Additionally, individuals living with dementia received soft-bristled toothbrushes during focus group sessions. Hard copies of research materials were kept in a secure and locked place at the university campus. All electronic files were stored on an encrypted computer. After five years, all data will be destroyed using the University of Alberta confidential information services.

Rigour

Rigour, or the reliability and validity of the study is used to make evaluations of the worthiness, strengths and limitations of the research, and to help potential researchers determine if the findings are credible and useful (Mayan, 2009). The usefulness of a qualitative study is reflected in trustworthiness. Trustworthiness is maintained by Guba and Lincoln's (1985) framework of credibility, transferability, confirmability, dependability, and neutrality for assessing the quality of our research.

Credibility. Credibility refers to a study that is believable to critical readers and to the researchers who gathered the information (Lincoln & Guba, 1986). It assesses whether the findings make sense and if they are an accurate representation of the participants and data (Mayan, 2009). In order to meet this criterion, open-ended questions and probing questions were asked to not only encourage frank responses from the participants but to elicit detailed information and probe into unexplored areas. Reflexivity is a fundamental dimension of establishing credibility. Reflexivity is a critical research tool for interpreting data and drawing conclusions and is facilitated through memos. Reflexivity in qualitative research refers to the notion that the researcher is the research instrument (Braun & Clarke, 2013). Therefore, the researcher's ability to reflect on how their actions, positions, and viewpoints influence how the data is collected, what data is collected, and how data is analyzed is really important.

Another aspect of reflexivity is recognizing that as a dental hygienist, I entered into the research with assumptions and values through virtue of my practice. Our research team held debriefing meetings to challenge my assumptions and to help me consider alternative interpretations of the data. This form of analyst triangulation provided a check on selective perceptions and illuminated blind spots that I may have missed. Credibility in the context of this study means that my goal was to understand and represent my participant's perspectives and worldviews. My supervisors helped me shift from the mindset of an RDH working in geriatrics to view my collected research through an emic perspective. By peer debriefing with my supervisors, they were able to help me uncover biases and assumptions I had, but this was also an opportunity for catharsis. This was accomplished by open-ended questions, good facilitation, audio, and video recordings so that I could refer back to an accurate record of what was said and how it was said. Additionally, these biases were diminished by carefully reading and re-reading the transcripts with numerous rounds of coding, as concepts emerged. Triangulation of sources from perspectives of both ILD and CP participants allowed us to compare participants' differing viewpoints. We assured the accuracy of data collection by audio and video recording each session. The data was transcribed by a professional but was reviewed by the researcher in conjunction with the recordings to help ensure accuracy in the documentation of the transcripts.

Transferability. Transferability refers to the applicability of the findings to other settings, which readers can assess this through my provision of detailed thick description of the setting and participants (Mayan, 2009). Detailed accounts of methods, findings, and discussions provide information about the researcher, context, participants, and research process to help readers to decide whether our findings could be relevant to other settings and jurisdictions. In other words, provision of information ensures the accounts of our study and potential studies where our findings may be transferable.

Confirmability. Confirmability is used during the data collection and analysis phase to ensure that the findings are logical. To meet this requirement, we ensured that the findings and interpretations were directly linked to the data and that the process of coding, categorizing, and development of major themes was systematic in that we could trace how I arrived at codes/categories and themes, which was documented through an audit trail. My coding was also compared with that of my supervisors who are from different disciplines. Coding and re-coding seemed interminable at times especially when supervisors asked me to review and consider information from a different lens. I was continually challenged to demonstrate how my codes were linked to the data. At times, I needed to change my codes or challenge the interpretation we were considering. Furthermore, I compiled an audit trail of transparent description of the research steps taken from the start of my research project to the development and reported findings. My audit trail consisted of raw data such as written field notes, data reduction and analysis products including summaries of condensed notes from myself and my supervisor meetings, and data reconstruction and synthesis products. Process notes were taken throughout my journey as I found it very important to have a clear description of my research path.

Dependability. Dependability refers to the opportunity, post hoc, of reviewing how decisions were made through the research. During bi-weekly supervisory meetings were audio recordings and written notes were taken to record decisions related to this study. The write up of these meetings was used to form an audit trail to confirm a consistent, logical, traceable and a well-documented process. Data analysis meetings were audio recorded in progress.

Neutrality. Neutrality refers to the degree to which the results are a function solely of the informants and not of other biases, motivation, or views. For example, with one of our main themes surrounding autonomy, I viewed certain excerpts in a different way than my committee members who are not in the same occupation. We resolved these divergences through discussion and having to think through how and why my interpretation was appropriate and fitting within the context of the data. I recorded these meetings with my supervisors. I then read and re-read transcripts and re-coded the data to help ensure the analysis was grounded in the data and check that the analysis was not biased by my preconceptions

Even though I attempted to be as reflexive as I could, I still, by virtue of my professional education and experience had a certain lens through which I understood my project and data. Bias, in qualitative inquiry, is not necessarily negative, but it must be monitored and questioned. My supervisors were essential to helping me understand where my biases lay and their impact on my interpretations. For example, as an RDH working mostly in geriatrics, I value the consistency of healthcare providers, especially in those experiencing cognitive decline. However, throughout our FG sessions, CP participants expressed that this was not of concern to them or their loved one. CP 07 spoke to us about using the University of Alberta dental clinic as her and her husband's main dental providers due to reduced fees:

> CP 07: Well, I go to the university, the dentist place, so it's no problem. Sometimes I just have to be there. But the other day I just moved from there, and [he] was okay. I think at least if you tell him a little bit what's going to happen, so he was okay last visit, with another dentist. [Laughs]

Summary

In summary, in this chapter, I have outlined how and why a qualitative exploratory approach was most appropriate to help understand the oral self-care practices from the perspectives of the ILD and CP participants. Focus groups proved to be an effective way of collecting data because the synergistic effects shaped individual reflections, which would not have happened had the participants been alone in an interview. Throughout this study, I continually aimed to ensure that I, as a tool in the research, was presenting an accurate account of participants' perspectives and that the analysis that followed focused on using the emic views of ILD and CP participants to answer the research questions posed in this study.

Chapter Four

Findings

In this chapter, I will describe this study's findings from the data gathered from 20 care partners (CPs) and 9 community-dwelling individuals living with dementia (ILDs) using direct quotations to illustrate the central themes. Care partner and ILD participants' experiences and perspectives were used to develop descriptions and interpretations of current oral self-care practices and concerns of ILDs. Across all five focus groups (FGs) with CP and ILD participants, a consistent theme was the need to continue living rich and meaningful lives despite living with dementia. Care partner participants expressed their desire to respect the autonomy of their loved ones by preserving independence in activities of daily living (ADLs), including oral care practices. One of the ways that both CP and ILD participants tried to preserve an ILD's autonomy was by harnessing and relying on embodied habits around oral care that were learned in early childhood and believed to be practiced regularly. However, CP and ILD participants recognized that the ILD's abilities were decreasing as the disease advanced. This meant that CPs needed to use different strategies in order to foster as much independence as possible.

Three central themes surfaced in our analysis: 1) honouring personhood by maintaining autonomy; 2) transitioning through the levels of independence in oral care; and 3) relying on embodied habits. I developed a schematic model to clarify the dynamic and interwoven relationships between these themes (Figure 1). I will use this visual representation to provide context in which our data was interpreted and will aid in the explanation of notable observations and findings. Together these three themes constitute the practices and concerns of oral self-care in ILDs from both CP and ILD perspectives.

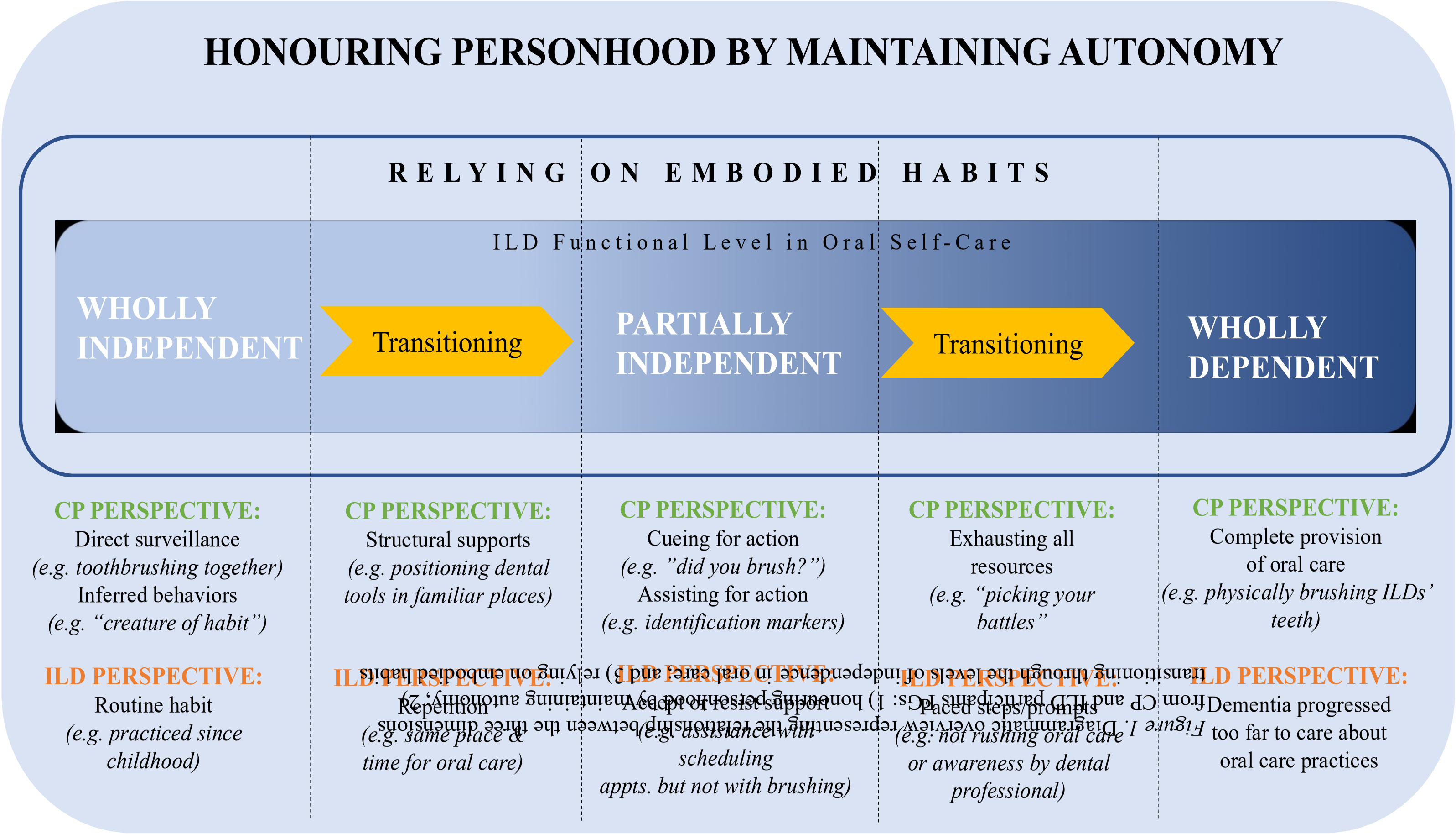

Figure 1. Diagrammatic overview representing the relationship between the three dimensions from CP and ILD participants FGs: 1) honouring personhood by maintaining autonomy; 2) transitioning through the levels of independence in oral care; and 3) relying on embodied habits

The first theme, *honouring personhood by maintaining autonomy*, was foundational throughout the data. Figure 1 depicts the importance of this theme by situating it on the outermost border, which encompasses every other category and theme. This theme is associated with an ILD's personality, identity, and capabilities.

The second theme, *transitioning through the levels of independence in oral care*, is used to reflect an ILDs actual functional level in ADLs despite their diagnostic category of dementia. These levels are not discrete entities, but in actuality are dynamic and denoted by transitioning arrows in Figure 1. This theme is associated with five identified stages of functional independence including: 1) wholly independent; 2) transitioning from wholly independent to partially independent; 3) partially independent; 4) transitioning from partially independent to wholly dependent; and 5) wholly dependent. As ILDs transitioned through levels of independence, CPs' focus changed from watching oral self-care practices to engaging in supporting oral care practices to some degree. Therefore, wholly independent is further expanded to include CP strategies of direct surveillance and assuming inferred behaviors to monitor oral care practices. Partially independent levels of functioning meant CPs started looking for providing cueing for action and assisting for action to support oral care practices. This theme and its transition stages are placed in the centre of Figure 1 as they straddle both ILD and CP perspectives of oral self-care practices.

The third theme, *relying on embodied habits*, involve both CP and ILD assumptions that oral self-care practices are part of early social conditioning, and as such, are being completed regardless of one's mental and physical capacities. This theme includes two subthemes: 1) evolving roles as a CP; and 2) strategies to promote oral hygiene practices. For the remainder of this chapter, I will describe these themes in detail and support these concepts with participant quotations.

Theme 1: Honouring Personhood by Maintaining Autonomy

Honouring personhood by maintaining autonomy is an overarching theme present in my model. Honouring personhood refers to remembering and respecting the person's personality, identity within society, and capabilities as she or he was before the development of dementia.

Personality

A few of our CP participants spoke about qualities and characteristics of their loved ones before and after being diagnosed with dementia. One CP, in particular, described her husband's pleasant personality as one of his best features:

> CP 16: That's the easiest part about him, he's very easygoing. He always has been, and that hasn't changed. He's very happy.

Care partner participants continued to honour their loved ones' positive attributes regardless of their diagnosis. Other CP participants spoke about noticeable behavioural changes they witnessed in their loved ones after they had been diagnosed. One CP participant mentioned that he often found it difficult to ask his wife questions about oral self-care without her responding with hostility:

> CP 10: So, the next morning I asked [about denture care]. She said, "Are you checking up on me?" I said, "Well, I happened to be here and looked," and she says "I know what I'm doing!" It's a very touchy situation. She is very unreliable. And I stay away as much as I can because it can get hairy.

At times, respecting a loved one's personhood supersedes any health, or in this case, oral health concerns that a CP may be trying to address with the ILD. Care partner participants may rationalize avoiding or skipping activities like oral self-care to preserve ILDs' dignity.

Identity within Society

Preserving an ILD's identity within society was important when honouring personhood. Some ILD participants mentioned it was important to raise awareness and dispel stereotypes that professionals and community members may hold about an individual living with dementia. One ILD participant said that it was important for her to disclose her diagnosis to healthcare professionals, such as dental professionals. She expressed that she wanted to inform her health care professionals that dementia is not a disease that exclusively occurs in seniors and that the disease can potentially have multiple manifestations:

> ILD 09: So, when you tell these professionals that educates THEM, right, so – all of a sudden, he doesn't see dementia and Alzheimer's as an old person's disease but he realizes anybody can get it, you know, and they're just regular people walking around doing their own thing. You know, they're not all in a nursing home. They're not, you know, in a wheelchair.

This quotation illustrates that some ILDs feel that raising awareness about their disease is important to eliminate societal labels that may misrepresent dementia. Participants expressed that social stigmas and negative attitudes surrounding dementia are reasons why ILDs do not want to be recognized by their disease, but rather as the people behind the diagnosis.

Conversely, some ILD participants wanted to limit the number of people that knew about their diagnosis. These participants explained that most people would have no idea that they had dementia unless it was disclosed. The young-onset ILD participants raised concerns related to social stigma and how they chose not to disclose because they did not want to be labelled as a person living with dementia. Consequently, several ILD participants voiced differing perspectives about voluntarily sharing/disclosing information related to their diagnosis to laypersons and to their dental professional(s):

> Interviewer: Some of the things that we're looking at is whether or not your dentists/hygienists have been informed [about the dementia diagnosis].
> ILD 07: Yeah.

> ILD 08: Okay. Like ILD 07, if they know, that's fine. But if they don't know and they don't need to know, I'm not volunteering, I'm not telling you. And I'd be mad at anybody who DID tell them.
>
> ILD 07: Absolutely. I want to savour those [people who do not know about the dementia diagnosis].
>
> ILD 08: Yeah. There'll be time enough when they will know. [Laughter]
>
> ILD 07: I'm telling you, ain't that the truth.

