Formal Caregivers Assisting Residents with Moderate and Severe Alzheimer’s Disease:

Investigating the use of Communication Strategies during Activities of Daily Living

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy

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Abstract

The prevalence of Alzheimer’s disease (AD) in Canada is on the rise, creating the need for evidence-based care practices designed to support individuals with AD and their care providers. Declines in memory, language, visual-spatial, executive abilities, and functional capacity associated with AD create the need for caregiver assistance during the completion of activities of daily living (ADLs). Unfortunately, assisting individuals with more advanced stages of AD is further complicated by communication breakdowns that occur in the dyad (i.e., caregiver and the individual with AD) established to meet a common goal: to complete ADLs. Clinically recommended communication strategies are the current solution used to support caregivers interacting with individuals with AD. However, there are limitations to these recommendations, including that the majority are based on caregiver experience, few are supported by empirical research, and little is known about which strategies are effective when assisting individuals with moderate to severe AD specifically during the context of completing ADLs.
This dissertation presents novel research studies that systematically examined formal caregivers’ use of communication strategies while successfully assisting residents with moderate and severe AD during the completion of a representative ADL. Two observational studies and one focus group interview study were conducted to address our hypotheses and research objectives. Key findings from the studies comprising this dissertation were: (1) caregivers used a variety of verbal and nonverbal task-focused communication strategies when successfully assisting residents with AD during the completion of a representative ADL; (2) the task-focused communication strategies caregivers most frequently used were supported by empirical literature and included the use of one direction or idea (i.e., proposition) at a time, closed-ended questions, and paraphrased repetition; (3) when assisting residents with severe AD, caregivers used the resident’s name, one proposition, and paraphrased repetition significantly more than when assisting residents with moderate AD; and (4) the communication strategies that caregivers perceived to use in their care practice indicate that person-centered dementia care is a central aspect to facilitating the completion of ADLs. This research is an important step towards the development of evidence-based communication strategies for caregivers assisting individuals with AD during ADLs.
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# Table of Contents

Abstract ................................................................................................................................. ii  
Acknowledgements .............................................................................................................. iv  
Table of Contents ................................................................................................................ vii  
List of Tables ...................................................................................................................... xii  

CHAPTER 1 INTRODUCTION AND LITERATURE REVIEW ..................................................... 1  
Dissertation Introduction ..................................................................................................... 1  
General Introduction .......................................................................................................... 3  
Literature Review ................................................................................................................ 5  
  Background ...................................................................................................................... 5  
    Defining Alzheimer’s disease .......................................................................................... 5  
    Clinical Diagnosis of AD ............................................................................................... 8  
    Cardinal Cognitive Symptoms: Memory, Language, and Praxis ................................. 9  
  Consequences of Cognitive Decline ................................................................................. 15  
    Communication and communication theory ............................................................... 15  
    Communication and individuals with AD ................................................................. 20  
    Functional declines and activities of daily living (ADLs) ........................................... 24  
    The role of caregivers ................................................................................................. 25  
    Formal caregiver assistance during ADLs and communication breakdown ............ 26  
  Current Communication Recommendations ................................................................. 27  
  Research Framework: Empirical Literature .................................................................... 28  
    Comprehension literature ............................................................................................ 28  
    Examination of communication strategies ............................................................... 30  
  Research Rationale .......................................................................................................... 33  
Summary .............................................................................................................................. 35
CHAPTER 2  EXAMINING SUCCESS OF COMMUNICATION STRATEGIES USED BY FORMAL CAREGIVERS ASSISTING INDIVIDUALS WITH ALZHEIMER’S DISEASE DURING AN ACTIVITY OF DAILY LIVING

Abstract .................................................................................................................. 36

Introduction ............................................................................................................ 37
  Purpose of the Study ............................................................................................. 43

Method .................................................................................................................... 45
  Study Design ......................................................................................................... 45
  Participants ............................................................................................................ 45
  Procedure ............................................................................................................. 47

Transcription and Data Coding Method ................................................................ 47
  Step engagement and step completion .................................................................. 48
  Task success ......................................................................................................... 49
  Communication strategies ....................................................................................... 49

Interobserver Agreement/Reliability ........................................................................ 52

Results ..................................................................................................................... 52
  Objective 1: To Examine Which Communication Strategies Caregivers use During the Completion of an ADL. ................................................................. 53
    Overall use of verbal communication strategies ............................................... 53
    Overall use of nonverbal communication strategies ......................................... 54
    Co-occurrence of communication strategies ..................................................... 55

  Objective 2: To Examine Which Communication Strategies Caregivers use When the ADL is Successfully Completed ...................................................... 58
    Verbal communication strategies .................................................................... 58
    Nonverbal communication strategies ................................................................. 58

  Objective 3: To Examine Which Communication Strategies are Related to Success Rate of the ADL ................................................................. 59
    Success rate ....................................................................................................... 59
CHAPTER 4 FORMAL CAREGIVERS’ PERCEPTIONS OF EFFECTIVE COMMUNICATION STRATEGIES WHILE ASSISTING RESIDENTS WITH ALZHEIMER’S DISEASE DURING ACTIVITIES OF DAILY LIVING

Abstract .................................................................................................................. 105
Introduction ............................................................................................................. 106
Method ...................................................................................................................... 111
Research Design ..................................................................................................... 111
List of Tables

Table 2-1 Coding scheme: Verbal and nonverbal communication strategies ........................................51
Table 2-2 Caregivers’ use of verbal and nonverbal communication strategies: Across all handwashing sessions and during successfully completed sessions ..........................56
Table 3-1 Characteristics of Participating Residents Grouped by AD Severity Level (N = 13) ........................................................................................................................................80
Table 3-2 Characteristics of Formal Caregiver Participants Grouped by AD Severity Level (N = 15) ........................................................................................................................................81
Table 3-3 Codes Included in the Multidimensional Observation Coding Scheme (MOCS) ........................................................................................................................................85
Table 3-4 Summary of Inter-coder Agreement Indices for Codes Included in the MOCS and for Coding of the Completion of Steps in the Task (n = 525 utterances) ........................................................................................................................................90
Table 3-5 Representative Discourse of Caregivers and Residents During a Toothbrushing Sessions Grouped by AD Severity Level ..................................................................................93
Table 3-6 Caregivers’ Use of MOCS Communication Strategies as a Function of AD Severity ........................................................................................................................................95
Table 4-1 Characteristics of Formal Caregivers Participating in the Focus Group Interviews (N = 10) ........................................................................................................................................113
Table 4-2 Caregivers’ Perceived Use of Communication Strategies Included in the Multidimensional Observation Coding Scheme (MOCS) .....................................................................117
Table 4-3 Examples of Caregivers’ Comments Pertaining to the Most Frequently Discussed Communication Strategies .......................................................................................................123
Table 4-4 Frequency and Extensiveness of Formal Caregivers’ Perceived Use of Communication Strategies ..........................................................................................................................124
Table 4-5 Emergent Themes Caregivers Perceived to be Useful While Assisting Residents with AD during the Completion of ADLs ....................................................................................127
Table 4-6 Frequency and Extensiveness of Formal Caregivers’ Perceived Use of Strategies Included in the Emergent Themes .............................................................................................130
Table 5-1 Proposed Evidence-based Communication Strategy Recommendations ........................................................................................................................................157
CHAPTER 1
INTRODUCTION AND LITERATURE REVIEW

Dissertation Introduction

This dissertation emanated from the identified need for novel research investigating effective communication strategies for caregivers supporting individuals with moderate and severe Alzheimer’s disease (AD) residing in long-term care (LTC), during the completion of basic activities of daily living (ADLs), also referred to as self-care tasks. The aim of the dissertation was to develop and implement research studies that systematically examined which communication strategies formal caregivers employ while assisting residents with moderate and severe AD during the completion of representative ADLs: handwashing and toothbrushing. More specifically, the purpose of this dissertation was to address four major research questions:

1. Which communication strategies do formal caregivers actually use to assist residents with moderate and severe AD during the completion of an ADL?

2. Which communication strategies are related to successful task completion?

3. Is there a difference in caregivers’ use of communication strategies as a function of disease severity?

4. Which communication strategies do caregivers perceive to be useful in their care practice?

The dissertation presents three projects designed to address the research questions. The ultimate goal of this research area is to help inform the development of evidence-based communication
guidelines devised to support caregivers assisting individuals with moderate to severe AD during self-care tasks.

Chapter 1 of this dissertation provides the background information on AD, including a summary of the hallmark cognitive symptoms associated with AD, with particular attention given to the impact AD has on language function, communication, and functional ability. Furthermore, relevant empirical research that provided the framework for this dissertation is reviewed. Finally, the rationale for this study is presented by demonstrating that the currently available clinically recommended communication strategies are limited and that there is a need for the studies included in this dissertation. Chapter 2 contains the first of three papers that report findings from the studies that examined formal caregivers’ use of communication strategies while assisting residents with moderate to severe AD during a basic ADL. This observational study investigated which task-focused communication strategies formal caregivers utilized while assisting residents with moderate to severe AD during the successful completion of handwashing. Chapter 3 reports on a cross-sectional observation study that compared formal caregivers’ use of task-focused and social communication strategies when assisting residents with moderate and with severe AD during the completion of toothbrushing. This second study extends findings from the first study by examining communication during a second ADL and by investigating communication strategies as a function of disease severity. Finally, in Chapter 4 the third study is reported, which examined formal caregivers’ perceptions of effective communication strategies while assisting residents with moderate and with severe AD during ADLs. Taken together, these studies demonstrated that formal caregivers utilize a variety of task-focused communication strategies in their care practice, with empirical literature supporting
the top most frequently employed strategies. Finally, the dissertation closes with a chapter summarizing key findings of these studies, the implications that research may have in clinical practice, as well as future research directions.

*Chapters 2, 3, and 4* are reprinted manuscripts of studies that were either published, submitted for publication, or in-press, respectively, at the time of the dissertation submission. Furthermore, the reader is advised that these chapters, particularly the individual introduction sections, may contain some redundant information as a result of the three paper dissertation format.

**General Introduction**

Interest in communication processes and communication difficulties affiliated with AD has grown in recent years. Conceivably, this increased interest is driven by an awareness that the fastest growing demographic in Canada is the aging senior population (65 years plus) (Health Canada, 2002) and older age is the strongest associated risk factor for AD (Savva & Brayne, 2009). Moreover, AD impacts an individual’s quality of life and quality of care, caregivers’ well-being, and society, both in terms of factors linked to the cost of informal care and the cost of health care. In particular, there is more societal attention to the important role of caregivers who inevitably become increasingly responsible for over-seeing the direct care of individuals with AD. Unfortunately, caregivers are faced with the challenges of adapting to cognitive declines associated with AD that are coupled with communication difficulties, which can contribute to caregiver stress and burden. More specifically, AD leads to progressive disability in three major domains: cognition, functional ability, and behaviour (Potkin, 2002). As the disease progresses, there is a marked decline in an individual’s ability to complete daily tasks,
leading to the need for a caregiver’s assistance. Cognitive decline, including language impairments and breakdown in communication, negatively affects the caregiver-care recipient dyad leading to increased time spent on functional activities and increased caregiver stress (Williamson & Shultz, 1993; Clark & Witte, 1991; Lubinski & Orange, 2000). Functional dependency of individuals with AD and strained relationships due to communication deterioration are strong predictors of placement in a long-term care facility (Williamson & Shultz, 1993; Steeman, Abraham, & Godderis, 1997; Lubinski & Orange, 2000).

Given the awareness of the escalating incidence of individuals living with the cognitive impairments associated with AD and the fact that there is currently no known cure for this progressive neurodegenerative disease, it is imperative that current research centers on interventions that support caregivers in their care practice that will, in turn, help facilitate optimal functional competence of individuals with AD over the course of the disease. In particular, language impairments associated with varying stages of AD contribute to communicative challenges during the caregiver-care recipient dyad interaction, and these communication breakdowns are apparent during the completion of ADLs. Therefore, there is a growing need for solutions to support the care of individuals with AD, which includes identifying and capitalizing on effective communication strategies that will increase the quality of life for both individuals with AD and their caregivers.

To date, the available recommended communication strategies for caregivers to aid in ADL completion are not clearly supported by empirical research. Current literature in this area is, for the most part, based on clinical experience rather than communication techniques derived from empirical inquiry (Small, Gutman, Makela, & Hillhouse, 2003). Furthermore, very few
studies have addressed communication during ADLs and, of those studies, the participants were typically individuals with mild-moderate AD and family caregivers (e.g. Small, Geldart, Gutman, 2000; Small & Gutman 2002; Small et al., 2003; Roberto, Richter, Bottenbreg & Campbell, 1998) rather than moderate-severe residents in LTC facilities and formal caregivers (e.g., personal support worker (PSW), which is a caregiver who assists people with physical and/or cognitive impairments during daily personal care needs). Thus, little attention has focused on communicative interactions of formal caregiver and residents with AD during completion of ADLs. Currently, there is a limited understanding about which communication strategies are actually utilized by formal caregivers interacting with moderate-severe AD residents in care facilities and which strategies are effective.

In sum, there is a lack of empirical research investigating formal caregivers’ use of successful communication strategies when interacting with individuals with moderate-severe AD during the completion of ADLs in the LTC setting. Therefore, the studies that comprise this dissertation systematically investigated the verbal and nonverbal communicative strategies used during the successful completion of a representative basic ADL.

**Literature Review**

**Background**

*Defining Alzheimer’s disease*

Dementia is a general term used to describe disorders that are characterized by an acquired cognitive impairment (Weiner, 2009) and AD is the leading cause of dementia, accounting for 50-80% of all dementias (Evans et al., 1989). Indeed, the World Health
Organization (WHO) in collaboration with Alzheimer’s Disease International recently reported that 35.6 million individuals were living with dementia worldwide in 2010, making dementia a global public health and societal care priority (World Health Organization, 2012). Furthermore, the WHO called for nations to take action to invest in systems to improve care and service for people with dementia and their caregivers. Moreover, in a recent report on the impact of dementia on Canadian Society, issued by the Alzheimer’s Society of Canada, it was stated that Canada is facing a “dementia epidemic”, with an estimated 500,000 Canadians currently living with Alzheimer’s disease or a related dementia (1 in 11 over 65 years), with prevalence rates rising to over 1.1 million, or 2.8% of the population, by 2038 (Alzheimer Society of Canada, 2010a). In addition, AD is the seventh leading cause of death in Canada, accounting for 2.8% of all deaths, and is the fourth leading cause of death in those aged 85 or older (Statistics Canada, 2011).

