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The Lived Experiences of Formal Caregivers in Communicating with Persons Living with Dementia in Their Own Homes

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

There is limited literature focused on formal caregivers' communication with persons living with dementia (PLWD) in home settings. Yet, there is an expected need and demand for formal caregiver support within home care. Thus, the aim of this hermeneutic phenomenological study was to understand better the lived experiences of personal support workers (PSWs) during their communication with PLWD in home environments. Three major themes were identified through thematic analysis of semi-structured interviews (N=15): (1) challenged by dementia-related impairments; (2) valuing communication in care; and (3) home is a personal space. Findings reveal that PSWs experience difficulties communicating with PLWD, despite recognizing the importance of communication in providing optimal care. The findings suggest that while PSWs possess good intentions, they do not possess the skills necessary to ensure effective interactions. Findings have implications for optimizing practice and enhancing quality of care.

Keywords: dementia, formal caregivers, personal support workers, PSWs, home care, homecare, communication, education, training

Summary for Lay Audience

Dementia is a general term used to describe a collection of symptoms that are caused by diseases that affect the brain. Numerous diseases can cause dementia, including Alzheimer's disease, Parkinson's disease, and stroke. Symptoms of dementia include, but are not limited to, memory loss, confusion, communication problems and difficulties with thinking.

Difficulties with communication impact caregivers who provide care for persons living with dementia. The current study aimed to understand better the lived experiences regarding communication between formal caregivers, specifically personal support workers, and persons living with dementia who reside in their own homes. The study focused on the home care environment because there is a lack of literature focused specifically on the experiences of communicating within the formal home care setting. Much of what is known currently comes from long-term care home settings, or informal home care contexts. However, it is expected that more formal home care will be provided to PLWD in their own homes. One in-depth interview was performed with each participant (N=15) in the study. Three themes were identified: (1) challenged by dementia-related impairments; (2) valuing communication in care; and (3) home is a personal space. Findings suggest that PSWs need additional education and training in order to enhance their communication skills and to improve the overall quality of care provided to persons living with dementia. Similarly, findings suggest that family caregivers of PLWD require dementia-related education and training, as well as resources outlining effective communication strategies to use with their relative living with dementia. Home care agencies can provide these resources to family members of PLWD, and should support PSWs further by offering continuing education and training, providing information regarding clients' social history, improving and standardizing documentation procedures,

ensuring continuity of care, and reducing employer-level barriers experienced by PSWs in relation to accessing education and training opportunities.

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Chapter 1

1 Introduction

1.1 Dementia

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), classifies dementia as a major neurocognitive disorder (NCD) (American Psychiatric Association [APA], 2013). However, the use of the term *dementia* is retained in this new definition (APA, 2013). Dementia is a syndrome, meaning that it is caused by various diseases, such as Alzheimer's disease, Parkinson's disease, and stroke, among others (APA, 2013). The diagnostic criteria for dementia include significant decline in one or more of the following domains: complex attention, executive functioning, learning and memory, language, perceptual motor, or social cognition (APA, 2013). Further, the decline must interfere with independence in everyday activities, such as with complex instrumental activities of daily living (IADLs), not occur exclusively in the context of delirium, or be better explained by the presence of another mental illness, such as schizophrenia or major depressive disorder (APA, 2013).

Age is the most significant risk factor for the development of dementia (van der Flier & Scheltens, 2005). Indeed, the prevalence of dementia rises with age (Wergeland, et al., 2014). Other-non modifiable risk factors include those related to genetics and gender (Prince et al., 2014). Modifiable risk factors fall under four major domains: cardiovascular factors, developmental factors, lifestyle factors, and psychological and psychosocial factors (Prince et al., 2014). The prevalence of dementia is projected to rise rapidly with increases expected both globally and in Canada (Alzheimer Society of

Canada, 2016; Prince et al., 2013). There are approximately 564,000 Canadians currently living with the condition, with that number expected to grow to 937,000 in the next 15 years (Alzheimer Society of Canada, 2016). It is important to recognize that although dementia occurs primarily among older adults, it is not considered to be a part of the normal aging process (Wong et al., 2016).

The features that are characteristic of dementia are either cognitive or non-cognitive symptoms (McKhann et al., 2011; Sandilyan & Dening, 2015). Cognitive symptoms associated with dementia can include memory-related deficits, agnosia, disorientation, apraxia, compromised visuospatial functioning, and impaired executive functioning (Duong et al., 2017). Changes in language abilities fit within the domain of cognitive symptoms (Sandilyan & Dening, 2015). Non-cognitive symptoms involve disturbances in mood, psychotic features, and changes in behaviour (Duong et al., 2017). Dementia is progressive, and its associated signs and symptoms may not be noticeable fully in the early clinical stage. However, they will gradually worsen and become more apparent with the ongoing changes that occur within the brain (Sandilyan & Dening, 2015).

1.2 Understanding the Communication Changes Associated with Dementia

Communication is a basic component of everyday life. It is the means through which feelings, wishes, and needs are expressed (Jootun & McGhee, 2011). Language is the system of spoken, written, or signed symbols through which we communicate (Robins & Crystal, 2020). Communication has a significant role in maintaining quality of life, preserving identity, and enabling a sense of security and belonging (Jootun & McGhee, 2011). Persons living with dementia (PLWD) undergo changes in their

language and communication (Rousseaux et al., 2010). Indeed, changes in language is one of the six key diagnostic features of dementia (APA, 2013). Communication difficulties hinder the opportunity for social interaction and impedes PLWD from expressing needs in a clear and effective manner. Communication difficulties complicate the caregiving experience.

Accordingly, the purpose of this study was to understand better the lived experiences of formal caregivers, specifically PSWs, in communicating with PLWD in their own homes. The following section will explore the communication difficulties experienced by PLWD, beginning with an outline of the semantic and pragmatic changes associated with dementia. Next, the effects of communication impairment on PLWD will be outlined further. Proceeding this, a review of two theoretical models, the Communication Predicament of Aging (CPA) model and the Need- Driven Dementia-Compromised Behavior (NDB) model will be presented. These models aid in developing a deeper understanding of the relationship between formal caregiver communication and the behaviours of PLWD. The first model, the CPA model, provides a useful framework that allows for a better understanding of how and why caregivers modify their communication based on perceived communication deficits of older adults. It highlights further the negative effects of overaccommodated communication on the well-being of older persons. The second model to be discussed is the NDB model. The NDB model posits that behaviours exhibited by PLWD, such as aggression, are the result of unmet needs. The role of formal caregivers' communication in eliciting behaviours is noted in this model.

1.2.1 Communication-Related Changes in PLWD

PLWD experience significant changes in their communication-related abilities (Rousseaux et al., 2010). Changes in semantic levels of language processing and in pragmatics result in communicative impairments which impede opportunities for participation in meaningful interactions (Ryan et al., 2005). Semantics is concerned with the meaning of language. Semantic impairments experienced by PLWD include paraphasias (unintended words), problems with reading and listening, comprehension of words and sentences, word-finding difficulties, and deficits in verbal fluency, among several other features. PLWD also experience significant changes in their pragmatic skills. Pragmatics refers to the use and understanding of language based on contextual influences. Pragmatic problems among PLWD involve difficulties associated with the social uses of language. Pragmatic problems include issues of prosody, logical organization of discourse, the use and comprehension of gestures and figurative language, presenting new information, responding to open-ended questions, adapting to the social partner's knowledge (Rousseaux et al., 2010), and repetitive statements and questions, among other features (Bourgeois et al., 1997; Hamdy et al., 2018; Reeve et al., 2017; Savundranayagam et al., 2005).

1.2.2 Impact of Communication Impairment on PLWD

Communication deficits affect all aspects of daily life for PLWD (Downs & Collins, 2015). Communication impairments not only present difficulties for PLWD in receiving care to meet physical needs, but further impacts their ability to obtain care that fulfils their psychosocial and emotional needs (Cohen-Mansfield et al., 2015).

Impairments in semantic levels of language processing and in pragmatics impede the

ability of conversational partners to follow the thoughts of PLWD, and to maintain conversation (Ryan et al., 2005). As dementia progresses, the ability of PLWD to communicate effectively becomes increasingly impaired. Conversational partners may perceive inaccurately PLWDs efforts at communication as meaningless and confused (Acton et al., 2007; Stein-Parbury et al., 2012). When communication is misperceived, efforts aimed at developing a connection with PLWD declines, resulting in isolation, and a diminished sense of belonging (Acton et al., 2007). PLWD residing in long-term care (LTC) homes, in which there often are multiple opportunities for interactions to occur between caregivers and residents, generally experience paradoxically limited social communication with staff (Ward et al., 2008). Difficulties with communication experienced by PLWD contribute to this lack of social interaction (Ward et al., 2008). When interactions between PLWD and LTC staff do occur, they are task-oriented, contain directives, and are brief or entirely silent (Ward et al., 2008; Williams et al., 2009; Savundranayagam, 2014). This pattern of interaction is similar to that of acute care environments, in which PLWD, especially those with communication impairments, receive limited interactions with nursing staff, often spending a majority of their time alone (Norbergh et al., 2001).

When PLWD are unable to obtain the care necessary to meet their needs due to impairments in communication, they can exhibit behaviours such as vocalizations, aggression, and wandering that are attempts to communicate (Algase et al., 1996). However, these behaviours often are viewed as challenging or difficult by formal caregivers (Schneider et al., 2019; Van Vracem et al., 2016; Wang et al., 2013), negatively impact formal care providers' emotions and contribute to burden or distress

(Holst & Skar, 2017; Rapaport et al., 2018; Schneider et al., 2019; Van Vracem et al., 2016; Zwijsen et al., 2014), negatively affect formal caregivers' feelings towards PLWD and their perceptions of PLWD (Holst & Skar, 2017; Polacsek et al., 2010; Rapaport et al., 2018; Wang et al., 2013), and adversely impact interactions between formal caregivers and PLWD (Holst & Skar, 2017; Rapaport et al., 2018; Wang et al., 2013). Furthermore, the display of these behaviours affect the decision to relocate PLWD to more formal care settings (Afram et al., 2014; Brodaty et al., 2014; Gaugler et al., 2009; Luppia et al., 2008; Park et al., 2018; Risco et al., 2018; Toot et al., 2017), and result in the use of psychotropic medication (Holst & Skar, 2017; Mulders et al., 2019; Ozaki et al., 2019) or coercive action (Holst & Skar, 2017). PLWD with communication difficulties face also negative consequences stemming from reduced opportunities for interaction and social isolation (Downs & Collins, 2015) including depersonalization, disempowerment and objectification (Kitwood, 1990).

The use of elderspeak, or over-accommodated communication, is widespread among formal care providers who communicate with PLWD in LTC homes (Williams et al., 2009). Characteristics of elderspeak, sometimes referred to as patronizing talk or secondary baby-talk, include simple grammar and vocabulary, short sentences, slow rate of speech, inappropriate use of terms of endearment, and high volume and pitch, among other features (Kemper & Harden, 1999; Williams et al., 2009). Certain features of elderspeak, like repetition, may aid in enhancing the performance of older persons (Kemper & Harden, 1999). However, other attributes, such as slow speech rate, do not help with older persons' comprehension, and result in older adults reporting lower levels of communicative competency (Kemper & Harden, 1999). It is important to be wary of

inappropriate over-accommodations in communication because those based exclusively on stereotypes are perceived to be restrictive and/or childlike (Savundranayagam et al., 2007). The Communication Predicament of Aging (CPA) model offers a framework which helps explain why formal caregivers engage in the use of certain communication behaviours with older adults, such as elderspeak, or reduce their attempts at communication entirely. It further emphasizes the negative effects of this type of communication on the well-being of older persons.

1.2.3 The CPA Model

The CPA model (as outlined in Figure 1) posits that social partners over-accommodate their communication when interacting with older adults. Over-accommodations are based on incorrect assumptions and stereotypes regarding the incompetence and dependence of older persons, as opposed to actual needs and deficits (Hummert et al., 2004; Ryan et al., 1995). The CPA model is portrayed as a negative feedback model. Developed in 1986 by Ryan, Giles, Bartolucci and Henwood, the CPA model starts with social partners' recognition of psychological, physiological, and sociocultural cues that indicate age-related changes. These cues are then understood as indicators of dependence and incompetence. The result is speech modifications marked by over-accommodated communication (oversimplification, elderspeak, secondary baby talk, patronization, or ignoring). This subsequently leads to the reinforcement of negative age-stereotyped behaviours, and constrained opportunities for satisfying interactions. Exposure to this communication predicament, and its associated constraints, is proposed to impact adversely the self-esteem and psychological well-being of older adults. In addition to reducing the older individual's chances for meaningful conversation,

inappropriate speech modifications by caregivers that are the result of perceived incompetence and dependence suggest a decline in capacity, helplessness, and loss of control (Orange et al., 1995).

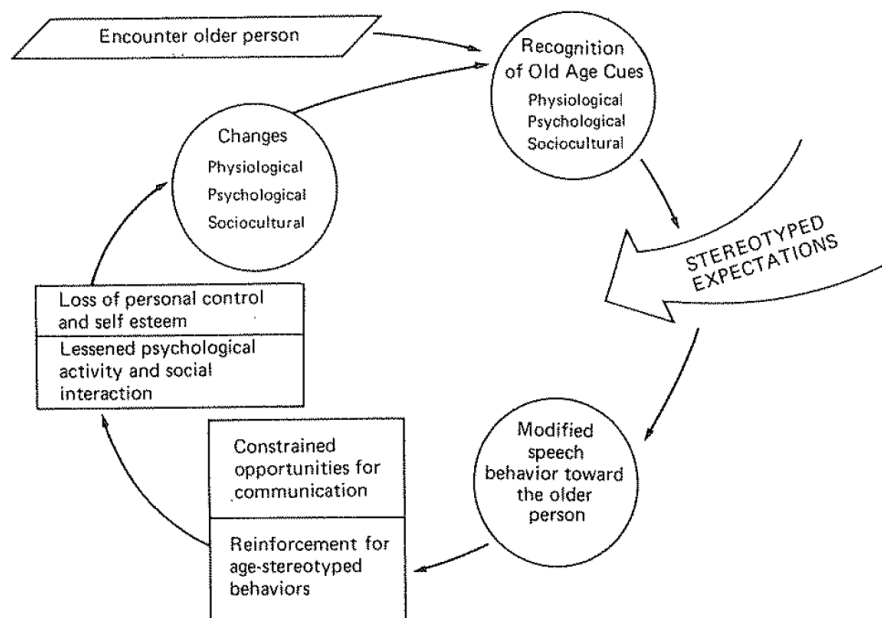


Figure 1. The CPA Model. Reprinted from “Psycholinguistic and social psychological components of communication by and with the elderly,” by E.B. Ryan, H. Giles, G. Bartolucci., & K. Henwood, 1986, *Language & Communication*, 6(1–2), p. 16.

1.2.4 The NDB Model

PLWD can exhibit behaviours such as aggression when caregivers do not communicate appropriately with them (Algase et al., 1996). The NDB model offers an explanation as to how behaviours commonly associated with dementia can reflect unmet needs of PLWD, including those related to appropriate interactions. The role of formal caregiver communication in eliciting such behaviours is noted in this model.

The NDB Model (Algase, et al., 1996) (see Figure 2) helps explain behaviours associated with dementia that are perceived by others as ‘disruptive’ (Algase et al., 1996). According to the model, behaviours such as wandering, vocalizations, and aggression stem from unmet needs or goals of PLWD. Needs-driven behaviours, therefore, “reflect the interaction of salient background and proximal factors found within either CI [cognitively-impaired] persons or their immediate environment or both” (Algase et al., 1996, p.10). The model posits that while needs-driven behaviors may appear objectively to be “disruptive, ineffective, or dysfunctional” (Algase et al., 1996, p.10), they may be the most integrated and significant reaction possible by PLWD due to the impact of background and proximal-related factors. The background factors that are involved in the production of need-driven behaviors involve fairly stable neurological, cognitive, health state, and psychosocial-related factors. Proximal factors are considered to be the fluctuating features of physical and social environment, as well as the needs and states of PLWD.

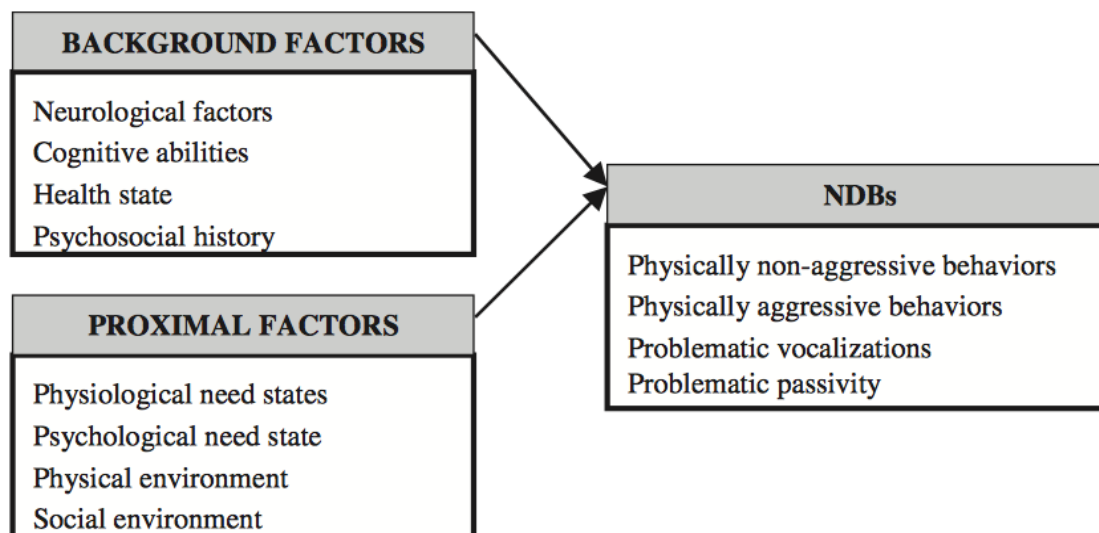


Figure 2. The NDB Model. Reprinted from “The need-driven dementia-compromised behavior model – a framework for understanding the behavioral symptoms of dementia,” A.L. Whall & A.M. Kolanowski, 2004, *Aging & Mental Health*, 8(2), p. 107

Needs related to communication is a proximal factor (i.e., psychological need state). The NDB model posits that the display of behaviours may stem from unmet needs for appropriate communication and the ways in which caregivers interact. Formal caregivers’ communication falls under proximal factors because communication problems are a feature of the social environment. According to the model, wandering and screaming behaviours are typically related to a greater time spent alone, and that the overall degree of agitation is associated with a lack of closeness within social networks. Similarly, interactions between the social environment and the physical environment can affect NDBs. For example, a comforting physical environment and a warm social environment, specifically one marked by caregivers’ pleasant and inviting nonverbal communication features, can collectively result in an atmosphere that is incongruent with aggressive behaviour (Algase et al., 1996). Indeed, needs-driven behaviors occur when formal caregivers utilize elderspeak over neutral communication (Savundranayagam et

al., 2016; Williams et al., 2009). Thus, it is imperative that formal caregivers possess appropriate and suitable communication skills to effectively interact with PLWD (Savundranayagam, 2014; Savundranayagam et al., 2016), and understand the needs for social interaction experienced by PLWD.