This excerpt suggests that some ILD participants would rather withhold their diagnosis until a time where this is no longer possible in the progression of their disease. Conversely, other ILD participants felt it was important to disclose this information:

> Interviewer 2: We just want to understand what type of communication [regarding dementia and oral care] you may have received or may not have received from your dentist or your dental hygienist.
>
> ILD 03: I don't think the dental office that I go to is even aware that I'm an Alzheimer's patient. I don't go around telling everybody.
>
> Interviewer 2: When they do a medical history, do they - they must know that you have been diagnosed with Alzheimer's?
>
> ILD 03: I don't know.
>
> ILD 04: Yeah, I've never had that question even presented. But I told mine [dental professional]. So, I assume they know. It's important to know.
>
> ILD 02: I told my [dentist] too.

Care partner participants were similarly inconsistent in sharing information about their loved one's dementia diagnosis. Several CPs indicated that they made sure the ILD's dental practitioner(s) knew that their loved one had dementia, while other CPs were unaware that it was necessary to have dental professionals know this information. One CP participant was adamant that the rest of the young-onset CP participants needed to be more assertive with dental professionals on their loved one's diagnosis and relevant dental information:

> CP 16: You're going to have to say to the dentist…
>
> CP 17: "Tell me." Yeah, and I've done it to the doctor but not the dentist. I've been more assertive at a doctor's appointment, but at the dentist, I sit in the waiting room and read my book.
>
> CP 16: Yeah, you need to tell them. You need to tell them that they should be giving you the feedback because he won't remember. He'll say he remembers, but he won't remember.
>
> CP 17: Exactly, yeah.

CP 19: Yeah, ILD 09 doesn't converse at all with the dentist. I drop her off and pick her up, and then he comes and talks to me. She doesn't really care what he's saying, so that's good.

Several participants reflected that having the CP involved in communication with the ILD's dental professional(s) could be beneficial to allow the ILD to complete their dental appointments independently, while still helping to ensure that the dental professional was aware of the ILD's health status and that the CP was informed of the dental professional's recommendations for oral care. This strategy was discussed as a mechanism to help ensure that the ILD's oral health was maintained as best as possible.

Remaining Abilities and Capabilities

Care partner participants also spoke about the importance of preserving an ILD's remaining abilities and capabilities to ensure one's personhood is valued. More importantly, these remaining abilities helped ILDs to maintain a sense of independence and freedom. One CP participant told us that regardless of her husband's diagnosis of young-onset dementia, he was still able to complete some complex tasks, such as driving a motor vehicle. This CP participant was happy to have her husband retain activities he was familiar with prior to his diagnosis. She explained how her husband would drive himself to the dentist, grocery store, library, or swimming pool unaccompanied:

CP 20: Like his last [dental] appointment, he could still go on his own.
CP 17: Is he driving?
CP 20: Yeah, he's a good driver still. He drives great. He just doesn't always know where he wants to go, but he has a Garmin.
CP 16: He can follow the instructions on the Garmin?
CP 20: Yeah, he still can do it. He's a good driver. But he just drives to the same place all the time now, like the grocery store, the swimming pool, or the library. Those three things he knows, and that's where he goes all the time. But when I'm with him, and he drives, he's a great driver. I just have to tell him where to turn, you know.

The conventional tasks and errands mentioned in this excerpt still require mental and physical capabilities. This CP participant was aware that her husband had moments of uncertainty with driving, an activity he had been practicing since he was a teenager but seemed unwilling to allow him to give that up, especially since he was still the driver when they were in the vehicle together. She went on to discuss how strategies like GPS-navigation can help to overcome obstacles without having to reduce some of her husband's responsibilities, and theoretically his freedom.

CP participants mentioned that their loved one's placed great importance on oral care prior to their diagnosis of dementia, however, were no longer capable of completing this task unaided. One CP participant reported that her mother practiced daily oral self-care and instilled the importance of oral care into her and her sisters at a young age:

> CP05: … [she was] somebody that's cared so much about her teeth before and brought us up to have good oral dental care.

However, this CP then discussed how due to the progression of the dementia, her mother was no longer able to maintain the same values she once held about oral care.

Care partner participants respected the ILD by supporting them as much as possible with respect to their personality, identity within society, and capabilities prior to the diagnosis of dementia. There was, however, a notable role change in the dynamic of a CP and ILD relationship. Given the close relationship, CPs shared with ILDs, as either a spouse or a child, honouring personhood of the ILD was vitally important to CP participants. Care partners expressed when an ILD develops dementia, the relationship shifts from an equal exchange of assistance, to a greater responsibility for daily care on the CP. The CPs attempted to juggle new roles, including more support and assistance while maintaining their loved one's independence. One of our CP participants expressed how she did not anticipate being both a spouse and caregiver simultaneously:

> CP16: You just don't expect to be doing that to an adult, right? You do it with your children. You don't expect to have to do it with your husband. So, I think it's all difficult.

This excerpt reflects the challenges of balancing an intimate spousal relationship with the added roles and responsibilities of caring for the ILDs activities of daily living while attempting to promote independence. The CP participants negative facial expressions, such as pursed lips and a furrowed forehead, were evident in the video data when discussing this difficult and potentially stressful subject matter.

Honouring personhood was the value that guided CP participants when supporting the ILDs in oral care practices, both daily and professionally. However, because oral care of an ILD was assumed to be completed based on learned habits, CPs also assumed that an ILD in the early phases of dementia could attend dental appointments unaccompanied. One CP participant mentioned that he would drive his wife to her dental appointment and then wait in the waiting room until she was done:

> CP 18: So I don't know if she told the dentist, because I'm not in the room sitting with her at the dentist's, you know, listening to what he's telling her or what the hygienist is telling her. I just drive her there and wait in the waiting room.

As reflected in this quotation, several CPs expressed that assumptions around an ILD's capability in completing daily oral care and in receiving professional care and instructions could be problematic. For example, several CPs discussed how information exchanged between dental professional and ILD might get lost or be misinterpreted. This then reflected how assuming the responsibility of discussing the ILDs diagnosis with the individual's dental professional(s) could help to ensure that relevant information was translated and was also seen as an opportunity for CPs to check if the dental professional(s) had been trained and educated in providing oral care for ILDs. Some CPs described this communication as having accountability between the CP, the dental practitioner and the ILD.

Care partner participants protected their loved one's autonomy in numerous ways. One of the ways CP participants did this was by overlooking or avoiding inaccuracies in information ILDs would share. One CP participant told us that her husband would go into his dental appointment unaccompanied while she waited in the foyer for him to finish. After the appointment, she would ask him how everything went, and her husband would respond with an answer she knew was incorrect, as he was trying to save face since he had forgotten what was actually said:

> CP 17: He knows he's forgotten, so he pretends he hasn't forgotten, and just says, "Oh, everything's good. [The dentist] said you should use the blue brush more." And I was letting that go, and then I'm thinking, "I don't think the dentist really said use a blue brush."

Before the dementia diagnosis, this ILD would attend his dental appointments alone. His CP tried to maintain this routine to preserve the ILD's independence. However, the CP articulated that because she was not present at the dental appointments, information communicated from dental professional directly to her husband may be forgotten. In this case, the CP participant was aware that what her husband mentioned to her was most likely inaccurate, but she avoided any confrontation to preserve her husband's pride.

As both CP and ILD roles changed in response to increasing limitations imposed by the dementia, several participants discussed having developed strategies to promote independence of the ILD, which was discussed as being integral to uphold their sense of self in the context of everyday responsibilities. The wife of an ILD diagnosed with early-stage dementia emphasized the importance of retaining her husband's independence by integrating self-prompting strategies such as writing down the day's events on a whiteboard. She reflected how using this strategy to prompt her husband without having to constantly remind him of the day's activities helped to support his independence:

> CP 08: …And I write things on the whiteboard, like when I get up in the morning I would write, 'Today we're going to the dentist,' and what time we were going to leave, so that he could read it, feel independent, and then get ready himself and I didn't have to rag on him about it. And that worked for us really well. So maybe once they start to forget to do the oral care, doing something as simple as that, not having to remind [them], but being able to write down the steps to read and still be independent, but you're helping by sort of nudging it a bit.

This CP participant felt accountable for streamlining a routine that the ILD could follow. This strategy promoted positive collaboration, between the CP and ILD, while still promoting the ILDs independence.

ILD participants spoke about living with dementia and how collaborative care strategies assisted them in maintaining a sense of independence. One ILD participant mentioned that his wife would place identification markers on his dental tools to help him identify which items were his and where he could return them once he finished oral self-care:

> ILD 07: Because of the Alzheimer's [my wife] puts a P at the bottom of the toothbrush as a marker. And then in the place where we put the toothbrushes too, she'll have that identification or else you never know where I put it. [Laughs]
>
> Interviewer: Okay. Tell me more about that.
>
> ILD 07: Well, it seems quite reasonable when you look at it, but unless you're living like we are with Alzheimer's it seems kind of extreme. And then those are the little things that you have to do– your routine cannot deviate, or else it can throw you off. Even something as simple as that, right? So let's say I use those little white things to floss. If they're put in a little plastic bag for me, and it's in a certain place, and if I don't see that, then either it'll make me a little uncomfortable or I might just skip the whole process through [lack of] memory. Yeah, memory. So the whole house and the yard and the garage is catered to that kind of person, right?

This ILD participant indicated that while he did require additional assistance through collaborative efforts, he and his wife developed a system of identification markers that worked to keep him independent.

Collaborative efforts in accessing dental care from a community dental office were mentioned by both participant groups. Individuals living with dementia and some CP participants believed dental appointments should be done unaccompanied, while the process of booking appointments and transportation to the dental clinic typically requires assistance and support from CPs. In the FG sessions, discussions around divided responsibilities and delegated tasks surfaced. Most ILD participants were forthcoming with requiring assistance from CPs for dental reminders and booking appointments:

> Interviewer: Have you experienced any difficulty making appointments at your current dental offices?
> ILD 07: No.
> ILD 08: To remember to do it is one thing. Doing it is no big deal.
> Interviewer: So, accessing the dental office, or getting there isn't really an issue?
> ILD 08: I don't drive anymore. My wife has to drive me.
> ILD 07: It's not that far, but nowadays I still have to write down the address even though I've been there lots of times, right? And again, I sort of go through my wife so that if I'm not comfortable going then she'd have to come.
> ILD 09: CP 19 just drives me there and back, because it's her dentist too, so she knows the secretary there and everything.

This quotation illustrated that ILD participants felt comfortable with dividing tasks that they once accomplished independently with their CPs.

Collaborative efforts between CP and ILD participants not only include developing feasible strategies to remember oral self-care, but also to carry out this activity of daily living (ADL). Care partner participants expressed the need to be alert and vigilant with how ADLs were managed. While there was an awareness amongst CP participants about the importance of oral care, they also knew that the long list of ADLs was often too demanding for their loved ones to complete. The daughter of an ILD expressed the importance of completing her mother's ADLs, yet she found it challenging for herself and mother to complete all of the routine tasks daily:

> CP 05: And for my mom at 90, she's exhausted after she's changed her clothes. So do we want to throw the brush on there too, and do her hair today? You know, we try to time it out or sort of schedule it out so she doesn't have to do everything. But if her clothes are changed once a week, we're doing well. And she does always put her pajamas on at night, so we should be cheering. [Laughs]

The daughter of the ILD reluctantly accepted that it was unrealistic to complete all ADLs daily because it was excessively onerous for her mother. The daughter's priority was to ensure her mother's comfort and wellbeing, so she often let some tasks go unaccomplished.

While CP participants spoke about the difficulties in managing their loved one's ADLs, other CP participants created strategies to overcome such obstacles. Care partner participants strongly desired to keep the ILD independent and have them complete ADLs alone and therefore special attention was given to the planning and pacing of these oral self-care activities. CP participants discussed listing steps to reduce information overload:

> CP 14: For him it's kind of one thing a day, and the minute you crowd three or four things into the day, anxiety mounts. He repeats "What are we going to do today?" over and over again. So I can see how writing brush your teeth maybe, but putting it down in ten steps I wouldn't –
>
> CP 08: Oh, no, I wouldn't - no, I wouldn't do ten steps but it would be, "Brush your teeth," and then, "Gargle," or whatever. I mean, simple, quick. Yeah, you couldn't do a big long list because ILD 06 would tune out too.

This excerpt between CP participants illustrates the differing levels of ability between ILDs to handle information and recall steps in oral care activities. Within each CP and ILD dyad, sustainable and management techniques were employed to ensure the completion of oral self-care. However, once current strategies failed or no longer worked, adaptation and new strategies needed to be implemented. The preferred way to foster an ILDs autonomy was to allow them to have the choice to freely make decisions for themselves. Having full autonomy was not always practical for an ILD with advanced dementia. Nevertheless, ILD participants spoke about choice and having the option to pick and choose the ADL that they wanted to complete in a day. One ILD participant mentioned that his wife was quick to assume he had forgotten to shave, but in actuality, he decided he just did not want to shave on that given day:

> ILD 08: And some days I choose not to shave and some days I choose to shave, and my wife says, "You should make yourself a list of what you do every day because you forget to shave." I didn't forget to shave; I chose NOT to shave. [Laughter]
>
> Interviewer 2: Chose not to shave. Okay. But the toothbrushing -
>
> ILD 08: It's [electric toothbrush] always in the same spot and I don't charge it all the time. I run it down and when I feel it doesn't have much jam anymore, I plug it in and let her charge up.
>
> Interviewer 2: Mm-hmm. So, there's nothing really specific in terms of the routine of how you go about brushing?
>
> ILD 08: No.

This ILD shared his perspective that CPs can be quick to assume tasks that are routinely completed, but missed on any given day, are usually attributed to the symptoms of dementia. This highlighted the notion of perceived independence versus actual level of independence. In some CP participants' efforts to honour ILDs' personhood, they frequently assumed there would be collaboration to achieve normative hygiene practices rather than being attributed to ILDs' personal choice about the need for, or priority of these practices.

Care partner participants articulated that oral care constituted a small part of the full range of ADLs. They viewed the ability to practice oral care as a minor component in an individual's overall general health. In one of our CP participant FG sessions, it was unanimous that oral care of the ILD was a low priority compared to other ADLs. Tasks related to maintaining appearance and physical presentation took precedence:

> CP 01: Well, I don't want to minimize dental care, but there are so many other bigger issues going.
>
> Interviewer 2: What are some of those bigger issues that are - that you feel are superseding?
>
> CP 05: Having a shower, washing your hair.
>
> CP 01: Changing your clothes.
>
> CP 05: Changing your clothes.
>
> CP 02: Incontinence.
>
> CP 05: Incontinence. This is at the top of the list.
>
> CP 01: Yeah, yeah.
>
> CP 07: Yeah, top of the list.

As ILD participants spoke about daily oral self-care, specifically toothbrushing, they shared how it was such an easy and mindless task and that they found our discussion and questions around oral care laughable:

> ILD 05: I can't think of anything much easier than brushing teeth. Yeah, I practiced that for quite a while.
> ILD 04: A year or two. [Laughs]
> ILD 05: Yeah, a couple of years. [Laughs]

Some ILD participants expressed that they found our questions about their oral self-care habitual practices odd. We saw in our video and audio recordings, definite tone changes including sarcasm and laughter when asked to detail the step-by-step process of brushing one's teeth. It was clear that ILD participants regarded oral care as an uninteresting topic and task.

Within the context of this study, the theme honouring personhood by maintaining autonomy is remembering and appreciating a person as they were before being diagnosed with dementia in terms of personality, identity with society, and capabilities. Both CP and ILD participants spoke candidly about the importance of supporting and maintaining autonomy of oral self-care through collaborative care efforts, relying on habits, and the use of practical strategies. To make sense of how autonomy and independence were preserved and promoted, we needed to understand how ILDs transitioned through decreasing levels of independence in oral care and how their CPs noticed and responded to these transitions. This was probed as our study progressed.

Theme 2: Transitioning Through the Levels of Independence in Oral Care

The second theme, transitioning through the levels of independence in oral care, has five stages that enhance our understanding that diagnostic categories do not necessarily align with one's level of independence, especially in the context of oral self-care. These "levels" of independence are typically reported as definitive categories, rather than gradients. Figure 1 captures the dynamic nature by the background colour gradient, as well as, transitioning arrows between each phase. The five stages are: wholly independent which encompasses CP responses of direct surveillance and inferred behaviours; transitioning from wholly independent to partially independent; partially independent which contains CPs cueing for action and assisting for action of the ILD; transitioning from partially independent to wholly dependent, and; wholly dependent which is the CP's provision of all aspects of oral care.