AD is an irreversible, progressive degenerative cortical disease that causes neurological changes leading to severe cognitive, functional and behavioural deterioration (i.e., progressive dementia) (Karantzoulis & Galvin, 2011; Thies & Bleiler, 2012). While the physiological changes that trigger the cause of AD remain unknown, the hallmark pathology is understood to be the neuritic plaques and neurofibrillary tangles, features that were first observed at autopsy over 100 years ago (Thies & Bleiler, 2012; Weiner & Lipton, 2009). Neurtic plaques, consisting primarily of amyloid beta (Aβ), build-up outside of the neurons, beginning in the parietal, temporal and frontal association areas (Braak et al., 1999; Karantzoulis & Galvin, 2011), with the highest concentration in the hippocampal region (Geldmacher, 2009). Conversely, neurofibrillary tangles, consisting of abnormal twisted strands of tau protein that present with a unique paired helical structure, accumulate inside the neurons, (Geldmacher,
2009; Thies & Bleiler, 2012). Neurofibrillary tangles first present in the medial temporal lobe structures (e.g., hippocampus) then spread throughout the temporal lobe, and extend to parietal and frontal association areas with disease progression (Braak et al., 1999; Karantzioulis & Galvin, 2011). The accumulation of amyloid outside neurons and tangles inside the neuron contribute to synaptic loss and neuronal death (Thies & Bleiler, 2012), causing the failure of information transfer in the brains of individuals with AD, which ultimately leads to cognitive and functional disability. Neuronal death not only leads to cortical atrophy in individuals with AD, but also leads to the decreased production of the neurotransmitters acetylcholine, serotonin, and norepinephrine, resulting in the loss of major communication messengers to the cerebral cortex (Geldmacher, 2009).

Several risk factors for AD have been identified; however advancing age remains the strongest risk factor for the onset of AD (Lindsay et al., 2002; Thies & Bleiler, 2012). For example, in Canada the prevalence of dementia has been estimated as 8% (per 1,000) of all Canadians over the age of 65 years, with the age-standardized rate of 2.4% for those between 65 and 74 and 34.5% of those 85 years and older (McDowell et al., 1994). In addition to advancing age, family history (Fratiglioni, Ahlbom, Viitanen, & Winblad, 1993) and the apolipoprotein E genotypy, E4 allele of apolipoprotein E, have a strong association with developing AD (Lindsay et al., 2002; Thies & Bleiler, 2012). Other modifiable risk factors have been identified, including cardiovascular disease (Breteler, 2000; Rosendorff, Beeri, & Silverman, 2007), diabetes (Biessels, Staekenborg, Brunner, Brayne, & Scheltens, 2006), reduced years of education (Lindsay et al., 2002), traumatic brain injury (Sivanandam & Thakur, 2012), and low social and physical activity (Williams, Plassman, Burke, & Benjamin, 2010).
**Clinical Diagnosis of AD**

Typically, individuals will receive a differential clinical diagnosis of probable AD following a thorough examination into the subjective complaints, made by an individual or a concerned family member, regarding the presence of cognitive symptoms that are impacting the individual’s normal social and functional abilities (Lipton & Rubin, 2009). To assess for probable AD, a medical professional will perform a comprehensive review of the individual’s medical and family history, conduct cognitive and neurological examinations, order blood tests and a brain scan (e.g., magnetic resonance imaging) to help rule out other possible causes, and obtain information from an informant (e.g., family member) (Thies & Bleiler, 2012).

Importantly, although clinical assessment provides an accurate indication of the clinical syndrome of probable AD, often referred to as Alzheimer’s dementia or dementia of the Alzheimer’s type (DAT) (Mason, McShane, & Ritchie, 2010), the “gold standard” for a confirmed diagnosis of AD is based on the presence of pathological plaques and tangles at autopsy (Beach, Monsell, Phillips, & Kukull, 2012; Geldmacher, 2009).

Recently, the National Institute on Aging (NIA) and the Alzheimer Association established a workgroup that recommended new diagnostic criteria and guidelines for AD in 2011 (McKhann et al., 2011). Notably, the new recommended criteria and guidelines identify three stages of AD (preclinical AD, Mild Cognitive Impairment due to AD, and dementia due to AD) and include the use of biomarker tests. However, more research is needed to establish these recommended criteria and guidelines in the clinical setting (Thies & Bleiler, 2012). Currently, the *Diagnostic and Statistical Manual of Mental disorder, 4th Edition, Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000) remains to be one of the predominant diagnostic
schema criteria for the diagnosis of dementia of the Alzheimer type both clinically and in research (Dubois et al., 2007). The DSM-IV-TR diagnostic criteria for dementia of the Alzheimer’s type includes the gradual onset and progressive decline of multiple cognitive impairments, with memory deficits at the forefront, plus deficits in one or more additional cognitive domains (i.e., language, visual-spatial processing, praxis, and executive function), which cause significant impairments in previous social and occupational activities. Further, the impairments cannot be explained by some other known cause and the deficits cannot have occurred exclusively during the course of a delirium (American Psychiatric Association, 2000). Following correct diagnosis, and assuming estimated onset is accurate, the average lifespan is estimated to be 8-10 years, but this number is variable given advances in medical care (Mendez & Cummings, 2003). AD is often considered a contributing factor to death, as AD can cause secondary complications, such as malnutrition, swallowing disorders, and immobility (Thies & Bleiler, 2012). These secondary conditions, in turn, have been shown to increase the risk of pneumonia, which is often the reported cause of death in individuals with AD (Beard et al., 1996; Burns, Jacoby, Luthert, & Levy, 1990).

*Cardinal Cognitive Symptoms: Memory, Language, and Praxis*

The hallmark neuropathological features associated with AD predictably target specific brain regions, including the temporal, parietal, frontal lobes, and occipital leading to cognitive deficits in the domains of memory, language, praxis, executive functioning, and visuo-spatial functioning. Indeed, Talwaker (1996) carried out a factor analysis on the Alzheimer’s Disease Assessment Scale-Cognitive subscale (ADAS-Cog) (Rosen, Mohs & Davis, 1984), one of the most commonly used tests to assess cognitive abilities in individuals with AD (Corey-Bloom, 2002), and reported three principal features of cognitive dysfunction in AD: memory (e.g.,
assessed by tests of recognition of words and orientation), language (e.g., word-finding difficulty and comprehension of words), and praxis (e.g., following commands and constructional praxis). In addition, executive functioning (e.g., planning, problem solving, judgment, and abstract thought) deficits have been reported to commonly occur in mild-moderate AD (McGuinness, Barrett, Craig, Lawson, & Passmore, 2010); however, considerable variations in the pattern of executive dysfunction in mild AD have also been reported (Stokholm, Vogel, Gade, & Waldemar, 2006). Importantly, depending on the severity of the disease, deficits in one or more of these domains contribute to the decline in an individual’s functional ability as well as changes in behaviour. Of note, the progression of AD is typically described by compartmentalized symptoms into time-course stages (early, middle, late) or by severity level (mild, moderate, severe), as each category is associated with common, predictable cognitive, functional, and behavioural features (for review see Corey-Bloom, Galasko & Thal, 1994). For the purpose of this dissertation, disease severity level is used to categorize the progression of AD.

Memory

The hallmark clinical symptom of AD is impairment in memory. Specifically, markedly affected is the declarative memory system, which includes the conscious memory of experienced events with temporal and spatial significance (i.e., episodic memory) and memories of factual knowledge (i.e., semantic memory) that can be accessed through free recall or recognition (Cullum & Lacritz, 2009; Deweer et al., 1994). Conversely, the procedural memory system, or the implicit (unconscious) memory of over learned skills (e.g., toothbrushing), is relatively spared until severe stages of AD (Deweer et al., 1994; Geldmacher, 2009). The prominent memory deficits associated with AD are characterized by sequential disruptions to
the two sub-categories of declarative memory. Initially, episodic memory is impaired and, as the disease progresses, semantic memory is also affected. Particularly, in mild stages of AD, recent memory and the remembering of newly learned material is typically the earliest clinical presentation of AD (Karantzoulis & Galvin, 2011). Because of the neuropathological disruption to the hippocampus and entorhinal cortex, individuals with AD are thought to have difficulty with encoding new event information into long term memory (Karantzoulis & Galvin, 2011). It is well documented that semantic impairments occur even in mild AD; however the nature of the impairment is unclear, as a controversy remains as to whether the observed deficits stem from a degradation in the semantic store or if the problem arises from difficulties accessing the semantic store and utilizing the information (Binetti et al., 1995; Giffard et al., 2001). As the disease progresses, memory deficits become more widespread and the ability to recall remote events and worldly facts stored in long-term memory also degrades (Geldmacher, 2009).

Language

While memory decline is the cardinal symptom of AD, with forgetfulness and recent memory loss presenting as the first symptoms of AD, memory is not the only cognitive domain affected early in the disease course. Specifically, language production and comprehension dysfunctions are a prominent clinical symptom of AD and are present across AD severity levels. Indeed, Alois Alzheimer himself recognized that language impairments were central to the disease (Alzheimer, 1901). It is well documented that difficulties in language are observed in the majority of individuals presenting with probable AD, even in the mild stages, and that deterioration in language is correlated with disease progression (Cummings, Benson, Hill, Read, 1985; Kempler, 1991). Recognizing individual variation, there is nevertheless a distinctive pattern of language decline at varying linguistic levels in AD: lexical knowledge (semantic
lexicon) and pragmatics (i.e., analysis of context and communication value of speech) are disrupted in mild to moderate stages of the disease, with a relative sparing of syntactic, phonological and morphological processes until severe stages of AD (Kempler, 1991). This presentation of language difficulties is highly related to patterns of cortical destruction and represents early neuronal atrophy in the temporal-parietal areas (perisylvian language area) and later damage to the frontal lobes (Zillmer & Spiers, 2001; Harasty, Halliday, Xuereb et al., 2001; Kempler 2005; Perry & Hodges, 1999). Accordingly, semantic impairments are at the forefront of language deterioration in AD, given that semantic function is believed to depend on intact temporal and parietal lobes (Kempler, 1991). Further, as AD progresses, so does involvement of additional brain regions, specifically the anterior portions of the frontal cortex, which are thought to play a vital role in syntactic ability and expressive fluency (Kempler, 1991).

Impairments at the level of lexical semantics present early in the course of the disease and are a prominent clinical feature of probable AD (Bayles, Tomoeda, & Trosset, 1992). However, relative to breakdowns at the lexical semantic level, evidence suggests that syntactic comprehension and production tend to be less impaired, at least until later in the course of the disease (Appell, Kertesz & Fisman, 1982; Kempler, Curtiss & Jackson, 1987; Schwartz, Marin & Saffran, 1979; Rochon, Waters & Caplan, 1994; Rochon, Waters & Caplan, 2000). Semantic impairment is believed to arise from either an underlying deficit in lexical access or degradation of the lexical representation, resulting in anomia for low frequency words as the predominant language impairment in mild AD, and word fluency impairment (Kempler, 1991; Ripich & Zoil, 1998; Bayles, 1982; Bayles, Tomoeda, &Trosset, 1992). Additional deficits include circumlocutions in conversations and difficulty comprehending abstract and complex ideas.
As AD progresses, semantic paraphasias (substitution of words with similar meaning), preseverative errors, stereotyped responses and circumlocutions increase (Corey-Bloom et al., 1994, Kempler, 2005; Zillmer & Spiers, 2000; Emery, 2000). Further, anomia becomes increasingly apparent as individuals’ errors of commission turn into errors of omission, and these errors become more prominent in discourse, until little to no verbal output is expressed (mutism) in severe AD (Davis, 2000; Glickstein, 1997). Interestingly, the pathological features of AD have recently been linked to logopenic progressive aphasia, which is a variant of primary progressive aphasia (i.e., language disorder that involves changes in production and comprehension of speech and written language), and includes clinical features of slow rate of speech from difficulty finding words, impaired sentence and phrase repetition, mutism (late stage), and difficulty swallowing (Gorno-Tempini et al., 2011).

In moderate AD, lexical semantic production problems worsen and these impairments are coupled with comprehension deficits (Appell, et al., 1982). By moderate severity levels of AD, language comprehension problems become quite evident, and individuals with AD have an increasingly difficult time understanding communicative interactions and responding appropriately in the conversation. In addition, they become less aware of these difficulties, thus self-monitoring of their speech errors (paraphasias) declines and communicative interactions with individuals with AD become quite challenging and frustrating. With respect to sentence comprehension, understanding by individuals with AD is facilitated by the use of fewer propositions (Rochon et al., 1994; 2000), the use of canonical (active) form (Small, Kemper, Lyons, 2000), and when sentences are non-reversible (Grossman & White-Devine, 1998). Individuals with severe AD present with both receptive and expressive language deficits, with
poor language initiation, verbal perseverations, stereotypical utterances, echolalia, and no use of gestures (Maxim & Bryan, 2006). However, individuals with severe AD retain some basic language skills, such as the desire to engage in conversation and participate accordingly in social conventions (e.g., greet)(Kim & Bayles, 2007).