1.3 The Rising Demand for Formal Home Care

PLWD typically need a high level of care (Brodaty & Donkin, 2009). Informal caregivers, defined as family members, friends or neighbours who provide unpaid care (Keefe, 2011), deliver a substantial amount of caregiving to older adults in Canada (Sinha, 2012). However, there has been a decreasing supply of informal caregiver support (Duxbury & Higgins, 2012). The shrinking availability of informal caregivers in Canada is affected by factors such as the increased participation of women in the workforce, geographic proximity, and a change in family structures (Keefe, 2011). Accordingly, the decreasing availability of informal caregiver support, in combination with the growing number of older adults in Canada who will require future care, is expected to contribute to the rising need and demand for formal caregiver support (Keefe, 2011). The growing number of older adults in Canada is expected to drive even further the demand for home-based dementia care services (Canadian Healthcare Association, 2009). Indeed, older adults desire to age-in-place (Brown & Teixeira, 2015). There is an increasing number of individuals with dementia living at home (Alzheimer Society of Canada, 2010), and shifts in healthcare policy and recommendations support home-based care for older persons (Ministry for Seniors and Accessibility, 2017; Ministry of Health and Long-Term Care, 2015; Sinha, 2012).

1.3.1 Formal Caregivers

Formal caregivers are paid employees who provide care for persons requiring support (Family Caregiver Alliance, 2014). Formal caregivers can include nurses, occupational therapists, physiotherapists, personal support workers (PSWs), and nursing assistants, among others (Williams et al., 2010). Formal caregivers can provide care in more formal care settings, such as LTC homes, and in community-based care settings, such as day programs, or in the home (Li & Song, 2019). They may complement or substitute the care provided by informal caregivers (Bremer et al., 2017). Front-line formal caregivers, such as PSWs, generally provide assistance with the most intimate and direct care tasks, including activities of daily living (ADLs), such as bathing, dressing, toileting and mobility, and instrumental activities of daily living (IADLs), such as shopping, cleaning and preparation of meals (Lum et al., 2010; Ontario Community Support Association, 2009).

1.3.1.1 PSWs

In Ontario, PSWs are unregulated health care providers in that they are not recognized officially under the Regulated Health Professionals Act (RHPA; Government of Ontario, 2017). The RHPA establishes which professions are regulated, defines controlled acts, details criteria for exemption, and establishes health regulatory colleges. Health regulatory colleges are in charge of assuring that regulated health professionals (RHPs) deliver health care services in a professional, safe, and ethical fashion (Ontario Ministry of Health and Long-Term Care, 2018). Examples of this include establishing standards of practice and investigating complaints regarding members involved in the profession. Since PSWs are not RHPs, they do not have a regulatory college, and thus,

lack a certification process, as well as a legislated scope of practice (Personal Support Worker [PSW] Registry of Ontario, 2018).

In Ontario, PSWs may assume tasks that are recorded in clients' care plans, are within the scope of their skills, education and training, and conform with the RHPA, as well as the Policies and Procedures outlined by the PSW Registry of Ontario (PSW Registry of Ontario, 2018). PSWs provide assistance with tasks that one would be able to perform if physically and/or cognitively capable (PSW Registry of Ontario, 2018). Such activities must be considered routine for the client receiving support when the condition of the client is predictable and or/stable (PSW Registry of Ontario, 2018). Activities carried out by PSWs can include assisting with ADLs and IADLs; providing socialization and companionship; documenting care; and reporting safety concerns or changes in clients' physical, cognitive and behavioural status (PSW Registry of Ontario, 2018). Additionally, PSWs may perform controlled acts, which are procedures and tasks considered as possibility harmful when executed by an unqualified individual (Personal Support Network of Ontario [PSNO], 2014; PSW Registry of Ontario, 2018). However, specific conditions must be met, such as, among others, the act meeting an exception as outlined by the RHPA or being delegated by a RHP, and PSWs being trained to perform the act (PSNO, 2014; PSW Registry of Ontario, 2018). Controlled acts typically performed by PSWs include, for example, administration of medications through injection or inhalation and wound care (PSW Registry of Ontario, 2018).

1.3.2 Home Care

Home care refers to nursing, homemaking, therapies, personal support and other related services provided in the home (The Expert Group on Home & Community Care,

2015). The demand for home care is expected to increase, as the aging population continues to grow (Canadian Healthcare Association, 2009).

As of 2008, 55% of Canadians aged 65 or older with dementia lived in their own homes (Alzheimer Society of Canada, 2010). The number is expected to increase to 62% by 2038 (Alzheimer Society of Canada, 2010). Indeed, many Canadian older adults wish to remain in their own homes for as long as possible (Brown & Teixeira, 2015; Government of Canada, 2012). *Aging in place* involves “... live[ing] safely and independently in your home or your community for as long as you wish or are able” (Government of Canada, 2012, p.2). Aging in place is connected with social connection, in addition to a sense of attachment, security, familiarity, identity, independence, and autonomy (Wiles et al., 2011). With adequate home care supports, many older adults can remain in their homes, reduce the need for hospitalization or LTC placement, decrease the likelihood of adverse physical injuries, such as falls, and experience improvements in physical function (Beswick et al., 2010). Adequate home-based supports also can lower the risk of mortality, reduce the financial burden on the healthcare system, increase resilience, help older persons cope with care-related needs, decrease daily burden, lower life stress, contribute to life satisfaction, lower levels of loneliness, and ensure quality of life (Cook et al., 2013; Kadowaki et al., 2015). Accordingly, enabling PLWD to remain in their own homes is a worldwide priority (Wimo & Prince, 2010). However, a diagnosis of dementia serves as one of the most significant risk factors associated with relocation to more formal care settings (Braunseis et al., 2012). Indeed, approximately 45% of Canadians aged 45 or older in LTC homes have a diagnosis of dementia (Wong et al., 2016).

Numerous researchers have examined the factors that influence relocation of PLWD to more formal care settings. Many have established that PLWD-related characteristics contribute to relocation (Afram et al., 2014; Brodaty et al., 2014; Gaugler et al., 2009; Kunik et al., 2010; Luppá et al., 2008; Luppá et al., 2012; Park et al., 2018; Risco et al., 2018; Stephan et al., 2014; Toot et al., 2017). However, there are conflicting reports in regard to which specific PLWD-related aspects affect LTC home placement of PLWD. There is a general consensus that factors such as neuropsychiatric symptoms (Afram et al., 2014; Brodaty et al., 2014; Gaugler et al., 2009; Kunik et al., 2010; Luppá et al., 2008; Park et al., 2018; Risco et al., 2018; Toot et al., 2017) and higher severity of cognitive impairment and poorer cognitive functioning (Afram et al., 2014; Brodaty et al., 2014; Gaugler et al., 2009; Luppá et al., 2008; Luppá et al., 2012; Park et al., 2018; Toot et al., 2017) affect the decision to relocate PLWD. The literature, however, has inconsistent findings in terms of the impact of other factors such as the age of PLWD (Eská et al., 2013; Luppá et al., 2008; Park et al., 2018) and the presence of physical health problems among PLWD (Luppá et al., 2008; Toot et al., 2017) on LTC home placement. Caregiving-related aspects are noted further to contribute to the placement of PLWD in more formal care settings. However, there are discrepancies also in the literature in terms of which caregiver-related characteristics contribute to relocation. Caregiver burden, for example is commonly associated with the decision to relocate PLWD to LTC homes (Afram et al., 2014; Brodaty et al., 2014; Eská et al., 2013; Gaugler et al., 2009; Luppá et al., 2008; Risco et al., 2018; Toot et al., 2017). Yet, the literature has conflicting reports on the impact of other caregiving-related factors such as caregiving hours (Luppá et al., 2008) and caregiver depression (Toot et al., 2017).

1.4 Formal Caregivers' Experience in Interacting with PLWD in the Home

Undoubtedly, there are many benefits associated with formal home care.

However, formal caregivers of PLWD in the home environment experience challenges related to care because of dementia-related impairments. Indeed, the literature shows that dementia-related impairments can act as a barrier to care provision. Findings from Beer and colleagues (2014) and Karlsson and colleagues (2014) demonstrated that care providers were challenged by the presence of cognitive impairments in home care clients. While the Beer and colleagues (2014) study was not specific to dementia care, participants nonetheless identified the presence of dementia as causing difficulties to providing care because of the challenges PLWD experience in understanding adequately the care being performed. When PLWD are unable to understand care due to the presence of cognitive impairments, they may respond by resisting care (Karlsson, et al., 2014). Karlsson and colleagues (2014) link this issue to difficulties formal home care providers can experience with assessing pain of PLWD when clients' ability to self-report is compromised. Participants in their study relied on the use of certain strategies when PLWD were unable to describe their pain in a verbal manner, including initiating conversation with family members of PLWD. Indeed, communication with relatives can compensate for information home care workers are unable to ascertain from care recipients themselves (Sims-Gould et al., 2015). Findings from Van Vracem and colleagues (2016) study revealed further that formal home care providers are challenged by a host of dementia-related impairments. Their study focused specifically on pacing and wandering, disruptions in the sleep-wake cycle, inappropriate dressing or disrobing, general restlessness, trying to get to a different place, handling things inappropriately,

and performing repetitious mannerisms (Cohen-Mansfield et al., 1989; Rabinowitz et al., 2005). Aggression and a lack of cooperation are cited also as complicating care for formal caregivers in the home care context (Schneider et al., 2019).

In addition to dementia-related impairments causing difficulties with care provision, the display of impairments can elicit also negative emotional responses from formal home care providers. Feelings of frustration and annoyance can arise in response to PLWD exhibiting repetition (Schneider et al., 2019). Formal home care providers experience also feelings of burden because of dementia-related impairments (Van Vracem et al., 2016). Encountering aggression and a lack of cooperation from PLWD can elicit further feelings of failure from formal home care providers and perceptions of an unsatisfying care experience (Schneider et al., 2019). Indeed, Ben-Arie and Iecovich's (2014) study, while not specific to dementia care, identified the presence of behavioural problems as being correlated significantly with high levels of job dissatisfaction among formal home care providers who recently resigned (Ben-Arie & Iecovich, 2014). Behavioural disturbances serve as a diagnostic feature of dementia (APA, 2013). The authors also identified the presence of memory impairment and poorer ADL and IADL functioning as being correlated significantly with high levels of job dissatisfaction. Memory impairment and interference with independence in everyday activities are also diagnostic features of dementia (APA, 2013). Higher levels of work effort and poorer quality of relationships with care recipients contributed also to job dissatisfaction among participants in Ben and Iecovich's (2014) study. The authors suggest that the presence of cognitive impairment in care recipients substantially hinders their ability to communicate with home care workers and to establish meaningful relationships. Indeed, building

relationships with PLWD is a source of job satisfaction for formal home care providers (Ryan et al., 2004; Turner et al., 2018). However, communication difficulties experienced by PLWD can impede opportunities for meaningful conversation (Ryan et al., 2005). The presence of dementia, especially advanced forms of the syndrome, has been shown to impact negatively relationship building (Turner et al., 2018).

Yet, the literature has established that it is possible to develop relationships with PLWD in the home (Hale et al., 2019; Schneider et al., 2019; Turner et al., 2018; Ryan et al., 2004). The development and maintenance of relationships, however, is typically led by formal caregivers because of the nature of dementia (Schneider et al., 2019). This is of importance because there are differences in how caregivers understand and perceive their role in meeting psychosocial needs of PLWD (Hansen et al., 2017). Hansen and colleagues' (2017) reported that formal caregivers differ in how they perceive psychosocial needs of PLWD, their responsibility in meeting these psychosocial needs, and how perceptions impacted care provision. Accordingly, the authors classified these differences under three "logics": the physical need-oriented logic, the renouncement logic, and the integrated logic.

In the physical need-oriented logic, physical and psychosocial needs were viewed by participants as separate entities, and only physical needs were deemed basic. Meeting psychosocial needs were not viewed as part of formal caregivers' responsibility. Further evident in this logic was a task-oriented focus that stemmed from lack of resources, including a lack of time. Performing care for PLWD, in particular, has been identified as a time-consuming process (Aasgaard et al., 2014; Turner et al., 2018). The nature of formal home care has been established as task-oriented, focused on measurable

outcomes, and lacking consideration for social aspects of health (Kristensen et al., 2017; Mole et al., 2019; O'Sullivan et al., 2017; Sundler et al., 2016; Sundler et al., 2017).

There often is limited time to address social care needs (Turner et al., 2018), despite home care workers' desire to have more opportunities for socialization with PLWD (de Witt & Fortune, 2019). Indeed, the task-oriented nature of home care also extends to communication (Sundler et al., 2017). Communication that occurs between home care workers and care recipients often is focused on task-oriented topics to a greater extent than on personal communication (Kristensen et al., 2017; Sundler et al., 2017).

Accordingly, home-dwelling PLWD often have unmet needs related to social interactions, relationships and company, and can experience further social isolation, boredom, loneliness, and a loss of identity (Chung 2006; Miranda-Castillo et al., 2013; O'Sullivan et al, 2017; Svanstrom & Sundler, 2015; Turdor Car et al., 2017). However, Schneider and colleagues (2019) assert that formal home care providers can use the performance of care tasks as opportunities to meet social needs of PLWD (Schneider et al., 2019). Similarly, Kristensen and colleagues (2017) argue that communication about tasks can nonetheless provide opportunities to talk to home care clients about personal matters.

The literature shows that it is indeed possible for formal home care providers to converse with PLWD during the performance of tasks, despite encountering issues related to limited time, and a lack of knowledge and awareness related to psychosocial care (Hansen et al., 2017). This aligns with features of what Hansen et al. (2017) refer to as the renouncement logic. In the renouncement logic, psychosocial needs are viewed by home care workers as a basic need, but physical needs are considered as more essential

and physical care is the priority. However, participants in Hansen and colleagues (2017) study were critical about the quality of interactions that occurred while simultaneously performing tasks. Additionally, while formal caregivers whose perceptions fall under the renouncement logic felt responsible, to an extent, in meeting psychosocial needs, they may have transferred the actual fulfillment of psychosocial care to family members, day programs, and volunteer organizations. Home-dwelling PLWD, however, may not have many opportunities for interaction outside of those with formal home care providers (Svanstrom & Sundler, 2015). Family members also appreciate instances in which home care workers provide care that extends beyond meeting solely physical needs to care that incorporates meeting social aspects of health (O'Sullivan et al., 2017; Polacsek et al., 2019).

The perception that psychosocial needs are a basic need, similar to physical needs, reflects the integrated logic (Hansen et al., 2017). Issues related to time were mentioned also by caregivers in Hansen et al.'s (2017) study whose perceptions aligned with this logic, yet care providers nonetheless prioritized taking the extra time to converse with PLWD when client needs related to psychosocial care exceeded what could be met through conversation that occurred during the performance of tasks. Under this logic, relationships and conversation are viewed as tools that could be used to maintain the well-being of PLWD, make care provision an easier process, and assess and learn more about PLWD.

Indeed, formal home care providers can identify the impact that their own interaction style has on the thoughts and behaviours of PLWD. Formal caregivers in Karlsson and colleagues (2014) study noted that when interactions with PLWD were

rushed, clients could experience distress due to the presence of cognitive impairment. Findings from Van Vracem and colleagues (2016) demonstrated also that care providers understand the importance of communicating effectively with PLWD who are verbally repetitive because ineffective caregiver communication can elicit agitation from PLWD. Home care workers have recognized further the need to refrain from being hurried and unfocused in their interactions with PLWD because it can elicit feelings of insecurity and unrest among clients (Hansen et al., 2017). However, this understanding demonstrated by participants in Hansen et al.' (2017) study required some acknowledgement regarding the importance of psychosocial needs for PLWD. Participants from Berglund et al.'s (2019) noted further the importance of exhibiting a positive attitude and a sense of calmness during the provision of care for PLWD because it impacted the atmosphere in the client's home. Additionally, it was expressed that care providers should avoid sharing that they were stressed or in a hurry when caring for clients. The reflection and self-awareness shown by participants in Berglund et al.'s (2019) study, however, was an outcome of receiving an educational program related to dementia care.

Possessing adequate abilities, skills and knowledge are important parts of providing optimal formal home care to PLWD (Polacsek et al., 2019). Accordingly, numerous researchers have made recommendations for education and training for formal home care providers of PLWD (Aasgaard et al., 2014; Butler, 2009; Cross et al., 2008; Ben-Arie & Iecovic, 2014; Roelands, 2005; Flojt et al., 2014; Hussein & Manthorpe, 2012; Jansen et al., 2009; Karlsson et al., 2019; Ledgerd et al., 2016; Polacsek et al., 2019; Samus et al., 2018; Tudor Car et al., 2017; Verkaik et al., 2017; Xu et al., 2018). Formal caregivers themselves recognize the need for dementia-related training (Flojt et

al., 2014), do not feel suitably trained (Toot et al., 2013), lack confidence (Cross et al., 2008), and have continuing education topics associated with dementia care that are of interest (Morgan et al., 2016). Numerous benefits have been associated with dementia-specific education and training, such as improvements in formal caregivers' communication skills, increases in formal care providers' understanding of dementia, and improvements in the health status of PLWD, among others (Berglund et al., 2019; Conway & Chenery, 2016; Courcha, 2015; Fenley et al., 2008; Goh et al., 2018; Guerrero et al., 2020; Hattink et al., 2015; Low et al., 2015; O'Sullivan et al., 2017; Rokstad et al., 2016; Smith et al., 2017; Tan et al., 2017; ; Nakanishi et al., 2017; Nakanishi et al., 2018; Messemaker et al., 2017; Riachi, 2018; Savundranayagam et al., 2020; Velzke, 2014; Wang et al., 2017).