Our CP participants discussed the ILD's perceived levels of independence. Even though ILD participants had been placed in dementia categories through medical diagnostic assessments and by the ASANT support groups, these categories did not necessarily reflect their capacity for independence in oral self-care. In the ILD participant FG, all nine participants stated that they were completely independent with regards to oral self-care practices (Table 3). During the FG sessions, assessment data was collected to calculate a Montreal Cognitive Assessments (MoCA) score for the ILD participants. ILD participants scores ranged between 12 and 26 (Table 2). Scores of 26 and above are considered healthy, 25-17 are considered as mild cognitive decline, and scores of 16 and below are considered cognitively impaired (Memoria et al., 2013). As previously highlighted in chapter 3, only one ILD participant scored 26. In this case, the spouse disclosed the participant practised cognitive assessment questionnaires on a routine basis, in an attempt to stay within the healthy range. Overall, our MoCA assessment indicated that the ILD participants were more severely cognitively impaired than ILD or CP participants reported and/or the ASANT support group categories indicated. The majority of the CP participants (n=10) assumed that their ILD loved ones were totally independent in oral care practices, while (n=7) noted some assistance was required; in other words, they were partially independent (Table 4). Very few (n=3) reported that the ILD had to be fully supported in all aspects of daily living

(Table 4). Therefore, the level of cognitive impairment assessed using the MoCA screening did not correspond to the assumed level of independence reported by CPs, self-reported level of independence by ILDs, or level of independence determined in data analysis with respect to oral self-care practices (Table 4).

Table 3

ILD Level of Cognitive Impairment and Self-Reported Oral Care Level of Independence

ILD #	MoCA Score	Diagnosis date	ASANT classification	Self-reported oral care level of independence
1	13	2016	Early-stage	Wholly independent
2	12	“long-time”	Early-stage	Wholly independent
3	21	2012	Early-stage	Wholly independent
4	22	2015	Early-stage	Wholly independent
5	Refused	2014	Early-stage	Wholly independent
6	19	2015	Early-stage	Wholly independent
7	23	2016	Young-onset	Wholly independent
8	26	2015	Young-onset	Wholly independent
9	16	2015	Young-onset	Wholly independent

As I further investigated, I noticed that independence was viewed in accordance to general ADL but when I looked at the data about oral self-care practices, either reported or assumed, the levels of independence were inconsistent. In order to understand the relationship between levels of independence, oral care practices and strategies to support these practices, I needed to sort out some general levels of independence with respect to daily oral care. Therefore, I have developed three levels of independence and two transition phases as an etically derived theme. These are: wholly independent (WI), WI to PI, partially independent (PI), PI to WD, and wholly dependent (WD).

The three levels of independence are dynamic, meaning each level is not a discrete entity but are gradients with flowing transition phases in-between. The first transition phase occurs from WI to PI, where ILD participants deliberately or consciously negotiate oral self-care practices through the use of repetitive behaviours. The second transition phase occurs from PI to WD, where denial or refusal of support for oral self-care practice occurs if steps in this task are not well-paced. These transition phases presented in our data as CP participants described the ways in which oral care practices were being reinforced and completed. Likewise, within each transition phase, CP participants employed strategies to ensure the task of oral care was being completed as independently as possible to preserve the dignity and autonomy of their loved one.

Table 4

Level of Independence Assumed by CPs, Self-Reported by ILDs, and Determined in Analysis

CP #	Assumed level of independence by CP	ILD #	MoCA Score (/30)	Self-reported level of independence by ILD	Level of independence determined in the analysis
CP 01	WI				
CP 02	PI				
CP 03	PI				
CP 04	WI				
CP 05	WD				
CP 06	PI				
CP 07	PI				
CP 08	WI	ILD 06	19	WI	PI
CP 09	WI	ILD 05	Refused	WI	PI
CP 10	WD	ILD 02	12	WI	WD
CP 11	PI				
CP 12	WI	ILD 04	22	WI	PI
CP 13	WI	ILD 03	21	WI	PI
CP 14	PI	ILD 01	13	WI	PI
CP 15	WI				
CP 16	WD				
CP 17	PI	ILD 08	26	WI	PI
CP 18	WI				
CP 19	WI	ILD 09	16	WI	PI
CP 20	WI	ILD 07	23	WI	PI

Note. The blanks present in this table are from the respite CP participant FG as they reported on the ILD, as a proxy or shadow data since the ILD did not participate in this study.

This table represents the level of dependence gathered from our FG sessions as reported by CP and ILD participants. The initial categorization was by ASANT, which was based on self-reported diagnosis. Then we conducted the MoCA to verify the level of impairment. An additional column in the table was added to represent the level of independence that was determined upon analysis of our data collected from the two ILD focus group sessions as well as the CP participant focus groups sessions. This analysis was based on what we learned through the focus group and was more specific to oral care-related activities which may or may not parallel the ASANT classification, MoCA score, assumed level of independence by CP, and self-reported level of independence by ILD.

Half of the CP participants (n=10) assumed the ILD were completely independent in ADLs, whereas, all of the ILD participants (n=9) assumed they were wholly independent. Interestingly, most (n=8) ILD participants were partially independent, with the remaining ILD being wholly dependent on assistance for all activities of daily living. CP participants held an optimistic perspective of the ILD for performing ADLs, in that, most assumed complete independence. Similarly, ILD participants were unanimous in voicing their independence in ADLs. Our analysis, on the other hand, suggests that both CP and ILD participants overestimated ability levels and that most were a step down from what was claimed. The levels of independence that will be further explored below include: WI, transitioning from WI to PI, PI, transitioning from PI to WD, and WD.

Wholly Independent (WI)

Being wholly independent refers to a community-dwelling ILD who is not dependent on another person for support with regard to ADLs, specifically oral self-care. Care partner participants determined this level of independence through their impressions gained by monitoring the ILD, either through direct surveillance or inferred behaviours. Direct surveillance occurred when CP participants visually witnessed the ILD completing oral self-care practices without any assistance. Inferred behaviours occurred when CP participants were unable to actually observe their loved one performing oral self-care but rather assumed the ILD was completing this task due to routine practices and assumptions of ADLs. Participants who were ILDs confirmed this level of independence by reiterating the automatic and habitual nature of the practice of oral self-care.

Within our FG sessions, ten of the twenty CP participants assumed that their loved ones were completely independent in their oral self-care practices and did not require any assistance, including prompts or cues to action. This means that half of our CP participants believed that the ILD was capable and wholly independent. One CP participant explained that while her husband may not have many teeth left, she believed that he was still doing an adequate job with his own oral care:

> CP 08: What ILD 06 does is totally independent, and he has very few teeth… Anyhow, so he doesn't have a lot of teeth left, but he's very good at brushing all over his mouth with an electric toothbrush… And he's really good left on his own.

This quotation suggests that the CP participant's perception about her husband's oral self-care had not changed since his dementia diagnosis. This CP and her husband both reported wholly independent levels of oral self-care; however, this ILDs level of independence determined by analysis placed him at the partially independent stage. The notable discrepancy between what the CP thinks, what the ILD self-reports, and what is actually being done highlights that CP and ILD perceptions related to level of independence may be inconsistent with the tools used within healthcare to assess cognitive decline. While outside the scope of this current study, the inconsistency related to perceived versus actual level of cognitive decline is an important area of future study. Care partners often used adjectives such as "very good" or "extremely good hygiene" to describe the quality of oral care practices of their ILD loved one when the ILD has been assessed by their CP as being wholly independent. However, these descriptions are hard to validate unless the CP was a dental professional. Similarly, when we asked ILD participants about needing assistance or support with daily oral self-care, the common response was they complete all tasks independently:

> Interviewer 2: …Do you take care of your teeth on your own or does somebody help you? Does somebody help you brush? Does somebody tell you to brush or remind you to brush?
> ILD 06: I do it all on my own, by myself.
> Interviewer 2: Okay. And you do it on your own at all - at both times, morning, and night?
> ILD 06: Yeah, yeah.

All nine of our ILD participants self-reported total independence with respect to ADL, more specifically, all aspects of oral self-care. In the early-stage and young-onset dementia participant FG sessions, not one ILD participant mentioned requiring assistance with the physical task of toothbrushing.

With 50% of our CP participants assuming and 100% of our ILD participants self-reporting complete independence, we needed to further investigate how these assumptions were made in order to better understand an ILDs practice of oral self-care. Care partner participants monitored the ILD through visual observations or through inferred behaviours. Individuals living with dementia stated that oral self-care was such a natural and basically automatic practice that they did not require any assistance in its completion. To reflect these beliefs, the classification of wholly independence from the CP perspective was further divided into direct surveillance and inferred behaviours, and from the ILD perspective, as an automatic embodied habit, as detailed in the subcategories that follow.

CP Direct Surveillance

Direct surveillance refers to the CP participants practice of directly observing an ILD perform oral self-care. Care partner participants reported ILD practices including applying toothpaste, brushing one's teeth, or flossing as direct surveillance. This technique allowed CPs to confirm that the ILDs were independent in ADLs, specifically in the task of oral self-care.

Care partner participants talked about how they deliberately planned to do oral care activities together with their loved one. Completing oral care activities together allowed CP participants to observe the ILD directly, and to confirm that oral self-care was being completed. For one of our CP participants, completing oral care together was a well-established practice:

> CP 19: And then in the commercial [on TV] we both go to the kitchen, and we both brush our teeth together…And like I said, it goes for two minutes, so and then in the next commercial I run them all back upstairs, and we've done that probably for 15 years, so it's nothing to do with her dementia. It's just a habit we've gotten into.

This CP participant mentioned the ILD's dementia had not affected oral self-care routines. For this CP and ILD dyad, oral care practices had been completed collectively for years and still required no assistance with the actual act of toothbrushing. The CP participant was a direct observer of the ILD, and therefore she could verify her loved one was wholly independent in oral self-care. Additionally, the CP articulated that this oral care strategy honoured the ILDs personhood because they continued to use the same routine for oral care as they did prior to the diagnosis.

Other CP participants described their experiences with direct surveillance of an ILD as intermittent glances throughout the practice of oral self-care. In two separate instances, CP participants mentioned that by peeking or hovering they were able to confirm the ILDs were independent:

> CP 08: And a peek now and then to make sure it's [toothbrushing] happening, to this point, he's really good at it.

“Hovering” seemed to be a common phrase CP’s used when discussing how they could verify oral self-care was occurring for their ILD loved one:

> Interviewer 3: So right now, is he in the bathroom alone when he’s doing his oral care?
> CP 17: He would answer that question ‘yes’, but I’m hovering and in and out to see.

In summary, direct surveillance within the study was a way for CP participants to observe ILD participants as they completed oral self-care activities. This technique was useful, in that, it allowed CP participants to deem their loved one as fully independent in ADL. Some CP participants took on a more active role by completing toothbrushing together, while others opted to hover in and out of the room to ensure the task was being completed.

CP Inferred Behaviors

For many CP participants, direct surveillance was not possible or appropriate, instead, they inferred that oral self-care was occurring based on associated behaviours. Care partners participants assumed that an ILD could start and finish most ADLs tasks. These assumptions were based on deep-rooted habitual practices; one of which was oral care practice. This meant that CP participants felt that they did not need to directly observe the ILD brushing or flossing their teeth but could infer that these practices were occurring from the evidence that implied oral care tools had been used (i.e. wet toothbrush bristles). This is the second technique CP participants used to confirm the ILD was wholly independent in oral self-care practices.

For example, one CP participant discussed how, despite her own morning routine differing greatly from that of her partner, she could hear the electric toothbrush turn on in the morning, and therefore the CP’s assumption was that the ILD was completing her own oral care independently. Additionally, the CPs assumption was supported by the fact that the ILD was a “creature of habit”:

> CP 19: [ILD09] looks after her own dental hygiene. I'm usually up before she is and she's a creature of habit. She gets up, she makes the same thing for breakfast every day. And then she goes up, and she always has her clothes set out from the night before and her toothpaste and her toothbrush, and her brush sitting there, and I can hear the electric toothbrush so I just – and it's got a two-minute timer, so I just figure it's going off.

Another CP participant used assumptions of past oral care habits, to infer that his wife was maintaining the health of her mouth:

> CP 12: And I know she's brushing, but I don't stand there and watch her. And she's always had very good, extremely good habits for hygiene.

This statement illuminates how CPs use embodied habits to infer oral care practices and behaviours are still being done. These inferred behaviours helped CP participants justify viewing the ILD as wholly independent with respect to oral care practices.

Many other CP participants also relied on hearing sounds associated with oral care to infer that self-care was being completed. Visual confirmation was not always necessary for CPs to assume the ILD was independent in toothbrushing. Since direct observation, in some of these cases, was not possible, most CP participants listened for the sound of the electric toothbrush. In the following excerpt, visual confirmation, sounds of brushing, and evidence such as used floss were all strategies CPs used to infer oral care was occurring:

> CP 18: [ILD*] does her own. I can hear the electric toothbrush in the morning. At night sometimes. She used to floss up until maybe two years ago, maybe even a year ago, and I'm not finding any floss in the garbage, because I empty the garbage once a week. I'm not finding any floss…and before that it was every night. She'd sit on the side of the bed and floss her teeth for 15, 20 minutes. So, she's not doing that as much anymore, if at all.

> CP 20: …If he doesn't shower then, or brush his teeth then, he'll brush them in our bathroom with the electric toothbrush. So, I don't always see him, but I hear it.

> CP 15: So I'm not really there. I do know that he brushes his teeth and then he flosses with a stick. It is an Oral B toothbrush that we got from the dentist. And I hear him in the bathroom, so I know he's doing them, but I'm not actually there.

Inferred behaviours presented in two ways, either as habitual tendencies or by hearing an electric toothbrush or seeing (or no longer seeing, i.e. floss from CP 18) used oral hygiene tools. These two methods aided CP participants in evaluating their loved ones' levels of independence.

ILD Perspective: Automatic Embodied Habit

The task of oral self-care from the ILD perspective was viewed as a well-practised, automatic embodied habit. One ILD participants compared the act of toothbrushing to breathing, making it an unconscious necessity:

> ILD 07: You just brush your teeth, okay? And your kids brush their teeth, and their kids brush their teeth. So, it's not like it's a transition time where you weren't used to that, or you didn't have access to all the things you require. It's right up there with breathing. You just brush your teeth.

All nine ILD participants self-reported they were wholly independent, meaning this practice was completed independently and all nine ILD participants regarded oral care as a taken for granted "second nature" habit, regardless of the dementia diagnosis.

Transitioning from Wholly Independent (WI) to Partially Independent (PI)

In the context of our study, the levels of independence were seen as a continuum rather than distinct checkpoints. Levels of independence flowed from wholly independent to partially independent to wholly dependent, with significant transitioning phases between each level. The first transitioning phase from WI to PI is where more support was required to ensure oral self-care practices are being completed by the ILD, but they were still completing oral care somewhat independently. Examples of additional support that CP participants would offer include reminders and setting up structural supports to complete the task of oral self-care. The second theme of transitioning through the levels of independence was reinforced by showing that oral self-care practices do not necessarily align with a diagnostic assessment and that the principles of oral self-care may need to be adapted as an ILD transition through these levels.

Although most CP participants were confident as to whether the ILDs were wholly independent or not, during the FG session a few CP participants realized that what they thought was happening, in terms of oral self-care, was not actually occurring. In the following example, the CP participant suddenly realized that the lack of needing to buy floss for weeks probably reflected that the fact her husband had not been flossing. This CP participant assumed that her loved one had always flossed because it was his routine prior to the diagnosis of dementia:

> CP 17: He claims to floss but the floss I haven't had to buy for quite a few weeks, so right this minute I just am realizing that he's probably not flossing and I haven't really noticed that till right now. He does, I think, a pretty good job of brushing.