**Praxis**

In addition to the memory and the language declines associated with AD, praxis, or the ability to plan and then carry out motor movements, is a chief cognitive deficit in AD (Talwalker, 1996). Moreover, praxis impairments have a significant impact on the completion of ADLs. Individuals with moderate to severe AD typically present with apraxia, which is the inability to execute learned voluntary motor actions despite intact sensory function (Geldmacher, 2009). Although apraxia has been observed in individuals with mild AD (Chainay, Lourarn & Humphreys, 2006; Willis, Behrens, Mack, & Chui, 1998), apraxic impairments appear to be more common as the disease progresses, which may be related to consequences of the advanced neo-cortical stages of AD (Derouesne, Lagha-Peerucci, Thibault, Baudouin-Madec, & Lacomblez, 2000). Two principal types of apraxia are observed in AD: ideomotor apraxia and ideational apraxia. Ideomotor apraxia, which is the most common type of apraxia observed in AD, is the difficulty in motor execution despite the spared knowledge of motor sequences (i.e., impairment in the production system) (Chainay et al, 2006). Ideational apraxia is the difficulty in activating the stored knowledge about the action gestures associated with an object (i.e., impairment in the conceptual system) (Lucchelli, Lopez, Faglioni, & Boller, 1993). Ideomotor apraxia makes tasks such as fastening buttons while dressing or using eating utensils challenging (i.e., spatial-temporal errors) while ideational apraxia impacts the handling
of everyday single objects (e.g., using a comb correctly) or carrying out complex tasks such as toothbrushing (i.e., content errors such as incorrect order of steps of the task) (Ochipa, Rothi, & Heilman, 1992).

In sum, memory (episodic and semantic) and language (production and comprehension) declines are prevalent even early in the disease course. As AD progresses, memory and language impairments worsen and apraxia emerges as a chief cognitive deficit. Apraxia has a significant impact on the completion of activities of daily living, both in terms of planning motor movements and in conceptual knowledge on how to use single objects or carry out as sequence of steps in a complex task. Combined, the three principal cognitive deficits, described in this section, have significant impacts on social and functional capacity of individuals with AD.

Consequences of Cognitive Decline

**Communication and communication theory**

Communication is the reciprocal exchange of information, thoughts, or opinions by speech, writing, signs, or some other medium between a sender and a receiver (www.dictionary.com). Language is the human faculty that supports communication and social participation, which are fundamental human experiences. With respect to oral language, in addition to verbal communication (i.e., communication by attaching meaning to words that are formed by sound), another mode of communication is nonverbal communication, which includes (1) paralanguage/para-verbal, or nonverbal elements of speech, such as linguistic prosody that conveys word boundaries, syntactic structure, and meaning (i.e., intonation,
rhythm, stress), affective prosody (e.g., emotional expression through prosodic features of speech), rate, pitch, and volume (Horley, Reid, & Burnham, 2010) and (2) nonverbal message content, which includes facial expressions, gestures, eye contact, touch, and body language. Together, verbal and nonverbal communication facilitates the complex exchange of information rich messages between two or more individuals. For the purpose of this dissertation, the discussion on communication will be limited to communication between two individuals, otherwise referred to as a dyad.

Theories of communication originate from a diverse range of disciplinary perspectives, including, but not limited to, sociology, psychology, economics, and linguistics (Craig, 1999). Of particular interest are the social psychology theories focused on interpersonal communication, or the face-to-face communication between two people to achieve a communication goal (Berger, 1996). The traditional basic interpersonal communication theory has been described using the transmission model of communication, which includes a sender or a source (who encodes message and creates signal) and a receiver or the destination (who decodes and interprets the signal) (e.g., Shannon and Weaver’s Communication Model (1949)) (Curnow, 2009). However, this basic model has been criticized because it is an oversimplification of that nature of communication, as it does not account for nonverbal communication nor does it address the social, cultural, and personal contexts (e.g., knowledge, attitudes, communication skills) associated with each of the participants and how these factors contribute to understanding or misunderstanding of the message (Craig, 1999; Kitwood, 1993). Certain theories are particularly salient to communication between dyads, and the frameworks of a select few have been applied to the communication occurring between a caregiver and an
individual with cognitive impairments associated with dementia. For example, symbolic interaction theory (Blumer, 1969) has attempted to account for the complexities individuals bring to the dyadic communication interaction, including meanings that individuals assign to people, things, and events and how meaning is derived from social interactions. Expanding upon the interpersonal communication theories and incorporating symbolic interaction theory, Kitwood (1993) states that communication is a reflexive process and meaning is created and negotiated between two people who each bring their own temperament, unique experiences, knowledge, expectations and emotions that each person is to interpret and respond to (Kitwood, 1993).

Kitwood (1993) described a framework for the person-centred theory of dementia care. This framework calls for a shift away from the traditional medical/institutional model of dementia care which focuses on the disease over the person. At the core of person-centred theory of dementia care is personhood, which holds that the individual is still a relational person despite failing cognitive and functional capacities, and individuals with dementia are still social beings who retain some abilities that allow for autonomy. Further, social relationships are fundamental to the acknowledgment of personhood. Kitwood (1997) emphasized the concept of personhood as applied to the care of individuals with dementia, which ultimately relies on communication between the caregiver and the individual with dementia. Specifically, Kitwood (1997) stressed that individuals with dementia are social and relational human beings that desire recognition, respect, and trust; therefore, dementia care must honor personhood despite cognitive declines. Caregivers communicating with individuals with dementia should focus their attention on the fact that they are communicating with a whole individual and not a diseased
brain, that individuals with dementia retain some communication abilities (i.e., verbal and nonverbal) at all stages of the disease, and, finally, that individuals with dementia bring their own experiences, knowledge, emotion and attitudes to the communication interaction. Based on person-centred dementia care, Kitwood (1997) also proposed strategies for positive communication interactions between caregivers and persons with dementia. These include using the individual’s name and using eye-contact (recognition), consulting the individual regarding their preferences and needs (negotiation), encouraging expressions of self (play), acknowledging the person’s emotions and using empathy (validation), and emphasizing the persons remaining abilities (facilitation).

Another theory of communication is Communication Accommodation Theory (Giles, Coupland & Coupland, 1991). In addition to accounting for the meaning each person brings to communication interactions, Communication Accommodation Theory provides a framework for explaining the shifts speakers make in their communication style when interacting with another individual (Giles & Ogay, 2007). Specifically, the concepts of divergence and convergence are used to describe the accommodations, particularly the shifts made to emphasize or minimize differences between the speaker and their interlocutor. Moreover, attempts to converge, or minimize differences, may be interpreted as over-accommodating and patronizing.

Communication accommodation framework has been applied to the context of inter-generational communication to explain the phenomena of patronizing communication, or “elderspeak” directed to seniors living in the community or residing in institutional settings, including those with dementia (Ryan, Hummert, & Boich, 1995). Elderspeak has been characterized to include short and simplified sentences, simple vocabulary, slowed speech,
elevated pitch and tone, and inappropriate use of endearing terms (K. Williams, Kemper, & Hummert, 2003; K. N. Williams, Herman, Gajewski, & Wilson, 2009). Of particular importance, the communication style of caregivers, or how caregivers communicate with older people with dementia may influence successful ADL interactions. For instance, the extensive use of elderspeak in LTC settings during ADLs has been documented (K. Williams et al., 2003; K. Williams, Kemper, & Hummert, 2005; K. N. Williams et al., 2009) and has been shown to contribute to communication breakdowns and resistance to care in individuals with dementia (K. N. Williams et al., 2009).

Stemming from the Communication Accommodation Theory, the Communication Predicament Model (Ryan, Giles, Bartolucci, & Henwood, 1986) brings focus to the influence of communication partners and the environments that may contribute to communication problems for elderly individuals. Further, the Communication Enhancement Model (Ryan, Meredith, MacLean, & Orange, 1995), whose development was prompted by the communication predicament the elderly can face in the community or in long-term care settings (e.g., fewer opportunities to participate in communication or inappropriate communication), stresses the importance of individual needs for appropriate communication. Further, the Communication Enhancement Model places high importance on recognizing the individual’s abilities, which in turn can empower both the elderly individual and the care provider during their interactions (Ryan et al., 1995). The framework of this model contends that communication impairments result from a disconnect, or imbalance, between the individual’s cognitive and communication capacity, on the one hand, and motivations, expectations, and opportunities that exist within their environment, on the other. Moreover, the Communication Enhancement
Model has been discussed in relation to its application to communication occurring in LTC, with an emphasis that this model provides a theoretical foundation for creating opportunities and selecting strategies to enhance communication between caregivers and residents with AD (Orange, 1995). For example, this framework holds that understanding the abilities and needs of individuals and selecting strategies that meet these unique communication encounters is essential (e.g., ADL context). In turn, residents’ increased participation in social and functional activities promotes health and well-being, as well as empowerment of both the residents with AD and the health providers (e.g., caregivers).

**Communication and individuals with AD**

As previously discussed, impairments in language affect several aspects of verbal production in individuals with AD, including word-finding difficulties, category fluency difficulties, poor repetition of low frequency sentences, difficulty with complex sentence production, semantic paraphasias, and eventually little to no verbal output is produced (Maxim & Bryan, 2006). Production difficulties are coupled with declines in language comprehension. In mild stages of AD, comprehension for complex sentences is impaired, followed by greater impairments in sentence comprehension in moderate stages of AD. Understandably, these language production and comprehension impairments have negative consequences on communication encounters with individuals with AD. Specifically, individuals with mild AD may use circumlocutions in conversation, demonstrate poor utterance completion, and have difficulty following complex conversations. With disease progression, individuals will have difficulty maintaining topics in conversation, will display shorter conversational turns, sentence coherence difficulties, and develop poor meta-awareness of their errors in conversation, thus
self-correction is impaired (Maxim & Bryan, 2006). Thus, together, production and comprehension declines associated with AD have consequences for communication. Moreover, more responsibility is inevitably placed on the communication partners of individuals with AD, as the non-impaired individual will have to accommodate the declining language abilities by adapting their information exchange process to support retained abilities at various stages of the disease.

Interestingly, relative to lexical-semantic impairments associated with AD, aspects of nonverbal communication have been shown to be preserved in mild to moderate AD (Bucks & Radford, 2004; Pashe & DiVenere, 2006; Rousseaux, Sève, Vallet, Pasquier, & Mackowiak-Cordoliani, 2010). For example, Rousseaux and colleagues (2010) examined individuals with mild to moderate AD in three communication domains: participation in communication (i.e., greeting, attention, participation); verbal communication (i.e., verbal comprehension, speech output, word production, syntax, verbal pragmatics, and intelligibility); and nonverbal communication (i.e., understanding gestures, producing gestures), pragmatics (adapting prosody, gaze duration, turn taking), and nonverbal feedback (adapting and emitting). Individuals with mild to moderate AD showed impaired verbal comprehension and word-finding difficulties; however, relative to the verbal communication impairments, nonverbal communication was mostly intact. Specifically, individuals with mild to moderate AD produced and understood gestures, and they did not display significant difficulties with nonverbal pragmatics.

While recognizing that findings regarding comprehension and production of emotional prosody in individuals with AD are inconsistent (Horley et al., 2010), emerging research on emotional processing in AD nevertheless suggests that individuals with AD, even those at
greater severity levels, preserve the ability to appropriately respond to and comprehend emotional prosody relative to other cognitive-linguistic abilities that show marked declines over the course of the disease (Bucks & Radford, 2004; Cadieux, 1997; Haak, 2006; Koff, Zaitchik, Montepare, & Albert, 1999; Roberts, Ingram, Lamer et al., 1996; Shimokawa et al., 2000; Shimokawa et al., 2001). For example, Roberts and colleagues (1996) reported that, relative to comprehension of emotional prosody, individuals with moderate AD were significantly more impaired on production of this form of nonverbal communication. Further, compared to normal elderly controls, individuals with mild and those with moderate AD were marginally and significantly impaired, respectively, on comprehension of emotional prosody; however, the two AD groups did not differ significantly from each other in the comprehension of emotional prosody. The authors suggested that, while comprehension deficits in emotional prosody may present themselves early in the disease, comprehension of emotional prosody may be resistant to further decline, relative to other cognitive decline associated with AD. In another study that examined emotional prosody processing relative to general cognitive ability in a sample of individuals with moderate AD compared to matched healthy older adult comparisons, Bucks and Radford (2004) reported that, while individuals with AD performed poorly compared to matched healthy controls on emotion and cognitive tasks, comprehension and production of emotional prosody was preserved relative to general cognitive decline. Further, there was no difference between normal controls and individuals with AD in the recognition of a variety of emotional processes (e.g., happiness, anger, fear). Bucks and Radford (2004) assert that findings from their study add to accumulating evidence that individuals with AD, even in the later stages, may retain much of their ability to recognize nonverbal emotional cues in verbal messages. Further, the authors recommend that communication strategies implemented during treatment and care of individuals with AD should consider emotional, along with functional and cognitive,
abilities to facilitate comprehension in people with AD, (e.g., intact implicit memory supported with emotional retrieval cues).

Another aspect of nonverbal communication that has been examined in individuals with AD is the use of gestures. While the ability of an individual with AD to produce co-verbal gestures (e.g., referential gestures during conversation) has been shown to parallel declines in speech production associated with AD, explained as possibly due to a common underlying central semantic-conceptual disorder (e.g., Carlomagno, Pandolfi, Marini, Di Lasi, & Crutilli, 2005; Glosser, Wiley, & Barnoski, 1998), preliminary research suggests that comprehension of gestures may be less impaired relative to other linguistic impairments (Pashek & DiVenere, 2006; Rousseaux et al., 2010). In a recent novel study, Pashek & DiVenere (2006) examined whether comprehension of two-step verbal commands was facilitated when accompanied by pantomime (meaningful) gestures. The major finding in this study was that auditory comprehension improved when verbal commands given to individuals with mild to moderate AD were followed by pantomime gestures and this finding was observed for almost all participants. Pashek & DiVenere (2006) also reported an unexpected finding that disease severity was unrelated to the ability to benefit from gestures, possibly indicating that individuals with moderate AD retain sufficient semantic memory to benefit from gestural support in verbal messages. The facilitating effect of gestures was explained by an argument based on modality-specific encoding in semantic memory. Specifically, they suggested that the cortical areas that support nonverbal communication may be affected to a lesser degree in AD in earlier stages of the disease (e.g., right posterior inferior cortex (Kellenbach, Brett, & Patterson, 2001)) than cortical areas that are implicated in semantic memory that support auditory verbal information (left temporal cortex). Pasheck & DiVenere (2006) also stressed that this line of research is in its
infancy, thus additional research investigating caregivers’ spontaneous use of communication strategies, including nonverbal communication, that contribute to improved comprehension in individuals with AD is warranted.