The ability to apply skills acquired through education and training, however, can be impacted by structural barriers (O'Sullivan et al., 2017; Savundranayagam et al., 2020; Rokstad et al., 2016). Structural barriers refer to employer-level and government-level challenges (Savundranayagam et al., 2020). The task-oriented nature of home care work, which has already been noted previously in this thesis, has been identified further as limiting the ability of formal home care providers from translating knowledge and skills acquired through training into practice (O'Sullivan et al., 2017; Savundranayagam et al., 2020). Savundranayagam and colleagues (2020) also identified the shortage of front-line workers, specifically PSWs, in Canada as a government-level barrier that can impact the application of skills obtained through training. Issues related to recruitment and retention, however, can be addressed through providing formal caregivers with training (Rokstad et al., 2016; Snayde & Moriarty, 2009), emphasizing the need for employer support

(Savundranayagam et al., 2020). Yet, there are employer-related barriers that affect caregivers' ability to attend training, including difficulties with scheduling and income loss (Savundranayagam et al., 2020). Additionally, home care workers do not receive sufficient client-related information (Beer et al., 2014; Franzosa, et al., 2018; Swedberg et al., 2013) and this limits also caregivers' ability to translate knowledge and skills into practice (O'Sullivan et al., 2017; Savundranayagam et al., 2020). Continuity allows care providers to develop greater knowledge about PLWD (Karlsson et al., 2014), and the importance of continuity in dementia care has been discussed in the literature (Aasgaard et al., 2014; Berglund et al., 2019; de Witt & Fortune, 2019; Jansen et al., 2009; Karlsson et al., 2014; Polacsek et al., 2019; Ryan et al., 2004; Ryan et al., 2008; Schneider et al., 2019; Toot et al., 2013; Rothera et al., 2008; Verkaik et al., 2017). Yet, consistency is not always a reality in home care. As noted previously in this thesis, Sims-Gould et al. (2015) assert that interactions with relatives can compensate for information home care workers do not have or are unable to ascertain from care recipients themselves. Families can act as a valuable source of information about PLWD (Gerrish, 2001; Karlsson et al., 2014; Polacsek et al., 2019). However, the presence of families within the home environment and their involvement in care is not always beneficial (Beer et al., 2014; Gerrish, 2001; Lotfi Fatemi et al., 2019; Schneider et al., 2019). Involvement of family in formal home care reflects the nature of providing care in the "intimate" home space (Sims-Gould et al., 2015). While staff-family interactions occur in LTC homes, since families continue their caregiving role when their relatives move to LTC homes (Cohen et al., 2014; Utley-Smith et al., 2009), this contact is "intermittent" (Hale et al., 2019). Families' involvement in the care of individuals living in LTC homes can be limited further by

factors such as issues with transportation and the need to attend to other commitments (Port, 2004). Additionally, the personal nature of the home space can offer valuable insights into the history of PLWD (Savundranayagam et al., 2020). Indeed, the literature has shown that the home environment impacts caregivers' experiences with caring for PLWD (Soilemezi et al., 2019).

This chapter aimed to outline literature relating to the care and communication experiences of formal caregivers who care for PLWD who live in their own homes. While the literature provided insights into these experiences, there are nonetheless limits of the existing literature. Firstly, there are issues associated with the sample in numerous studies. Issues include: inclusion of both formal and informal caregivers; inclusion of formal caregivers from other care settings, such as LTC homes and day centres; inclusion of health care providers who do not provide hands-on care services, such as care coordinators; and a small sample size. Secondly, most included studies did not focus explicitly on communication, but rather on the broader context of caregiving. Research studies that focused specifically on communication were concerned with the feasibility and impact of communication education and training interventions. Thirdly, some studies lacked a dementia-specific focus while others only mentioned briefly PLWD. Fourthly, a majority of studies were performed in countries outside of Canada. The findings of these studies are thus not entirely reflective of the Canadian health care context.

1.5 Statement of the Problem

With nearly every nation in the world experiencing increases in the number and proportion of older adults, the prevalence of dementia is concurrently expected to rise. Traditionally, informal caregivers provided a majority of the care to older persons.

However, a decrease in the future availability of informal caregiver support is expected. Taken together, these factors are expected to contribute to the need and demand for formal caregiver support. Similarly, a shift from LTC home-based dementia care to home-based dementia care is anticipated, given variables such as the rising number of PLWD predicted to remain in their own homes. Formal dementia home care is an increasingly significant area of study. Literature pertaining to formal dementia home care exists, but there are limitations with existing literature, as outlined previously. Additionally, much of the literature with a communication-specific focus comes from LTC home settings or informal care contexts (Bourgeois, et al., 1997; Hamdy et al., 2018; Kolanowski et al., 2015; Richter et al., 1995; Savundranayagam et al. 2005; Savundranayagam et al. 2007; Savundranayagam, 2014; Savundranayagam et al., 2016; Small et al., 2000; Small et al., 2003; Stanyon et al., 2016; Wang et al., 2013; Ward et al., 2008; Williams et al., 2009). With 131.5 million individuals worldwide expected to develop dementia by 2050, and an increasing number of PLWD utilizing formal caregiving services and wishing to remain in their own homes, the communication experiences of formal caregivers who care for PLWD in their homes needs further exploration.

1.6 Research Objective

The objective of this study was to understand better the lived experiences of formal caregivers, specifically PSWs, in communicating with PLWD who live in their own homes. The following research question was examined: What are the lived experiences of PSWs in communicating with PLWD in their own homes?

Chapter 2

2 Method

This study used a hermeneutic phenomenological research approach to understand better the lived experiences of PSWs communicating with PLWD who live in their own homes. A secondary analysis of existing data was performed. This section will outline the interpretivist paradigm, phenomenology as a research methodology, and the rationale for its use in this research study. Information pertaining to sampling and recruitment, data collection, data analysis, ethics, and rigor will be described further.

2.1 Paradigm

A research *paradigm* is a “...collection of logically related assumptions, concepts or propositions that orient thinking and research” (Kafle, 2011, p.193). Paradigms are characterized by assumptions regarding ontology, epistemology, methodology, and methods (Bunniss & Kelly, 2010; Rehman & Alharthi, 2016). Paradigms guide the way in which reality is understood and the manner in which it is studied (Rehman & Alharthi, 2016). There are multiple paradigms that can be used to inform one’s research (Ponterotto, 2005). The current study was guided by the interpretivist paradigm.

The interpretivist paradigm acknowledges multiple, diverse realities (Schwandt, 1994). Interpretivism maintains that reality is constructed and developed in the mind of an individual (Hansen, 2004), and rejects the concept of a single, verifiable reality (Rehman & Alharthi, 2016). This belief in multiple, constructed realities, also referred to as the *relativist* position, reflects the paradigm’s ontological viewpoint (Ponterotto, 2005). *Ontology* is concerned with “the nature of reality and being” (Ponterotto, 2005,

p.130), and poses the question: “What is the form and nature of reality and, therefore, what is there that can be known about it?” (Guba & Lincoln, 1994, p.108). According to interpretivism, reality is subjective, and is impacted by the particular context of a given situation, such as the individual’s perceptions and experiences, the social environment, and researcher-participant interaction (Ponterotto, 2005).

The interpretivist paradigm, as outlined by Pontoretto (2005), posits further that meanings are concealed and require reflection to be made apparent (Schwandt, 1994; Sciarra, 1999). It is believed that this reflection can be facilitated through researcher-participant interaction (Ponterotto, 2005). Interpretivism acknowledges that this interaction is required to uncover more profound meaning, and seeks to co-construct knowledge from this researcher-participant interaction (Ponterotto, 2005). These characteristics of interpretivism reflect its epistemological views, in which there is an emphasis on the importance of a transactional and subjective relationship between the researcher and participant (Ponterotto, 2005). *Epistemology* concerns “the relationship between the ‘knower’ (the research participant) and the ‘would-be-knower’ (the researcher)” (Ponterotto, 2005, p.131), and poses the question: “What is the nature of the relationship between knower or would-be-knower, and what can be known?” (Guba & Lincoln, 1994, p. 108). Researcher-participant interactions are vital to chronicling participants’ ‘lived experience’ for interpretivists (Ponterotto, 2005).

As this study sought to understand the communication experiences of various formal caregivers who care for PLWD in the home environment, there was extensive acknowledgement of the multiple perspectives held by PSWs, as well as significant recognition of the influence of various contextual factors, such as individual experience,

on these realities. The study's ontological positioning, therefore, is aligned with that of the interpretivist paradigm. Additionally, the subjective and transactional nature of the researcher-participant relationship permits subsequent co-construction of knowledge to occur during the interview process, further aligning with the epistemological view held by interpretivists.

2.2 Phenomenology

Phenomenology is concerned with the study of lived experience (van Manen, 1997). Phenomenology poses the question "What is this or that kind of experience like?" (van Manen, 1984, p.37) as it attempts to attain a deeper understanding of everyday experiences (Laverty, 2003; van Manen, 1997). Phenomenology has two main approaches: descriptive and interpretive (hermeneutic). Descriptive phenomenology seeks to understand lived experience without conceptualization or categorization (Husserl, 1970). The descriptive method aims to highlight the essential features of the lived experience particular to a group of individuals (Lopez & Willis, 2004). Researchers are required to forgo any prior personal knowledge related to the phenomena of interest (Flood, 2010; Lopez & Willis, 2004), a concept commonly referred to as *bracketing*. As outlined by Flood (2010), bracketing not only prevents the study from being influenced by researcher biases and preconceptions (Drew, 1999), but further acts to ensure scientific rigor (LeVasseur, 2003). Additional assumptions of descriptive phenomenology include the concepts of universal essences and radical autonomy (Flood, 2010; Lopez & Willis, 2004).

Interpretive phenomenology, also commonly referred to as hermeneutic phenomenology, goes beyond description of essential features and universal essences to

search for meanings embedded within everyday practices (Lopez & Willis, 2004). Hermeneutic phenomenology alleges that human reality is located in the world, and believes that human beings are already in, and therefore, unable to separate themselves from the world (Stewart & Mickunas, 1974). As discussed by Lopez & Willis (2004), hermeneutic phenomenological approach to inquiry adopts a stance in which it is believed that the extent to which persons are embedded in their world results in subjective experiences which are intricately tied to social, political, and cultural contexts (Heidegger, 1962). Unlike descriptive phenomenology, bracketing is not consistent with hermeneutic approaches. Rather, presuppositions and knowledge are important to inquiry (Flood, 2010; Lopez & Willis, 2004). Further, in contrast to descriptive phenomenology, hermeneutic phenomenology permits the use of theory. However, the use of theory is not intended to generate hypotheses, but to rather aid in developing a deeper understanding of lived experience (Lopez & Willis, 2004). Co-constitutionality, a concept that refers to the researcher and participant collaboratively exploring meanings of experience, is also a crucial component of hermeneutic phenomenology (Lopez & Willis, 2004). This study utilized a hermeneutic phenomenological research approach due to its alignment with the objective of the current study, and the ontological and epistemological positioning of the primary investigator (PK). van Manen's (1990, 1997) approach to hermeneutic phenomenology guided this study.

2.3 Hermeneutic Phenomenology

Hermeneutic phenomenology, as guided by Max van Manen (1990, 1997), seeks to assist individuals in acquiring a deeper understanding of phenomena from the perspective of those involved. van Manen's (1990) methodological approach incorporates

elements of both descriptive and interpretive (hermeneutic) phenomenology: “it is descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena” (p. 180). van Manen’s (1990) phenomenology seeks the essence of phenomena, as to van Manen, “the aim of phenomenology is to transform lived experience into a textual expression of its essence” (p. 36). Phenomenological research is further described by van Manen (1997) as a “poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world” (p. 13).

Though van Manen (1997) does not have a set of rules or methods with which he approaches phenomenology, he speaks of phenomenological research as an interplay between six research activities, and further rejects the notion of bracketing, rather suggesting that researchers recognize and acknowledge any assumptions, as presuppositions may “persistently creep back into our reflections” (van Manen, 1990, p. 47). The following six-stage methodological structure, as outlined by van Manen (1997), served as a framework for the research method as a whole: (1) Turning to the nature of lived experience; (2) Investigating experience as we live it; (3) Reflecting on essential themes; (4) The art of writing and re-writing; (5) Maintaining a strong and oriented relation to lived experience; (6) Balancing the research context by considering parts and whole.

2.4 Ethics

Ethics approval for this study was received from the Health Sciences Research Ethics Board (HSREB) at the University of Western Ontario (HSREB file number 107789). Refer to Appendix A for the approval notice.

2.5 Sampling and Recruitment

The current study is a qualitative component of the Be EPIC project, an evidence-informed, person-centered communication intervention for PSWs caring for PLWD in home care. Participants for the current study were recruited from those who were originally involved in the larger Be EPIC intervention. Recruitment for Be EPIC involved contacting home care agencies within London, Ontario, and providing organizations with information related to the intervention. Agencies were asked to share these details with their PSWs, and those who were interested in participating in the study were placed in contact with Be EPIC, and further screened for eligibility. Additional recruitment strategies for Be EPIC included the placement of informational posters on various community boards, and advertisements through the South West Health Line, Twitter, and Kijiji.

Participants enrolled in Be EPIC were asked whether they were interested in participating in this qualitative sub-study. Participants who expressed interest were required to meet the inclusion criteria, which included: age 18 years or older, completion of the PSW program at the college level, current work employment in home care, a minimum of six months experience with PLWD, able to attend all training sessions for the person-centered communication intervention, sufficient communication skills in

English to participate in the training, and consent to audio recording of interviews. This selection process reflects a purposeful sampling approach, in which participants are chosen based on their ability to most appropriately inform the study's research aims and phenomena of interest (Creswell, 2007). Individuals who did not meet all of the inclusion criteria listed above were thus excluded from participation in this sub-study. In total, 15 PSWs initially recruited for Be EPIC demonstrated interest in partaking in this qualitative component and deemed eligible for participation. Participants were provided with a letter of information and consent form (Appendix B). The number of participants recruited for the current study reflects the 'typical' number of individuals involved in phenomenological studies, which can vary from as few as 3-4 individuals, up to 10-15 (Creswell, 2013).

2.6 Data Collection

Hermeneutic phenomenology permits the use of various data sources including personal experience, art, observation, and interviews (van Manen, 1997). Interviews are a common method for data collection used in hermeneutic phenomenology (Wright-St. Clair, 2015). The use of a semi-structured approach, which utilizes a guideline of questions and/or topics, as opposed to a rigid question-and answer interview, allows for a variety of notions and questions to arise within and across interviews, and further evokes the ability to explore lived experience (Wright-St. Clair, 2015). The use of a semi-structured approach and open-ended questions further allows opportunities for participants to share experiences that could not have been anticipated by the interviewer (Wright-St. Clair, 2015). Accordingly, a semi-structured interview guide was developed for use in the study. The interview guide included open-ended questions intended to

facilitate conversation around communication experiences of PSWs who care for PLWD in the home (See Appendix C for full interview guide). One in-depth interview was conducted with each participant prior to participation in the intervention, by a research assistant originally involved in Be EPIC, in a location of the PSWs choosing. Participants were asked initially broad context questions regarding their typical workday and workweek, followed by questions related to their experience in providing care for, and communicating with, PLWD in their homes. For example, the first few questions posed by the research assistant included:

“Please walk me through the typical workday for you” and “what is your workweek like?”

Which were then followed by:

“What is your experience in providing care to persons with dementia in their own homes?” and “What is your experience in communicating with persons with dementia in their own homes?”

The semi-structured interviews were audio-recorded and then transcribed orthographically verbatim by four undergraduate research assistants trained in the lab protocol for transcriptions. During the pre-intervention interview process, field notes, including reflexive notes, were compiled also by the research assistant involved in conducting the interviews. Field notes serve multiple functions in qualitative research, as noted by Phillippi and Lauderdale (2018), including: documenting sights, sounds, smells of the physical environment; prompting researchers to attentively observe their surrounding environment and interactions; encouraging researchers to reflect and identify

any potential bias; supplementing language-focused data; providing context for data analysis; facilitating study design; and increasing rigor (Elo & Kyngas, 2008; Emerson et al., 2011; Mulhall, 2003; Phillippi & Lauderdale, 2018; Rodgers & Cowles, 1993; Sandelowski, 1994; Tsai et al., 2016).

The availability of audio-recorded interviews, as well as field notes, are of particular importance because it helps to address many epistemological concerns associated with the fact that this study was a secondary analysis of existing data, and thus the primary investigator did not conduct the interviews (Long- Sutehall et al., 2010). A lack of personal involvement in data production and generation are less of an issue when the primary investigator has access to audio recordings of the interviews and field notes (Long- Sutehall et al., 2010). Audio recordings offer an accurate summary of proceedings, and further provide additional details through capturing elements of emphasis and tonality (Given, 2008). When field notes, in combination with other sources of study information, are available and accessible, they permit transmission of the complete depth of the study's context (Phillippi & Lauderdale, 2018).

2.7 Data Analysis

Consistent with hermeneutic phenomenology, data analysis in the current study was an inductive, iterative process (Wright-St. Clair, 2015). Thematic analysis, as informed by the work of van Manen (1997), was the primary method of data analysis. According to van Manen (1997), there are three distinct approaches that can be utilized to uncover or isolate thematic aspects of a phenomenon: the wholistic or sententious approach, the selective or highlighting approach, and the detailed or line-by-line approach. The wholistic or sententious approach involves viewing the text as a whole and

capturing its overall meaning. The selective or highlighting approach involves highlighting phrases or statements that are essential to the experience under study. The detailed or line-by-line approach involves careful examination of every sentence or group of sentences within the text and subsequent consideration about what they reveal about the phenomenon or experience in question. All three approaches were utilized in this study.