Through virtue of the discussion occurring in the FG sessions, most CP participants came to realize that some of their assumptions about the level of independence in the ILD, specifically with regards to oral self-care, was not accurate. Through these realizations, CP participants started to report that they, in fact, needed to provide a little more support to ensure oral self-care practices occurred for their ILD loved one. Generally, this was through structural supports such as setting up dental supplies. One CP participant described the established oral self-care routine her, and her husband developed that directly mimicked her husband's medication routine:

> CP 08: We've set up a regiment of how he does things, and he is really good, to this point, about following them because he has so few teeth and he needs to preserve what he does have left, so.
>
> Interviewer 3: And you described that you set up a regiment. What do you mean by that?
>
> CP 08: Well, there's certain things that we do because they're repetitive and it's easy for him with his illness to be able to remember repetitive things. And so, the toothbrush is there and the toothpaste is there and the mouthwash is there. It's in the same place all the time. And that's the same thing with his medications. He does his own medicating, but I have the morning ones lined up in a row, and anything for noon and anything for supper. So, he's used to those kinds of very routine things.

Care partner participants started to discuss various structural supports they used to assist the ILD with their oral care practices. These supports were based on well-established routines and were used in order to maintain the ILD's independence with oral self-care. The main role of the CP participant, in this case, was the set-up of the dental supplies and medications, the remainder of the task was solely the ILD's responsibility.

Most CP participants were keen that the ILDs were performing oral self-care alone, however, some CP participants still felt responsible for verifying that toothbrushing was actually happening. One CP participant spoke to us about a recent change that occurred with her husband's oral care practice, in that she now needed to witness toothpaste going on the toothbrush to ensure her husband's teeth were being maintained independently:

> CP 01: I'm in charge of ensuring that [ILD*] actually brushes his teeth, but he brushes them himself. And I watch just to make sure that the toothpaste goes on the brush. And that's a recent development, in the last few weeks.

As this was a recent development in her and her husband's oral care routine, she noted a transition point where she realized she needed to be present to confirm the completion of oral self-care.

Partially Independent (PI)

Partially independent, within the context of our study, was harder to distinguish in the FG data, as many CP participants believed their loved ones were either wholly independent or wholly dependent. However, as the FG discussions evolved CP participants began to realize that their loved one might be less able to independently complete ADLs, like oral care, than what the CP had presumed prior to participating in this research. Table 4 references CP participants' assumed level of ILD independence, where less than half believed their loved one to be partially independent. From the ILDs' perspective, there was a unanimous consensus of wholly independence, however, from our gathered data (n=8/9) almost all the ILD participants were partially independent. This signified that, while our participant groups had differing dementia diagnoses, they did not necessarily correlate to the performance of oral self-care practices. In our study, PI from the CP participants' perspective refers to assisting an ILD complete oral care practice by either cueing for action or assisting for action. WI and PI differ, in that CP participants with wholly independent ILDs inferred the practice was being completed, whereas PI required cueing, assisting, and supervision simultaneously. From the ILD perspective, PI means that they were willing to accept or were resisting CP efforts to support them in oral care. Partially independent oral care had two subcategories: CP cuing for action and CP assisting for action.

CP Cueing for Action

Cueing for action involved both supervision and suggestions from the CP participants to the ILDs to initiate oral care behaviours. The majority of our CP participants used verbal reminders to prompt ILD participants to complete oral self-care. Verbal cues were typically very broad, such as, "Did you brush your teeth?" Direct instructions about tasks involved in brushing one's teeth were not frequently given, such as, "Find your toothbrush, find your toothpaste, uncap the toothpaste." Broad cues reportedly worked in our participant groups, since CP participants would then supervise to ensure the practice was actually performed:

> CP 17: [ILD 08] does most of his care himself if I tell him to do it. So just after breakfast I just say, 'Did you remember to brush your teeth?' And usually that's enough, and he'll go in.

One CP participant spoke to us about the importance of the ILD actually performing the practice of oral self-care, however, she had to continually remind him to brush his teeth by using specific commands and by supervising him in the process:

> CP 07: We sort of remind him to brush his teeth, right? And as much as possible, I would like him to do it himself. But like I said, supervise again... And then the denture, you know, remind him again to have that in the solution, just remind him as much as possible and let him do that.

This CP participant gave instructions to her ILD loved one for both denture care and oral self-care to brush his natural dentition. Regardless of having to cue and oversee the ILD, this CP participant was adamant about having her husband retain as much independence as possible.

Persistent verbal reminders were key to having an ILD participant successfully initiate the process of oral self-care. In the following example, the CP participant acknowledged her husband's autonomy and preference for independence but gave reminders, observed him completing care, and "picked her battles" by choosing to not prompt her husband to floss:

> CP 06: My husband basically brushes his own teeth, but I have to be there to remind him to do it, to make sure he does it. And that's all he does. He won't floss, and even the brushing sometimes, he doesn't brush properly. But he won't let me do it [Laughs].

This CP explained that even though she recognized the quality of toothbrushing might be compromised when her husband completed oral care independently, she emphasized that his desire to brush independently superseded ensuring quality of oral health care. Therefore, the CP spoke about letting her husband continue to complete his own oral self-care and related it back to preserving his sense of personhood. In addition, she confirmed that while her husband might be completing the activity, she needed to initiate the behaviour. Boundaries of responsibility for remembering oral care shifts to CPs, as the ILD experiences cognitive decline from being wholly independent to partially independent while ILDs attempts to maintain the actual physical nature of oral care.

CP Assisting for Action

Assisting for action was a technique used by CP participants to promote independent oral self-care. Care partner participants used support strategies to allow the ILD to perform the manual portion of oral self-care independently. This took form by marking and placing dental tools in accessible areas and purchasing supplies when needed. One CP participant talked about how making individual markings on both the toothbrush head and its storage place would trigger the ILD to remember which toothbrush was his:

> CP 20: One thing that just recently started to happen is we have an electric toothbrush, but he doesn't always remember which head is his, and he lost a couple. I don't know where [Laughs], but we're trying to mark where to keep his, make a mark on it so he knows. Because they have little coloured rings, but he wouldn't remember what colour was his, so we're trying to write his initials on there.

This technique provided the ILD participant with the reassurance that the equipment was his own. This strategy guaranteed the ILD some level of independence with external support from the CP participant. Another useful strategy that this CP participant shared with us in the FG session, was the use of labels when supplies, such as toothpaste, ran out:

> CP 19: I had a problem with [ILD 09] not telling me – she would say, "Oh, yesterday I ran out of toothpaste," and it was like, oh. So, I bought her six and the last one, there's a sticker on it saying, "Tell [CP 19] to buy more toothpaste."

Again, this option allowed the CP participant to set up some added support that was not directly involved with the actual oral care activity.

ILD Perspective: Accepting or Resisting CP Efforts to Support

From the ILD perspective, PI means that they are either willing to accept or resist CP participant efforts to support them in oral care. Some ILD participants recognized certain changes as their dementia advanced and thus were willing to accept CP efforts to support them in aspects of oral care. One ILD participant spoke about how he had begun to confirm scheduled appointments with his wife since he had the tendency to imagine booking appointments that were never actually planned:

> Interviewer 2: So, you make some of your own appointments?
> ILD 01: Yeah, and that's diminishing over time. Because I can tell her that I'm going to do something first thing in the morning. Like I'll say, "I'm going to call my doctor…and I'm going to make an appointment this morning. But nowadays I think it's just there has to be follow-through, or I won't know that I've actually done it. I could actually fictionalize an

> appointment and stuff like that, and go there, right? Just because I've written it down, but really, there was no substance there.

This quotation reflects an awareness that ILDs have with respect to requiring additional supports. Some ILDs participants were able to notice their limitations, and as such, accepted that assistance from their CP was necessary.

Other ILD participants spoke about how the task of oral care was so personal and intimate that it surpassed responsibilities of what the ILD was willing to accept from their CP. Some ILDs said that accepting help with oral self-care challenged social boundaries of the CPs. One ILD stated that he would much rather be institutionalized than to have his wife, who was a Registered Nurse, assist him in nightly oral care:

> Interviewer 2: So, are your care partners ever involved in your oral care routines?
> ILD 08: Oh, God. Heaven forbid… Heaven forbid.
> Interviewer 2: No?
> ILD 08: No, if she has – if I get to the point where she has to brush my teeth for me, send me away to a home somewhere. Don't – don't – you've got better things to do with your life than brushing my teeth at night. [Laughs]
> Interviewer 2: Really? So, if you do get to a point where you need assistance with oral care, you would prefer that she NOT do that for you?
> ILD 08: Yeah. Because I'd probably need care in a hell of a lot of other places, okay?
> ILD 07: You're not up for that?
> ILD 08: To me that's – I mean, she's a nurse, she'd do it, but she's my wife.

This discussion showed that some ILD participants were much more resistant to their CPs' assistance and help in oral self-care.

In summary, though partially independent (as a level of independence) was much more challenging for both participant groups to self identify, in our assessment of the data the majority of the ILD participants are actually in this category (Table 4). Partially independent ILDs required assistance, from CP participants' perspectives and this included cues for action or assisting for action. Additionally, PI from the ILD perspective was demonstrated by either a willingness to accept assistance from a CP or resisting any efforts to support routine oral care.

Transitioning from Partially Independent to Wholly Dependent (WD)

The second transitioning phase occurs between partially independent to wholly dependent (WD). This phase within the levels of independence is associated with CP participants who have exhausted all resources and strategies of assisting an ILD to complete oral self-care semi-independently before having to step in and complete the task for the ILD. Several CP participants discussed how dental professionals often prompt CPs by asking about an ILDs oral care routine, by performing treatment on an ILD, and/or making recommendations on how improve the current oral health status of the ILD.

One of our CP participants spoke about how giving verbal cues to brush one's teeth and mouth actually creates problems such as agitation. This participant mentioned that in giving any directions to an ILD, one should avoid rushing or else the ILD would actually forget what they were supposed to be doing:

> CP 17: If I rush him. That is the biggest problem. Like, 'What are you doing in there? Are we going to go soon?' Then it's not going to go well.

In this particular case, the care partner noted that strategies that had worked well for other CP and ILD participants were ineffective for her ILD loved one. Therefore, for this ILD, the CP provided more directed guidance to avoid confusion and complete oral self-care.

Another CP participant described how if he saw food impacted between his wife's teeth, he would advise her to brush her teeth immediately. He would then notice that she would come out of the bathroom, but the electric toothbrush was still on. Somewhere between cueing his wife to go brush and the washroom, she may have become confused and was unable to complete the task:

> CP 18: What I'm noticing, is that she's got pieces of food in her mouth and her teeth and when she opens her mouth we just tell her to go brush her teeth or there's something on your teeth, but you know, she just – she probably gets confused too because I've seen, or I've heard the machine [electric toothbrush] go and then she's walking down the hallway. And I'll say, 'Oh, you forgot to turn it off.' So, she turns around and goes back and forgets what she's supposed to do there.

This CP participant noticed that more guidance and supervision was required for his wife as she became confused when given directives, indicating that her level of independence had transitioned from PI to WD.

Some CP participants did not recognize the need for additional assistance in their loved one's oral care. Within our FG data, participants reported that dental professionals often initiated conversations with CPs about the oral health status of the ILD in attempt to improve their current oral health. This CP participant told us that he assumed everything was going well with his wife's mouth and teeth until the dentist directly asked if she was cleaning her teeth and denture:

> CP 10: I assumed everything was going good until we had to go to the dentist. She's got an upper plate and a partial in the bottom, to get it checked out. Then he asked me, "Is your wife cleaning her?" I said, "As far as I know. She's got a bathroom upstairs, I've got mine downstairs, and I do basically everything except her own personal care. She takes care of that." So I was quite surprised. When we got home I asked her, she said, "Well, what do I do?" So I told her get her denture, put it in a glass with a pill and your own teeth, you take your partial and brush it." [She said] "I don't have nothing." I said, "It's all in your cabinet."

This quotation illustrated how an activity such as oral self-care is often assumed to be completed independently unless indicated by dental professionals or vigilant CP participants who notice declining behaviours in ADLs. Similarly, another CP participant explained how she was unaware of her mother's oral health status until the dentist reported numerous concerns:

> CP 05: So we didn't realize that things were going amiss. But now, this past year's been really bad for her teeth. A lot of them have broken off, and our dentist says, 'Let's just deal with it one tooth at a time,' rather than like if we got her dentures at ninety, you know.

This CP spoke about how she was pleased that the dental professional took into consideration her mother's age and cognitive status when developing a patient care plan. This CP indicated that she appreciated that the dental professional was understanding and attentive to her mother's most imminent oral concerns.

Other CPs described how dental professionals made suggestions about products or tools that might make oral self-care easier for the ILD, as well as to ease the load on the CP themselves:

> CP 17: He uses a rotating head on his brush too, because the dentist did suggest that we do that, that it would be a better job.

This phase of transition from PI to WD was associated with CP participants who have exhausted all their strategies to encourage oral self-care of an ILD. Sometimes, CP participants are actually unaware of the current state of the ILDs mouth until the dental professionals brought this to their attention and suggested feasible treatment planning and oral care recommendations.

Wholly Dependent (WD)

Wholly dependent refers to the complete provision of all aspects of oral care for the ILD. ILD participants explained that WD occurred when the dementia has progressed too far to care or be aware of the state of their own mouth and/or teeth. CP participants also discussed how, for an ILD who is wholly dependent, oral care cannot be completed without considerable or complete assistance by a care partner. If this level of assistance cannot be provided, oral care typically is not completed. One CP participant spoke to us about the difficulty in providing oral care for her mother, and indicated that her mother would only allow either her or her sister to assist in toothbrushing:

> CP 05: My mom has just quit taking care of her teeth completely, and probably about the last five years it's gotten quite bad. Now her teeth are breaking off. I use those little sponge

> things, and so she'll only do it if my sisters or I are there and say, 'Mom, you know, we're going to clean your teeth.' That's about it.

Care partner participants who provide this level of care for their ILD loved one discussed an awareness that the ILD was no longer adequately completing his or her own personal care. Consequently, CPs spoke about "stepping up" to complete oral care for their ILD loved one. One CP participant was getting assistance from a homecare worker who was also instructed to complete oral care, even if force was required:

> CP 16: He's not doing his own teeth at all anymore… He wasn't doing a good job, so I have to do that. Weekdays when I'm working, the home care workers comes in after I leave, so as far as I know she's doing that. She says she doesn't have any trouble doing that because she's forceful with him.

The same CP participant talked about the unpleasant and intimate nature of performing toothbrushing on the ILD as he had become reliant on her assistance in care:

> CP 16: So he's going [Moaning noise] and pushes everything, so I find him very frustrating but I do it, so it's getting easier for me because I've sort of built up my tolerance…and it really, really bothers me doing the front teeth, because it sprays in my face. It's very problematic brushing the teeth, keeping them clean.

This CP spoke candidly about the challenges of a spouse assuming a role of direct care that she was not anticipating nor prepared to complete. In the video data, this CP participant displayed negative body language, as her arms were in front of her chest with a furrowed brow. Even her tone through the discussions of assisting in oral care activities sounded as though she found it very challenging to assume this role.

In addition, one of our ILD participants, who was deemed WD from FG data was unable to answer most oral care related questions or would answer with short "yeah" and "no." From our video data, when Interviewer 2 asked where this ILD participant would use a denture brush, she motioned to her bottom and laughed. From her husband's retellings of her oral care, she now required full assistance. This ILD participant never overtly mentioned that she required this additional assistance, however from our data and from her husband's answers, we were aware that she was WD with respect to oral care activities.

Summary

In summary, as we talked with the CP participants, it was evident that there was a continuum of the levels of independence that CPs acknowledged and tried to support as a way to preserve the ILDs sense of autonomy but to balance that with ensuring that these essential ADL were actually completed. Care partner participants monitored their loved one if they thought their loved one was independent; they watched and listened to see whether toothbrushing and flossing were done and looked for evidence such as supplies dwindling as a reassurance that self-care was being completed. However, at various points, CPs realized that brushing and/or flossing was not being remembered or was not being done adequately. This initiated a period of transition into partially independent care, where the CPs needed to cue the ILD through reminders or by providing structural support such as preparing dental equipment the night before. The last level was wholly dependent care where it was clear to the CP participants, through their own observations or recommended by their dental professional that they needed to actually provide physical interventions to ensure oral care occurred.