In sum, while language declines associated with AD affect verbal communication abilities, some forms of nonverbal communication remain relatively preserved until late in the disease progression. Person-centred theory of dementia care provides a framework to approach dementia care that supports the continued participation of the individuals through their social relationships, recognizing the concept of personhood in everyday care and communication.

**Functional declines and activities of daily living (ADLs)**

Given the insidious nature of this disease, the progressive degeneration in memory and language, as well as decline in other domains including visuo-spatial orientation, object recognition, executive functions (e.g., abstract reasoning, visual attention, planning, executing sequences of events), and praxis, it is clear that many premorbid aspects of individuals’ lives will have been altered, leaving communication and functional impairment as core symptoms of the disease (Zillmer & Spiers, 2001; Gauthier, Gelinas & Gauthier, 1997; Gauthier, Panisset, Nabantoglu & Poirier, 1998; American Psychological Association, 1994; Tekin, Fairbanks, O’Connor, Rosenberg & Cummings, 2001). Functional capacity is a reliable indicator of dementia symptomatology and can be used to detect early onset AD (Reisberg, Finkel, Overall, Schmidt-Gollas, Kanowski, & Lehfeld, et al., 2001). Functional impairments correspond to deterioration of spontaneous initiation and planning of the task followed by decline in successful completion of the task (i.e., planning a sequence of steps and efficiently using proper tools to carry them out) (Gauthier & Gauthier, 1990). Performance of activities of daily living (ADLs) is
an accurate indicator of functional ability (Gauthier et al. 1997). ADLs involve the sequential completion of multiple steps for success of the task and failure to finish an activity can occur as result of breakdowns at any of these steps. In mild AD, individuals will begin to have difficulty independently completing more complex ADLs (i.e., instrumental ADLs), such as managing finances or preparing a meal, and as the disease progresses, individuals will become functionally dependent for the completion of basic self care tasks, such as dressing or toothbrushing. Furthermore, reduced functioning has been associated with negative changes for the individual with AD including, increased emotional distress, depression, increased behavioural disturbances, institutionalization, and decreased survival rates (Potkin, 2002; Tekin et al., 2001).

The role of caregivers

The impact of the cognitive and functional declines associated with AD typically falls on a caregiver of the individuals with AD. Caregiver assistance, often a family member who may have little training or prior experience with AD, becomes increasingly important as the AD progresses, given declining ability to independently complete daily tasks. Caregiving is associated with several costs, including economic costs associated with loss of potential earning, the costs associated with formal caregiver services and supports, and caregiver’s own health care costs (Moore, Zhu, & Clipp, 2001). Moreover, in addition to economic costs associated with caregiving, at each severity level caregivers report that cognitive declines, including language impairments and breakdown in communication, negatively affect the caregiver-care recipient dyad leading to increased time spent on functional activities and increased caregiver stress and caregiver burden (Williamson & Shultz, 1993; Clark & Witte, 1991; Lubinski & Orange, 2000; Small, Gelbart, & Gutman , 2000). For instance, Small and colleagues (2000) examined the relationship between functioning in daily activities and communication problems
with family caregivers and individuals with AD. Family caregivers reported that communication was problematic in a variety of ADLs, including the basic self-care task of using the bathroom (Small et al., 2000). Difficulty completing ADLs coupled by communication deterioration have been reported by caregivers to be two of the strongest predictors of placement in a long-term care facility (LTC) (Williamson & Shultz, 1993; Steeman, Abraham, & Godderis, 1997; Lubinski & Orange, 2000).

**Formal caregiver assistance during ADLs and communication breakdown**

With the progression of AD, there is a continuous increase in the care needs of individuals living in the community and by the moderate to severe stages of the disease, institutional care is often necessary. Indeed, is estimated that three in ten individuals by age 65 and five in ten individuals by the age of 75 years will require institutional care (Statistics Canada, 2008) and it has been estimated that 47% of those residing in LTC have a diagnosis of AD or a related dementia (Alzheimer Association, 2010). Once in LTC, formal caregivers (e.g., personal support workers, health care aids and nurses) are responsible for assisting individuals during the completion of basic ADLs. Unfortunately, the worsening of communicative function and other cognitive domains in residents with AD complicates formal caregivers’ efforts to complete ADLs. Regrettably, formal caregivers are no better able to facilitate communication than informal caregivers: poor communication in LTC facilities is the foremost cause of patient dissatisfaction (Caris-Verhallen, de Gruijter, Kerkstra & Bensing, 1999; MacLeod Clark, 1985; Davies & Fallowfield, 1991) and the impoverished communicative environment of LTC facilities is well documented (Lubinski, 1995; Kaakinen, 1995; Lubinski, Morrison & Rigrodsky, 1981; Sigman, 1985; Jones & Jones, 1985).
The majority of communication between caregivers and care recipients takes place during daily care routines; thus, communication is disproportionately functional in nature, or task driven, and not socially orientated (Caris-Verhallen, Kerkstra, van der Heijden & Bensing, 1998; Caris-Verhallen et al., 1999). Indeed there is a need to increase effective and positive communication interactions between residents with AD and their caregivers, as it is well documented that individuals with severe dementia are at a higher risk of experiencing fewer opportunities to communicate, as compared to older adults without dementia, ultimately contributing to social isolation (Hubbard, Cook, Tester, & Downs, 2002), and long-term care settings contain limited communication opportunities for individuals with cognitive impairments (Hopper, 2003; Kaakinen, 1995; Lubinski, 1995). Further, it is documented that residents in LTC with dementia are both capable of communication and seek out opportunities to engage in communication, but are often excluded from planning and participating in their own care (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). This is concerning, as residents in LTC rely primarily on caregivers and staff for communication needs as well as interpersonal relationships (K. N. Williams, Ilten, & Bower, 2005). Moreover, literature suggests that formal caregivers are not better equipped than informal caregivers to manage communication difficulties associated with AD and most often have a poor understanding of the communication needs of AD residents (Hopper, 2001; Lubinski & Orange, 2000; Koury & Lubinski, 1991).

**Current Communication Recommendations**

Clinicians and support resources may offer a variety of communication strategies to assist caregivers when communicating with individuals with AD; however, these recommendations are largely derived from clinical sources based on intuitive experience rather than empirical research (Small, Gutman, & Makela, 2003). Common clinically recommended
communication prompts, otherwise known as communication strategies, include: slowed speech rate, using verbatim repetition only, using closed-ended questions (yes/no responses) or simple choice questions while avoiding open-ended questions, using simple sentences/ reduced syntactic complexity (e.g., canonical form and nonreversible), asking one question or giving one direction at a time, minimal use of pronouns, use of circumlocutions, maintaining eye contact, approaching the person slowly from the front, eliminating environmental distractions, and using exaggerated facial expressions (Hopper, 2001; Small et al., 2003; Clark, 1995; Ripich, et al., 1999; Ripich et al., 1995; Sheldon, 1994; Orange et al., 1995; Clark & Witte, 1991; Lee, 1991; Glickstein, 1997).

**Research Framework: Empirical Literature**

*Comprehension literature*

Although several of the clinically recommended communication strategies are intuitively appealing, empirical research investigating language comprehension in individuals with AD indicates that some of these strategies are, in fact, not helpful. For example, slowed speech rate is a commonly recommended speech accommodation but Tomoeda and colleagues (1990) found that slowing of speech did not improve comprehension of sentences, and actually was counterproductive given that individuals with AD have deficits in working memory. Similar findings have been reported in subsequent studies (e.g., Small, Andersen, & Kempler, 1997a; Small, Kemper, & Lyons, 1997b). For instance, Small and colleagues (1997a) reported that slowed speech rate only benefited comprehension in individuals with preserved working memory, had no effect on the comprehension of individuals with moderately impaired working memory, and had a detrimental effect on those individuals with
the most severe working memory deficits. Small et al. (1997b) reported similar findings with regards to caregivers’ slowed speech rate. The authors also reported that sentence comprehension in individuals with mild to moderate AD increased with the use of verbatim or paraphrased repetition, indicating that repetition should not be limited to verbatim only and that individuals with AD can understand more complex sentences following the use of repetition. While Small and colleagues (1997b) found that simple sentences (syntactically simple) were comprehended better than more complex sentences in individuals with AD, Rochon and colleagues (1994, 2000) reported that sentence comprehension in individuals with AD was related to the number of propositions (meaningful units) and not syntactic complexity. In addition, closed-ended questions have been shown to be effective communication strategies (Ripich et al., 1999; Small et al., 2003) but should not be the exclusive question type used when interacting with individuals with AD. Indeed, findings indicate that individuals with AD understand open-ended questions in particular contexts (Tappen et al., 1997; Small & Perry, 2005). For instance, Small & Perry (2005) investigated types of questions (closed-ended/ open-ended) used and communication outcomes during spousal caregiver conversations with individuals with mild to moderate AD. Results indicated that spousal caregivers used yes/no questions and open-ended questions to a similar extent while conversing with their spouse with AD. Moreover, while communication was more successful with the use of closed-ended questions than open-ended questions that placed more demands on semantic memory (i.e., general world knowledge) than episodic memory (i.e., events of the past), the authors noted that open-ended questions that drew upon semantic memory should not be avoided, because, relative to episodic memory, semantic memory is spared.
In addition, clinical recommendations for nonverbal communication are provided, including: establishing eye contact, sitting face-to-face, using gestures to help explain commands, using a calm tone of voice, using instrumental touch to guide person through tasks, using overemphasis and exaggerated facial expression as well as keeping distractions in the environment to a minimum, giving the patient time to respond, and moving slowly (Bartol, 1979; Sheldon, 1994; Small et al., 2003). To date, there is an identified gap in research on nonverbal communication and dementia (Hubbard, Cook, Tester, & Downs, 2002) and to the best of our knowledge, there is no empirical research investigating the effectiveness of caregivers’ use of a variety of nonverbal strategies used with individuals with moderate to severe AD during ADL completion.

**Examination of communication strategies**

Preliminary research investigating the effectiveness of communication strategies used by caregivers during ADL completion is emerging (Small et al., 2000; Small & Gutman 2002; Small et al., 2003; Roberto, Richter, Bottenberg, & Campbell, 1998). While Small, Gelbert & Gutman (2000) were the first to explore caregivers’ reported experience of ADLs that were at high risk of communication breakdown with individuals with dementia, Small & Gutman (2002) were the first to explore family caregivers’ reported use of 10 recurring communication strategies recommended to caregivers and their perceived effectiveness of these communication strategies used during ADL completion. The authors reported a positive correlation between caregivers’ reported use and perceived effectiveness of the communication strategies. Further, use of communication strategies did not significantly vary as a function of disease severity. However, this study was limited to caregivers’ reported use of communication strategies and their perceived effectiveness of the strategies. Small,
Gutman, Makela, & Hillhouse (2003) extended this line of research by investigating the actual use of the 10 commonly identified communication strategies during completion of a set of ADLs reported by caregivers as problematic to complete in the home (conversation, setting the table, using the phone, getting something on request). Audio-taped recordings of interactions between 18 individuals with AD and their spouses indicated that caregivers frequently used a sub-set of verbal strategies (one question/direction at a time, not interrupting, using simple sentences, paraphrased repetition, and yes/no questions) and infrequently used verbatim repetition or slowed speech rate. Further, only one strategy, simple sentences, correlated with disease severity. These findings highlight family caregivers’ differential use of communication strategies during completion of ADLs, some of which are consistent with current empirical research and inconsistent with current clinical recommendations. While this is the only study that has systematically examined the effectiveness of communication strategies during the completion of ADLs and provides insight into communication strategies utilized during a variety of ADLs, this study is limited to individuals with mild to moderate AD and to family caregivers. Further, this study used audio-taped recordings to examine a selection of frequently used verbal communication strategies, with the inclusion of few nonverbal communication strategies. Finally the representative ADLs in this study encourage more conversation than one would expect to observe during basic procedural ADLs completed in the LTC setting.

Findings from the studies by Small and colleagues just reviewed show that caregivers make speech behavior modifications when interacting with individuals with AD to promote relationships through communication (see also the Communication Enhancement Model, Ryan et al., 1995), and a growing body of research has focused on examining effective
communication during conversation (e.g., Hendryx-Bedalov, 1999; Orange, Lubinski, & Higginbotham, 1996; Orange, Van Gennep, Miller, & Johnson, 1998; Orange, 2001; Tappen, Williams, Barry, & DiSesa, 2001; Wadensten, 2005). While findings from this area of research are informative, it is unclear if communication recommendations are transferable to the directive communication occurring during completion of basic procedural ADLs most often found in the LTC setting. In addition, evaluation of formal caregiver communication training programs has been investigated (e.g., Bourgeois, Dijkstra, Burgio, & Allen, 2003; Burgio et al., 2001; Dijkstra, Bourgeois, Burgio, & Allen, 2002; Ripich, Ziol, Fritsch, Durand, 1999; Ripich, Ziol, & Lee, 1998; Ripich, Wykle, & Niles, 1995), with recent systematic reviews reporting beneficial results of caregiver communication training on the amount of communication occurring (Egan, Bérubé, Racine, Leonard, & Rochon, 2010; McGilton et al., 2009), positive effects on staff members’ communication knowledge and skills (McGilton et al., 2009), as well as positive effects on the staff members’ quality of care, caregivers relational skills (McGilton et al., 2003) and residents’ quality of life (Beeber, Zimmerman, Fletcher, Mitchell, & Gould, 2010; Levy-Storms, 2008; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). In addition, some of the training programs have reported the beneficial effects of the strategies included in the conversation training programs, such as the use of positive regard (Burgio et al., 2001), affective touch, eye contact, smiling (van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005), and the use of open-ended questions (Caris-Verhallen, Kerkstra, Bensing, & Grypdonck, 2000) (see for review Levy-Storms, 2008). However, the majority of the individual strategies included in these training programs have not been investigated empirically at an individual level (McGilton et al., 2009), or particularly during the context of ADL completion. Thus, it is unclear which communication strategies are effective and which communication strategies
may have no effect, which strategies may potentially hinder communication between caregivers and individuals with AD during ADLs, or what set of strategies is best suited for individuals with AD across levels of severity.