Data analysis commenced with the primary investigator listening to each audio-recorded interview to become familiar with the data. Field notes were also consulted, and reflexive and reflective notes were kept to record any thoughts and feelings that emerged during this stage. Maintaining a reflexive and reflective journal outlining events, observations, interpretations and thoughts associated with the research process is consistent with hermeneutic phenomenology, with reflexive and reflective accounts being able to serve as the contextual basis for the research itself (Wright-St. Clair, 2015). Following this stage of analysis, every interview transcript was first read as a whole. Similar to the previous step, field notes were again consulted, and additional reflexive and reflective notes were made. Participant stories were compiled in this stage. Participant stories provide insight into each of the PSW participants' personal experience and provide an understanding of the text as a whole. Refer to Appendix D for an example of the participant stories. Proceeding this step, transcripts underwent re-readings through NVivo, a qualitative data analysis software. During these re-readings, statements within transcripts deemed to be significant were highlighted and subsequently coded. Coding allows for the organization and grouping of similarly coded data into categories on the basis of a shared common characteristic – “the beginning of a pattern” (Saldana, 2009, p.

8). The coding process began with both the primary investigator and the research supervisor (MYS) independently coding the same transcript. Following this, the primary investigator and MYS jointly reviewed codes to identify similarities and differences, until a minimum of 80% agreement was reached. Disagreements were resolved through discussion. This process was then repeated with an additional two transcripts, until the same level of consensus was reached. Following this agreement, the primary investigator independently coded the remaining transcripts.

The next stage in data analysis occurred after an initial list of codes were generated. It involved a review of developed codes, during which those with shared characteristics were organized and grouped together. This categorization process continued until themes emerged. These themes represented participants' statements and phrases that were essential to the phenomenon under study (Van Manen, 1997). Emerging themes were consistently questioned and reflected upon to allow for a greater understanding of lived experience. There was continuous movement between the identified themes and raw transcribed data in order to ensure that themes were reflected in the interview text (Wright-St.Clair, 2015). Each theme was then assigned a representative theme name. For example, *Being self-aware and self-reflective about communication* emerged through participants' narratives pertaining to their acknowledgement that the manner in which they communicated impacted PLWD. Following the recognition of initial themes, they were further reflected upon and grouped together to generate major themes that characterized the essential lived experience in question. For instance, *Being self-aware and self-reflective about communication* and *Treating communication as a need* were related and thus resulted in the major theme of

Valuing communication in care. Proceeding the identification of major themes, phenomenological descriptions were prepared, which described the essences of the lived experience, supported by participant narratives. This writing “strives for precision and exactness by aiming for interpretive descriptions that exact fullness and completeness of detail, and that explore to a degree of perfection, the fundamental nature of the notion being addressed in the text” (van Manen, 1997, p.17).

2.8 Rigor

This research study demonstrated various markers of quality in qualitative research, including Tracy’s (2010) rich rigor and credibility. Tracy (2010) argues that rich rigor, defined as “the sufficient, abundant, appropriate and complex” use “of theoretical constructs, data sources, contexts, and samples” (p. 841) provides richness to a qualitative study, in addition to providing face validity, a concept used to determine whether research appears to be appropriate and reasonable. Regardless of smaller sample sizes, rich rigor can be achieved through adequate care and practice of data collection and analysis procedures (Tracy, 2010). With regard to the use of interviews, evidence of rigor can include: the number and length of interviews, the breadth and appropriateness of the interview sample, the types of interview questions asked, and the number of pages of interview transcripts (Tracy, 2010). The current demonstrated evidence of rigor with its interview practices, as a total of fifteen in-depth interviews were conducted with participants, with the average duration of interviews surpassing 51 minutes. The average number of pages of interview transcripts further exceeded 16 pages. Though the length of interviews varied, the duration is believed to be adequate given that it permits a period of sustained engagement. The richness of participant descriptions, variety in descriptions,

self-disclosure, and the sheer amount of data collected from each participant further allows for in-depth analysis, and can effectively address the research question. By utilizing data collection and analysis methods closely aligned with the chosen research paradigm and methodology, specifically, the use of semi-structured interviews, and subsequent contemplation and reflection of the data through rereading interviews; relistening to audio recordings; highlighting, exploring, and reflecting on significant material; consulting field notes and reflections; and developing and revising themes, this study can successfully explore the lived experience of participants.

Tracy (2010) defines credibility as “the trustworthiness, verisimilitude, and plausibility of the research findings” (p. 842). Credible studies and research “are those that the readers feel trustworthy enough to act on and make decisions in line with” (Tracy, 2010, p. 843). Qualitative credibility can be achieved through the use of practices such as thick description, crystallization, and/or multivocality. Thick description involves detailed illustrations that help to identify meanings located within cultural contexts, and providing abundant detail that allows researchers to *show* their data, allowing readers to form their own conclusions, rather than *tell* the reader how to interpret the data (Tracy, 2010). The current study demonstrated thick description through the use of direct quotations from PSWs related to their communication experiences with PLWD in the home. This allowed for “showing” rather than “telling” of data (Tracy, 2010). Similarly, multivocality, the inclusion of multiple varied voices in the research process, was also evident in the study as multiple PSW opinions and perspectives were utilized in the research. Crystallization, defined as “the practice of using multiple data sources, researchers, and lenses” (Tracy, 2010, p. 844) was demonstrated through the use of

“...multiple researchers, and numerous theoretical frameworks” (p. 844). This study employed the use of multiple individuals in the data analysis phase, in addition to the use of various theoretical frameworks, including the CPA and NDB models.

2.9 Declaration of Self

My interest in cognitive and mental healthcare initially began during my time as a cooperative education student at a Mental Health Inpatient Unit, located in an urban Toronto hospital. While this role involved attending to various clerical and administrative tasks, such as preparing and updating patient charts, and answering telephone calls, it further provided invaluable opportunities to interact with patients, both one-on-one, and in group settings. It was through these interactions and experiences in which I first encountered dementia, and persons living with the condition. Though my knowledge of dementia was quite limited at the time, the unique needs of PLWD quickly became evident. As did the caregiving difficulties associated with the provision of formal care for PLWD. I quickly recognized that while the provision of care to PLWD was challenged by a variety of factors, such as the display of various behavioural and psychological symptoms, it was often further complicated by the profound effects of the condition on communication abilities.

While my interest in working with individuals with dementia stems from my cooperative education experience, my knowledge about cognitive and mental health, and older adults in general, did not grow until I began my university education. Having pursued an undergraduate degree in Health Sciences, I was exposed to a variety of health-related topics, including aging, mental health, marginalized populations, and speech and language disorders. My graduate school education has further contributed to my

knowledge in key areas of health and aging. Through these learning experiences, I have been able to garner in-depth knowledge regarding these respective subjects, which has not only expanded my knowledge base, and complemented my first-hand experience of working with PLWD, but further reinforced my desire to perform research in the mental and cognitive health field. I strongly believe the findings from this research will serve as an invaluable resource that I will utilize in my future work with persons living with mental and cognitive health issues.

Chapter 3

3 Findings

The objective of this study was to understand better the lived experiences of PSWs in communicating with PLWD in the home. Interview data for this study were collected as part of the Be EPIC project, an evidence-informed, person-centered communication intervention for PSWs who care for PLWD in the home environment (Savundranayagam et al., 2020). Thematic analysis was used to investigate the research objective and identify major themes.

This section will begin with an overview of participants' demographic data. Proceeding this, a profile of the dementia-specific impairments encountered by PSWs in home care will be presented. This serves as a backdrop for describing and interpreting participants' communication experiences with PLWD in the home. Following this, the three major themes that emerged through thematic analysis will be presented: (1) challenged by dementia-related impairments, (2) valuing communication in care, (3) home is a personal space. All direct quotations are accompanied with the alphanumeric codes used to refer to specific participants.

3.1 Demographic Data

Table 1 provides the demographic data for the fifteen PSWs who participated in the current study. Of these 15 participants, 13 (86.7%) were women. Participants ranged in age from 22 years to 58 years, with a mean age of 35.3 years. Twelve participants (80%) self-identified as White (Non-Hispanic), two participants (13.3%) as Black/African-Canadian, and one participant (6.7%) identified as Asian. A majority of

participants (i.e., n=14, 93.3%), attained a college degree, while one participant (6.7%) was a high school graduate, and held a diploma or General Education Development (GED) certificate.

The length of time participants worked in home care ranged extensively from 8 months to 20 years and 2 months. The amount of hours worked/week by participants varied from 22 hours to 70 hours, with an average of 38.1 hours. Four participants (26.7%) provided care for one to five clients/week, four participants (26.7%) cared for six to 10 clients/week, and seven participants (46.7%) provided care to more than 10 clients/week. A majority of participants (i.e., n=12, 80%) received training on how to care for PLWD, while the remaining three participants (20%) did not receive training.

Prior to employment in their current job, one participant (6.7%) worked in general nursing, three participants (20%) worked in special care units for PLWD, two participants (13.3%) had work experience in hospital settings, and five participants (33.3%) worked in long-term care homes. Additionally, three participants (20%) had some experience in home care, and six participants (40%) previously worked for home health agencies. Three participants (20%) had no prior experience working in healthcare systems. Three participants (20%) had other forms of employment experience not listed in the questionnaire, such as housekeeper. Three participants (20%) further reported that they were employed in their first job role.

Table 1*Demographic Data*

Variable	N	%
Sex		
Women	13	86.7
Men	2	13.3
Age		
Mean (Range)	35.3 (22-58)	-
Ethnicity		
White (Non-Hispanic)	12	80
Black/African-Canadian	2	13.3
Asian	1	6.7
Education		
High school	1	6.7
College	14	93.3
Years in home care		
Mean (Range)	6.8 (0.7-20.2)	-
Hours/week working in home care		
Mean (Range)	38.1 (22-70)	-
Number of home care clients		
1-5	4	26.7
6-10	4	26.7
>10	7	46.7
Training		
Yes	12	80
No	3	20
Type of organization employed in prior to employment in current job		
General nursing	1	3.4
Special care units	3	10.3
Hospital	2	6.9
Long-term care homes	5	17.2
Home	3	10.3
Home health agency	6	20.7
No prior experience in healthcare systems	3	10.3
Other	3	10.3
First job	3	10.3

3.2 Profile of Persons Living with Dementia in the Home

Participants described the various dementia-specific communication impairments encountered in their experiences of interacting with PLWD in their own homes, including: impaired verbal language production, in that clients were non-verbal or minimally verbal; problems with topic management; verbal repetition; verbal aggression; slurred speech; and reversion to a native language. Table 2 summarizes these impairments and provides supporting examples.

Table 2

Communication Impairments of PLWD as Reported by PSWs

Communication Impairment	Example quote(s)
Impaired Verbal Language Production	<i>"He couldn't talk, yeah. He couldn't talk.."</i> (PSW_01_01)
Problems with Topic Management	<i>"...it's like she start from A and then like, jump maybe y'know, A to Z and all that and this going round without any sense..."</i> (PSW_01_08)
Verbal Repetition	<i>"And of course every day they ask me the same questions."</i> (PSW_01_09) <i>"...they would say the same things over maybe 2 and 3 or 4 times...each day."</i> (PSW_01_16)
Verbal Aggression	<i>"And she would scream the whole time."</i> (PSW_01_11)

Communication Impairment	Example quote(s)
Slurred Speech	<i>“And he loves the F-word. That’s common with them, though.”</i> (PSW_01_14)
Reverting to Native Language	<i>“Or she’s slurring words...”</i> (PSW_01_17) <i>“...so they go back to the first thing they knew which was their dialect or something so they don’t speak the English...They just speak their dialect.”</i> (PSW_01_15)

PSWs reported also that they encountered numerous memory and behavioural impairments in their experiences of interacting with PLWD in the home, including: memory loss, confusion, repetitive actions, reverting to the past, wandering, physical aggression, resistiveness to care, delusions, hallucinations, sundowning, mood or personality changes, inappropriateness, suicidal ideations, poor judgement, denial of dementia, impaired visuospatial abilities, and difficulties with attention. Table 3 summarizes the memory and behavioural impairments, and provides supporting examples.

Table 3*Memory and Behavioural Impairments of PLWD as Reported by PSWs*

Memory/Behavioural Impairment	Example quote(s)
Memory Loss	<p data-bbox="656 512 1308 604">“...like some of them can’t remember short-term.” (PSW_01_05)</p> <p data-bbox="656 655 1382 800">“...I’ve had clients, who, they can’t remember long time ago, they can remember what they did ten minutes ago.” (PSW_01_02)</p>
Confusion	<p data-bbox="656 852 1414 1108">“...I had one client with a stoma and he was sitting in the bed. And he says, ‘Oh, you’re late.’ I said, ‘No, no. In fact, I’m fifteen minutes early.’ And he says, he says, ‘Well, it’s Tuesday.’ I said, ‘Oh no, it’s Monday night.’” (PSW_01_09)</p>
Repetitive Actions	<p data-bbox="656 1159 1409 1304">“Um but he’s repetitive...So he shaves, and then he shaves, and then he shaves, and then he shaves, and then he says, ‘I think I’ve missed a part.’” (PSW_01_01)</p>
Reverting to the Past	<p data-bbox="656 1356 1414 1501">“And another fella, his was he’d get up in the middle of the night. He’s going to work... You know. So it, it, it’s definitely part of their background.” (PSW_01_03)</p>
Wandering	<p data-bbox="656 1549 1414 1858">“She [family caregiver of PLWD] said, they went, they went to bed...And she lock all doors. She probably has, huge house, and they have probably two, three exit doors... And she said, ‘Around midnight, I woke up and he [PLWD] wasn’t there.’ ‘And, Probably,’ she said, ‘Took me ten, fifteen minutes to check all the all the house’...Basement,</p>

Memory/Behavioural Impairment	Example quote(s)
	<i>rooms, and stuff. Wasn't there. She opened the door, and it was snowing, wintertime too. She saw the footprints went all the way to the field. She called her son and her son came, they went to cornfield somewhere, couple five, six hundred metres away...He was there, standing in undershirt and underwear...Minus probably twenty or something.</i> ” (PSW_01_10)
Physical Aggression	<i>“She bite me... I went down to wash her legs... and she got my arm with her teeth.”</i> (PSW_01_14) <i>“...I've had that happen a few times where they, they just grab you. Or they swing at you.”</i> (PSW_01_03)
Resistiveness to Care	<i>“And most of them, they refuse care.”</i> (PSW_01_10)
Delusions	<i>“Um, she says, ‘Is he gone, is he gone, is he gone?’... she doesn't recognize her husband as being her husband... she thinks her husband, her own husband, the person that she lives in the house with, is an imposter.”</i> (PSW_01_17)
Hallucinations	<i>“I have a lady that, yeah, her husband is sitting at the end of the table and I know it's dementia...But he was, he died a year ago and she swears he's sitting at the table with us.”</i> (PSW_01_14)
Sundowning	<i>“Um, he had Alzheimer's. And he had sun downs like you wouldn't believe. It started at four o'clock in the afternoon. And it would go until the middle of the night. And he would um sing. Like he would lay in bed and he would just hum</i>

Memory/Behavioural Impairment	Example quote(s)
	<i>and hum and hum and hum and hum. He would sing and sing and sing.</i> ” (PSW_01_01)
Mood or Personality Changes	“ <i>Or they go from moods to moods every five minutes.</i> ” (PSW_01_17)
Anger	“ <i>Wasn’t the man I met from the beginning.</i> ” (PSW_01_14)
Inappropriateness	“ <i>And then they get angry...</i> ” (PSW_01_05)
Inappropriateness	“ <i>And he says, ‘I’m not gonna eat that chink-y chink-y rice.’</i> ” (PSW_01_01)
Inappropriateness	“ <i>So, um, like he would grab my hand and he would kiss my hand</i> ” (PSW_01_03)
Inappropriateness	“ <i>And he says to me after lunch, he says, ‘so are we gonna go upstairs and make love?’</i> ” (PSW_01_01)
Depression	“ <i>...he starts to cry cause he’s got the depression...</i> ” (PSW_01_01)
Suicidal Ideations	“ <i>...the guy he was just diagnosed and I walked in and he had a shot gun. And he was gonna kill himself.</i> ” (PSW_01_11)
Poor Judgement	“ <i>And then she gave me her diamond ring.</i> ” (PSW_01_14)
Denial of Dementia	“ <i>Like I have a client with dementia, he says he doesn’t, but he does.</i> ” (PSW_01_14)

Memory/Behavioural Impairment	Example quote(s)
Impaired Visuospatial Abilities	<i>“Sometimes he has difficulties with his shoes or understanding placement of his clothes.” (PSW_01_01)</i>
Difficulties with Attention	<i>“Um and they [PLWD] shift gears a little faster too...because they’ve got stuff going on in there. And one little thing will seem to trigger them. And they’ll be off in another direction...Where kids [living with Cerebral Palsy] are usually pretty more focused on what’s happening at the time.” (PSW_01_11)</i>

3.3 Theme 1 – Challenged by Dementia-Related Impairments

This theme highlights the difficulties experienced by PSWs in communicating with PLWD stemming from dementia-related impairments. It is comprised of three subthemes: dementia-related impairments as barriers to communication, the emotional toll of communicating, and consequences of communication breakdowns initiated by PSWs.

3.3.1 Subtheme 1 – Dementia-Related Impairments as Barriers to Communication

The PSW participants expressed that there were situations in which they found communication with PLWD to be “*challenging*,” “*difficult*,” or “*hard*.” PSWs noted that various dementia-specific communication, and memory and behavioural impairments exhibited by PLWD were difficult to respond to and challenged the experience of

communicating. The dementia-related communication impairments cited by PSWs as posing difficulties to communicative encounters included: impaired verbal language production, reversion to a native language, and problems with topic management. The dementia-specific memory and behavioural impairments mentioned by participants as being challenging to respond to involved: wandering, suicidal ideations, reversion to the past, resistiveness to care, and physical aggression. Many participants expressed that it was challenging to communicate with PLWD who experienced communication-related impairments. Situations in which PLWD demonstrated impaired verbal language production was among the most commonly cited by PSWs as presenting challenges to the communication experience. Participants expressed that when PLWD experienced impairments in verbal language production, communication could be difficult due to the lack of verbal reciprocity in communicative encounters.

PSW_01_05, for example, stated that communication with minimally verbal PLWD was “...*difficult. Because like, we talk for someone to respond.*”

Instances in which PLWD were minimally verbal was similarly noted as presenting challenges to PSWs’ communication experiences. PSW_01_17 discussed that communication with minimally verbal PLWD was “*hard*” because it was difficult to make meaning of clients’ attempts at communication.