Theme 3: Relying on Embodied Habits

Oral hygiene related embodied habits are those practices that people learn as part of their social conditioning early in life and is a social norm practised throughout one's life. Within our study, relying on embodied habits of oral self-care is having a normative expectation that one brushes their teeth, ideally two times a day, and flosses daily. Most people in Western societies learn this practice in early childhood and continue to practice it throughout life. In the context of our study, relying on embodied habits was a way for CP participants to assume oral self-care was being completed. From the ILD perspective, habits such has toothbrushing were thought of as automatic, regardless of a dementia diagnosis. This theme appeared when CP participants were discussing ways to maintain an ILDs autonomy, which was often by relying on preexisting oral self-care habits. Two additional subcategories will be discussed within this theme, including: the evolving role of a CP and overcoming concerns of oral self-care practices using various strategies.

One ILD participant spoke to us about the engrained nature of oral self-care. He touched on the fact that it was a habit that formed at a young age and was practised as part of a routine. In fact, he mentioned that maintaining his oral self-care routine helped him work through symptoms of his dementia:

> ILD 07: Again, I reiterate that it's one of the positive things about the routine, and that just happens to be one of those things, so in that way it's self-serving that you brush your teeth because it helps you stay in that whole process of routine, and in a way, it's rewarding for you too. And I've always had good teeth. I haven't had a lot of cavities or anything like that, so again, that's something that's been engrained since you were a young child and since your first dental appointment. That's one of the last sort of things I would imagine would leave your consciousness or your sub-consciousness.

This ILD participant's statement encompasses the whole theme and shows that while forgetfulness is common with dementia, by maintaining a routine that has been engrained for years, one might be able to still complete oral self-care independently. Care partner participants would make statements about never forgetting something as routine or basic as toothbrushing, regardless of the overall decline they have witnessed in the ILDs. One CP participant even compared toothbrushing to riding a bike as the criteria for never forgetting:

> CP 12: They've done it all their life, and I don't think it's - it's like riding a bicycle, you never forget how.

Regardless of the challenges CP participants may face when dealing with other aspects of the ILD, they still viewed oral self-care as an activity that one would never forget.

Similarly, other CP participants shared the same belief that the process of performing oral self-care is involuntary and automatic:

> Interviewer 2: Did you say that your wife brushes her own teeth, or that you do?
> CP 04: Oh, yeah. That's never been an issue.
> CP 05: That's not an issue.
> CP 04: No, I haven't had to get into that. That's just automatic. She gets her little plate in and out. It's ingenious what they can build. This one passes over the roof of the mouth and has a couple of extra teeth. But I really don't know how many teeth she has.
> Interviewer 2: She has no problems doing her own?
> CP 04: No, it's just automatic, yeah.
> Interviewer 2: It's just automatic?
> CP 04: Yeah.

This CP participant's wife had, what seemed to be, a more complex dental history with a mixture of both natural dentition and partial or complete dentures. Despite the complexity of the ILDs mouth, her husband still believed that she was capable of completing this automatic task.

Other participants reinforced that a habit or task that has been done throughout someone's life is assumed to be hard to forget. In the following case, a CP participant mentioned that toothbrushing typically occurred consistently throughout someone's life, whereas taking medications usually happens in the later years of one's life. Therefore, toothbrushing should be one of the last engrained habits to be forgotten:

> CP 04: I think one of the differences with brushing teeth is it's something you really have done all your life. If you haven't taken medication until you're older, it's hard to keep track of the days or, you know, remembering to take it, even if you have a Dossett.

This comparison between toothbrushing and taking medications presented by a CP participant assumes that habits from early childhood are forgotten last, which is typically how dementia is explained to loved ones. Throughout the FG session, both CP and ILD participants would often respond abruptly when asked to detail the steps of caring for one's teeth:

> ILD 04: There's nothing difficult about it. You just go do it and get on with it.

These engrained habits were sometimes hard to simplify into distinct steps because they have been seen as one large activity for so many years. Some CP participants spoke about the breakdown in these embodied habits with the progression of dementia. One CP participant voiced how her mother would enter a washroom but forgot the reason she was there and leave without having done anything involving mouth care:

> CP11: If she walks into the bathroom and she doesn't know what this is for, she may have a vague idea in her mind that she needs to brush her teeth, and by the time she's looked over the counter, I mean she may have thought she HAS brushed her teeth. I know she's getting them cleaned at the dentist but I really don't know what she's doing in between. So it may still be happening. If I ask her she'll say she's doing it. You know, because like everyone else has said, she has been doing this for years, but I can see that there's definitely going to be, if not yet, definitely would be an issue. And leaving an itemized list would mean nothing.

Some CP participants recognized, that at some point, through the progression of dementia that these embodied practices might not be done to completion or at all.

Both CP and ILD participants stressed the importance of daily oral self-care. Throughout the FG sessions, adjectives describing the unconscious, involuntary, and almost automatic nature of routine oral care practices reassured the CP participants that this activity was most likely occurring. At the different levels of independence, these engrained habits become a facilitator or inhibitor of good oral care practices and influenced the way CP participants were supporting the ILD loved one. While participants relied on embodied habits to guide these self-care practices to completion, others noticed that habitual breakdown was possible as the dementia progressed. This is where we began to see realizations occurring through the FG process itself and the emergence of a more supportive role change for CP participants.

Evolving Role as a CP

Both CP and ILD participants talked about the need to recognize and negotiate their roles, as the ILDs needs changed and grew over time. Some CP and ILD participants talked about this as a natural evolution of the dementia. In particular, CP participants who were spouses of an ILD, naturally stepped in to assist more, as the ILD's level of independence decreased over time. One CP participant spoke to us about the difficulty becoming more involved, especially because she does not want the ILD loved one to see it as an insult:

> CP 08: So you try and be helpful. So, I get what you're saying, and when you were talking, then I am projecting it forward and thinking, yeah, because when it comes that he's forgetting to do it, then it's a problem on how you're going to be able to approach the fact that you need to help this person do this, when they're seeing it as a putdown.

This CP realized the importance of becoming more involved, but their main concern was how the ILD would view the added assistance. Another CP participant described the challenges faced with all other ADLs, not just oral care. She discussed that all of it was difficult and that she felt responsible to complete all of these tasks for her husband, as she realized he was not doing an adequate job:

> CP 16: Getting dressed, going to the bathroom, showering. My husband, you know, he just needs help with absolutely everything and NONE of it is easy.
>
> CP 16: He's not doing his own teeth at all anymore… He wasn't doing a good job, so I have to do that.

This CP participant did not provide consent for her husband to participate in the ILD focus group session, even though it was occurring at the same time as the FG session she took part in. She described her role change as very taxing and requiring a lot of attention and adaptation when required. This same CP participant talked about techniques for performing oral care on someone else's mouth and how it varies greatly from brushing one's own teeth. The main challenge this CP discussed was the lack of cooperation from the ILD which meant the CP found it a frustrating and unpleasant experience. Some CP participants viewed completing an ILDs oral care as a purely technical act, while others found that it violated social norms and found it to be a physically offensive task:

> CP 16: And so, I use the pick end to clean out the food because you can't brush it with all that food in it. So I clean it out as good as I can, and it really bothers me doing it. Like he's got his tongue going, pushing things out of the way all the time. He's not doing it on purpose; he thinks he's helping. So he's going [Moaning noise] and pushes everything, so I find him very frustrating but I do it, so it's getting easier for me because I've sort of built up my tolerance.

Throughout the levels of independence, CP participants discussed resistance to completing a loved one's daily oral care. One CP participant, who was a practising nurse, mentioned that she would like to be more involved in her ILDs oral care, but she gags at the sight of it:

> CP 17: I need to be more of a watcher but I'm a gagger so I'm not sure how that's going to go either.

This CP participant who had formal training in personal care activities expressed she felt an added level of disgust with someone else's oral care.

One CP participant elaborated on the physical reaction she experienced when brushing her husband's teeth, noting her personal aversion to it:

> CP 16: Just however long it takes me to go around and do it, and it really, really bothers me doing the front teeth, because it sprays in my face. It's very problematic brushing the teeth, keeping them clean.

This activity is quite problematic for a spouse to complete in an ILD, especially because CPs receive no formal training in oral care provision. This CP participant explained how intimate care activities violate the normative boundaries between husband and wife. She mentioned that aspects of personal care, not just oral care, are hard to complete, especially because this dependency is unexpected in an adult:

> CP 16: It does make me feel grossed out but so does wiping his bum, so you know, you just don't expect to be doing that to an adult, right? You do it with your children. You don't expect to have to do it with your husband, but. So I think it's all difficult.

Even though these CP participants were committed to their new role in supporting the ILD in ADL, there were some activities that challenged social norms and were difficult to complete.

Strategies to Promote Oral Hygiene Practices

Care partner participants rely on the engrained habits of the ILD as much as possible, but when these habits become insufficient, due to a decreasing level of independence, CP participants then implement supportive strategies. This theme was quite pervasive in the FG data, with ILD participants suggesting their own supportive strategies. Since CP participants were stepping into a new assistive role, some of their recommended strategies were attempts to make the task of oral care much easier for themselves. One such example was the suggestion to removal all-natural dentition of an ILD and have them replaced with a denture prosthesis:

CP 05: Maybe at an early stage you pull them all out and put dentures in. [Laughs]

Conversely, some CP participants realized that dentures might, in fact, cause more confusion in an ILD and recommended this suggestion be avoided:

CP16: Losing their teeth and then having to get dentures. [Laughter]
CP17: That would be a party in itself.
CP15: Yeah, some people don't wear theirs.
CP17: Yeah.
CP15: …Like some people just – and I would think if they'd had their teeth all pulled when they're later on in the dementia, I think they probably won't wear them. But I could be wrong.

Another CP participant jokingly questioned if the concept of canine biscuits for humans would be a useful strategy for oral care in an ILD:

CP 14: Every time I see that ad on TV about a dog and dog biscuits [Laughter], I think well, if you can do that.

Although some CP participants made recommendations that they thought could help an ILD to complete oral care independently, others made suggestions to assist in their own comfort in the role of CP when performing their loved one's mouth care:

Interviewer 3: And what would make it – so if you were doing it, what would make it easier for you to help?
CP16: A facemask.

Some CP participants completely avoided addressing practical strategies, but focused on reflecting back prior to their loved one's dementia diagnosis:

CP 01: A magic wand. [Laughter]
CP 05: Yeah, I wish I could go back five years, maybe ten years.
CP 02: I couldn't say he had the greatest oral health before the dementia, so that's just - it's already like, you know, he probably wouldn't have all the dentures and that kind of stuff if he took better care of his teeth back then. So now it's just whatever you can do, yeah.
CP 03: He doesn't care now.
CP 05: I think that's a lot of it. They just quit caring. Like my mom, all the things that she cared about, yeah, they - like if she's - ten years, if she could see what her mouth looked like, she would be horrified. She doesn't care.
CP 06: Yeah. That's what I find. He doesn't care.

Some CP participants were at a loss and did not know what would make oral self-care easier for an ILD or for the CP to help provide oral care for their ILD loved one:

Interviewer: What could make it easier for you to care for their mouth or their teeth?
CP 02: [Laughs] I don't know what other solution. He could brush, or he won't brush. I don't know.

When asked what would make your loved one's oral care easier, most CP participants responded with possible dental tool recommendations that they thought would make the physical task of oral care easier:

CP 18: But the electric toothbrush, to me would sound a lot better than the hand brush. And then picks, that's better than handheld floss.
CP 15: We used to have the handheld floss and he's moved to the picks, and I think that came from the dentist.

CP 08: Well, I really like those little picks instead of the dental floss. Because I think that they're easier to do and we have a drawer full of dental floss. And now we've quit the dental floss.

Lastly, CP participants recommended structural supports to assist ILDs in oral self-care. Most CP participants opted to introduce concepts and ideas that have worked for other ADLs to assist ILDs in oral self-care:

> CP 17: I thought about a step by step thing. This was for something else, not oral care, but still in the washroom, and it worked perfectly the first time, but then he threw away the steps because he'd finished them, and I haven't repeated that.
>
> CP 08: I have a basket that sits on - right on the end of the vanity, and it has everything in it, everything that he would need except for the humungous bottle of Listerine. But, you know, he knows that that's in the bottom cupboard. But everything is right in front of him all the time, so it's easy to remember, you know? …so he doesn't have to look for it so he doesn't have to remember where it was put. And that seems to help for us.

Relying on embodied habits was universal amongst our participant groups. Throughout the FG sessions, numerous strategies for overcoming the difficulties with oral self-care was discussed. Care partner participants' roles continued to change as the ILD's dementia progressed, and as such, the suggestions that were vocalized tended to be easier for the CP themselves than the ILD.

Chapter Five

Discussion

This research study was centred on the experiences of oral care practices and concerns from the perspectives of 20 care partner (CP) participants and 9 community-dwelling individuals living with dementia (ILD) participants. The results outlined in chapter four highlighted CPs' desire to honour an ILD by maintaining their autonomy and sense of personhood. The ILD participants similarly stressed the importance of maintaining as much autonomy as possible, wherein oral self-care was emphasized as an ADL that helps one preserve independence in the face of a dementia diagnosis. Trusting existing embodied habits, such as toothbrushing, appears to help ILD and CP participants explain current or assumed oral self-care habits, thereby preserving sense of personhood, in early to mid-stages of dementia. However, as CP participant focus groups (FGs) evolved, many CPs also identified the need to develop strategies to help them determine when the ILD loved ones transitioned to a stage of dementia that required more assistance with oral self-care.

In this discussion chapter, I will analyze and interpret the findings from the present study in the context of existing literature. I will begin by outlining how the ILD and CP participant groups spoke openly about respecting and honouring a person, regardless of their dementia diagnosis. I will then explain how activities of daily living (ADLs), such as oral care, are viewed as a habitual practice and therefore are assumed to be completed. I will describe how CP burden is a barrier that can hinder oral self-care practice in ILDs. Finally, I will examine the important role dental professionals can and should assume in providing education, access to care, and other oral care support to ILDs and CPs.

The Person Behind the Diagnosis

Throughout our data, honouring personhood by maintaining autonomy was the underlying and motivating concept that influenced the development of our three main themes. The most salient finding from the current study is the desire of ILDs and CPs to maintain personhood of the ILD. Central to maintaining personhood is respecting that the ILD is a person who brings a wealth of information to share about their experiences of living with dementia. Consequently, research that seeks to understand practices and concerns of ILD's related to oral self-care needs to include the emic perspectives of ILDs. Individuals living with dementia have been excluded as participants or marginalized in studies about dementia because of the assumption in their ability or appropriateness to act as a research participant (Hubbard, Downs, & Tester, 2003; Velzke & Baumann, 2017; Wilkinson, 2002). Therefore, historically a proxy, such as a nurse or a caregiver, provides the voice of these potential research participants (Velzke & Baumann, 2017; Wilkinson, 2002). In analyzing current study findings centered around honouring sense of personhood, understanding factors that enhance ILDs' autonomy in research is of utmost importance, as identified by both ILD and CP study participants.

In addressing our primary research question on understanding the practices and concerns of community-dwelling individuals living with dementia, CP and ILD participants identified that it was integral to hear the voices of those living with dementia. As highlighted in the methodology chapter, an advantage of focus group methods is the synergistic effect that comes from the interaction between participants. Focus groups facilitated the participation of individuals living with dementia by enabling them to prompt one another as the discussion progressed. Hearing responses directly from the ILD participants helped us to access nuanced information that has historically been overlooked or reported by a proxy. The interaction between the participants through the FGs furthered the current body of knowledge by understanding ILD participants' emic perspectives of their own oral self-care practices. In addition, video data from ILD participant FGs allowed us to extract observational moments of an ILD to develop a deeper understanding and meaning of oral self-care. Some literature addresses the complex and often difficult verbal interactions with persons living with dementia and have suggested that considerable attention be given to observational data (Hubbard et al., 2003). Likewise, having familiar oral care props present in the ILD participant FG sessions was a way to trigger their memory and tailor our discussion around oral self-care practices. The presence of these oral care props also allowed ILD participants to touch, feel, hold, and sometimes physically use the props, without conscious thought. Succinctly, FG methods, video recordings, and oral care props helped to maintain ILDs' autonomy and personhood as active, engaged research participants.