In sum, empirical literature supports a sub-set of clinically recommended communication strategies, including the use of one direction or question at a time, paraphrased or verbatim repetition, closed-ended questions, and open-ended questions. However, some of the clinical recommendations are not supported by empirical findings, including the use of slowed speech, the use of verbatim repetition only, and the recommendation to avoid the use of open-ended questions. In general, the majority of the clinical recommendations are based on intuitive clinical experience and caregiver experience and not on validated empirical research. In addition, the current recommended communication strategies are typically offered to support caregivers in the context of conversation with individuals with AD, and not necessarily during the context of ADLs.

**Research Rationale**

There is a growing awareness of the “dementia epidemic” that is facing families, healthcare settings, and society (i.e., the economic burden in the face of limited resources). Those living with AD in the community and, as the disease progresses, in the LTC setting, participate in daily life activities with the support of caregivers. Unfortunately, the caregiver – care recipient dyad is faced with challenges stemming from the multiple functional and communication difficulties. Moreover, the challenges that occur during the completion of ADLs continuously change and are exacerbated with disease progression. Clinically recommended communication strategies are the current solution available to caregivers to support their care
practice when assisting individuals with AD. However, there are several identifiable limitations of this current solution:

1. The majority of the recommended strategies are based on clinical experience or self-reports;

2. There is limited systematic research investigating the effectiveness of clinically recommended communication strategies specifically during the context of ADL completion;

3. While limited research is available on informal caregivers’ use of effective communication strategies when assisting individuals with mild to moderate AD during instrumental ADLs, no research had investigated which strategies formal caregivers employ while assisting residents with moderate to severe AD during basic ADLs;

4. Many of the recommended strategies have not been examined for efficacy at the individual level or when used in conjunction with other strategies.

The extent to which individual strategies, or the combination of strategies, contribute to improved communication during the completion of a basic ADL is largely unknown. In sum, the specific characteristics of prompting, both verbal and nonverbal, have not been studied thoroughly and this dissertation was motivated by the need for systematic research to identify empirically supported communication strategies that facilitate comprehension in individuals with moderate to severe AD, translating into successful completion of basic ADLs in the LTC setting.
Summary

This chapter presented the background for this dissertation and outlined the motivation for this research area. This chapter addressed communication theory relevant to the context of caregivers interacting with individuals with cognitive impairments and outlined the current empirical literature that supports this research area. Empirical findings on comprehension abilities of individuals with AD guided the decision regarding which communication strategies would be examined in this dissertation, particularly those strategies that were included in the research hypotheses. This chapter paid particular attention to reviewing the language declines associated with AD and how these impairments impact communication and functional ability, resulting in the need for caregiver-care assistance and further highlighted the communication challenges faced by the caregiver-care recipient dyad during the completion of ADLs. This chapter surveyed the clinically recommended communication strategies available for caregivers interacting with individuals with AD and presented a discussion on the limitations of the current solutions available to caregivers, leading to the presentation of the rationale for the proposed solution: empirically supported communication strategies specific to the completion of ADLs. To this end, two studies were carried out in this dissertation in which verbal and nonverbal communication was observed in caregiver-resident dyads in the LTC environment during a handwashing task (Chapter 2) and an oral care task (Chapter 3). A third study examined formal caregivers’ perceptions of effective communication strategies while completing ADLs (Chapter 4).
CHAPTER 2
EXAMINING SUCCESS OF COMMUNICATION STRATEGIES USED BY FORMAL CAREGIVERS ASSISTING INDIVIDUALS WITH ALZHEIMER'S DISEASE DURING AN ACTIVITY OF DAILY LIVING

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Abstract

Purpose: To examine formal caregivers’ (i.e., employed in long-term care) use of task-focused verbal and nonverbal communication strategies while assisting residents with moderate to severe Alzheimer’s disease (AD) during the successful completion of an activity of daily living (ADL). Based on the literature, the authors hypothesized that caregivers’ use of 1 proposition, closed-ended questions, and repetition would be of most benefit.

Method: Twelve caregiver–resident with AD dyads (hereafter referred to as caregiver–resident dyads) participated in this observational study. Each dyad was videorecorded on 6 separate
occasions while completing handwashing. Handwashing sessions were transcribed and systematically coded for the use of communication strategies during completion of the ADL.

**Results:** Caregiver–resident dyads successfully completed 90% of all handwashing sessions, and caregivers employed a variety of communication strategies. Consistent with our hypotheses, during successful task completion, caregivers most frequently provided individuals with AD with 1 direction or idea (i.e., proposition) at a time, closed-ended questions, and paraphrased repetition. Caregivers also frequently used encouraging comments and the resident’s name during the task; however, use of these strategies was not correlated to task success rate.

**Conclusion:** This study adds to the limited body of evidence supporting the use of specific communication strategies by caregivers assisting individuals with moderate to severe AD during successful completion of ADLs.

**Introduction**

Individuals with Alzheimer’s disease (AD) exhibit progressive impairments in communication and functional abilities. Notable communication breakdowns typically occur while caregivers assist during the completion of activities of daily living (ADLs). AD is a progressive neurodegenerative disease with insidious onset that is commonly identified according to the differential clinical criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (4th edition; American Psychiatric Association, 1994), which characterizes AD as having deterioration in three domains: cognition, social or occupational functioning, and behavior. Declines in memory, language, executive functioning, and visuospatial functioning are hallmarks of AD and are associated with typical functional and behavioral disturbances (Cummings, 2004; Potkin, 2002). Although forgetfulness and recent memory loss are most often the first clinical symptoms of AD, shortcomings in language abilities are present in the majority
of cases at the earliest stages of the disease, with deterioration in both production and comprehension abilities as the disease progresses (Appell, Kertesz, & Fisman, 1982; Cummings, Benson, Hill, & Read, 1985; Kempler, 1991). As such, interactions with individuals who have AD may become quite challenging and frustrating for communication partners, such as family members, friends, and caregivers.

Declines in multiple cognitive domains associated with AD alter premorbid aspects of individuals’ lives, leaving functional impairment a core symptom of the disease (American Psychiatric Association, 1994; S. Gauthier, Gelinas, & Gauthier, 1997; Potkin, 2002; Tekin, Fairbanks, O’Connor, Rosenberg, & Cummings, 2001). Functional decline can be accurately measured by assessing performance of ADLs. In mild AD, performance on instrumental activities, which encompass complex tasks (e.g., finances), is an initial indicator of decline, and as the disease progresses, basic activities (e.g., self-care tasks) become problematic (S. Gauthier et al., 1997). In particular, the progressive deterioration characteristic of AD has been linked to declines in the ability to plan spontaneously, initiate the correct sequence of steps of a task, and use the appropriate tools for carrying out the steps of a task, which eventually have a negative impact on the person’s ability to complete a task spontaneously (L. Gauthier & Gauthier, 1990).

Furthermore, reduced functional capacity can lead to many changes for individuals living with AD and has been shown to predict depressive symptoms (Holtzer et al., 2005), increased behavioral disturbances (Logsdon et al., 1998), institutionalization (Gaugler, Yu, Krichbaum, & Wyman, 2009), and decreased survival rates (Heyman, Peterson, Fillenbaum, & Pieper, 1996; also see Potkin, 2002; Tekin et al., 2001).

Caregiver assistance during ADLs becomes increasingly important as AD progresses, given the declining ability to complete daily tasks independently. Caregivers report that at each
stage of the disease, cognitive decline, including language impairments and breakdown in communication, negatively affects the caregiver–care recipient dyad, leading to increased time spent on functional activities, increased caregiver stress, and increased care-giver burden (Clark & Witte, 1991; Lubinski & Orange, 2000; Small, Geldart, & Gutman, 2000; Williamson & Schulz, 1993). Caregivers have reported that difficulty completing ADLs, which is coupled with communication deterioration, is among the strongest predictors of placement in a long-term care (LTC) facility (Gaugler et al., 2009; Lubinski & Orange, 2000; Steeman, Abraham, & Godderis, 1997; Williamson & Schulz, 1993). Once in LTC, formal caregivers (e.g., health care/nursing aides and registered nurses) are responsible for assisting individuals during the completion of basic ADLs. Unfortunately, the worsening of communicative function and other cognitive abilities in residents with AD complicates formal caregivers’ efforts to complete ADLs. Moreover, the majority of communication between caregivers and care receivers takes place during these daily care routines and is functional in nature (i.e., is task driven rather than socially oriented; Caris- Verhallen, Kerkstra, van der Heijden, & Bensing, 1998).

Interest in communication processes in AD and the impact of communication breakdown on caregiver–care recipient dyads has increased during the past decade. There is a growing body of research that focuses on effective caregiver–resident communication during conversation (e.g., Orange, Lubinski, & Higginbotham, 1996; Orange, Van Gennep, Miller, & Johnson, 1998). In addition, communication training programs have been developed and evaluated, with several studies reporting beneficial results of caregiver training (e.g., Bourgeois, Dijkstra, Burgio, & Allen, 2004; Burgio et al., 2002; Dijkstra, Bourgeois, Burgio, & Allen, 2002; Ripich, Ziol, Fritsch, & Durand, 1999; Tappen, Williams, Barry, & DiSesa, 2001). Moreover, recent systematic reviews evaluating the effectiveness of communication training interventions for
formal care providers of individuals with dementia residing in LTC facilities have supported the beneficial outcomes of some training programs (Egan, Bérubé, Racine, Leonard, & Rochon, 2010; McGilton et al., 2009; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). However, it is unclear which individual communication strategies are effective, ineffective, or potentially hindering during the completion of ADLs.

A variety of clinically recommended verbal communication strategies are available to caregivers of individuals with AD, such as slowed speech rate, verbatim repetition, closed-ended questions (yes/no response to question), simple sentences/reduced syntactic complexity, asking one question or giving one direction at a time, and minimal use of pronouns (e.g., Beck, Heacock, Rapp, & Mercer, 1993; Clark & Witte, 1991; Goldfarb & Pietro, 2004; Hopper, 2001; Lee, 1991; Ripich et al., 1999; Sheldon, 1994; Small, Gutman, Makela, & Hillhouse, 2003). However, it has been noted that these recommendations are generally not based on empirical research (Small, Geldart, & Gutman, 2000; Small, Kemper, & Lyons, 1997, 2000; Small et al., 2003) and some may be unhelpful. For example, slowed speech rate is a commonly recommended speech accommodation; however, Tomoeda, Bayles, Boone, and Kaszniak (1990) found that not only did slowing of speech fail to improve comprehension of sentences, it was counterproductive given that individuals with AD have deficits in working memory. Similar findings were reported in subsequent studies (Bourgeois et al., 2004; Burgio et al., 2001; Dijkstra et al., 2002; Small, Andersen, & Kempler, 1997; Small, Kemper, et al., 1997). Small, Kemper, and Lyons (1997) also reported that individuals with mild to moderate AD showed improved comprehension of complex sentences with the subsequent use of verbatim repetition and with paraphrased repetition, suggesting that syntax need not always be overly simplified and that repetition should not be limited to only verbatim repetition.
Although some recommended communication strategies have been found to impede communication, research suggests that other strategies assist comprehension in individuals with AD. Small, Kemper, and colleagues (1997) found that syntactically simple sentences were comprehended better than more complex ones by individuals with AD. Rochon, Waters, and Caplan (1994, 2000) found evidence to suggest that sentence comprehension is not solely a function of syntactic complexity. In their studies, sentence comprehension by individuals with AD was related to the number of propositions in the sentence (i.e., better comprehension associated with fewer propositions), lending support for the communication strategy of providing individuals with one direction or one idea at a time. Use of closed-ended questions is another communication strategy that researchers have examined and have shown to be effective for caregivers interacting with individuals who have AD (Ripich et al., 1999; Small et al., 2003; Small & Perry, 2005; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997).

In addition to verbal communication strategies, the use of nonverbal communication strategies has also been recommended, including establishing eye contact, sitting face to face, using gestures to help explain commands, using a calm tone of voice, using instrumental touch to guide a person through tasks, using overemphasis and exaggerated facial expression, keeping distractions in the environment to a minimum, giving the patient time to respond, and moving slowly (e.g., Bartol, 1979; Beck et al., 1993; Goldfarb & Pietro, 2004; Sheldon, 1994; Small et al., 2003). To date, there is a paucity of research examining the influence of nonverbal communication strategies on the promotion of successful communication with individuals who have dementia (Hubbard, Cook, Tester, & Downs, 2002). To our knowledge, there is no empirical research investigating the effectiveness of caregivers’ use of nonverbal strategies with individuals who have moderate to severe AD during ADL completion.
Preliminary research investigating caregivers’ use of effective communication strategies during completion of ADLs is emerging (e.g., Roberto, Richter, Bottenberg, & Campbell, 1998; Small, Geldart, et al., 2000; Small & Gutman, 2002; Small et al., 2003). In a study by Small, Geldart, and colleagues (2000), caregivers identified several daily activities that entailed communication problems, including using the telephone, using the bathroom, and preparing meals. Small and Gutman (2002) further explored family caregivers’ reported use of 10 commonly recommended communication strategies for use during ADL completion. They found a positive correlation between caregivers’ reported use and perceived effectiveness of the communication strategies, with the strongest correlations being shown by the use of short, simple sentences; closed-ended questions; verbatim repetition; and approaching the person slowly and from the front. In addition, the use of communication strategies did not significantly vary as a function of disease severity. Although these results are interesting, this study is limited by the fact that the results are based on self-report and perceived effectiveness rather than on a more objective assessment.