PSW_01_03 similarly shared that communication with PLWD, who were minimally verbal, presented difficulties accurately understanding and interpreting clients’ true needs or wants:

Um I saw a client not too long ago, everything was ‘mhm,’ ‘mhm,’ ‘mhm,’ ‘mhm.’ Meaning I’m thinking okay everything is okay. But it may not be...Right? He’s just used to saying that. Or that’s, that’s his thing. So, and he didn’t say words. He just “‘mhm,’ ‘mhm’ [=! Laughing]...So, like I say, you think everything is okay but it’s not necessarily.

Several participants shared that it was difficult to communicate with PLWD who were unable to speak English, either due to reverting to a native language, or a general lack of English proficiency. Participants expressed that in these situations, language barriers arose in the communication dyad, resulting in difficulties in ensuring a successful communicative encounter. PSW_01_03, for instance, described reversion to a native language as the most significant challenge she encountered in her interactions with PLWD, as it posed difficulties in recognizing and understanding clients’ wants:

Language is huge...Language. Um yeah that’s probably the biggest challenge right there...Oh um, say Italian. Or you know, like ethnicity or whatever. Yeah, that is the biggest thing because often they revert back to speaking their own language, right?...So they may know some English, you know. Or before they, they knew a lot more English...But they’ll jump back to their home language. And that’s a challenge... Because not only are you trying to figure out what it is they want. Um, but you’re trying to understand their words.

An additional communication-related impairment that was cited as presenting challenges to communication involved instances in which PLWD exhibited problems with topic management. This was noted by PSW_01_17, who expressed that

communicating with clients who experienced issues with misalignment of topic was “hard,” as in these situations, PLWD “...make no sense of what they say...Like they’re try to tell you +// You try to tell them, uh, ‘Have you eaten today?’ and he, he’s talking, he, him or she’s talking about weather.”

Many participants expressed that they found it difficult to communicate with PLWD who experienced certain memory and behavioural impairments. Some PSWs, for example, shared that it was difficult to communicate with PLWD who wandered, either due to challenges associated with successfully convincing, or redirecting these individuals. PSW_01_11 described also difficulties communicating with a client who expressed suicidal ideations because of challenges associated with effectively redirecting the client:

And for the whole six hours +// And she liked to walk. So I was walking her around the block...And down the street and everything. And to the park. And you know. And no matter what I said, it always came back to, ‘I could kill myself that way.’ ‘I could, I could jump out of here.’ ‘And I could be dead.’ Or, ‘if I just ran on the road would I die?’ ‘How fast would I die if I ran out on the road?’ ‘If I just stopped eating.’ And it was continuous...

Situations in which PLWD reverted to the past was also cited as posing difficulties to the communication experience by PSW_01_03. She shared that it could be challenging to communicate with clients who reverted to the past, as it was difficult to determine if what was being communicated by PLWD pertained to a prior, or recent experience:

And, and sometimes, you know, they could be in their mind reverting back to something that happened to them when they were a kid. But here I am I'm trying to think okay, what they're saying has something to do with what's going on right now. But it's not...So that's a huge challenge. Like where, where, what time in their life are they at? At that moment? But if they can't tell me I have no idea, right?

Resistiveness to care was another behaviour exhibited by PLWD that was reported as being difficult to respond. PSW_01_07 expressed that *“it can be a challenge to get them to cooperate,”* and further shared that communicating effectively to gain consent to perform care was an aspect of caregiving which she found to be the most difficult. Others similarly noted difficulties in communicating successfully with PLWD to facilitate the performance of care, specifically when PLWD demonstrated physically aggressive behaviours. PSW_01_12, for example, shared: *“But sometimes [the client is] a little bit aggressive. Like, so hard to like, so hard to get him down to the washroom.”*

3.3.2 Subtheme 2 – The Emotional Toll of Communicating

It became apparent through participants' narratives that communication negatively impacted the emotional states of PSWs in numerous ways. Participants shared that they experienced feelings of frustration and fear in their communication experiences with PLWD. PSWs expressed further that communication required patience and that there was potential for formal caregiver burnout. It was evident that certain dementia-specific impairments significantly contributed to these negative feelings. Some participants stated further that they lacked confidence and experienced guilt over their insecurity to communicate effectively with PLWD.

Participants often used the term “*frustrating*” in describing their experiences communicating with PLWD. The tendency for participants to have to repeat themselves, as well as care tasks when interacting with PLWD, was commonly cited as contributing to PSWs’ feelings of frustration. PSW_01_03, for instance, shared that she viewed the experience of communicating as “*frustrating,*” as the forgetfulness of PLWD resulted in the need to constantly repeat herself:

The communicating to them, um, sometimes can get frustrating because they forget what you’ve already said. [=! Laughing]...Or you may have gone through the whole routine of you know, this is how we’re going to wash our hands. Hoping it sticks, but it doesn’t. And you have to go through the same instruction every time.

PSW_01_09 similarly expressed that the need to repeat herself when communicating with PLWD was often “*frustrating,*” as well as “*stressful,*” and that this required her to mentally prepare herself prior to engaging in interactions with clients: “*I prepare myself before I enter the doorway. If this is going to be frustrating, stressful, constantly repeating yourself and constantly telling what to do.*”

PSW_01_09 shared further that patience was required when communicating with PLWD who exhibited verbal aggression. She expressed that in these situations, it took “*willpower*” to refrain from responding to PLWD in a negative manner:

“[PLWD] was very verbally aggressive with me...And she was quite um, uh, ‘You should know what you’re doing. You don’t have to ask me what I need.’...Then she’d

order me back. 'Sweep the floor!,' 'Pull down my bed.' It was kind of, took a lot of willpower not to snap back at them."

PSW_01_10 similarly noted the potential for burnout when PSWs encountered physical and verbal aggression from PLWD. He expressed: *"...care provider or caregiver, uh, will burned himself or herself. Especially if it is bad one. ...I mean, you know, aggressive, swearing and that...Everybody, we are, you know, we are professional but still doesn't, uh, sound nice to our ears."*

Others described the experience of interacting with PLWD as *"scary," "uneasy,"* and *"intimidating."* Most participants who viewed communication with PLWD in this manner specifically noted that these feelings stemmed also from fears relating to PLWD exhibiting physically and verbally aggressive behaviours. PSW_01_14, for instance, expressed that she found interactions with a client who *"aggressively growled,"* and *"...took food and flung it"* as *"very intimidating."* PSW_01_09 similarly stated that she was *"nervous"* at times to interact with PLWD, due to fears of encountering aggressive behaviours: *"I wasn't too sure if they were going to be aggressive to me...So that made me nervous."* She further elaborated on this statement, sharing: *"... 'cause you don't know when they are going to turn on you...It could be sweet as pie and then all of a sudden, boop, hit you in the head or something."* Being fearful of interactions with PLWD due to the *"unpredictability"* of dementia, and its commonly associated symptoms, was further expressed by PSW_01_11. She shared that she was *"uneasy"* in her interactions because *"I don't know where they're at."* She compared the experience of preparing for an interaction with a client who had solely physical health issues, with that of PLWD, viewing the former as more predictable than the latter:

...I think it's the unknown. I think it's the big unknown. When you're going into give somebody a bath and they've had surgery on their hip or something, you know pretty much what you're walking into, right?...With dementia you don't know what you're walking into. Like I could be walking into a guy's standing there with a shot gun. I could be walking in to somebody trying to hang herself. I could +//. You don't know what you're gonna walk into...Um, yeah but I think, I think the unknown makes me uneasy.

While some PSWs' narratives revealed feelings of frustration and fear in their overall experience of communicating with PLWD, others expressed a lack of confidence in their ability to interact successfully with PLWD. These participants doubted, and sometimes expressed guilt over whether they had the capacity to ensure a successful communicative encounter with clients. PSW_01_01, for example, shared that she had a tendency to question her communicative decisions when interacting with PLWD, and that this self-doubt prevented her from providing the best possible care:

And so sometimes I think that when I'm with my clients, I'm thinking to myself, 'Ok well that was just stupid.' 'What the heck did I just do?' Right? Cause I'm like does it make sense? Am I doing the right thing? Am I saying the right thing? Do I sound like, you know, I don't know what I'm talking about. So I do a lot of second guessing of myself. That's my problem... Um, so I think what's holding me back from providing better care is the second guessing that I do.

PSW_01_16 similarly shared feelings of uncertainty, and a lack of confidence in her communication skills, particularly in situations in which PLWD experienced delusions.

She expressed that in these circumstances, she was unsure as to how to proceed in encounters and ensure a successful communicative outcome:

...there's a lot of clients that say 'oh so and so is hiding under my bed' or whatever right...And to calm them down and say, like my thing is like do you say 'oh okay', like you agree with them? Or do you just not address it?

PSW_09 similarly stated that she experienced feelings of nervousness in her ability to communicate effectively with PLWD, and achieve a successful outcome: *"I was a little nervous. I have to admit. I was nervous... 'Cause I wasn't too sure if I was able to convince the person."* She further expressed feelings of guilt when unable to do so:

Sometimes I find that if I'm in the middle of something and they decided that they don't want to do it anymore, and like it's half done... And that half, I feel like I'm neglecting the client...And I can't convince them. Like you know, 'We have to wash your bottom,' for example."

Conversely, it was noted by some participants that *"communication...comes with experience"* (PSW_01_03).

3.3.3 Subtheme 3 – Consequences of Communication Breakdowns Initiated by PSWs

Several PSWs shared that there were instances in which they were unsuccessful in their attempts to communicate with PLWD (i.e., communication breakdowns).

Participants expressed that despite their best efforts at ensuring successful communicative encounters, breakdowns in communication occurred. Communication breakdowns

resulted in negative consequences for the overall encounter though eliciting anger or verbal aggression from PLWD, or contributing to a lack of reciprocity in interactions.

The relationship between communication breakdowns and anger among PLWD was demonstrated by PSW_01_01. She shared that despite the use of various strategies when communicating with a client who frequently exhibited inappropriateness, she often was unable to ensure a successful communicative encounter, resulting in the client becoming angry:

Now it's getting to the point where I don't know what to say to him anymore....I've um tried to validate his feelings. I've tried to, to explain things to him. I've tried to redirect him in a different way. Sometimes that doesn't work and so now he's getting to the point where he's getting a little bit cross.

PSW_01_10 shared a similar narrative in which despite having tried “everything” to convince a wandering client to remain in the home, he was not successful in the communicative interaction. This essentially led to breakdowns in communication, and the subsequent display of verbally aggressive behaviours from the client:

And he was heading towards the road, and I said, 'Where are you going?' And he said, 'I'm going home.' And I said, 'Let's go back, we'll have a conversation.' Didn't work. And he started screaming 'Oh, he's going to kill me, he's going to kill me.'

Several participants' narratives also revealed that communication breakdowns could result in a lack of reciprocity in communicative encounters with PLWD. PSWs

shared that when breakdowns in communication occurred between themselves and their clients, communication could be “*minimal*” (PSW_01_01) or virtually non-existent.

PSW_01_11, for instance, expressed that she often experienced communication breakdowns when attempting to interact with PLWD who did not speak English. The breakdowns resulted in “*no communication*” between herself and these clients.

PSW_01_08 similarly detailed her own experience with encountering a lack of reciprocity in interactions with PLWD, stemming from breakdowns in communication.

She expressed that despite attempting to communicate with clients, she often experienced virtually no reciprocity from PLWD: “*Yeah, it’s like, sometimes, it’s like you are talking to the wall. I feel that you know, cause you look at their eyes and it’s blank....And it’s like, you try to say something and it’s not really getting in.*”

3.4 Theme 2 - Valuing Communication in Care

Valuing communication in care, a major theme, refers to PSWs’ understanding of communication as an important aspect of providing care to PLWD. Two subthemes comprise this theme: treating communication as a need, and being self-aware and self-reflective about communication.

3.4.1 Subtheme 1- Treating Communication as a Need

Several participants in this study recognized the need to communicate with PLWD as a way in which to enhance the well-being of clients through socialization. PSWs acknowledged social communication as a fundamental need for PLWD and recognized their role in fulfilling needs related to interactions. Participants viewed communication as an important aspect of care for PLWD, rather than viewing

communication and care as two entirely separate, unrelated entities. It became evident that time served as an important factor in PSWs' ability to recognize and address clients' needs for communication.

PSW_01_13, for instance, expressed that he believed engaging in social interaction with clients was a crucial component of providing care for PLWD. He stated that some clients did not get much social contact outside of their interactions with PSWs, thus engaging in social communication with these individuals was critical:

I strongly believe that part of the care is to socialize. A lot of these elders don't see anybody, uh once a week and you're their coffee, you're their banter, you're their gossip...You know. Give 'em a bit of smile.

PSW_01_02 similarly recognized the communication needs of PLWD, sharing that she attempted to keep the lines of communication open when providing care for PLWD. This was due to the fact that she noticed that all clients enjoyed participating in conversation, regardless of any impairments they may experience: *"And I try to keep that language barrier open, communication going. And, and they seem to like it no matter what the ethnicity. Or the culture barrier. Or any of, even Alzheimer's. They like being engaged in conversation."* PSW_01_11 noted further the need to *"talk"* to PLWD while providing care because it offered clients a sense of security that could not otherwise be accomplished if care was performed without interaction. She elaborated further, expressing that this differed from the experience in LTC home settings, in which tasks were performed with virtually no conversation: *"[in the] nursing home you just do it. That's what I hate it."*

This was echoed by several others who described LTC home settings as limiting their opportunities to recognize and meet the communication needs of PLWD residing in such settings. LTC home environments were described as “...*factories for humans*” (PSW_01_13), and as “...*a production!*” (PSW_01_14), in which strict time constraints, and high workloads impeded the ability to interact meaningfully with PLWD.

PSW_01_07, for instance, expressed: “... *the nursing home setting, usually you're like, you have a set amount of time...To get like, say, 6 people done... And there's no, none of that one-on-one relationship.*” PSW_01_10 similarly noted the emphasis placed on time in LTC settings, stating “*in long-term care facilities, it's kind of time, it's about time, it's not about residents.*” The “*rushed*” nature of LTC, consequently, was cited as significantly restricting opportunities for meaningful communication:

To be honest, in long term care you don't have even time to communicate and have a conversation with that kind of person...It's just 'good morning', put clothes on, give sponge bath or something, put him in chair, and bang, to the dining room. (PSW_01_10)

In contrast, home care was described as providing opportunities to treat communication as a need for PLWD. PSWs noted that the time allotted for the provision of home-based care significantly contributed to this. PSW_01_02, for example, expressed that despite having a schedule to adhere to when providing care in the home, it nonetheless provided enough time to engage in social communication with PLWD, and develop a better understanding of the individual:

You're on a schedule too, but you actually get to interact and say, 'hey how you doing?' You can sit for five minutes and say, 'what's going on in your life?' 'What you've been up to?' 'What did you do last night?... you get to relax and understand the client.

Similarly, PSW_01_07 shared that the ability to communicate meaningfully while providing care in the home was facilitated by having time to interact one-on-one and the fact that there was no need to rush the care routine: “... like in home care you do get a lot of one-on-one time instead of having to rush.” Having one-on-one time contributed also to PSWs’ ability to communicate and develop a deeper understanding of the individual: “Home care is like one-on-one with someone. You are spending time one-on-one. Get to know the person and feel more and do things with them” (PSW_01_05). While many participants expressed that home care provided opportunities to interact meaningfully, some PSWs did, however, note that employers stressed the importance of maintaining professional boundaries.

3.4.2 Subtheme 2 – Being Self-Aware and Self-Reflective About Communication

Many PSW participants in this study acknowledged that the way in which they communicated with PLWD affected clients’ thoughts and behaviours. Participants noted the impact that one’s verbal and non-verbal communication can have on PLWD. A majority of participants who discussed the impact that their verbal communication could have on PLWD specifically highlighted the negative effects that directive communication could have on clients’ behaviours. These participants noted that when their communication was overly directive, PLWD responded by demonstrating resistiveness to

care. PSW_01_09, for instance, stated *“instead of ordering, you should suggest,”* as when communicative was directive, PLWD *“...won’t acknowledge that. They fight you back.”* PSW_01_15 similarly noted that when PSWs rushed communication, it could be interpreted by PLWD as being directive. PLWD subsequently reacted by resisting care: *“Most time I find it when they feel rushed...Then they start to rebel...they rebel with us is like [PSW:] ‘Okay, you have to, you have to go in shower. [PLWD:]‘No I’m not going’... ‘Not today’... ‘Not on your terms, today.’”* PSW_01_14 noted further that it was important to refrain from threatening PLWD with repercussions for their actions because it could elicit agitation from clients: *“You don’t threaten. It’s not going to do any good...That just gets him agitated.”*

The impact of PSWs’ non-verbal communication on PLWD also was noted by many participants. Of the PSWs who stated that non-verbal communication affected PLWD, most specifically referred to body language and attitude. Participants stated that when they exhibited positive body language and attitude when interacting with PLWD, positive responses from clients were elicited in return. PSW_01_02, for example, discussed the importance of exhibiting a *“relaxed”* attitude when interacting with PLWD because this resulted in clients feeling similarly relaxed: *“a big amount of making the clients relax is that you show that you’re relaxed. And then you don’t get them all wound up. And you find that they work more better with you”*

The opposite effect was noted when PSWs displayed negative body language and attitude during encounters with PLWD. Participants expressed that in such situations, clients often reacted in an unfavourable manner. PSW_01_02, for instance, highlighted

the need to be aware of one's own body language and attitude during interactions with PLWD, as it could inadvertently elicit a negative response from clients:

Like you, you know your body language. And if you come off too bossy. Or too harsh. Or too shy or timid. And it's like, you can't do that. Like you're going into somebody that's got Alzheimer's, they're gonna trigger something...So you watch your body language.

PSW_01_14 similarly discussed the need to be attentive to one's own physical behaviours, as it could complicate the overall caregiving process. She specifically expressed that when PSWs lacked a confident attitude, PLWD could react in ways impeded the ability to communicate, and provide care: “... if you show fear with anybody with Alzheimer's or dementia? They gotcha. They got your number. And you're not going to get anywhere to help them...”

Some participants further highlighted the impact of body language and attitude on clients' feelings of being genuinely cared for. PSW_01_02, for instance, expressed the importance of body language in instilling this feeling in PLWD, as this could not be accomplished solely through verbal means: “...words are nothing. Words are never anything, even to someone you're talking to. It's your body language that's gonna tell, tell them how much you actually care” PSW_01_16 similarly noted the importance of exhibiting a “happy” attitude in ensuring clients felt sincerely cared for, stating: “...they need to see you're happy to be there, you know they see that you care for them genuinely...”