Current literature on group reminiscence therapy suggests that the use of familiar props, aids, or photographs can evoke personal experiences and memories in individuals living with dementia (Kim et al., 2006). Reminiscence therapy was adapted from Butler's (1963) life review, where he suggested that reminiscing about the past would serve as an adaptive function for older adults (Butler, 1963). Our current study supports Butler's (1963) research, and within our ILD participant FGs no substantial challenges were encountered. Individuals living with dementia were able to speak candidly about personal choice, delegating responsibilities, and the physical task of oral self-care. While many of our ILD participants were reluctant to admit any substantial changes occurred after being diagnosed with dementia, they were willing to provide information with regards to how their ADLs and IADLs had been slightly adapted to allow CPs to provide supportive strategies to help maintain independence. Our research study engaged ILDs as active research participants, despite earlier literature claims of this population being unable or unfit to participate due to the signs and symptoms associated with dementia (Sutcliffe et al., 2015; Velzke & Baumann, 2017; Wilkinson, 2002). To encourage and empower autonomy of ILDs, future studies can use strategies adopted in the current study to include ILDs in research on dementia. Findings from our research therefore adds to the current body of literature by providing strategies to include ILDs in research in a way which promotes their sense of autonomy and personhood.

Our study findings identify that at the core of honoring personhood is to see the person despite limitations associated with the dementia. Findings from the current study indicate this is achieved by recognizing the ILD's personality, acknowledging their identity within society, and by encouraging autonomy in remaining capabilities such as oral self-care. As previously mentioned, studies have historically not included ILDs as research participants; however, the concept of the person behind the diagnosis has been extensively studied and continues to evolve through the inclusion of individuals living with dementia in research.

The current study also expands existing knowledge of dementia research by helping to view the disease through a more holistic lens, namely the perspectives of individuals living with the disease. In fact, the construct of maintaining personhood is of such importance in understanding oral health care practices and concerns of ILDs that this concept is situated as the uppermost circle of the model developed from this study (Figure 1). Honoring personhood by maintaining autonomy encompasses every other emerging idea, concept, and theme regarding oral health care practices of ILDs.

Findings from my study regarding honouring personhood by maintaining autonomy align with recent literature that emphasizes the need to encourage routine activities for ILDs to help foster a greater sense of self and personhood (Chung, Ellis-Hill, & Coleman, 2017; Marent, Wieczorek, & Krajic, 2018). In fact, our study findings indicated that CP participants believed maintaining personhood and autonomy becomes a priority of even greater importance after an individual is challenged with cognitive decline compared to individual's autonomy prior to the dementia diagnosis. When autonomy and personhood are challenged, preservation of autonomy and personhood becomes more overtly valued. Previous research suggests that preserving as much autonomy as possible by maintaining routines and practices creates a link and a sense of continuity to an individual's previous life, prior to the dementia diagnosis. (Chung et al., 2017; Marent et al., 2018). This idea of sense of continuity as a part of preserving personhood was infiltrated into every theme of my research, and has important implications related to the support and care collaboration between CPs and ILDs in everyday activities, such as oral self-care.

Care partner participants felt responsible for supporting an ILD in carrying out a variety of daily tasks. With the CPs stepping into a more assistive role, they found that they were constantly involved in decision-making for their ILD loved one. Simultaneously, CP participants felt inclined to encourage the ILD to take an active part in everyday activities, especially in activities that had specific meaning to that person or set in place a routine, both in their past and present life situations. At times, several CP participants spoke to how they felt a sense of internal conflict in assuming a more assistive role while still encouraging autonomy of their ILD loved one. For example, within our study, we saw that CPs made decisions for their ILD to maintain autonomy and personhood including allowing the ILD to drive, attending dental appointments unaccompanied, as well as completing personal care and oral care activities independently. In interpreting these findings in the context of the research questions posed in this study, it is important that oral care practices are developed to enable an ILD to maintain as much autonomy as possible, while concurrently helping the CP to feel engaged and aware of the ILD's oral health needs, so that the CP can be supportive in oral health ADLs as appropriate and in line with the amount of support required as the ILD transitions through levels of independence.

Although CP participants stressed honoring an ILD's personhood by maintaining autonomy through respecting their loved one in terms of personality, identity, and remaining abilities; ILD participants focused on how their diagnosis affected their identity within society. One of the barriers that hinders the complete understanding of personhood in dementia is the diagnosis or label itself (Garand, Lingler, Conner, & Dew, 2009). From a healthcare perspective, diagnostic labels like dementia are a way to classify individuals for both treatment and research purposes. In other words, diagnostic labels distinguish groups by a set of definable boundaries (Garand et al., 2009). Despite the benefits of diagnostic labels, such labels often create stereotypes, stigmas, and discrimination (Riley, 2012). Data from the majority of our ILD participants stressed the avoidance of labels. Individuals living with dementia mentioned that there would come a time, when they would no longer have the choice to keep their diagnosis a secret or hidden, as their appearance, diminished capabilities, and inability to communicate would be telltale signs their disease has progressed beyond a point in which voluntary disclosure was a choice.

Our participants were aware of the progressive nature of dementia, which typically results in the deterioration of cognitive, behavioural, and social functioning over time (Garand et al., 2009; Pierce, Lamers, & Salisbury, 2016). Their knowledge about the disease process, which was in part informed by their attendance at regular ASANT support group meetings, helped them understand how dementia typically progresses, as well as signs and symptoms common with cognitive decline. Our findings from the ILD participant FGs demonstrated a passive attitude with respect to disclosing their diagnosis to dental professionals both in hopes to avoid associated stigmas and to also limit the number of people that knew. For other ILD and CP participants, the idea of disclosing the diagnosis to dental professionals did not cross their mind as information that may affect their dental appointment, oral care, and possible dental treatment, at least not in the earlier stages of the dementia. The idea of withholding their diagnosis from those they felt did not need to know, gave the ILD control over one aspect of their disease. In a sense, nondisclosure helped to maintain a sense autonomy and personhood by avoiding the label of a dementia patient. This brings to bear important implications for dental professionals, which are discussed in further depth later in this chapter. One example that has relevance for dental professionals providing oral health care for ILDs, is that in addition to nondisclosure of their diagnosis, Riley (2012) indicated that anxiety is a common behavioural and psychological symptom of dementia that can be exacerbated in unfamiliar settings, changes in routine, and worry over how others may respond to their diagnosis (Riley, 2012). Without awareness of the dementia diagnosis and familiarity with these typical associated symptoms, a dental professional might possibly misinterpret the source of an ILD’s anxiety. As ILDs and CPs strongly value personhood and autonomy, dental professionals can help support the person behind the diagnosis by being familiar with patient management strategies to ease anxiety associated with unfamiliarity of a dental office setting. Even if the ILD has a history with the dental office, the ILD may feel like it is unfamiliar if they are in the later stages of the disease. Similarly, dental professionals need to be prepared to respond to ILDs disclosing their dementia diagnosis in a way that does not create anxiety for either the ILD or CP, but rather focuses on maximizing autonomy in oral self-care.

Honouring the person behind the dementia diagnosis also has implications for strategies that CP used to support their ILD loved one in ADLs including oral care. In our study, the strategies used by CPs varied greatly depending on the progression of the ILD's dementia. The fundamental principle guiding the approach and strategy CPs took in addressing oral self-care was maintaining autonomy and ensuring the ILD was at the centre of the decision-making process for aspects of the ILD's care in which they were capable. Initially, CP participants often agreed to suggestions that they may not have been completely sure of, but which the CP felt helped to honour their loved one's personhood and maintain autonomy in routine activities. For example, CPs cited choosing to have their ILD loved one complete dental appointments unaccompanied and yet acknowledged that the information the ILD was relaying to the dental professional might potentially be incorrect. In understanding values and expectations around personhood, CP's made decisions around oral care to support and respect an ILD's autonomy and to promote the ILD's sense of success by enabling them to maximize their retained abilities which linked them to their past self or routine activities they performed before the onset of dementia. A direct example from this study is encouraging an ILD to brush their own teeth, even if cognitive decline may affect the thoroughness of oral self-care.

However, practices to help maintain oral care of an ILD encompass considerations well beyond the oral cavity. For example, CP participants often referenced letting ILDs drive to familiar locations around the community. CP participants discussed the need to control the parameters of such activities so that they could be completed successfully and enhance a sense of continuity of self. In this particular example, controlling the parameters could be using GPS-navigation or being in the passenger seat when the ILD is driving. These factors highlight considerations with respect to accessibility of dental practices for ILD patients. Accessibility factors are developed later in this discussion chapter, but it is important to understand that by adjusting and negotiating the social context of the ILD and creating a safer and more encouraging environment, routine practices including oral care, may be better maintained and may limit the negative impact of the dementia (Chung et al., 2017).

This study also considered the concerns, values and expectations of care partners related to the oral health of their ILD loved one. One of the common concerns articulated by CPs was that they experienced increasing difficulty in verbal communications with the ILDs as the dementia progressed. To help preserve personhood CPs explained that rather than continuously reminding their loved one to complete oral self-care, which CP's felt could be perceived as nagging, they promoted and encouraged independence by collaborative care strategies such as ensuring oral care tools were labelled with identification markers, writing out simple instructions on a whiteboard, and or pacing out suggestions to reduce ILD confusion and negative behaviors. Care partners attempted to engage the ILD in daily routine activities that helped the ILD to exercise their will and sense of control. Therefore, the CPs' promotion of oral self-care, through passive strategies, can be interpreted as an attempt to preserve the ILD's self-worth and wellbeing. Ultimately, personhood was an overarching priority in how CPs supported the ILD loved one; however, CPs also recognized there were often barriers that hindered fully achieving autonomy because of the symptoms associated with progression of the disease. An implication from this finding is that dental professionals need to be prepared to support not only ILDs in maintaining personhood, as related to oral self-care, but also be ready to engage CPs in identifying strategies to help the carer in their assistive role. These considerations are further developed later in the discussion chapter as commentary on the role of the dental professional.

Assumptions in Oral Self-Care

Another central theme within our study was the practice of oral self-care as an embodied habit. This means that ADLs such as toothbrushing were viewed by participants as an engrained behavior that is almost undertaken without conscious thought. Just like bathing is an act of personal self-care that brings social implications, so too does oral care. The mouth and teeth are subject to personal, public, and professional judgement in that poor oral care can affect an individual's social interactions and own personal self-esteem (McKenzie-Green, Giddings, Buttle, & Tahana, 2009). Because of the possible social ramifications of not maintaining bathing or oral self-care as part of one's routine, participants in this study spoke to how these actions are embodied habits within oneself. It can be interpreted that these actions (i.e. bathing, toothbrushing) are "things that you just do" because of a normative social convention.

Care partner participants discussed how as dementia worsens, ILDs progressively require assistance with more aspects and activities of daily living. During FG sessions, CPs discussed the progressive changes in ILD function and behaviour, which resulted in CPs having to step in and assist their ILD loved one with ADLs. While CPs commonly discussed that part of the assistive role of being a care partner is to help with ADLs and IADLs as the ILD's dementia progresses, oral self-care was an ADL that CPs indicated they typically were less involved in supporting. Several CP's discussed that they believed the ILD was completing the task of oral self-care independently, which through synergistic discussion from the FGs, several participants recognized that the ILD may in fact not necessarily completing this adequately. For example, through the FG discussions, several CPs realized that the ILD loved one was not completing oral care because dental care products were not being used (i.e. floss was not seen in the garbage and the electric toothbrush was still running after the ILD exited the bathroom). The disconnect between CPs' assumption around ILD's oral self-care versus actual oral self-care completed by the ILD originated in a belief that because oral health was an engrained habit that the ILD was undertaking oral self-care in the same way they had done prior to the dementia diagnosis.

Oral self-care habits are like all other habits, in that, routine behaviours repeated regularly become customary (Paganini-Hill, White, & Atchison, 2012). The routineness of oral self-care similarly led CPs and IDLs to consider oral care as an embodied habit. Despite all the breakdowns in functioning and changes in behaviours that CP participants witnessed in their ILD loved one, they still rationalized that the task of toothbrushing was still performed daily. To reinforce the concept of embodied habit, CP participants rationalized that oral self-care of the ILD was being completed daily, as it had always been done prior to the dementia diagnosis. Many of the CP participants initially justified their assumptions that their ILD loved one was performing routine oral self-care by referring to the ILDs past behaviours of “good” or “great” oral care practices. Only through synergistic discussion during FGs did numerous CP participants start to realize that perhaps what they thought was being done in terms of ILD oral self-care, was in fact not happening. These realizations helped CP participants assess their ILDs’ oral self-care practices more clearly as they began to realize that assistance with respect to oral care was required, as it was with other ADLs. Similarly, several ILDs initially described oral care as something that one just does, and almost seemed to feel confused as to why one would research oral self-care of ILDs. However, again synergistic discussion led several ILDs to feel that support for oral self-care may become necessary with more advanced stages of dementia. The incongruence of perceived need for care versus actual need for care bears implications for dental professionals providing oral care for ILDs.

In understanding oral care practices of community-dwelling ILD’s and the aforementioned incongruence, findings from the current study regarding toothbrushing as an embodied habit can be interpreted in context of Self-Care Deficit Theory (Orem, 1991). Orem's (1991) Self-Care Deficit Theory in Nursing describes and explains the ability of individuals to care for themselves (Hartweg, 1991). This theory explains that a deficit in self-care occurs when there is an imbalance between the capabilities of the individual and the need for action. Self-care is described as a learned behaviour or as a deliberate action. However, in situations where all or some abilities are inoperable, someone like a family member, must perform the self-care; this is now termed dependent care (Hartweg, 1991). As discussed with both participant FGs, many of the activities completed as part of normal daily living eventually become challenging for an ILD to complete independently. Self-Care Deficit Theory indicates that ADL skills that are mastered early in life are relatively more preserved in senior years when compared to higher level tasks (Orem, 1991). Therefore, this theory can help to explain CP participants' belief that oral self-care would continue to be practiced following the dementia diagnosis because toothbrushing is a task that people complete throughout their life. Consequently, the perception of both ILDs and CPs was that toothbrushing would be a skill that would be hard to forget. To an extent, these ILD and CP perceptions and assumptions are affirmed by research which has found that instrumental activities of daily living (IADL) impairment often presents in mild cognitive impairment or early stage dementia, whereas basic ADL declines are often not present until moderate or later stages of dementia (Mlinac & Feng, 2016).

However, toothbrushing is actually a complex task with multiple steps, and consequently the embodied habit may indeed be subject to challenges with cognitive decline. When the task of toothbrushing is broken down, there are twenty-five distinct and identifiable steps in brushing one's teeth (Wehman & Kregal, 2017). While the action of brushing teeth does not on the surface seem overly cumbersome, as thought by both CP and ILD participants, the multi-step process to adequately achieve oral self-care makes toothbrushing a relatively complex ADL task. Consequently, individuals living with mild cognitive decline may either unintentionally skip steps or fail to complete one or all of the steps. This study finding has considerable implications for dental practitioners providing oral care for ILD patients. For example, the use of ILD self-reports, CP assumptions, MoCA cognitive assessment tool, and levels of independence determined by our analysis (see Table 4) can be clinically useful to help CPs and dental professionals explore and develop strategies to help ensure ILD's have adequate support for completing the task of oral care. Also, incorporating performance-based measures of ADL functioning may facilitate developing support strategies for ILDs (Mlinac & Feng, 2016). Currently these assessment tools of cognitive decline do not include assessment of an ILD's ability to complete oral self-care. As current study findings highlight that CP's perception of an ILD's ability to complete oral self-care may not actually reflect true ability, development of validated tools to assess an ILD's ability to complete oral self-care is an area for future research. Assessment of actual or true ability to complete oral self-care is important because ILDs who are not able to adequately complete oral health care may be at a higher risk for oral health and systemic health complications associated with poor oral hygiene.

Care Partner Role Responsibilities

The main purpose of this research study was to understand oral self-care practices and concerns of community-dwelling individuals living with dementia. Through our inquiry, care partner roles in supporting oral health care needs of ILD's often arose during CP participant focus groups. In fact, CPs indicated that there are unique considerations related to supporting an ILD in oral care relative to other ADLs such as bathing and toileting. One important aspect of understanding how care partners are coping with gradually increasing role responsibilities and increasingly intimate physical care is related to the relationship that the CP has with the ILD outside of the role of caregiver. Care of an ILD living in the community is often provided by spouses/partners, adult children, or friends (Pilgrim & Schiebel, 2018). Literature suggests that approximately 80% of care partners are family members, with spouses constituting the vast majority of familial CPs (Hall et al., 2014). In our study, seventeen of our CPs were spouses and three were an ILD's adult child. Providing care to a loved one living with dementia can be challenging emotionally, physically, and financially (Pilgrim & Schiebel, 2018). Caregiver or care partner burden describes the emotional burden experience through informal caregiving (Hall et al., 2014).