Small et al. (2003) extended this line of research by investigating the actual use of 10 of the most commonly identified communication strategies during completion of a set of ADLs that caregivers have reported as being problematic in the home (i.e., engaging in conversation, setting the table, using the phone, getting something on request). Audiotaped recordings of interactions between 18 individuals with AD and their spouses indicated that the caregivers frequently used a subset of verbal communication strategies (one question or direction at a time, not interrupting, simple sentences, paraphrased repetition, and yes/no questions) and infrequently used verbatim repetition or slowed speech rate. Further, only one communication strategy—the use of simple sentences—correlated with disease severity. These findings
highlight family caregivers’ differential use of communication strategies during completion of ADLs, some of which are consistent with the current empirical research and inconsistent with the current clinical recommendations (e.g., slowed speech rate and verbatim repetition only). This study is notable in that it was the first systematic attempt to examine the effectiveness of communication strategies used by caregivers assisting individuals with AD during the completion of ADLs. However, it is limited in scope by the authors having studied only individuals with mild to moderate AD and family (as opposed to formal) caregivers. Further, the authors of this study used audiotaped recordings to examine a selection of frequently used verbal communication strategies, with the inclusion of two nonverbal communication strategies observed by the researcher during the home visits. Finally, the representative ADLs in this study provide contexts that can encourage more conversation than one would expect to observe during the completion of basic self-care tasks in the LTC setting. Basic self-care tasks rely more heavily on procedural discourse (i.e., step-by-step instructions on how to accomplish a task). In sum, research to date has not systematically investigated the specific characteristics of the verbal and nonverbal communication strategies (or prompts) used in LTC facilities to facilitate comprehension in individuals with moderate to severe AD during successful completion of basic ADLs.

**Purpose of the Study**

The current study was motivated by two sets of gaps: (a) the gap between the use of empirically supported communication strategies and those actually being used in formal care settings during interactions with residents with moderate to severe AD and (b) the gap between the use of empirically supported communication strategies and those clinically recommended. Further, to date, much of the research has focused on caregiver perceptions of effective
communication strategies, on effective communication strategies in the conversational setting, or on the performance of individuals with AD in an experimental setting. Few studies have focused on what actually occurs in the caregiver–resident dyad in a naturalistic setting during the completion of ADLs (i.e., ADLs that are more procedurally than conversationally based). In addition, few studies have identified which individual communication strategy contributes to success of the task. The purpose of this study was to describe the communication strategies employed by formal caregivers assisting individuals with moderate to severe AD during a self-care task—specifically, handwashing—and to investigate the effectiveness of verbal and nonverbal communication strategies used by formal caregivers during completion of a basic ADL. The objectives were as follows:

1. To examine which communication strategies caregivers use during the completion of an ADL.

2. To examine which communication strategies caregivers use when the ADL is successfully completed.

3. To examine which communication strategies are related to success rate of the ADL.

On the basis of the literature to date, we hypothesized that caregivers’ use of the verbal communication strategies of one proposition, closed-ended questions, and repetition (both verbatim and paraphrased) would be most beneficial to individuals with moderate to severe AD during handwashing. We also examined the use of the nonverbal communication strategies of guided touch, comforting touch, touch for attention, demonstrating actions, handing an object to the individual, and pointing to an object (strategies frequently clinically recommended).
However, the paucity of research examining this issue did not allow us to develop any specific hypotheses regarding their use.

**Method**

**Study Design**

In the current study, we used a systematic observational design to measure communication behaviors of formal caregivers assisting individuals with moderate to severe AD during the completion of handwashing (a basic ADL). We employed verbatim transcription of the handwashing sessions to assess the caregivers’ use of task-focused communication strategies and accomplished this as follows: (a) conducted a real-time video recording of the formal caregiver–resident dyad interaction while participants were completing handwashing; (b) produced an orthographic transcription of these interactions using the Systematic Analysis of Language Transcripts (SALT; Miller & Chapman, 2008), a computer-based software program that generates quantitative data on linguistic elements of speech; and (c) coded the computer-based transcripts using the standardized notation system of SALT with the manual addition of a priori operationally defined codes particular to this study (for a review of the method of transcription see Lapadat & Lindsay, 1999). Before conducting this research, we received ethics approval through the University of Toronto Office of Research Ethics and from the LTC facility’s affiliated hospital Research Ethics Board Office.

**Participants**

Initially, we recruited 13 individuals diagnosed with moderate to severe AD from an LTC facility in Toronto, Ontario, Canada; however, due to the death of one resident, 12 residents with AD participated (11 women and one man). A criterion-based sample was used for
participant recruitment. All residents had a diagnosis of AD in their medical records; were right handed; and did not have a history of stroke, depression, psychosis, alcoholism, drug abuse, or physical aggression toward caregivers. To obtain an updated measure of disease severity, we administered the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Cognitive impairment ranged from moderate to severe (average score = 6 of 30, \( SD = 6.3 \), range = 0–18). Nine residents were classified as having severe AD (score <10), and three residents were in the range of moderate AD (score = 10–19). The participants’ average age was 88.1 years (\( SD = 6.1 \), range = 76–99); they had an average of 12.5 years of education (\( SD = 0.7 \), range = 12–14); and the average number of years at the LTC facility was 2.6 (\( SD = 2.0 \), range = 4 months – 5.5 years).

In addition, 12 formal caregivers working the day shift at the LTC facility participated. In general, staff readily agreed to participate in the study; only two caregivers declined participation. All caregivers met the following inclusion criteria: They were female, had at least 1 year of experience working with individuals with AD, and reported that they were able to speak English comfortably. The average age was 53.5 years (\( SD = 5.0 \), range = 47–59), the average number of years of education was 13.34 (\( SD = 1.8 \), range = 11 – 16), and the average number of years working with individuals with AD was 15.9 (\( SD = 8.2 \), range = 3 – 33). Two of the caregivers were registered nurses, and the remaining 10 caregivers were health care aides. Ten of the caregivers indicated that they had received onsite communication-skills training directed at working with individuals with dementia; one caregiver indicated that she had received offsite communication training (during educational training); and one caregiver indicated the absence of any communication skills training for this population. No further
information about caregiver communication training was available. All 12 caregiver–resident dyads participated in the entire study.

**Procedure**

Video recordings of formal caregivers assisting individuals with AD through the handwashing task were collected. Each caregiver was randomly assigned a resident with AD from the pool of participants with AD residing on the caregiver’s regular care unit. All caregivers were familiar with the resident whom they assisted; however, the assigned caregiver may or may not have been the resident’s usual care provider. Each formal caregiver–resident dyad met on six separate occasions to complete a handwashing session. During this study, 72 handwashing sessions were video recorded (with audio); a session took an average of 133.5 s ($SD = 57.1$, range = 48–278 s) to complete. At the beginning of each handwashing session, caregivers were instructed to use any verbal and nonverbal strategy needed to assist the resident with AD in successfully completing the task. The reason for the use of six sessions was to collect a large enough corpus of data to allow analysis at the dyad level as well as collapsed across dyads. Following the first video recorded session with the caregivers, a baseline video recording was collected. For the baseline, the caregiver was asked to describe her daily morning care routine. The purpose of the baseline video was to obtain an estimate of the caregivers’ typical speech rate. We were unable to collect baseline video for one caregiver; therefore, for task and baseline comparisons, we excluded this dyad from the analysis.

**Transcription and Data Coding Method**

All handwashing sessions were included in the overall analysis. The same rater (one of the authors) transcribed and coded each of the 72 handwashing sessions into SALT, a software
program that researchers have used to examine procedural discourse of individuals with AD (e.g., Ripich, Carpenter, & Ziol, 1997). Transcription of communication interactions during handwashing sessions was structured according to six identifiable steps described in previous research: (a) turn on the water, (b) wet the hands, (c) use the soap, (d) rinse the hands, (e) turn off the water, and (f) dry the hands (e.g., Mihailidis, Barbenel, & Fernie, 2004). Further, these steps are similar to the Toronto Public Health standards implemented in hospital and LTC settings; thus, training of the formal caregivers was not required. The beginning and the end of each step of the task were determined by a verbal indicator (e.g., “Turn on the water” or “It is time to rinse your hands”) or a behavioral indicator (e.g., the resident turned the water off; the resident began to dry his or her hands). Residents with AD can demonstrate a breakdown in this ADL at any one of the steps involved in proper handwashing (e.g., revert back to previous steps, skip steps, get “stuck” on one step), and caregivers are needed to provide guidance and help them through the task. To understand how the participants used communication strategies during completion of the task, we used operationally defined codes belonging to three main categories: (a) step engagement and step completion, (b) task success, and (c) communication strategies.

**Step engagement and step completion**

We coded the end of each step to indicate whether or not the resident was given the opportunity to participate and whether the resident or the caregiver completed the step of the task. Note that because the focus of this study was on overall task success, we did not separately perform additional analysis regarding the steps of the task.
**Task success**

Upon completion of the task, we coded each session for success by assessing step completion. A session was considered successful when a resident completed at least one of the steps in which he or she was given the opportunity to participate. This meant that 65 sessions were considered to be successful, with residents’ performance ranging from one to all steps successfully completed in a session. A session was considered unsuccessful when a resident did not complete any of the steps in which they were given the opportunity to participate. There were seven unsuccessful sessions. Flexibility in the sequence of steps was permitted (e.g., using soap before wetting the hands), and functional completion of the task was the primary consideration for defining task success. However, we also measured time to complete the task because research has shown that time taken to complete an ADL is a reliable predictor of disease severity and caregiver burden (Marin et al., 2000).

**Communication strategies**

Caregiver utterances were the coded unit of analysis in this study and were defined as phonological units as outlined by SALT conventions; these utterances were represented by the completion of a thought (marked by falling/rising intonation or by the presence of a pause). Caregiver utterances were identified as containing one or more communication strategies, defined as any communication behavior that served to prompt the resident through the steps of the task. Our coding method differs from other observation schemes that limit utterances to a single scoring category (i.e., mutually exclusive codes) for verbal behaviors (e.g., Roter’s Interaction Analysis System [RIAS]; Roter & Larson, 2002). Our coding also allowed for the exhaustive examination of caregivers’ use of all communication strategies and for the
description of combinations of codes used during task completion because utterances were not restricted to a single communication code. Communication strategies belonged to two major categories: task-focused verbal communication strategies and task-focused nonverbal communication strategies. Task-focused verbal communication strategies were defined as any verbal utterances provided by the caregiver to prompt the resident with AD through the task. Eleven were included in this study (see Table 2-1). Task-focused nonverbal communication strategies were defined as any nonverbal behaviors, including physical prompts (e.g., guided touch) and modeling/gesturing prompts (e.g., demonstrating the action), that the caregiver used to assist the resident through the task. Six were included in this study (see Table 2-1). It was possible to have more than one nonverbal code within a single utterance. Nonverbal behaviors could also be coded for in the absence of a verbal utterance.

The task-focused communication strategies of interest were established a priori and were based on previous research investigating frequently occurring communication strategies used in caregiver–resident interactions (Small & Gutman, 2002; Small et al., 2003); strategies recommended in caregiver communication training programs (e.g., Ripich et al., 1999); public resources available to caregivers of individuals with AD (e.g., Alzheimer Society of Canada, Alzheimer Society of Toronto, Alzheimer’s Association); and results from pilot data collected for this study based on one formal caregiver–resident dyad during three handwashing sessions.
Table 2-1

Coding scheme: Verbal and nonverbal communication strategies.

<table>
<thead>
<tr>
<th>Communication Strategies</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal Strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. One proposition</td>
<td>Single direction, request, or idea present in utterance</td>
<td>&quot;Turn the water on&quot;</td>
</tr>
<tr>
<td></td>
<td>(typically one phrase or clause)</td>
<td></td>
</tr>
<tr>
<td>2. Two propositions</td>
<td>Two directions, requests, or ideas present in caregiver's utterance</td>
<td>&quot;Get the towel and dry your hands&quot;</td>
</tr>
<tr>
<td>3. Verbatim repetition</td>
<td>Caregiver repeats previous message with same words or utterance</td>
<td>&quot;Turn the tap like this, turn the tap&quot;</td>
</tr>
<tr>
<td>4. Paraphrased repetition</td>
<td>Caregiver restates previous message using different wording</td>
<td>&quot;Turn the water on&quot; &quot;Turn the taps to get some water&quot;</td>
</tr>
<tr>
<td>5. Closed-ended question</td>
<td>Questions that can be answered with yes or no response</td>
<td>&quot;Can you turn the taps on?&quot;</td>
</tr>
<tr>
<td>6. Open-ended question</td>
<td>Questions that allow for more elaborate response</td>
<td>&quot;How do you wash your hands&quot;</td>
</tr>
<tr>
<td>7. Simple-choice question</td>
<td>Caregiver provides response options for resident to choose from</td>
<td>&quot;Do you want the soap or the towel?&quot;</td>
</tr>
<tr>
<td>8. Verification question</td>
<td>Caregiver clarifies/verifies resident’s request or response</td>
<td>&quot;Are you telling me you are done?&quot;</td>
</tr>
<tr>
<td>9. Use of the resident’s</td>
<td>Caregiver uses resident’s first or last name</td>
<td>&quot;Mrs. X, here is the soap&quot;</td>
</tr>
<tr>
<td>name</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Encouraging comments</td>
<td>Verbal praise directed toward resident</td>
<td>&quot;Good, you are doing a good job&quot;</td>
</tr>
<tr>
<td>11. Explanation of actions</td>
<td>Caregiver explains what they are going to do with the resident</td>
<td>&quot;I am going to help you wash your hands today&quot;</td>
</tr>
<tr>
<td>a Speech rate</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Nonverbal strategies

| 12. Guided touch          | Caregiver uses physical touch to guide resident during a step of the task | Caregiver guides resident's hand to the soap                                                  |
| 13. Comfort touch         | Caregiver uses touch to indicate support/ reassurance during the task    | Caregiver touches the shoulder of the resident                                                 |
| 14. Attention touch       | Caregiver uses touch to gain or re-gain resident's attention when off task| Caregiver touches the resident's hand to begin rinsing                                         |
| 15. Demonstration gesture | Caregiver illustrates with action how to perform a step of the task      | Caregiver shows resident how to use soap                                                      |
| 16. Hand object to resident| Caregiver provides object to resident                                    | Caregiver hands towel to resident                                                             |
| 17. Pointing              | Caregiver visually indicates direction of an object necessary for a step of the task | Caregiver points to the soap                                                                  |

*aSpeech rate was a communication strategy examined, but was not coded for in the transcripts. Speech rate was examined by comparing words/min in the baseline video to the average words/min in the handwashing sessions.
**Interobserver Agreement/Reliability**

A second person who was trained on code definitions transcribed and coded 20% of the handwashing sessions; this enabled us to establish interobserver agreement/reliability. First, we calculated interobserver agreement for the transcription of the caregivers’ dialogue using point-by-point percent agreement. Mostly adequate (>80%; House, House, & Campbell, 1981) agreement was obtained (words = 87%; number of utterances = 81% overall session duration = 100%; total step duration = 78%; step segmentation assignment = 86%). Second, we calculated Cohen’s kappa ($k$) statistic to assess reliability of codes indicating step completion and success of the task, yielding excellent ($k = .842, p = .00$) and substantial ($k = .659, p = .01$) agreement, respectively (Landis & Koch, 1977). Third, we used an intraclass correlation coefficient (ICC) to calculate reliability of coded verbal communication strategies related to our hypotheses, which was the appropriate statistic to use for categories that are not mutually exclusive (Shrout & Fleiss, 1979). Reliability was excellent for utterances marked with one proposition, paraphrased repetition, verbatim repetition, and closed-ended questions ($k = .831, k = .919, k = .906,$ and $k = .970$, respectively) and was moderate for utterances marked with two propositions ($k = .690; $ Lee, Koh, & Ong, 1989). The ICC could not be computed for open-ended questions due to insufficient occurrences of this strategy in the data.