While most participants who discussed the impact of their non-verbal communication on PLWD emphasized body language and attitude, others discussed the effects that prosodic features of speech production could have on clients. Prosodic features of speech production are defined as/refer to “the rhythm, stress, and intonation of speech” (American Psychological Association, 2014). PSW_01_10, for instance, noted the effect that one’s tone of voice could have on PLWD. He specifically shared that if a PSW’s tone was “*scary*,” clients consequently reacted in a fearful manner: “*If voice something scary, client will be scared too, especially dementia clients.*” PSW_01_13 similarly noted the impact that one’s tone, as well as intonation, could have on PLWD, expressing that changes in his own tone and intonation, could accordingly elicit changes in clients’ own communicative behaviours: “*...you know they get, somebody with dementia gets flustered easy, so intonation and tone and voice is really. If you go up, they go up.*” PSW_01_11 also discussed the impact of rate of speech on PLWD. She expressed that it was important to ensure that one was not speaking too quickly because this could make clients feel as though PSWs did not want to be present in the care situation: “*Like if you’re talking really fast...They’ll think well she doesn’t even want to be here.*”

3.5 Theme 3- Home Is a Personal Space

A third theme, home is a personal space, includes the ways in which the intimate home environment itself influenced PSWs’ experiences in communicating with PLWD. The third theme is comprised of two subthemes: the dual nature of families’ presence and involvement, and availability of environmental cues.

3.5.1 Subtheme 1 – The Dual Nature of Families’ Presence and Involvement

For the first subtheme, the dual nature of families’ presence and involvement, some participants reported that providing care to PLWD in the home environment entailed “*dealing with family of the dementia patients*” (PSW_01_11). This was stated as different from the LTC home setting where such interactions did not occur frequently: “*... in nursing home, you’re only dealing with that one person. You’re not dealing with the family too*” (PSW_01_11). It became apparent that the presence of families in the home environment, and their participation in care, influenced participants’ overall experience in communicating with PLWD. However, narratives that provided insight into the ways in which these factors influenced the experience varied extensively. Some narratives highlighted the positive role families could play in PSWs’ experiences in communicating with PLWD. PSWs noted that families could interpret and translate when communication barriers arose in the PSW-PLWD dyad, convince and persuade PLWD when clients demonstrated resistiveness to care, and provide client-related information. Conversely, other narratives revealed the negative impact families’ presence and involvement could have on the communication experience. PSWs expressed that families could limit their opportunities for communication with PLWD, and interact ineffectively with PLWD, making subsequent PSW-PLWD interactions more difficult.

Some PSWs reported that families could enable successful communicative encounters between themselves and PLWD in situations where the communicative competence of PLWD was challenged. Successful communication was achieved typically by families aiding with the interpretation of clients’ wants and needs, and when

communication barriers emerged between PSWs and PLWD. PSW_01_15, for instance, shared that she found the presence of families within the home beneficial when PLWD were non-English speaking, either due to their experience with reverting to a native language or a general lack of English proficiency. She expressed that in such situations, there was a reliance on family members present within the home environment to aid with translation: *“Most times it’s helpful when the family members are home...Because that way the family member will be able to interpret what they are saying.”* PSW_01_12 shared a similar narrative in which she expressed that it was helpful to communicate with the families of PLWD who *“can’t express their own feelings very well,”* as they could provide insights in clients’ needs, wants, and feelings.

Similarly, PSW_01_09 reported that families could help facilitate effective encounters when she was unsuccessful in her attempts to convince or persuade PLWD and gain clients’ cooperation. She explained that since family members were familiar to PLWD, clients would often demonstrate a willingness to abide by their families requests more so than her own:

...if I ask [PLWD] for instance, ‘[PLWD], can you uh, let’s go into the bathroom and get ready for bed?’ Um, he will say something like, ‘No.’ Or just ignore you. Or not even comprehend what you are saying... And then the family member will step in and say, ‘Come on [PLWD], let’s go in the bathroom.’ Because it’s a familiar person, and they take them by the hand, they have a tendency to get up and walk [to the] bathroom...and then you do all the procedures...

It also was apparent that the opportunity to interact with families in the home environment contributed to some PSWs ability to acquire the information necessary to facilitate a more successful communicative encounter with PLWD. Many participants noted that agencies included only “*very, very basic*” (PSW_01_03) information regarding PLWD in clients’ charts. Several PSW expressed further that notes left by other PSWs who had cared for their clients at an earlier point in time could often be inadequate. Thus, it was evident that some PSWs relied on the opportunity to communicate with family members present in the homes of PLWD as a way in which to attain important information pertaining to clients.

PSW_01_01, for example, shared that communicating with families could reveal valuable insights into the social history of clients. She, as well as others, discussed the importance of knowing the social history of PLWD in order to facilitate positive interactions. As a hospital to home PSW, PSW_01_01 expressed that she strongly desired to be in the home immediately upon a client’s discharge from the hospital in order to have the opportunity to interact with all members of the family, and obtain this information:

If the person’s coming home on their first day, and I’m gonna be their primary caregiver, I like to be there the first day they come home... ‘Cause the family is all there. And it gives me, and it gives me an opportunity to find out everything I need to know about the client. Well, what were they like before?...What did they, you know...

PSW_01_16 similarly expressed that she valued the opportunity to communicate with families of PLWD in home care, as it provided her with the ability to attain information pertaining to how the client's day was progressing. She stated that since she was not always with the client throughout the entire course of the day, she often relied on interactions with families who were present within the home as a way in which to acquire this information:

I think sometimes um communicating with the family so that you can get just an idea of how their day is already started...Because quite often we are not there right when they get out of bed or. You know, um so just to get a bit of the feeling how things are progressing that day.

Conversely, several participants expressed that the involvement of families in the provision of home-based dementia care could complicate the overall experience in communicating with PLWD. Several PSWs specifically noted that families could restrict and limit opportunities to engage in meaningful communication with their clients. PSW_01_05, for example, shared that the presence of families within the immediate care environment, in itself, could be “awkward” and negatively influenced her comfort level in engaging in social interactions with PLWD: “*You feel like you always have to do something when the family is around. You can't sit down and just relax. You have to like do the dishes, do the laundry...*” PSW_01_03 also expressed that families could become too deeply involved in the provision of care, and subsequently interfere with her ability to develop a better understanding of the client, and build a meaningful relationship through interaction:

You know, when you you're trying to develop that bond. Or trying to get that understanding that works for you and that person, you know. And they're always interjecting. Or don't pay attention. Or this is what they want. So it doesn't give you an opportunity to really learn it yourself.

PSW_01_03 also noted that families could rush the care routine, due to their own experiences with caregiver burnout, which, in-turn, impeded her ability to make meaning of clients' attempts at communication:

Family are burnt out. They just want to keep em quiet. Get em to bed [=! Laughing]...that's all they want. They want their rest. And you can't blame them, but they just poopoo a lot of it off. Right? But it's, it's important to that person at that time.

It also was evident that families negatively affected participants' encounters with PLWD through ineffectively interacting with their relatives. PSWs reported family members could often elicit negative reactions from PLWD, due to the way in which they communicated, which complicated PSWs' subsequent encounters with the clients.

PSW_01_10, for instance, stated: *"I have one guy, right now, ninety-two, and he was dentist, and Air Force and everything...And sometimes his, uh, family kind of pushing him...And they just escalate things, and then it's harder on me when I come."*

PSW_01_08 shared a similar narrative, stating that she preferred that families weren't present in the home, as their interactions with relatives could lead to PLWD exhibiting agitated behaviours: *"Actually, most of the time I prefer that there is no family...Because*

it depends on like some, some clients, the family is like overdoing things. And then the client ended up getting agitated.”

3.5.2 Subtheme 2 – Availability of Environmental Cues

For the second subtheme, availability of environmental cues, several PSWs reported that they drew upon personal objects in the homes of PLWD to facilitate successful interactions with clients. Specifically, participants stated that they used pictures in the home to either relate and connect with clients, or to enable task completion. PSW_01_05 expressed that the experience of communicating with PLWD could “*play in your favour*” in the home, due to the ability to reference pictures in the physical home environment and promote successful communicative encounters:

It [communication] can play in your favour at their home...They have pictures in the house...So you can always go back to referring to those pictures...So it can play in your favour in that sense, that you have something to talk about. To refer to, bring them back to reality.

This statement was supported by other narratives, in which participants described drawing upon pictures in the home environment to facilitate conversation. PSW_01_08, for example, shared “*And if I see pictures on the walls, like, ‘Oh they’re pretty,’ and all that of this and that. That’s what I do.*” PSW_01_09 further echoed this statement, expressing “*Um, then I would look at pictures on the walls....And ask them, ‘Who are these people?’ and sometimes they would know.*”

Pictures were also used as a way in which to enable successful task completion. PSW_01_05, for instance, shared that she used pictures to “*distract*” PLWD during the

performance of physical care tasks, such as bathing: “*Um, I would try to distract them...Yeah, like, especially pictures. Pictures seem to help a lot.*” PSW_01_08 similarly expressed that the referenced pictures in the home environment in order to gain cooperation from her client who demonstrated resistiveness to care and physical aggression:

“...and then after the coffee, I was like, I remind her, ‘Your son is coming’ and she was like ‘Who’s my son?’ and I was like ‘This is your son right?’ I point a picture...’Your son,’ and you know, I was like, ‘he’s coming to bring you out for shopping.’”

Chapter 4

4 Discussion

The purpose of this study was to understand better the lived experiences of formal caregivers, specifically PSWs, in communicating with PLWD while providing home care. The current study is unique in its purpose and findings. Based on a thorough search of the published literature, this is the first study to explore fully PSWs' lived experiences of communicating with PLWD in the home. Findings from this study provide insights into the challenges experienced by PSWs in regard to communicating with PLWD, their acknowledgement of communication as an important aspect of care, and the impact of the personal nature of the home space on their experiences with communication. This section will outline the three major themes identified through thematic analysis, along with their respective subthemes, implications, and limitations and recommendations for future research.

4.1 Theme 1- Challenged by Dementia-Related Impairments

Difficulties communicating with PLWD can be the result of impairments in semantic and pragmatic communication on the part of PLWD (Savundranayagam et al., 2005). Accordingly, it was evident in the present study that dementia-related impairments exhibited by PLWD challenged PSWs' experience with communication. Participants expressed that they encountered difficulties with interacting effectively with PLWD in situations where they displayed impaired verbal language production, reversion to a native language, problems with topic management, wandering, reversion to the past, suicidal ideations, resistiveness to care, and physical aggression. The literature has

similarly shown that formal caregivers experience difficulties in interacting with PLWD due to dementia-related impairments, regardless of care setting. Indeed, the home care literature has demonstrated that impairments experienced by PLWD challenge formal caregivers' experience with care (Beer et al., 2014; Karlsson et al., 2014; Van Vracem et al., 2016; Schneider et al., 2019). Formal home care providers have reported that the presence of dementia can result in challenges with clients' comprehension of care activities (Beer et al., 2014; Karlsson et al., 2014) and result in a lack of cooperation (Karlsson et al., 2014). These have been linked to challenges faced by care providers in the context of pain assessment, when PLWD demonstrate a diminished ability to communicate (Karlsson et al., 2014). Schneider and colleagues (2019) and Van Vracem and colleagues (2016) have similarly reported that dementia-specific impairments can be problematic and challenging to formal home care providers' experience with care. In LTC settings, formal care providers have struggled with communicating, specifically, with PLWD due to dementia-related impairments for decades (Richter et al., 1995). More recent communication literature from LTC contexts has suggested that difficulties with communication still persist (Wang et al., 2013). In Wang and colleagues' (2013) study, it was evident that formal care providers' perception of dementia-specific impairments as complicating their experiences with communication could stem from an unfamiliarity with dementia. Home care workers similarly can lack knowledge and understanding of dementia (Polacsek et al., 2019). When formal care providers, regardless of setting, do not have sufficient knowledge and understanding of dementia, they can demonstrate the inability to attribute impairments to the diagnostic and associated features of the syndrome or as a reflection of unmet needs (Polacsek et al., 2010; Wang et al., 2013).

This can result in negative perceptions of PLWD and lead to ineffective formal caregiver communication (Polacsek et al., 2010; Wang et al., 2013). Indeed, aside from memory impairment, many formal home care providers are not aware fully of the diagnostic and associated features of dementia (Roelands et al., 2005) and acknowledge the need to improve their knowledge and competence. Adequate knowledge and understanding of dementia can facilitate positive care experiences (Polacsek et al., 2010). However, formal caregivers experience difficulties communicating with and caring for PLWD even when they are able to recognize that the impairments displayed by PLWD reflect an unmet need (Karlsson et al., 2014; Wang et al., 2013). This points to a need for education and training that includes content on the features of dementia. It further highlights the need to ensure that education and training includes a component focused on effective communication strategies. Many training interventions are focused on enhancing dementia literacy and while they are typically successful in achieving their purpose, improvements in the area of communication skills is necessary (Goh et al., 2018).

The current study revealed also that PSWs' emotional states could be negatively impacted by the experience of communicating with PLWD. For example, PSWs expressed feelings of frustration in situations where the forgetfulness of PLWD required PSWs to constantly repeat themselves and care tasks. Cognitive deficits related to learning and memory are common features of dementia (APA, 2013). When PLWD experience impairments in the ability to obtain and remember newly presented information, they can often exhibit symptoms such as misplacing objects, getting lost on familiar routes, forgetting appointments and events, and repetitive verbalizations (McKhann et al., 2011). Repetitive statements and questions reflect changes in the

pragmatic skills of PLWD (Savundranayagam et al., 2005). Aligned with our findings, the formal home care literature has demonstrated that care providers experience frustration and annoyance in response to situations in which PLWD exhibit verbal repetition (Schneider et al., 2019). Within the informal home care context, repetitive questioning has been a long-standing source of frustration for informal caregivers (Small et al., 2000). More recent literature suggests that repetitive questioning continues to frustrate informal caregivers (Hamdy et al., 2018). Literature focused on formal caregivers of PLWD in LTC homes, however, has somewhat contrasting findings (Stanyon et al., 2016; Wang et al., 2013). In Wang and colleagues' (2013) study, repetitive verbalizations appeared to frustrate some formal care providers in their interactions with PLWD. In contrast, in Stanyon et al.'s (2016) study, care staff accepted that they would need to repeat themselves when interacting with PLWD. Participants acknowledged the need to accept and accommodate for the impairments exhibited by PLWD during encounters, with little indication of frustration (Stanyon et al., 2016). This suggests that formal caregivers are less likely to be frustrated with repetitive verbalizations when they view it as a normal symptom associated with dementia and accommodate communication accordingly. Repetitive verbalizations are indeed common among PLWD at all stages (Reeve et al., 2017). This, again, reinforces the need for education and training due to its ability to increase formal home care providers' knowledge and understanding of the diagnostic features associated with dementia. Additionally, education and training are crucial because the use of effective communication strategies has been shown to aid both formal and informal home caregivers in managing repetitive behaviours (Bourgeois et al., 1997; Guerrero et al., 2020). Training has been

shown also to help formal care providers in remaining calm and managing their negative emotions (Guerrero et al., 2020). This further reinforces the need to ensure that education and training interventions include modules that focus on signs and symptoms of dementia, as well as communication skills.

PSWs in this study further expressed feelings of fear in interacting with PLWD. The need for patience and potential for burnout were noted also. These negative emotions were most often related to the display of verbal and physical aggression by PLWD. Formal home care providers who care for PLWD are at risk of encountering aggression from clients (Karlsson et al., 2019). Indeed, aggression is a common impairment displayed by PLWD who reside at home (Kunik et al., 2010) and especially so among those with the frontal and behavioural variants of frontotemporal dementia. The display of aggression is a way that PLWD indicate unmet needs and reflects changes in communication-related abilities (Algase et al., 1996; Karlsson et al., 2014). However, there are conflicting reports in the literature regarding formal caregivers' understanding of aggression as reflecting unmet needs. Polacsek et al.'s (2019) study suggests that formal home care providers can experience challenges in attributing aggression to unmet needs of PLWD. Conversely, other studies have shown that formal caregivers do indeed attempt to understand the underlying meanings of aggression (Karlsson et al., 2014; Rapaport et al., 2018). Yet, even when formal caregivers attempt to link aggression to unmet needs, they can still feel frightened by it (Rapaport et al., 2018). Indeed, understanding needs was not always easy for care staff in Rapaport et al.'s (2018) study. Aggression was still viewed as unpredictable, despite care providers' identification of aggression as indicating unmet needs. PSWs in our study who were fearful of aggression

similarly perceived aggression as unpredictable. Additionally, it was evident also that some care staff in Rapaport et al.'s (2018) study experienced challenges in attributing aggression to unmet emotional needs. In such instances, some care staff believed residents were attempting to be deliberately demanding. In contrast, aggression as a reflection of unmet physical needs was widely accepted by care providers, but they acknowledged that it could still be overlooked. Formal caregivers can have negative feelings towards PLWD who exhibit aggression, even when they attribute aggression to the symptomology associated with dementia (Holst & Skar, 2017). Similar to our findings, the need to remain calm when PLWD exhibit aggression has been noted in the literature (Rapaport et al., 2018). When formal care providers have negative feelings towards PLWD due to the display of aggression, the quality of care provided to PLWD can be compromised (Holst & Skar, 2017). Additionally, when caregivers' experience feelings of fear in relation to aggression and anticipate harm, they may fail to approach and respond to PLWD in an effective manner (Rapaport et al., 2018). This can further compromise the care received by PLWD. Home-dwelling PLWD who demonstrate aggression experience also a higher risk for relocation to more formal care settings, use of psychotropic medication, and injury to self (Kunik et al., 2010). When formal caregivers possess effective communication skills, however, encounters with aggression can be reduced (Savundranayagam et al., 2020). Continuity of care has been recommended also to reduce the display of aggression by PLWD (Karlsson et al., 2019).