Care partner burden is known to be considerable when caring for individuals living with dementia compared to caring for individuals with other medical conditions (Etters et al., 2008; Hall et al., 2014; Pilgrim & Schiebel, 2018). This burden is even greater in ILDs that are community-dwelling because ILDs in community may not have as much care support from healthcare providers and aides compared to ILDs in LTC homes (Tremont, 2011). Our study specifically targeted participants diagnosed with dementia living in the community, therefore CP burden was anticipated to be higher than the burden associated with institutionalized ILDs. According to Hall et al. (2014), an ILD's degree of independence in performing IADLs was closely linked to CP burden, meaning the more dependent an ILD was with respect to an instrumental activity of daily living, the more stress a CP faced (Hall et al., 2014). This finding means that CPs may need to have support for ADLs such as toothbrushing. These supports are considered within the role of the dental hygienist in this chapter.

Care partners in our study who are a spouse of an ILD often experienced transitions or role changes within their marital relationship after their partner received the dementia diagnosis.

In our young-onset CP focus group, participants expressed how they had relinquished the mindset of couplehood to become a better CP for their loved one. One CP focus group had care partners who were employed either in full or part-time jobs, which complicated their work-life balance, adding to care partner burden. Care partner participant groups often expressed frustration about their current situation through the tone of their voice when sharing stories, and by their body language related to assuming this new role. Participants with ILDs in more progressed dementia stages communicated how occasionally providing basic care felt like reverting back to taking care of their children. Dental hygienists providing care for ILDs need to be cognizant that CPs may feel challenged in the transition to role of carer. Dental professionals can support CPs by being aware of possible resources and directing them if and when they are needed. Literature supports that these types of support groups can help reduce CP stress (Etters et al., 2008; Hall et al., 2014; Pilgrim & Schiebel, 2018).

Care partners articulated concerns and beliefs which impeded daily oral care of an ILD. One of the concerns some CP participants expressed was that the ILD would become upset if they attempted to aid or support them in brushing their teeth. This concern was paralleled in the ILD focus group sessions where participants stressed that they would much rather have a complete stranger perform their oral care activities than their spouses. In addition, one ILD whose wife was a Registered Nurse said he would much rather be institutionalized than have her brush his teeth daily. Occasionally, there was a sense that CPs did not feel that oral care was important enough to cross relationship or intimacy boundaries. Oral care, in some instances, can be viewed as a very intimate personal care practice (Chadwick, Chapman, & Davies, 2018). Some of our CP participants who actually assisted the ILD in oral care practices expressed great distaste for this activity and when asked what could make oral care easier a blunt response of "a facemask" was the answer. Therefore, our CP and ILD participants agree that the concept and action of having a CP assisting or performing oral care for their ILD loved one were deeply disliked and crossed relationship boundaries. This left both participant groups wanting advice on how to best provide support for someone in daily oral self-care practices. Dental professionals can help to normalize this experience by discussing how CP involvement in an ILD's oral self-care can help maintain the oral health, social acceptability, and self-esteem of the ILD. Preservation of these aspects on the person can contribute to a continued sense of personhood.

The concept of care partner or caregiver burden is not new. There is a great deal of research examining which resources and supports are most helpful for CPs of individuals living with dementia (Pilgrim & Schiebel, 2018). Informal care partners take on a new role and are expected to perform ADLs for their loved ones. These classic ADLs involve feeding, bathing, and toileting, which are well documented in current literature (Hall et al., 2014; Mlinac & Feng, 2016). Conversely, care partner burden related to oral care has not been extensively researched. Findings from the current study suggest there are unique factors related to providing oral care support. Interestingly, care partners within our FGs, expressed numerous anxieties and concerns associated with assisting a loved one's oral self-care, while they verbalized a calmness with supporting ADLs around incontinence and grooming. Toothbrushing is a unique ADL that CPs are expected to perform to maintain an ILDs overall health and quality of life. The findings from the current study highlight that CPs may not be adequately informed of how to support toothbrushing and what resources might help to support completion of this ADL. Future research can focus on co-creating strategies and resources with CPs to reduce care partner burden associated with oral self-care.

Role of the Dental Hygienist

Dental hygienists are registered dental professionals that work independently or alongside a dentist and or other dental professionals to provide preventative oral health services, to educate and empower Canadians to embrace oral health as an integral part of overall systemic health (Canadian Dental Hygienist Association, 2017). Canadian dental hygienists practice using a client- or patient-centred approach to provide care that is in the patient's best interest (College of Registered Dental Hygienists of Alberta, 2009). An underpinning of patient-centred care is that the client and their family are at the centre of their own health care decisions. This involves actively listening to clients and families, to engage them as a member of the healthcare team when making care decisions and to balance the dental professional's knowledge and expertise with the family's opinions and personal health knowledge. As stated by Edvardsson and Innes (2010) one important outcome of a patient-centred approach in treating ILDs encompasses:

> Valuing people with dementia and those that care for them; treating individuals living with dementia as a person; looking at the world from the perspective of the person with dementia; and providing a positive social environment to facilitate and promote wellbeing (Edvardsson & Innes, 2010).

Findings from the current study emphasize that a primary goal of patient-centred care is the maintenance of personhood in all areas of care and support of ILD patients. This approach attempts to honour the individual who may be struggling to be seen and heard behind the diagnostic label of their disease, which study participants emphasized can threaten personhood.

Early intervention by dental professionals is an important implication in this study. Dental professionals can support individuals' sense of autonomy and personhood, dispel assumptions associated with oral self-care as an embodied habit and support care partners in their roles through early assessment and patient/CP education. With early-onset dementia, routine dental care must be performed to eliminate the potential for pain, disease, infection, and to restore the dentition and or dentures. It is critical to anticipate future oral decline in treatment planning and to institute aggressive preventative measures, such as the use of topical fluoride, chlorhexidine, or both (Chen et al., 2013). Inclusion of early preventive and restorative treatment in early stages of dementia can help to preserve personhood by eliminating pain and infection that could compromise systemic health. An ILD's self-esteem may also be better preserved by prevention and treatment of oral disease, which when left unattended could affect physical appearance and possibly influence social interaction. Oral health care to preserve personhood was valued and prioritized by both CP and ILD participants. Therefore, oral health education and anticipatory guidance for CPs can help them maintain the ILDs' autonomy and personhood.

Dental hygienists need to be equipped to encourage and coach ILDs and CPs about common oral disease manifestations and provide anticipatory support for oral self-care. For example, this study highlights that dental professionals should use an anticipatory guidance approach to discuss common misconceptions related to oral care as an embodied habit for ILD patients. Additionally, dental professionals need to be cognizant of care partner burden associated with ILD care and prepared to work collaboratively to find patient-centred solutions. Current study findings indicate that when the dementia has progressed to where independent oral self-care is no longer possible, both CPs and ILDs find the transition stressful. Care partners and family members must be instructed on assisting their loved one with daily oral hygiene care, but preserving personhood means that this ongoing conversation between the dental professional, CP and ILD needs to recognize that this assistive role can be challenging.

Study Implications

My study helped me develop an understanding of factors that affect oral self-care practices in community-dwelling individuals living with dementia. I believe that my description of practices, beliefs, normative habits, and perceptions about the impact of dementia on oral self-care from the perspective of both ILDs and CPs can assist dental professionals to anticipate concerns and help improve current practices of community-dwelling ILDs and CPs. Accounts from both participant groups in the current study, accompanied by existing research from other disciplines, reinforce that oral self-care practices and concerns of an ILD are subject to multiple influencing factors including CP attitudes and applied strategies, community setting, and the stage or progression of dementia. Suggested recommendations that follow focus on achievable future steps to improving oral health outcomes in community-dwelling individuals living with dementia.

The first recommendation from this study is with respect to raising awareness of the impact of dementia on the ability of ILDs to complete what is assumed to be automatic and deeply engrained habitual practices such as oral care. An associated implication is to raise awareness of the oral manifestations associated with progressive disorders such as dementia. Once an individual receives a dementia diagnosis, he or she is offered support through well-established organizations that advocate for those living with dementia, such as ASANT. These organizations are outlets for ILDs and CPs to both receive and give information with regards to current challenges and complications of dementia. While ASANTs provides in-person and online resources, there is limited information provided regarding oral and dental care. Therefore, through collaborative efforts, ILDs, CPs, ASANTs, researchers, and dental hygienists could establish an oral health informational resource, either online or in-person, to offer pertinent information on what to expect, the signs and symptoms of oral pain, common oral manifestations associated with dementia, strategies on maintaining oral health, and other information that could support CPs in developing confidence and competences in oral care practices of the ILDs.

Furthermore, educational institutions need to ensure that classroom and clinical education for dental and dental hygiene students incorporates curriculum content pertaining to patients living with dementia. With the Canadian demographic trend in age increasing (Statistics Canada, 2015), future and current dental professionals need to be competent and comfortable in interacting with, and treating individuals living with dementia (Dougall & Fiske, 2008). As I discovered in my study, it is not always easy to identify if a person is in early stages of dementia and it not always clear when a CP should be invited to be a part of the clinic consultation. My study findings indicate that ensuring a CP is present may provide essential information from inferred monitoring that indicates adequacy of oral self-care. This raises tensions between respecting autonomy and person-centred care when bringing in the CP (Edvardsson & Innes, 2010; Sloane et al., 2013). Dental professionals should establish a collaborative relationship with their patients and their family/care partner in delivering oral health care treatment. It is essential that health history questionnaires, including cognitive functioning and ability, be disclosed to dental professionals as they will be able to tailor oral care strategies to better suit the patient's needs. Similarly, proper education and training for dental professionals may help improve knowledge pertaining to living with dementia and how to best support them and their care partners as well as improve communication between ILD patient, CP, and dental professional to encourage dental professionals to involve the ILD and their CP into treatment planning and decision making (Chiappelli et al., 2006; Edvardsson & Innes, 2010). This level of knowledge, transparency, and open communication will help the ILD to foster trust in their dental professionals.

At the professional level, the Canadian Dental Hygienists Association (CDHA) and various provincial associations and colleges have published numerous journal articles outlining and detailing dental hygiene visits with patients living with dementia. These in-print and online publications have encouraged professional awareness. Canadian dental hygiene associations and regulatory colleges can strengthen support for the provision of dental hygiene services in individuals living with dementia by developing position statements and policies that encourage professionals to provide preventative oral care or to seek training if needed. These position statements have potential to offer guidance to dental hygienists with regards to best practice, deliver consistent messaging, and serve as a foundation for developing strategy and policy to promote education and uptake.

The scope of practice for Registered Dental Hygienist varies across Canada. Alberta has one of the broadest scope of practice in which dental hygienists can practice independently and provide mobile services. Similar to Alberta, Nova Scotia dental hygienists have no additional restrictions to performing dental hygiene therapy in alternate practice settings, whereas dental hygienists in British Columbia and Manitoba have restrictions that limit the provision of dental hygiene therapy to specific practice settings and under the supervision of a dentist. In provinces with broad scopes of practice such as Alberta and Nova Scotia, the provision of mobile dental hygiene services could help promote oral care in both community-dwelling and long-term care individuals living with dementia. Dental hygienists should continue to advocate for the underserved population and work with both provincial and national governments and organizations, such as Alberta Health Services (AHS) and Government of Canada, to create tax incentives for dentists or dental hygienist providing mobile oral care services to community-dwelling individuals living with dementia. While mobile dental hygiene services were not the primary focus of our study, findings suggest that oral health care to community-dwelling individuals living with progressed stages of dementia will increase access to this population, as most will no longer be eligible to drive. In addition, these mobile services have the potential to increase patient adherence by decreasing patient confusion, as treatment can be provided in a familiar and comfortable setting. These study findings suggest ways to honour personhood of an ILD by maintaining their autonomy. Likewise, having a resource such as a provincial dental directory could help identify mobile dental practitioners and facilitate access to care. This resource would be beneficial to assist non-dental professionals to support ILDs in accessing oral care, and it could also help support dental professionals who do not feel comfortable providing care to this cohort, and as such could refer care in accordance with practice guidelines.

As of January 2018, AHS released a policy titled "Oral Hygiene - Provincial Continuing Care Designated Living Option" with the principle objectives to promote oral health, to prevent oral disease, to provide standardized recommendations and care, and to provide a framework for training health care providers in the provision of oral hygiene in residents living within an institution (Alberta Health Services, 2018). This policy will certainly promote accountability and raise awareness about oral hygiene in the context of long-term care homes or assisted living residences. However, these goals do not focus on community-dwelling individuals living with dementia, rather they prioritize those individuals living in long-term care homes or assisted living residences. Dental professionals need to advocate the government and organizations for equal priorities in both community-dwelling and institutionalized individuals living with dementia.

The current study also highlights the desire to improve interprofessional collaboration in individuals living with dementia oral healthcare practices. Since some CPs are still working full or part-time jobs, their loved ones typically stay home or attend support programs. Within these programs, numerous resources for nursing and occupational therapy are provided. It would be beneficial to include dental professionals information as a resource option. The inclusion of dental professionals could play a role in reducing barriers to the community or mobile dental hygiene services. With mobile dental hygiene services, transportation is no longer an issue and this, in turn, could help reduce care partner burden, as there would be no need to coordinate their schedules. Lastly, educational institutions and program directors are well situated to promote interprofessional collaboration at the faculty level between medicine, nursing, dentistry, and dental hygiene to facilitate consistent messaging across all disciplines.

Study Limitations and Implications for Future Research

This study sought to advance knowledge to influence the better provision of oral self-care in community-dwelling individuals living with dementia. Through understanding current practices of ILDs, this study provides a model that could help shape future strategies for improved implementation and uptake of oral self-care from both ILD and CP perspectives. Amongst the strengths of this study are the various participant profiles and the diverse understanding of the task of oral care and its importance. In addition, participants' comments are current, address the problem in a local context, and are lived experiences. However, an inquiry through research is a continuous process, and no single study achieves complete understanding, but rather raises new questions to help illuminate and advance current practices.

To the best of my knowledge, this is the first study to qualitatively explore community-dwelling individuals with dementia current oral care practices and concerns, from their perspective, as well as, their primary care partners perspective. Previous research has explored oral health status of those living with dementia predominately in the context of long-term care homes or other institutional settings.

This qualitative exploratory research design was based on uncovering new concepts rather than relying on preexisting ones. Participants were purposively selected, with the assistance of ASANT, to have diagnostic diversity. Six of the nine ILD participants were diagnosed with early-stage dementia, with the remaining three being diagnosed with young-onset dementia. Shadowed data from seven CP participants were with respect to ILDs who were placed in the respite dementia category. According to Morse (2001), data gathered by research participants in which they “speak-for-others” are deemed as shadowed data and are used to obtain information about a person or groups that are otherwise inaccessible (Morse, 2001). Additionally, CP participants had a range of employment from full-time, part-time, or retired. Current employment status of CP participants was relevant to this study as we were querying about added supports and possible intervention strategies used by CPs to completed an ILDs oral care. However, studies focusing on further progressed dementia, such as moderate to severe, typically took place in an institutional setting and as such oral care was either done independently or by the assistance of a care aide or nursing staff and not typically a family member. Consequently, the factors that affect oral self-care from our studies perspective may not be representative of all individuals living with dementia. Therefore, readers are encouraged to consider transferability of study findings in this context.

The impact of demographic variability was not explored in this study. The extent to which demographic variability affects practices and concerns of oral self-care in ILDs may potentially have implications for transferability of findings to other areas within Canada. There may be important differences that affect oral care between provinces that are yet to be explored, which may help with understanding oral self-care concerns in a national context.

While several participants, in both participant groups, spoke to us about some of the transitions that occurred as the dementia progressed, it is important to highlight that at the time the research was conducted, participants in the study were already placed in ASANT-specified dementia categories as either early-stage or young-onset dementia. Longitudinal case studies that follow individuals throughout the years and as the dementia progresses may support a deeper understanding of factors that influence oral care practices as one transition through the levels of independence.