**Results**

We conducted a one-way, within-subjects analysis of variance (ANOVA), with session as the within-subjects variable, in order to investigate possible change in strategy use by caregivers across sessions. Mauchly’s test indicated that the assumption of sphericity had been violated, $\chi^2(14, N = 12) = 0.028, p = .004$; therefore, we corrected $dfs$ using Greenhouse–Geisser
estimates of sphericity ($\eta = .57$). The results showed that there was no significant effect of session on caregivers’ overall use of communication strategies, $F(2.83, 31.14) = 0.974$, $p = .41$.

As such, the data from each caregiver–resident dyad were collapsed across sessions for the remaining analyses. Results are presented below relative to each study objective.

**Objective 1: To Examine Which Communication Strategies Caregivers use During the Completion of an ADL.**

*Overall use of verbal communication strategies*

We summarized caregivers’ overall use of verbal and nonverbal communication strategies using the entire data set, which included all coded utterances at each step of the task. Frequency counts were obtained for the total occurrences of all verbal and nonverbal communication strategies across all handwashing sessions ($N = 72$) as well as for the frequency of sessions with each communication strategy present. Percentage of handwashing sessions in which formal caregivers used at least one of the communication strategies was also calculated. Relative frequency proportion scores (frequency of each verbal communication strategy used, divided by the total of all verbal communication strategies employed) were calculated. To examine speech rate, we compared words per minute in the baseline video to the average words per minute of each caregiver during completion of the ADL (collapsed across the six sessions).

Caregivers produced a combined total of 1,691 utterances, of which 78% contained one or more communication strategies. During an average handwashing session, caregivers produced 23.49 utterances ($SD = 15.12$), with 18.22 ($SD = 12.96$) of those utterances being coded as containing one or more communication strategies. An average session contained 23.36
(SD =14.11) verbal and 7.81 (SD = 5.13) nonverbal communication strategies. Across all sessions (collapsed across caregivers), caregivers most frequently used verbal communication strategies including providing the resident with one direction or idea (i.e., proposition) at a time, using closed-ended questions, providing encouraging comments, using paraphrased repetition, and using the resident’s name. Caregivers least frequently used verifying questions, an explanation of their actions, and open-ended questions. A simple-choice question was used only once across all caregivers. The 12 caregiver participants showed no significant difference between the average relative frequency of paraphrased repetition (M = 0.086, SD = 0.056) and verbatim repetition (M = 0.065, SD = 0.048) across handwashing sessions, t(11) = −1.403, p = .188. Finally, caregivers significantly decreased their speech rate (words per minute) when communicating with residents during the handwashing task (M = 36.5, SD = 19.8) as compared with the baseline description task (M = 116, SD = 36.8), t(10) = 9.203, p < .001.

**Overall use of nonverbal communication strategies**

Relative frequencies were also calculated for task-focused nonverbal communication strategies. Overall, caregivers’ most frequent use of nonverbal communication strategies, found in at least 58% of all handwashing sessions, included guided touch, demonstrating the action to the resident, handing an object to the resident, and pointing to an object. The most infrequently used task-focused nonverbal communication strategies were using touch to comfort the resident and using touch to get the resident’s attention. Table 2-2 presents the data for both task-focused verbal and task-focused nonverbal communication strategies.
Co-occurrence of communication strategies

Of all the coded utterances, 42% contained a single code (one proposition = 13%; closed-ended question = 9%; encouraging comment = 8%; verifying question = 4%; all other strategies < 3%). Caregivers used the co-occurrence of two task-focused communication strategies in 41% of the coded utterances (verbal/verbal communication strategies = 24%; verbal /nonverbal strategies = 17%). The most frequent two communication strategy combinations included one proposition + paraphrased repetition (6%), one proposition + verbatim repetition (5%), and one proposition + guided touch (4%). Caregivers used the combination of three communication strategies infrequently (verbal only = 5%; mixed = 12%).
Table 2-2
Caregivers' use of verbal and nonverbal communication strategies: Across all handwashing sessions and during successfully completed sessions.

<table>
<thead>
<tr>
<th>Communication strategies</th>
<th>No. of sessions with strategy present</th>
<th>% sessions with strategy present</th>
<th>No. of times strategy used</th>
<th>% use of strategy</th>
<th>Caregivers' mean use of communication strategies during a session</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall (N =72)</td>
<td>Successful (N = 65)</td>
<td>Overall</td>
<td>Successful</td>
<td></td>
</tr>
<tr>
<td>Verbal strategies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. One proposition</td>
<td>72</td>
<td>64</td>
<td>100</td>
<td>98</td>
<td>619&lt;sup&gt;b&lt;/sup&gt; 441&lt;sup&gt;b&lt;/sup&gt; 35 36 8.6 6.7</td>
</tr>
<tr>
<td>2. Two proposition</td>
<td>50</td>
<td>39</td>
<td>69</td>
<td>60</td>
<td>144 86 8 7 2.0 2.2</td>
</tr>
<tr>
<td>3. Verbatim repetition</td>
<td>42</td>
<td>33</td>
<td>58</td>
<td>51</td>
<td>124 75 7 6 1.7 2.3</td>
</tr>
<tr>
<td>4. Paraphrased repetition</td>
<td>48</td>
<td>42</td>
<td>67</td>
<td>65</td>
<td>178&lt;sup&gt;b&lt;/sup&gt; 122&lt;sup&gt;b&lt;/sup&gt; 10 10 2.5 3</td>
</tr>
<tr>
<td>5. Closed-ended question</td>
<td>54</td>
<td>45</td>
<td>75</td>
<td>69</td>
<td>215&lt;sup&gt;b&lt;/sup&gt; 148&lt;sup&gt;b&lt;/sup&gt; 12 12 3.0 3</td>
</tr>
<tr>
<td>6. Open-ended question</td>
<td>11</td>
<td>7</td>
<td>15</td>
<td>11</td>
<td>16 10 1 1 0.22 0.61</td>
</tr>
<tr>
<td>7. Simple-choice question</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1 1 0 0 0.014 0.12</td>
</tr>
<tr>
<td>8. Verification question</td>
<td>24</td>
<td>18</td>
<td>33</td>
<td>28</td>
<td>54 38 3 3 0.75 1.3</td>
</tr>
<tr>
<td>9. Resident’s name</td>
<td>55</td>
<td>44</td>
<td>79</td>
<td>68</td>
<td>178&lt;sup&gt;b&lt;/sup&gt; 131&lt;sup&gt;b&lt;/sup&gt; 10 11 2.5 2.8</td>
</tr>
<tr>
<td>10. Encouraging comments</td>
<td>50</td>
<td>48</td>
<td>69</td>
<td>74</td>
<td>180&lt;sup&gt;b&lt;/sup&gt; 148&lt;sup&gt;b&lt;/sup&gt; 10 12 2.5 2.9</td>
</tr>
<tr>
<td>11. Explanation of actions</td>
<td>21</td>
<td>14</td>
<td>29</td>
<td>22</td>
<td>45 18 3 1 0.63 1.18</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>1754</td>
<td>1218</td>
<td></td>
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<td>51</td>
<td>13</td>
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<td>44</td>
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<td></td>
<td>38</td>
<td>8</td>
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<td></td>
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<td></td>
<td>58</td>
<td>12</td>
<td>2</td>
<td>51</td>
<td>75</td>
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<tr>
<td></td>
<td>193^c</td>
<td>42</td>
<td>2</td>
<td>113^c</td>
<td>107^c</td>
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<td></td>
<td>122^c</td>
<td>24</td>
<td>1</td>
<td>72^c</td>
<td>85^c</td>
</tr>
<tr>
<td></td>
<td>34</td>
<td>7</td>
<td>1</td>
<td>20</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>31</td>
<td>6</td>
<td>0</td>
<td>18</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>2.7</td>
<td>0.58</td>
<td>0.028</td>
<td>1.6</td>
<td>1.5</td>
</tr>
<tr>
<td></td>
<td>3.4</td>
<td>2.1</td>
<td>0.16</td>
<td>2</td>
<td>1.3</td>
</tr>
</tbody>
</table>

Relative frequency = frequency of verbal or nonverbal strategy use/ total number of all verbal or nonverbal strategies used. ^bDenotes the top five most frequently used verbal strategies. ^cDenotes the top four most frequently used nonverbal strategies.
Objective 2: To Examine Which Communication Strategies Caregivers use When the ADL is Successfully Completed.

With respect to Objective 2, caregivers’ use of communication strategies during successful task completion was derived from a subset of the data, which included only those handwashing sessions considered to be successfully completed by the resident (n = 65).

Verbal communication strategies

Caregiver–resident dyads successfully completed 90% of all handwashing sessions. Further, with the exception of turning the water on and turning the water off, the majority of caregivers provided residents with the opportunity to participate in the steps of the task, with few instances of skipping a step or completing a step without encouraging resident participation. During successfully completed sessions, caregivers used verbal communication strategies similar to those that caregivers most frequently used overall (see Table 2-2). The one exception was the use of the resident’s name, which was more frequently used than paraphrased repetition (see Table 2-2). The use of one proposition accounted for 84% of the proposition-type codes, closed-ended questions accounted for 75% of all question types, and paraphrased repetition accounted for 62% of repetition types used by caregivers.

Nonverbal communication strategies

Caregivers’ use of nonverbal communication strategies during successful task completion revealed a different pattern of most frequently used strategies than that observed during overall frequency of use. Although guided touch remained the most frequently used strategy in successful task completion, pointing to the object was the second most frequently
used, followed by handing an object to the resident and demonstrating the action to the resident. Guided touch accounted for 83% of all physical prompts, and pointing to the object accounted for 38% of nonverbal communication strategies involving modeling/gestures.

**Objective 3: To Examine Which Communication Strategies are Related to Success Rate of the ADL**

To identify which strategies were specifically linked to successful completion of the task in its entirety (i.e., “success rate”), we determined the number of sessions (out of six) for which each participant successfully completed all steps of the task in which he or she was given the opportunity to participate. We used the resulting proportion in calculating a Pearson correlation coefficient to examine the size of the relationships between success rate and caregivers’ overall use of task-focused communication strategies as well as between success rate and caregivers’ relative use of specific communication strategies.

**Success rate**

There was a large significant negative correlation between the average number of verbal communication strategies used by caregivers and task success rate, $r(10) = -0.588$, $p = 0.044$, but there was no relationship between the average number of nonverbal communication strategies used and task success rate, $r(10) = -0.388$, $p = 0.213$. There were large significant negative correlations ($p < 0.05$) between the relative frequency of use and task success rate for the following task-focused communication strategies: verbatim repetition, $r(10) = -0.605$; use of verifying question, $r(10) = -0.638$; and guided touch, $r(10) = -0.598$. A large positive correlation between task success rate and the use of pointing to an object approached significance, $r(10) =
Further, there was no significant relationship between the use of slowed speech (average words per minute across all sessions) and task success rate, $r(9) = .140, p = .681$. There was a large significant positive correlation between success rate of the task and MMSE score, $r(10) = .586, p = .05$. Finally, there was no significant relationship between task success rate and caregivers’ years of experience working with individuals with AD, $r(10) = .111, p = .731$, or between task success rate and the average time taken to complete the task, $r(10) = -.505, p = .094$. There was no significant relationship between the average time spent on the task and the average number of task-focused verbal communication strategies used, $r(10) = .396, p = .203$; however, we observed large significant positive correlations between the average time to complete the task and the use of open-ended questions and verifying questions, $r(10) = .805, p = .002$, and $r(10) = .631, p = .028$, respectively. A large negative correlation between the use of encouraging comments and duration of the task approached significance, $r(10) = -.564, p = .056$.