PSWs in this study further lacked confidence in their ability to interact with PLWD and some expressed guilt over this. This is aligned with other home care literature, which has similarly shown that formal home care providers can lack

confidence in their ability to care for PLWD (Cross et al., 2008). This is not a surprising finding, given that home care workers who provide direct care services in the home possess minimal qualifications, despite comprising a large part of the dementia care workforce (Hussein & Manthorpe, 2012). Formal caregivers acknowledge the need for dementia-specific training and demonstrate the desire to develop competence through continuing education (Flojt et al., 2014; Morgan et al., 2016). Indeed, Savundranayagam and colleagues (2020) suggest that PSWs' formal training fails to equip PSWs with the skills necessary to address dementia-specific communication, and memory and behavioural impairments adequately. The authors note that this is despite the increasing prevalence of dementia and the important role played by PSWs in the care of PLWD. Training, however, has shown to be effective in increasing formal home care providers' confidence, perceived competency, self-efficacy, and use and knowledge of communication strategies, (Fenley et al., 2008; Low et al., 2015; O'Sullivan et al., 2017; Smith et al., 2017; Tan et al., 2017; Guerrero et al., 2020; Savundranayagam et al., 2020). This, in-turn, can lead to enhanced job satisfaction and better retention (Savundranayagam et al., 2020). This is especially important given the current shortage of PSWs in Canada (Savundranayagam et al., 2020).

PSWs in this study reported that there were occasions in which they were unsuccessful and experienced communication breakdowns, despite their best efforts at communicating with PLWD. Breakdowns in communication resulted in negative consequences, including the elicitation of anger and a lack of reciprocity in interactions. Literature from LTC contexts has similarly demonstrated that communication breakdowns occur between formal care providers and PLWD in LTC homes.

Breakdowns in communication can result in the display of behaviours such as physical aggression, resistiveness to care, and distress (Kolanowski et al., 2015; Savundranayagam et al., 2016; Williams et al., 2009). These studies emphasize the role of formal caregiver communication in contributing to communication breakdowns and triggering certain behaviours. Findings from Kolanowski and colleagues (2015) demonstrated that differences in the cultural backgrounds of formal caregivers and PLWD could precipitate communication breakdowns and result in the display of physical aggression. Similarly, the display of resistiveness to care by PLWD has been linked to the use of elderspeak and overly directive speech by formal caregivers (Savundranayagam et al., 2016; Williams et al., 2009). Savundranayagam and colleagues (2016) and Williams and colleagues (2009) both suggest that effective communication by formal caregivers can prevent resistiveness to care. Research involving informal caregivers within the home context relatedly shows that communication breakdowns can result in negative consequences, including a lack of reciprocity (Small et al., 2000). Concurring further with literature from LTC contexts, it has been determined that the use of ineffective communication strategies, such as slowed speech rate, contributes to communication breakdowns experienced by informal caregivers (Small et al., 2003).

4.2 Theme 2- Valuing Communication in Care

PSWs in the current study acknowledged the need to communicate with PLWD as a way in which to enhance the well-being of PLWD through socialization. This suggests that PSWs are able to recognize social engagement as an important need for PLWD (Algase et al., 1996; Hansen et al., 2017). PSWs appeared to prioritize participating in social communication with PLWD, and this was seemingly despite the potential

dementia-related impairments encountered by PSWs. This demonstrates that socializing with PLWD is possible regardless of the communication abilities of PLWD and the stage of dementia experienced. This is in contrast to Ben-Arie and Iecovich's (2014) findings, which suggest that cognitive impairment can limit clients' communication with home care workers. Indeed, it has been demonstrated that PLWD can contribute and partake in conversations when caregivers interact effectively (Savundranayagam et al., 2016). Possessing effective communication strategies are thus vital in engaging in meaningful interactions with PLWD (Polacsek et al., 2019). Socialization is important to both formal care providers and PLWD. For formal caregivers, engaging in socialization with PLWD is beneficial because it allows care providers to learn about the life histories of PLWD (Savundranayagam et al., 2020). Being knowledgeable about one's history supports formal caregivers' ability to be person-centered (Kitwood, 1997). When care providers use person-centered communication in their encounters with PLWD, the quality of interactions can be enhanced (Savundranayagam et al., 2016). Socializing with clients is also important for formal home care providers because it contributes to the establishment of meaningful relationships, which serves as a source of job satisfaction (Ben-Arie & Iecovich, 2014). Indeed, building relationships with PLWD is a source of job satisfaction for formal home care providers (Ryan et al., 2004; Turner et al., 2018). For PLWD, communication is important because it has a significant role in maintaining quality of life, preserving identity, and enabling a sense of security and belonging (Jootun & McGhee, 2011). Interactions with formal care providers are particularly important for home-dwelling PLWD who live alone because this may be the only source of interaction possible (Svanstrom & Sundler, 2015). When PLWD do not have social interactions with

others, they can experience negative outcomes such as loneliness, loss of identity, and boredom. Formal caregivers, however, can lack competence in understanding the social needs of PLWD (Hansen et al., 2017). Training can help care providers understand better the social needs of PLWD (Smith et al., 2017).

It was apparent further in the current study that home care provided the time and opportunity to recognize and to address the communication needs of PLWD. The ability to engage in one-on-one interactions in home care and the subsequent opportunities to develop genuine client-formal caregiver relationships has been a unique and long-standing feature of home care (Kane et al., 1994). Recent research by Riachi (2018) has reinforced this notion further by demonstrating that one-on-one time with PLWD provided formal caregivers with the opportunity to become closer with PLWD through interaction. However, in contrast to our findings, much of the existing literature cites issues of time and a task-oriented focus in home care as impacting the ability of formal home care providers to interact meaningfully with PLWD. The discrepancy in findings, however, may be attributed to the fact that many participants in our study often contrasted matters related to time and tasks to LTC home settings. One-on-one encounters are possible in LTC home environments and are highly valued by staff because they provide opportunities for contact with PLWD and the development of relationships (Stanyon et al., 2016). However, organizational factors can limit this ability (McGilton & Boscart, 2007). Consistent with findings from this study, time constraints, increasing workloads, and inadequate staffing have been shown to impact the ability of care staff to establish meaningful relationships with residents in LTC homes (McGilton & Boscart, 2007). These factors are in addition to characteristics associated with residents'

communication abilities and cognitive status (McGilton & Boscart, 2007). Another potential explanation for the discrepancy in findings between our study and other home care studies is the possibility that participants in the current study used the performance of tasks as opportunities to engage in conversation with PLWD (Hansen et al., 2017; Kristensen et al., 2017; Schneider et al., 2019) but did not engage in social interactions outside of what was possible during task provision. Indeed, it was expressed explicitly in the narrative provided by PSW_01_11 that she engaged in conversation during care tasks. Yet, the quality of these interactions has been questioned (Hansen et al., 2017). Additionally, the discrepancy in findings may be attributed to the fact that a majority of participants in our study (n=12) received dementia-related training. In addition to training being able to help PSWs understand better the social needs of PLWD, it has been suggested that training and continuity can make care less-time consuming (Aasgaard et al., 2014; Rokstad et al., 2017) which may provide time for meaningful interactions. While participants in our study noted that the home care environment provided opportunities to interact meaningfully, some PSWs, however, noted that employers stressed the importance of maintaining professional boundaries. This is consistent with literature which has established the existence of professional boundaries in dementia home care (de Witt & Fortune, 2019).

PSWs also acknowledged and recognized that the way in which they communicated with PLWD impacted clients' thoughts and behaviours. PSWs noted that when they communicated in a negative manner, PLWD similarly reacted in a negative way. Conversely, PSWs expressed that when they communicated in a positive manner, PLWD responded positively. This is consistent with findings from the formal home care

literature that demonstrates that care providers of PLWD can be aware and reflective about the ways in which they communicate (Berglund et al., 2019; Hansen et al., 2017; Karlsson et al., 2014; Van Vracem et al., 2015). Participants in these studies noted the importance of interacting effectively with PLWD due to the impact it could have on clients. Similarly, findings from LTC contexts has demonstrated that formal care providers are self-aware about the impact of their own attitudes, actions, thoughts and reactions in eliciting impairments from PLWD (Clifford & Doody, 2018). Clifford and Doody (2018) suggest that this self-awareness is critical in understanding impairments exhibited by PLWD. Findings from our study and those aforementioned indicate also that formal caregivers are able to identify that impairments exhibited by PLWD are needs-driven behaviours related to communication (Algase et al., 1996). Self-awareness and self-reflection can be contingent on having an understanding of the importance of communication in care and possessing appropriate skills (Berglund et al., 2019; Hansen et al., 2017). Once again, the self-awareness and self-reflection demonstrated by participants in the current study may reflect the fact that most of the PSWs (n=12) received dementia-related training prior.

4.3 Theme 3- Home Is a Personal Space

PSWs in this study noted that providing care in the home environment involved interactions with family members of PLWD. PSWs expressed that this differed from LTC environments, in which these interactions did not occur as frequently. Involvement of family in formal home care reflects the nature of providing care in the “intimate” home space (Sims-Gould et al., 2015). Contact with families in LTC homes is “intermittent” (Hale et al., 2019). However, staff-family interactions nonetheless occur in LTC homes

because family continue their caregiving role when their relatives move to a LTC home (Cohen et al., 2014; Utley-Smith et al., 2009). Yet, staff-family interactions and family involvement in care are ultimately reliant on family visitations. Factors such as transportation and the need to attend to other commitments can serve as barriers to family visits for individuals living in LTC homes, and limit families' participation in care (Port, 2004). While some PLWD who receive home care services live alone (Svanstrom & Sundler, 2015), it was evident through the narratives of participants in the current study that the regular presence of family was a common feature of many homes in which PSWs provided dementia care. This subsequently impacted PSWs' experiences in communicating with PLWD overall. There were both positive and negative implications associated with the regular presence of families and their involvement in care. This coincides with home care literature that has demonstrated that families of clients can be helpful (Beer et al., 2014; Gerrish, 2001; Karlsson et al., 2014; Riachi, 2018; Sims-Gould et al., 2015) but also a hindrance (Beer, et al., 2014; Lotfi Fatemi, et al., 2019; Schneider et al., 2019; Sims-Gould et al., 2015). PSWs in the current study noted that families could impact their experiences in communicating with PLWD in a positive manner by interpreting and translating when communication barriers arose in the PSW-PLWD dyad, convincing and persuading PLWD when care was resisted, and providing information about the client's social history and how the client's day was progressing. These findings are consistent with other home care literature. Gerrish (2001), for example, demonstrated that family members could help with the interpretation of clients' needs and wants when there was a lack of shared language between the formal caregiver and home care client. Participants in Gerrish's (2001) study demonstrated a preference for family members to

translate for home care clients over the use of professional interpreters. They noted that it could be beneficial to use family members to translate for non-English speaking clients, despite potential issues that could arise with using family members for this purpose. Findings from Beer and colleagues (2014) showed also that family members could facilitate successful formal caregiver-client encounters by persuading clients to cooperate with care when they display resistiveness. Additionally, several home care studies have shown that family members can provide formal caregivers with valuable information pertaining to clients (Karlsson et al., 2014; Polacsek et al., 2015; Riachi, 2018; Sims-Gould et al., 2015). PLWD can experience impairments that prevent them from expressing themselves adequately (Karlsson et al., 2014). Home care workers also receive limited information pertaining to their clients (Beer et al., 2014; Franzosa, et al., 2018; Savundranayagam et al., 2020; Swedberg, et al., 2013). Indeed, Sims-Gould et al., (2015) assert that interactions with family can act as a way in which to compensate for details that home care workers do not receive or are unable to ascertain from care recipients themselves.

Our findings showed also that the presence of family members in the home, and their involvement in care, could negatively impact PSWs' experiences in communicating with PLWD. PSWs expressed that families could limit their opportunities for communication with PLWD, and interact ineffectively with PLWD, making subsequent PSW-PLWD interactions more difficult. While some aspects of these findings are consistent with the literature, others differ. Consistent with our study are the findings from Beer and colleagues (2014) which demonstrated that some families could ineffectively interact with the home care recipient through acts such as placing demands

on the client and making distracting comments. This subsequently could upset clients or distract them. Schneider et al. (2019) similarly established that relatives of PLWD did not always interact appropriately with PLWD. Similar also to our findings are those from Sims-Gould et al. (2015), which revealed that formal home care providers can feel monitored or “watched” in their role. Lotfi Fatemi and colleagues’ (2019) study demonstrated also that formal care providers felt dominated by families and did not feel as though they were able to act independently (Lotfi Fatemi, et al., 2019). Rather, formal caregivers felt that they must act in-line with families’ wishes and desires. PSWs in this study experienced comparable struggles because it was evident that PSWs’ interactions with PLWD could be impacted significantly by families’ needs and desires. In contrast with our findings, however, is the notion that family caregivers appreciate instances in which formal caregivers engage in socialization with PLWD (O’Sullivan et al., 2017; Svanstrom & Sundler, 2015; Polacsek et al., 2019).

Several participants in this study shared that they used environmental cues, specifically images, as a way in which to facilitate successful communicative encounters with PLWD. Literature has shown that images are effective stimuli for promoting communication by PLWD, particularly those that depict generic images (Astell et al., 2010). Astell and colleagues (2010) found that when PLWD were presented with personal images, such as those taken at weddings, during holidays, and/or include family members, PLWD were more likely to engage in describing and labelling, rather than story telling. Additionally, PLWD could experience challenges with recognizing individuals in the images and could confuse and mislabel family members. However, PLWD were typically aware that these images contained members of their family.

Conversely, when PLWD were presented with generic images, such as those depicting Christmas scenery, PLWD were able to produce rich, detailed narratives that provide insight into their life histories. This occurred even when PLWD were in the later stages of dementia. Astell and colleagues (2010) suggest that generic images have the ability to evoke personal memories that are not limited to a specific place or era. Generic images are not bound to a correct answer and provide a “failure-free” experience (Astell et al., 2010). This suggests that conversing around generic images allows caregivers to learn more about PLWD and that generic images are effective stimuli for promoting conversation even when PLWD are in the later stages of dementia (Astell et al., 2010). Relatedly, findings from Lee and colleagues (2016) showed that formal caregivers from LTC homes acknowledge the importance of having personal belongings of PLWD in residents’ rooms because it provides PLWD with a sense of familiarity. While not specific to images, care staff expressed that when personal items were present in the care environment, PLWD demonstrated a higher receptiveness to care and exhibited a better mood. It was also noted that personal belongings provided opportunities for interaction between formal caregivers and PLWD and had an overall positive impact on care.

The findings of the current study have a close relationship with both the CPA model and NDB model. PSWs in the current study held negative perceptions of their communication experiences with PLWD due to clients displaying various dementia-related deficits. The CPA model highlights the impact of negative perceptions and stigma on formal caregivers’ communication with PLWD. The model posits that caregivers may communicate ineffectively with older adults because of incorrect assumptions and stereotypes regarding the incompetence and dependence of older persons, as opposed to

actual needs and deficits (Hummert et al., 2004; Ryan et al., 1986; Ryan et al., 1995). Many challenges with communication stem from formal caregivers' lack of knowledge about dementia (Wang et al., 2013). When formal caregivers fail to communicate in ways that accommodate for the unique needs of PLWD, impairments can be sustained and the communication experience, as well as PLWD, are continued to be perceived in a negative manner (Wang et al., 2013). Additionally, opportunities for PLWD to communicate are also restrained and the overall well-being of PLWD is negatively affected. The use of ineffective formal caregiver communication can elicit further needs-driven behaviours from PLWD (Savundranayagam et al., 2016; Williams et al., 2009). Indeed, the NDB model posits that when formal caregivers do not interact in ways that meet the communication-related needs of PLWD, or fail to identify and address other needs experienced by PLWD, PLWD may display various impairments to indicate unmet needs. This is consistent with the findings of the current study also. Taken together, this suggests that PSWs in our study lack sufficient dementia-specific knowledge and communication-related skills. Conversely, however, other findings from the current study demonstrated that participants identified communication as an important need for PLWD, and understood the impact of their own communication style on the thoughts and actions of PLWD. These are posited by the NDB model and in contrast to our earlier findings, indicate that PSWs have some understanding of the importance of communication in the care of PLWD. There is evidently a disconnect between PSWs intentions and actions regarding communication with PLWD.

4.4 Implications

The findings of this study offer implications for PSWs, family caregivers, and employers with regard to enhancing the quality of care for PLWD. The findings highlight the strong need for communication-related training for PSWs who care for PLWD. It was evident PSWs experienced difficulties in communicating with PLWD and as discussed previously, the literature has demonstrated that challenges with communication can stem from a lack of formal caregiver knowledge regarding dementia (Wang et al., 2013). Participants in our study recognized the communication needs of PLWD and further acknowledged the impact of their communication on the thoughts and behaviours of PLWD. Yet, they still experienced challenges with communication during their encounters with PLWD. This suggests that while PSWs possess good intentions and understand that importance of communication in care, they lack sufficient knowledge and skills required to ensure effective interactions. Indeed, it has been established that PSWs' formal training does not prepare them adequately to manage dementia-specific communication, and memory and behavioural impairments (Savundranayagam et al., 2020). This is despite the fact that home care workers who provide direct care services comprise a large component of the dementia care workforce (Hussein & Manthorpe, 2012). It may be possible that a lack of skills and knowledge contribute to the display of impairments PSWs encountered from PLWD in the home. Ultimately, there appears to be a disconnect between PSWs intentions and actions. Thus, education and training are strongly recommended. This suggestion is aligned with the recommendations of numerous researchers (Aasgaard et al., 2014; Butler, 2009; Cross et al., 2008; Ben-Arie & Iecovic, 2014; Roelands, 2005; Flojt et al., 2014; Jansen et al., 2009; Karlsson et al.,

2019; Ledgerd et al., 2016; Polacsek et al., 2019; Samus et al., 2018; Tudor Car et al., 2017; Verkaik et al., 2017; Xu et al., 2018). Several dementia-specific training interventions have been developed and implemented for formal home care providers with promising results (Goh et al., 2018). Both PLWD and formal caregivers benefit from the outcomes associated with formal caregiver education and training. Suggestions for education and training content is noted elsewhere in this thesis, however, it is important to include opportunities for PSWs to practice communicating with simulated patients (Savundranayagam et al., 2020). This is because findings from the current study demonstrate that even when caregivers have some awareness regarding the importance of communication in care for PLWD, care providers still experience issues with communication when interactions occur.