It is important to acknowledge that qualitative research focus groups are an interaction between the researcher, as the instrument in research, and the participants. While this interaction and synergy is a major strength of qualitative research in developing thick, rich data, the researcher must be aware of how such sessions may have unintentional biases that may impact study findings. Chapter three includes a statement of reflexivity where I discussed my own biases and disciplinary lens when viewing this study.

Future research related to the implementation of strategies to improve oral health status and oral self-care in this underserved population is an important next step. An important step in the process towards advancing oral care is additional education and training for CPs on what to expect and how to manage oral care when dependency increases. Current CP participants have medical resources and support group sessions offered at ASANTs, none of which cover oral health care concerns and future probabilities. This current study reinforces this need based on participants accounts of the importance of education in facilitating oral care practices of their loved ones. To gain a better understanding of how this form of training can take place, we looked to the literature that focused on effective training strategies for professional caregivers such as, nurses and care aides, in long-term care homes. The literature showed that in-person training sessions and online webinars produced a significant difference between pre- and post-knowledge test results (Bonwell, Parsons, Best, & Hise, 2014). This approach not only increased oral care knowledge of caregivers but it encouraged a change in patient care that can be implemented in other facilities and health-related tasks (Bonwell et al., 2014). Next phases of research need to transition into testing possible home care strategies and online and in-support group educational sessions around oral care, in informal caregivers such as, a spouse or adult child, in a community setting, to address this noticeable gap.

Data were collected from the Edmonton Alzheimer's Society, and thus participants included in the present study were relatively active and engaged in support groups and health-seeking behaviours. This could potentially skew the findings from ILDs and CPs who are less involved in the community and dementia support networks. Future research should involve sampling strategies that target ILDs in the community that do not use support services. In addition, the sample in the present study targeted only English-speaking ILDs and CPs, therefore all those who cannot speak English were excluded. Given that Edmonton is an ethnically diverse city, a future direction would be to gain perspectives of non-English speakers to assess whether oral self-care practices and concerns also vary according to different cultures.

Participants in this study identified that there was an evident lack of awareness and knowledge with regards to oral self-care in community-dwelling individuals living with dementia. Participants spoke about how having educational sessions directed towards expectations will increase comfort and acceptance, while decreasing anticipation and anxiety. Moreover, as the baby boomer cohort ages, those diagnosed with dementia will face various challenges that CPs and dental professionals need to be equipped to support. Community engagement research aims to precipitate a change in healthcare through direct involvement with community members. This method of research might be a beneficial future step for community-dwelling individuals living with dementia and their care partners with respect to oral care.

Conclusion

The present study provides a foundational understanding of the practices and concerns of oral self-care from the perspectives of community-dwelling individuals living with dementia and their care partners in Edmonton. Understanding these practices and concerns is a critical underpinning towards developing supportive strategies by both CPs and dental professionals. To improve the provision of oral self-care in an ILD, we must address this interconnected structure by addressing CP attitudes, societal stigmas, and dental professional knowledge and training. Much of the data from this study can help to inform strategies to enhance and advance these changes. Honouring personhood by maintaining autonomy, transitioning through the levels of independence in oral care, relying on embodies habits together provide a model for future research focused on implementation strategies that could help improve an ILDs quality of life. It is hoped that this study will contribute to this advancement by promoting mechanisms to improve daily and routine oral care for community-dwelling individuals living with dementia.

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Appendix A.

Information Sheet to Authorized Representative

Study Title: Examining oral health practices, concerns and access in community dwelling older adults living with dementia

This information letter is part of the process of informed consent. It is intended to give you a basic idea of what the research is about and what it means for you and your care partner to participate. If you would like more information, please ask. Take the time to read this carefully.

What is the research study about?

Oral health is likely to get worse as dementia progresses, causing increased incidence of mouth disease and decay, which can lead to tooth loss, changes in eating habits, diet, and discomfort. Access to oral health care for older adults becomes increasingly difficult as they age, but people with dementia may experience additional challenges. This study hopes to find out what the oral health practices and access to oral care are for community dwelling older adults with dementia and their care partners. We also hope to learn what the concerns for oral healthcare are among community dwelling individuals with dementia and their care partners.

What do we hope to learn?

- What tasks of oral care you and your care partner find difficult
- What you and your care partner’s oral health concerns are
- What kind of access you and your care partner have to oral health care
- How accessible oral health care is for you and your care partner

What role can you play in the research?

- In a 1.5-hour group discussion with other care partners, a researcher will ask you to discuss your thoughts oral care and access to oral health care.
- Provide consent for your care partner to participate in a separate 1.5-hour group discussion about oral health.
- The group discussions will be audio recorded and video recorded.

Do you have to take part in the study?

- No one has to take part in the group discussion, but we welcome anyone who wants to participate in the group discussion.
- You are free to leave the discussion group at any time or refuse to answer specific questions. Your care partner will also be free to leave the discussion group at any time.
- You may request to have all, or portions of the content you or your care partner provided at the group discussions deleted up to December 31, 2016.

What are the benefits of taking part in the study?

- Individuals who participate in the study might be glad to know they are contributing to improving care for older adults.
- You can provide your opinions, which will help guide the development of future research.
- You will receive a $20 gift card for taking part in the discussion group. Your care partner will also receive a gift card. If you decide to leave the discussion group early, you will still receive the card.

What are the risks of taking part in the study?

- It will take about 1.5 hours for you to participate in the discussion group.
- It will take about 1.5 hour for your care partner to participate in the discussion group.
- You or your care partner may feel uncomfortable sharing your experiences in a group with others.

Will information about me be kept private?

- All information you provide will be kept private.
- Only the researcher and the research assistants will have access to the information that you provide. We cannot guarantee that others from the group will maintain the confidentiality of what is said during the group discussion.
- The researcher will store all information in a specialized data storage facility a minimum of five years.
- Your name will not appear in any research reports.
- Focus group content, with all names and identifying information removed, may be used by other researchers. They will have to receive ethics approval from the University to use this information.

Who can you contact if you have questions about the study?

- If you have questions about the study, contact Dr. Minn Yoon at 780-492-6574.
- If you have concerns about this study, you may contact the University of Alberta Health Research Ethics Office at 780-492-0302. This office has no connection to the study.

Appendix B.

Announcement of Study at Alzheimer Society of Alberta & Northwest Territories

Research Study
Oral health practices, concerns, and access for community-dwelling older adults with dementia

What is this study?

This study hopes to find out what the oral health practices and access to oral care are for community dwelling older adults with dementia and their care partners. We also hope to learn what their concerns for oral healthcare are.

What role can you play?

- You will be asked to participate in a 90-minute discussion group on your experiences with oral health practices and oral health care.

- You will be asked to provide consent for your family member with dementia to participate in a 45-minute focus group on oral health practices and oral health care.

You and your family member can participate if you both meet ALL of the following criteria:

1. **You** are the primary caregiver of the person with dementia,
2. **You and your family member** can speak English,
3. **Your family member** has been diagnoses with dementia,
4. **Your family member** lives at home (not in residential care)

Participation in this study is **voluntary.**

There are **no known risks** associated with participation in this study.

If you would like to know about this study, please contact ***Dr. Minn Yoon*** at
(780) 492-6574
minn.yoon@ualberta.ca

Appendix C.

Focus Group Guide (Community-Dwelling Individual Living with Dementia)

I expect the focus group session will take approximately 90 minutes for both persons living with dementia and care partners. The focus group will be audio-recorded and transcribed. I may also make some hand-written notes while you are speaking. Questions asked will be provided in text for your reference. You are free to not respond to any question if you so choose.

The project is being conducted in accordance with the Freedom of Information and Protection of Privacy Act and the information will only be used for educational purposes such as program improvements and academic publications and presentations.

1. Tell me how you care for your teeth?
    a. *Prompt:* Is there a certain routine you follow?
    b. *Prompt:* How many times a day do you brush your teeth/dentures?
2. What is hard about taking care of your teeth?
    a. *Prompt:* Are there particular steps that are difficult?
3. What could make it easier to care for your teeth?
    a. *Prompt:* What would make it harder?
4. Are there any future concerns you have about your teeth?
5. Are there any concerns about receiving dental care?
    a. *Prompt:* Is the dentist one you had been seeing in the past?
    b. *Prompt:* Describe how easy or difficult it is to make an appointment
    c. *Prompt:* Is it easy or difficult to receive oral health care
6. Is there anything else you would like to share with us?

Appendix C.

Focus Group Guide (Care Partner)

1. Please describe how you or your family member typically care for your family member's mouth/teeth?
    a. *Prompt:* Is there a certain routine that is followed?
    b. *Prompt:* On average, how many times a day do they brush their teeth/dentures?

2. What do you think is challenging in their daily oral care?
    a. *Prompt:* Are there particular steps that are difficult?

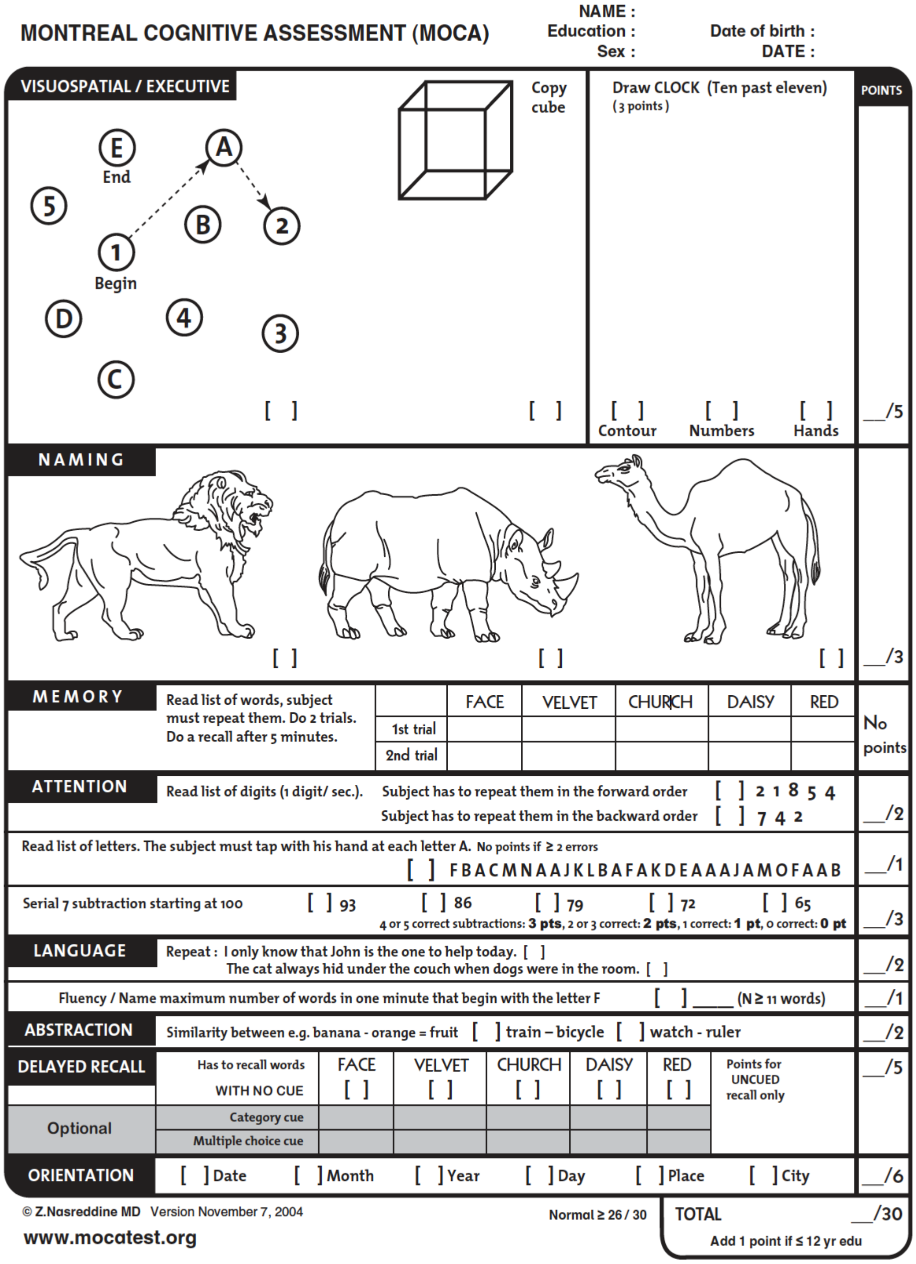
3. What could make it easier to care for their mouth/teeth?
    a. *Prompt:* What would make it harder?

4. What are some of the oral health concerns you have as their disease progresses?

5. What has been your experience in accessing dental care from their dentist?
    a. *Prompt:* Is the dentist one they had been seeing in the past before their diagnosis?
    b. *Prompt:* Describe how easy or difficult it is to make an appointment and receive oral health care for your family member.

Appendix D.

Montreal Cognitive Assessment (MoCA)



MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education :
Sex :
Date of birth :
DATE :

		POINTS
VISUOSPATIAL / EXECUTIVE [ ]	Copy cube [ ]	
Draw CLOCK (Ten past eleven) (3 points)	[ ] Contour [ ] Numbers [ ] Hands	___/5
NAMING	[ ] [ ] [ ]	___/3

MEMORY Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2 ___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B ___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 ___/3
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] ___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words) ___/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler ___/2

DELAYED RECALL

	FACE	VELVET	CHURCH	DAISY	RED	
Has to recall words WITH NO CUE	[ ]	[ ]	[ ]	[ ]	[ ]	Points for UNCUED recall only
Optional Category cue						
Multiple choice cue						

___/5

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City ___/6

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www.mocatest.org

Normal ≥ 26 / 30 TOTAL ___/30
Add 1 point if ≤ 12 yr edu

Appendix E.

University of Alberta Health Research Ethics Board Approval Form

Date:	November 17, 2015	
Study ID:	Pro00060323	
Principal Investigator:	Minn-Nyoung Yoon	
Study Title:	Examining oral health practices, concerns and access in community dwelling older adults living with dementia	
Approval Expiry Date:	Wednesday, November 16, 2016	
	Approval Date	Approved Document
Approved Consent Form:	11/17/2015	Information Letter_Dentistry Experts_Oral Health Practices_Oct 8, 2015.doc
	11/17/2015	Consent_AuthRep_Oral Health Practices_October 8, 2015.doc
	11/17/2015	Information Letter_Authorized Rep_Oral Health Practices_Nov 9, 2015_Clean.doc
	11/17/2015	Consent_Dentistry Expert_Oral Health Practices_Oct 15, 2015.doc

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application, including the following, has been reviewed and approved on behalf of the committee.

- Letter of Initial Contact Caregivers Oral Health Practices (11/9/2015)
- Letter of Initial Contact Dental Professionals Oral Health Practices (11/9/2015)
- Assent Script (11/9/2015)
- Assent Form Older Adults (11/9/2015)
- Focus Group Questions Caregiver (11/4/2015)
- Focus Group Questions Person with Dementia (11/4/2015)

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health should be directed to (780) 735-2274.

Sincerely,

Anthony S. Joyce, Ph.D.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

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Appendix F.

Consent Form for Authorized Representative

Title of Project: Examining oral health practices, concerns and access in community dwelling older adults living with dementia		
Part 1: Researcher Information		
Name of Investigator: Minn N. Yoon, PhD **Affiliations**: School of Dentistry; University of Alberta **Contact Information**: 780-492-6574 (minn.yoon@ualberta.ca)		
Part 2: Consent of Authorized Representative of Participant		
	Yes	**No**
Do you understand that you are asked to be in a research study?		
As the one who makes decisions for the person with dementia, you are asked to consent to have the person with dementia participate in a research study. Do you understand this?		
Have you received and read a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study for yourself and the person with dementia?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to take part in this study and are free to refuse to have this person with dementia participate in the study? You may withdraw yourself or the person from the study at any time. You do not have to give a reason.		
Have you received an explanation of confidentiality of information?		

Do you understand who will have access to the information gathered from these discussion groups?		
Do you understand that you and your family member will be audiotaped and videotaped during the discussion groups?		

Part 3: Signatures

This study was explained to me by the following person:

____
Researcher's Name

I agree that myself and the person with dementia may take part in this study. I am legally authorized to make decisions for this person.

____
Name of Authorized Representative

____
Name of Participant with Dementia

____
Signature Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate and have the above-named person with dementia participate in the study.

____
Researcher's Name

____
Signature Date