The study revealed further the need for families to receive dementia-related education and training that equips them with the knowledge and skills necessary to communicate effectively with PLWD. This is because it was evident that family members of PLWD could complicate formal caregivers' experience with communication through interacting ineffectively with care recipients. This suggestion is consistent with Xu and colleagues (2018) who recommended dementia-specific education training for family members of PLWD. We suggest also that family members of PLWD encourage PSWs to participate in social activities and interactions with PLWD, and refrain from interfering in PSWs interactions with PLWD. This may help to improve the quality of care for PLWD by allowing PSWs to feel comfortable in addressing social needs rather than being focused on care that addresses solely physical needs. Engaging in socialization and relationship building is important for both formal home care providers and PLWD, as

detailed previously. Additionally, home care agencies can help to improve families' knowledge and skills on how to communicate effectively with their relative living with dementia by sharing resources that outline effective communication strategies.

Nevertheless, despite the challenges posed by families to PSWs' experience with communication, we acknowledge that family members can compensate for some difficulties associated with home care work that impact interactions, such as by providing PSWs with information about clients' social histories. However, we strongly urge employers to provide PSWs with information pertaining to clients' social histories. As already noted, these details help PSWs in engaging in quality interactions with PWLD. Yet, home care employers often fail to provide their own staff with this vital information.

Similarly, we suggest also that home care agencies improve and standardize documentation procedures because issues with inadequate chart notes were expressed by participants in the current study. Moreover, it is important that employers offer ongoing opportunities to PSWs to enhance or update their communication skills. Providing opportunities for continuing education and training is crucial because our findings demonstrate that PSWs experienced challenges with communication, despite a majority of participants (n=12) having received training prior. Employer support is an important aspect that can influence participation in training (Savundranayagam et al., 2020). PSWs can experience barriers in attending training that are employer-related, such as difficulties with scheduling and income loss (Savundranayagam et al., 2020). Not only does education and training have a positive impact on caregivers' communication abilities and the quality of care, it helps further with retention and recruitment. This is vital considering the current shortage of PSWs in Canada (Savundranayagam et al., 2020). It

also allows for the potential of ensuring continuity of care. However, continuity is possible also with the appropriate restructuring and organization of existing resources (Aasgaard et al., 2014).

4.5 Limitations and Future Directions

Despite providing valuable insights into the experiences of PSWs in communicating with PLWD in the home, this study nonetheless has limitations. This study is a hermeneutic phenomenological study. Thus, findings are not meant to be generalizable to all PSWs. Rather, the study's findings are intended to provide a better understanding of the phenomenon of interest.

Most participants were Caucasian. Therefore, the experiences described by participants may not be fully representative of the communication experiences of individuals belonging to other racially diverse groups. In Ontario, visible minorities comprise a large percentage of the PSW labour force (Lum et al., 2010). There are also distinctions in how different cultures view dementia (Davis & Smith, 2013). Thus, it is imperative that future studies investigating this phenomenon include more participants from different ethnic groups that represent the range and proportions of current work profiles.

Similarly, our study did not collect information pertaining to the native language(s) of our participants. Nor did we inquire about any hearing, speaking, or cognitive impairment the PSW participants may have experienced. These factors may have impacted their experiences in communicating. Future studies should ensure that this

information is gathered from participants as these details may help to explain or inform findings.

Geographical location also served as a limitation in this study. Participants were limited to an urban city in Southwestern Ontario. Thus, findings do not include or acknowledge a rural perspective. Formal caregivers in rural home care settings face unique challenges in providing quality care to clients, such as distance, weather, terrain, limited support for information technology, and scarce resources (Anderson, 2006; Forbes et al., 2012). PLWD in rural settings do indeed utilize formal home care services (Forbes et al., 2012), and as such, future studies should focus on exploring the communication experiences of PSWs who provide home care to PLWD in rural settings.

The identification of specific communication strategies used by PSWs in home care was not the explicit focus of this study. Thus, there is still limited knowledge in this area. Future research should explore fully the strategies used by PSWs in their communication with PLWD in the home and analyze their effectiveness.

The fact that all participants were recruited from PSWs interested in participating in a person-centered communication intervention also may have affected findings. One possibility is that participants may have concentrated more on discussing the challenges they encountered in communicating with PLWD because PSWs demonstrating interest in communication interventions encounter challenges in communicating and may be more inclined to openly acknowledge these difficulties. Situations that challenged PSWs and their experience with communication breakdowns may not have been focused on to the same extent if participants were not recruited through an intervention study aimed at

improving communication skills. A second possibility is that while these PSWs experienced difficulties in communicating, they also recognized the importance of communication and valued its significance. It is reasonable to assume that PSWs interested in improving their communication techniques understand the impact of communication on those they care for. This is reflected in the findings. Future studies should limit the amount of participants recruited from education and training interventions, or include exclusively participants who are not involved in education and training programs.

4.6 Conclusion

PLWD undergo changes in their communication-related abilities. This, in-turn can impact formal caregivers' experiences in caring and communicating with PLWD. What is known about formal caregivers' communication experience with PLWD has come mainly from LTC home settings. However, there is an anticipated shift from LTC home-based care to formal home-based care for PLWD. While literature regarding formal dementia home care exists, it often lacks a communication-specific focus. This hermeneutic phenomenological study provided a better understanding of PSWs' experiences in communicating with PLWD in their own homes. Participants in the current study experienced a paradox in regard to their communication experiences with clients living with dementia. PSWs encountered challenges with communication, despite understanding the importance of communication in the overall care for PLWD. Participants experienced difficulties with communication due to the display of dementia-specific impairments, had negative emotional responses to their experiences with communication, and dealt with negative consequences stemming from communication

breakdowns. On the other hand, PSWs treated communication as a need for PLWD and acknowledged the impact of their communication on the thoughts and behaviours of PLWD. The personal home space itself impacted also PSWs' experiences with communication. The regular presence of family members within the homes of PLWD could benefit PSWs communication experiences with PLWD in some instances, but adversely impact communication in others. Additionally, the home environment provided PSWs with environmental cues, specifically images, that could be used to promote communication with PLWD.

Continuing education and training are necessary to bridge the gap between PSWs intentions to communicate effectively with PLWD and their ability to actually do so. Families are in need also of additional knowledge and skills related to dementia care. This can be obtained through dementia-specific education and training, and/or home care agencies providing resources to families outlining effective communication strategies that can be used with their relative. Additionally, families should encourage PSWs to partake in social interactions and activities with PLWD, and refrain from interfering in PSW-PLWD interactions. Home care agencies can also promote more successful communication experiences between PSWs and PLWD further through providing PSWs with the social histories of clients, improving and standardizing documentation procedures, ensuring continuity of care, and offering continuing education and training opportunities. It is hoped that the findings from the current study support PSWs' ability to acquire additional dementia-specific skills and knowledge, and enhance the quality of care provided to PLWD who live at home.

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Appendices

Appendix A: Ethics Approval Form



Date: 10 March 2020

To: [REDACTED]

Project ID: 107789

Study Title: Enhancing person-centered communication among home care staff

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

REB Meeting Date: 23/Mar/2020

Date Approval Issued: 10/Mar/2020

REB Approval Expiry Date: 23/Mar/2021

Dear [REDACTED]

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

[REDACTED]

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: Letter of Information and Consent Form



Health Studies

Project Title: Enhancing person-centered communication among home care staff – Sub-study

Principal Investigator: [REDACTED], Western University, Faculty of Health Sciences

Research Partners: [REDACTED] London Ontario

Letter of Information

Invitation to Participate

You are being invited to participate in a research study that examines the lived experience of homecare personal support workers who work with clients with dementia.

Purpose of the Letter

The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research.

Purpose of this Study

The purpose of this study is to examine the lived experience of homecare personal support workers in communicating with clients with dementia, their experiences of formal training in dementia care, and their experiences with the person-centered communication intervention.

Inclusion Criteria

Individuals who meet the following criteria are eligible to participate in this study:

- Age 18 years or older
- Completion of the PSW program at the college level
- Current work employment in home care
- A minimum of 6 months experience with clients with dementia
- Able to attend all training sessions for the person-centered communication intervention
- Sufficient communication skills in English to participate in the training program
- Consent to audio recording of interview

Exclusion Criteria

Individuals who do not meet **all** of the criteria listed above are not eligible to participate in the study.

Study Procedures

If you agree to participate, you will be asked to complete a face-to-face or telephone interview with a member of the research team at a location of your choice. It is anticipated that the entire task will take approximately one half hour over one session. However, you are welcome to take as much time as you need. There will also be an option for email follow-up and clarification after the initial interview, if this is more convenient for you. The interviews will occur two weeks prior to and two weeks after participating in the person-centered communication intervention.

Possible Risks, Harms, and Inconveniences

For some individuals, there may be a risk for stress or anxiety while recounting work experiences with clients with dementia. Providing rest breaks will help to minimize potential stress, anxiety, and/or discomfort.

The use of audio recording equipment can be uncomfortable for some individuals. Audio recording equipment will be placed as unobtrusively as possible to minimize the potential for stress and anxiety associated with this component of the study.

Possible Benefits

This research project may benefit you by increasing your:

- Increased knowledge and skills regarding person-centered communication strategies and their impact on interactions with persons with dementia.
- Increased use of individualized care strategies.
- Increased confidence in working with clients with dementia.
- Peer support from other participants and facilitators.

Society as a whole may benefit from this project due to the fact that improved skills in person-centered communication may improve the quality of home care provided by PSW participants to persons with dementia. Family caregivers are also likely to benefit from improved care provided to their relatives with dementia.

Compensation

You will not be compensated for your participation in this research.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you withdraw from the study, your data collected up until the point of your withdrawal will be kept in the study.

Confidentiality

All data collected will remain confidential and accessible only to the investigators of this study. Your personal information will not appear on any of the research data. This includes your name, address, email address. We will keep this personal information for the duration of the study, which ends after the 3 month post-training follow-up session.

The hardcopy paper research records of your data will be retained for 7 years and stored in the following manner: locked in a cabinet in a locked, secured office in the [REDACTED]

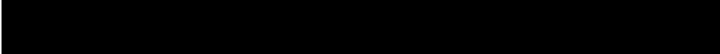
Electronic research records will be kept for 7 years and stored in the following manner: a secure,

password protected, encrypted cloud file storage system. Audio data will be saved for 7 years and later archived on a secure drive at Western.

Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

Contacts for Further Information

If you require any further information regarding this research project or your participation in the study you may contact any of the following individuals:

- 

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, email: ethics@uwo.ca. Please note that participants do not waive any legal rights by signing the consent form below.

Publication

If the results of the study are published your name and video images will not be used. The results of this study may be presented at research conferences or community meetings.

This letter is yours to keep for future reference.

Consent Form

Project Title: Enhancing person-centered communication among home care staff – Sub-study

Study Investigator's Name: [REDACTED]

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I do not waive my legal rights by signing the Consent Form.

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

Appendix C: Interview Guide



Interview Questions

1. Please walk me through the typical workday for you.
2. What is your workweek like? (Context question)
 - a. Number of clients?
 - b. Number of clients with dementia?
3. What is your experience in providing care to persons with dementia in their own homes?
4. What is your experience in communicating with persons with dementia in their own homes?
5. What is your experience in training related to care for persons with dementia, who live at home?
 - a. Ask about the type of training they got at school
 - b. Was there continuing education?
 - c. Has your work expanded on your education since you started working there?
 - d. Have you had home care specific education?
6. What enabled you to be able to attend this training? What were some barriers from attending this training?
7. What aspects of your experience in home care drove you to seek out and attend additional training?
8. Why home care versus long-term care?
9. Have you worked in other positions as a PSW? How do they compare to home care?
10. What is your support system like at work?
 - a. From where do you get support?
 - b. Do you feel you have enough support in home care?
 - c. How does the support you receive in home care compare to other positions?

Appendix D: Participant Stories

Participant	
PSW_01_01	<p>Female. Communication with PLWD can be very difficult because of impairments. Not always successful with communication and has experienced breakdowns in communication. Insecure with communication abilities at times and can't always come up with the right thing to say. Important to know social history of PLWD. Care plans can be inadequate. More time in home care than LTC homes. Home care is one-on-one and allows for a deeper understanding of clients. Work with families in home care. Family can aid in facilitating effective interactions. There are some professional boundaries in home care that need to be abided by.</p>
PSW_01_02	<p>Female. Dementia-related impairments can challenge communication. Quality of client charts is mixed. The way you communicate with PLWD can have an impact on clients. Experience helps with communication. Tries to communicate with PLWD because clients like interactions. Get to spend quality time with PLWD in home care. Home care has a schedule, but leaves time to interact. LTC homes have strict rules and time constraints. Professional boundaries in home care.</p>
PSW_01_03	<p>Female. Dementia-specific impairments complicate communication and also make it a frustrating experience. Communication comes with experience. Given only basic information about clients. Important to know client-related information. Lack of time to interact meaningfully with individuals in LTC homes. LTC homes are too fast paced. Not enough time or staff in LTC homes. Have more time in home care. Can have meaningful interactions in home care. Families can hinder communication with PLWD in numerous ways..</p>

PSW_01_05	Female. Communication with PLWD can be frustrating and difficult due to impairments. The home environment can be a good setting for communication because there are personal pictures in the environment. Home care is also one-on-one and allows PSWs to get to know clients and do more with them. Lack of interaction in LTC homes because of staffing issues and heavily task-oriented focus. Having family in home care environment can hinder opportunities for interactions.
PSW_01_07	Female. Communication can be challenging due to PLWD displaying dementia-related impairments. Can experience difficulties communicating properly. LTC homes have time constraints and many individuals to care for. Lack of one-on-one attention in LTC homes. More time to be one-on-one in home care. Don't have to rush in home care.
PSW_01_08	Female. There are challenges with communication due to clients exhibiting dementia-related impairments. Can experienced breakdowns in communication. Uses pictures in the home to initiate conversations and relate to client. Families in the home can complicate interactions with PLWD.
PSW_01_09	Female. Communication is challenging, stressful, frustrating, unpredictable, and nerve-wracking because of dementia-related impairments. Communicating requires patience. Not always confident in communication abilities. Feelings of guilt when unable to ensure successful interaction. Mindful of communication style because it impacts PLWD. Home care is one-on-one and not rushed. Lack of time and rushed in LTC homes. Family can facilitate more successful interactions with PLWD. Tries to use pictures in the home environment to initiate interactions.

PSW_01_10	Male. Communicating with PLWD is difficult because of dementia-related impairments. Communication can also result in burnout. Experienced communication breakdowns. Aware of the impact of communication style on PLWD. No time to interact with PLWD in LTC homes. LTC homes focus on time, lack staff, and are like factory settings. Can give more to clients in home care settings. Families can make interactions more difficult.
PSW_01_11	Female. Has encountered challenges with interactions due to dementia-related impairments. Has experienced communication breakdowns. Communication can be virtually non-existent if you don't know how to interact properly. Interactions with PLWD can be uneasy because you don't know what to expect. Attentive to impact of communication style on PLWD. Important to communicate with PLWD during care, which is possible in home care but not in LTC homes. Home care is one-on-one. Have to deal with families of PLWD in the home.
PSW_01_12	Female. Communication can be difficult because of dementia-related impairments. Communication with PLWD can sometimes be non-existent. Have to deal with families in home care much more often than in LTC homes. Families can facilitate better interactions with clients. Charts include basic information about client (e.g. birthday), medical history, and family contact information.
PSW_01_13	Male. Communication can be frustrating. How you communicate impacts PLWD. LTC homes are rushed and like factories. Can connect with clients in home care. Socializing is an important part of care and there are opportunities to socialize in home care. There are also professional boundaries in home care.
PSW_01_14	Female. Communication can be an intimidating experience. Important to be aware of how you communicate with PLWD. Can't socialize

	properly with PLWD in LTC homes. LTC homes are like production lines and have high workloads. Charts are inadequate.
PSW_01_15	Female. Communication can be difficult because of dementia-specific impairments. Attentive to the impact of own communication style on PLWD. Home care has opportunities for interactions. Can spend quality time with PLWD in the home. LTC homes have high workloads and time constraints. Families can help with interactions when communication barriers arise.
PSW_01_16	Female. Communication can be challenging. Not always confident in communication abilities. Sometimes uncertain on how to communicate. Important to watch how you communicate. LTC homes are like factory settings. Lack of time in LTC homes. More time in home care. Home care is one-on-one. Home environment involves presence of families. Families can facilitate more successful interactions.
PSW_01_17	Female. Communication can be hard and frustrating because of dementia-related impairments. Charts are of mixed quality.

Curriculum Vitae

Pabiththa Kamalraj

EDUCATION

Master of Science
University of Western Ontario, London, Ontario
Health & Rehabilitation Sciences, Health & Aging
2017-present

Bachelor of Health Sciences
University of Western Ontario, London, Ontario
Honors Specialization in Health Sciences
2013-2017

RELATED EXPERIENCE

Graduate Teaching Assistant
University of Western Ontario, London, Ontario
Health Policy 3400
2018

Graduate Student Assistant
University of Western Ontario, London, Ontario
Sam Katz Community Health and Aging Research Unit, Dr. Marita Kloseck
2018

Research Assistant
University of Western Ontario, London, Ontario
Caregiving Research Lab, Dr. Marie Savundranayagam
2017-2019

Research Assistant
University of Western Ontario, London, Ontario
Dr. Shannon Sibbald
2016-2018

Cooperative Education Student
Toronto General Hospital, Toronto, Ontario
Mental Health Inpatient Unit
2011-2012

PUBLICATIONS

Savundranayagam, M.Y. & **Kamalraj, P.** (in press). Person-centered communication among formal caregivers of persons with dementia. In Victor R. Preedy & Colin R. Martin (Eds.), *The Neurosciences of Dementia: Diagnosis and Management*. London, U.K.: Elsevier Inc.

PEER REVIEWED CONFERENCES

Kamalraj, P., Savundranayagam, M. Y., Orange, J.B., & Kloseck, M. (2020, March submitted). *Lived experiences of formal caregivers in communicating with persons living with dementia in their homes*. Abstract submitted to annual meeting of the Gerontological Society of America, Philadelphia, PA.

Kamalraj, P., Savundranayagam, M.Y., Orange, J.B., Kloseck, M. (2018, February 1). *Understanding the Communication Experience of Formal Caregivers Who Work with Clients with Dementia in the Home Environment*. Oral presentation at the annual Health and Rehabilitation Sciences Research Conference. London, ON.

AWARDS AND SCHOLARSHIPS

Western Graduate Research Scholarship
2017-2019

Western Scholarship of Distinction: Entrance Scholarship
2013

University Health Network Bette J. Johnston Director's Award
2012

Earl Haig Secondary School Cooperative Education Award
2012