To control for possible variables that might have influenced the relationship between communication strategy use and task success rate, we computed partial correlation coefficients correcting for the effects of disease severity and caregivers’ years of experience working with AD. The inverse relationship between task success rate and overall use of communication strategies, as well as the inverse relationship between success rate and use of verbatim repetition, was no longer evident after controlling for disease severity; however, large significant negative correlations persisted between task success rate and the use of a verifying question, as well as between task success rate and the use of guided touch, when all controls were applied, $rab.cd(8) = -.643, p = .045$, and $rab.cd(8) = -.72, p = .019$, respectively.
**Disease severity**

MMSE score was not significantly correlated with caregivers’ average use of verbal or nonverbal communication strategies, $r(10) = -0.489, p = 0.106$, and $r(10) = -0.378, p = 0.226$, respectively, or with the average time taken to complete the task, $r(10) = -0.219, p = 0.495$. There were large significant negative correlations between MMSE score and the relative frequency of use of the following communication strategies: verbatim repetition, $r(10) = -0.821, p = 0.001$; paraphrased repetition, $r(10) = -0.584, p = 0.05$; and caregiver demonstrating an action, $r(10) = -0.754, p = 0.005$. We also observed a large positive relationship between MMSE score and the use of encouraging comments that approached significance, $r(10) = 0.571, p = 0.052$. A large positive significant correlation between MMSE score and the nonverbal strategy of handing the object to the resident was observed, $r(10) = 0.639, p = 0.025$.

**Caregiver experience**

Large negative correlations between caregiver experience and paraphrased repetition, $r(10) = -0.573, p = 0.051$, and between caregiver experience and the use of guided touch, $r(10) = -0.565, p = 0.056$, approached significance. A large marginally significant positive correlation between caregiver experience and the use of handing the resident an object, $r(10) = 0.545, p = 0.067$, was also present.

**Discussion**

This is the first systematic observation study to report on formal caregivers’ use of verbal and nonverbal communication strategies (grounded in empirical findings and clinical recommendations), as well as co-occurrence of these strategies, while caregivers assisted
residents who have moderate to severe AD during the completion of a basic ADL—specifically, handwashing. The analyses focused on (a) the use of verbal and nonverbal communication strategies during successful handwashing sessions and (b) the correlations between communication strategies and task success rate.

**Use of Communication Strategies During an ADL**

Findings from this study indicate that, overall, formal caregivers routinely use a variety of verbal and nonverbal communication strategies when assisting individuals with AD during handwashing. Further, in this study, all but three residents with AD were severely impaired with functional and communication difficulties, yet, with caregivers’ provision of various communication strategies, AD residents participated in their self-care and were able to successfully complete the task for the majority of all handwashing sessions. Caregivers used nonverbal communication strategies during the majority of handwashing sessions; however, most of these strategies were supplemented by verbal communication strategies. Individuals with moderate to severe AD successfully completed 90% of the handwashing sessions with caregiver assistance.

**Verbal communication strategies**

Findings from this study support our hypotheses that residents with AD would benefit from caregivers’ use of one idea or direction at a time, closed-ended questions, and paraphrased repetition (listed in order of frequency), as we observed that caregivers used these communication strategies most frequently during successful task completion. These results are consistent with those of Small et al. (2003). Verbatim repetition was not observed in the top
most frequently used task-focused verbal communication strategies and, therefore, was inconsistent with our hypothesis that caregivers’ use of this strategy would benefit residents with AD; however, we found that verbatim repetition was present in half of all handwashing sessions, and there was no significant difference between caregivers’ relative frequency of use of the two repetition types. This finding supports those of Small, Kemper, et al. (1997) and Small et al. (2003), both of which suggest that caregivers consider both types of repetition to facilitate comprehension in individuals with AD.

The finding that verbal praise was in the top five frequently used task-focused verbal communication strategies is consistent with other investigations reporting the frequency of communication strategies occurring between caregivers and residents during care routines in the LTC setting (e.g., Bourgeois et al., 2004; Burgio et al., 2001). Further, caregivers in our study likely used verbal praise to provide positive feedback to residents about their progress through the steps of the task. Indeed, this suggestion is consistent with a study by Dijkstra et al. (2002) indicating that caregivers’ use of positive feedback with individuals who have dementia can facilitate engagement in talking and topic maintenance in conversation, and this benefit is present even in later stages of dementia. Finally in this study, caregivers’ use of verbal praise also may have provided nonverbal information conveyed through emotional prosody (e.g., Bucks & Radford, 2004; Cadieux & Greve, 1997; but see Horley, Reid, & Burnham, 2010; Taler, Baum, Chertkow, & Saumier, 2008).

The fifth most frequently employed verbal communication strategy during successful completion of the task was using the residents’ names to gain their attention. Caregivers’ frequent use of this strategy is supported by findings from a study by Kim and Bayles (2007), in
which nearly all individuals with severe AD successfully recognized the spoken form of his or her name and responded appropriately to greetings from the examiner (e.g., shook hands or provided appropriate verbal response to greeting and closing remarks). We also found that, contrary to the findings of Small et al. (2003), formal caregivers did slow their speech during completion of the handwashing task as compared with the baseline task; however, slowed speech rate was unrelated to task success. This finding supports two convergent results regarding formal caregivers’ use of slowed speech. First, a growing body of literature reports an extensive use of “elderspeak,” which includes slowed speech, by caregivers assisting residents in LTC (e.g., Draper, 2005; Kemper & Harden, 1999; Williams, Herman, Gajewski, & Wilson, 2009). Second, empirical research indicates that slowed speech rate is not an effective communication strategy for increasing comprehension in individuals with AD (e.g., Kemper & Harden, 1999; Small, Andersen, et al., 1997; Small, Kemper, et al., 1997; Tomoeda et al., 1990).

**Nonverbal communication strategies**

During successful task completion, the most frequently used nonverbal communication strategies were guided touch, pointing to an object, handing an object to the resident, and demonstrating an action. We expected that guided touch would be the most frequently used nonverbal strategy, given that caring for older residents with moderate to severe AD in an LTC facility relies heavily on personal contact during the completion of basic self-care needs (Gleeson & Timmins, 2004). It is interesting to note that the frequent use of demonstrating an action (gesture) was found more often when the caregiver was interacting with higher functioning individuals during successful completion of the task. Research suggests that production of co-verbal gestures (e.g., referential gestures during conversation) may parallel
declines in speech production associated with AD, possibly due to a common underlying central semantic–conceptual disorder (Carlomagno, Pandolfi, Marini, Di Iasi, & Cristilli, 2005; Glosser, Wiley, & Barnoski, 1998). However, preliminary research suggests that comprehension of gestures may be less impaired relative to other linguistic and communication impairments. For instance, Pashek and DiVenere (2006) recently found that auditory comprehension improved when verbal commands given to individuals with mild to moderate AD were followed by pantomime gestures.

**Relationships Between Communication Strategies and Success Rate of the Task.**

**Verbal communication strategies**

Although we did not find any direct association between task success rate and any of the most frequently used verbal communication strategies, our findings regarding caregivers’ frequency of use of verbal communication strategies during successful sessions are consistent with reported findings from experimental research examining sentence comprehension in AD, including providing one proposition at a time and using repetition (Rochon, Waters, & Caplan, 1994, 2000; Small, Kemper, et al., 1997). The initial correlation between overall communication strategies used and task success rate indicated a relationship between formal caregivers’ greater use of verbal communication strategies and lowered task success rate. However, when we controlled for disease severity, this negative relationship did not persist, suggesting that caregivers’ overall use of task-focused strategies (verbal and nonverbal) may not be related to successful task completion alone but, instead, may be related to disease progression. It was surprising that although we found that disease severity was not related to caregivers’ overall use of communication strategies or to the time taken to complete the task, disease progression was
related to caregivers’ use of five task-focused communication strategies (verbatim repetition, paraphrased repetition, demonstrating actions, handing an object to an individual with AD, and using encouraging comments). Three of the strategies—verbatim repetition, paraphrased repetition, and demonstrating actions—were more often employed by individuals with more severe AD than by individuals with less severe AD, whereas caregivers employed handing an object to the resident and using encouraging comments less frequently with more impaired individuals. Another interesting finding was that although caregiver experience was not related to task success rate, experience was related to the use of three task-focused communication strategies in particular. More experienced caregivers used paraphrased repetition and guided touch less frequently, and less experienced caregivers used handing an object to the resident more frequently. Although these correlational findings are noteworthy, a more systematic examination of the relationship between caregiver experience and use of communication strategies is necessary.

**Nonverbal communication strategies**

Caregivers’ average use of nonverbal communication strategies was not related to task success rate; although guided touch was most frequently used in the analysis of successful handwashing sections, when all data were analyzed (proportion of success), use of this nonverbal strategy was associated with fewer instances of successful completion of the task. However, when disease severity was controlled, this relationship did not persist, suggesting that caregivers may be using guided touch with more functionally impaired individuals but also suggesting that it does not appear to have an effect on the outcome of the task. In addition, for individuals who were more severely affected, the caregivers were more likely to demonstrate an
action. In contrast, there was a positive relationship between caregivers’ increased use of handing objects to residents and assisting higher functioning individuals, suggesting that these individuals understand how to use an object necessary to the task.

**Disease severity and communication strategies**

As expected, we observed that the progression of AD was related to poorer outcomes on the handwashing task. Although we did not find the anticipated relationship between disease severity and an increase in caregivers’ overall use of task-focused communication strategies, with more strategies being used to accommodate for the cognitive declines in residents with AD, specific associations were noted. We observed a strong positive relationship between disease progression and caregivers’ relative use of verbatim repetition, paraphrased repetition, and demonstration gestures. Given the greater verbal comprehension deficits associated with progressing AD, the finding that caregivers make greater use of both types of repetition may coincide with a growing need for caregivers to provide clarifications following initial requests during steps of the task as the disease progresses. Our finding that caregivers used demonstration gestures more frequently as the disease progressed is not consistent with the findings of Pashek and DiVenere (2006). They reported no association between disease severity and the beneficial effects of using pantomime gesture following a two-step command. However, the participants in Pashek and DiVenere (2006) had mild to moderate AD, whereas in our study, the participants were in the moderate to severe range. The use of gestures may be more beneficial for those in the later stages of the disease as deficits in verbal communication increase and caregivers appear to incorporate more nonverbal communication strategies. We also
observed an association between higher functioning residents with AD and caregivers’ more frequent use of handing an object to residents and using encouraging comments.

In sum, the majority of participants in the current study were classified as having severe AD, yet they were able to successfully complete the representative basic ADL with continuous assistance from caregivers. Our current findings support some, but not all, of the clinically recommended communication strategies commonly suggested to caregivers of individuals with AD. For example, the current study supports the use of one idea or one instruction at a time and closed-ended questions; however, observations from the current study do not lend support for the use of verbatim repetition only or slowed speech rate. Furthermore, we found that caregivers frequently used two task-focused verbal communication strategies that are not commonly found in the clinical literature: verbal praise and use of the resident’s name. Finally, caregivers assisting individuals with moderate to severe AD frequently used task-focused nonverbal communication strategies that are not commonly found in the current clinical recommendations (e.g., pointing to an object, handing object to residents, and demonstrating an action).

Empirically determining the effectiveness of communication strategies is important to the validation of clinical communication recommendations. Despite the limitations of the descriptive and correlational nature of the study (e.g., causal inferences cannot be made, and generalizability is limited), our findings add to the limited body of research that has investigated the use of clinically recommended communication strategies and demonstrate that some strategies that are recommended in practice may not be supported by empirical research. Finally, the current study adds to the growing awareness that research is needed to understand which communication strategies are effective during completion of ADLs, which strategies are
appropriate across disease progression, and which strategies promote participation of individuals with AD in their own self-care. Indeed, it is appropriate to use communication strategies that reflect retained abilities across stages of the disease, holding autonomy and participation central to the experience of both caregivers and individuals with AD. Future studies are needed to examine formal caregivers’ use of communication strategies while assisting individuals with moderate AD and individuals with severe AD during different complex ADLs to support the validity and generalizability of these preliminary findings. Further, an examination of communication breakdowns and repairs during task completion will provide additional support for the effectiveness of task-focused communication strategies. Formal caregivers are important stakeholders in this research area, and as such, their perceptions of which communication strategies are effective when assisting residents with moderate to severe AD should be addressed. Together, these findings will help inform the development of evidence-based communication guidelines that can be examined for effectiveness following caregivers’ participation in a communication training program.

Acknowledgments

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2007 Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT), Toronto, Ontario, Canada; the 2006 Cognitive Aging Conference in Atlanta, Georgia; and the 2006 Celebrating Innovations in Health Care Expo, Toronto. We extend our greatest appreciation to the Seniors Health Centre, North York, Canada, and to all the individuals who participated in this research. We would also like to express our appreciation to Malcolm Binns, Jen Boger, Helen Ferley, and Chris Jokel for their assistance.
CHAPTER 3

QUANTITATIVE ANALYSIS OF FORMAL CAREGIVERS’ USE OF COMMUNICATION STRATEGIES WHILE ASSISTING INDIVIDUALS WITH MODERATE AND SEVERE ALZHEIMER’S DISEASE DURING ORAL CARE

This chapter was prepared as a manuscript that was submitted to a peer reviewed journal. At the time that this dissertation was submitted, this manuscript had been submitted to the Journal of Communication Disorders and was under review.


Abstract

This cross-sectional observational study examined formal caregivers’ use of task-focused and social communication strategies while assisting individuals with moderate and severe Alzheimer’s disease residing in a long-term care facility during a basic activity of daily living: toothbrushing. Thirteen formal caregiver-resident dyads were observed during a total of 78 separate toothbrushing sessions. All caregiver utterances occurring during the task were transcribed and coded for type of communication strategy utilizing a multidimensional observational coding scheme, which was developed a priori. Overall, the majority of residents, irrespective of disease severity, successfully completed toothbrushing with the support of caregiver assistance. Caregivers assisting residents with moderate and severe AD were found to use a variety of communication strategies, with task-focused strategies accounting for the
majority of use. For the most part, the communicative strategies employed did not differ across
disease severity. However, some differences were identified including the use of one
proposition, paraphrased repetition, using the resident’s name, and provision of full assistance,
with these strategies being used more often when assisting individuals with severe AD. This
study adds to the emerging literature supporting the use of specific communication strategies
while assisting residents with AD during the completion of daily tasks.

Introduction

In 2010, it was estimated that 35.6 million individuals worldwide were living with
Alzheimer’s disease (AD) or a related dementia, prompting the World Health Organization
(WHO) to call for action and to make investing in health and social systems that will improve
care and services for people with dementia and their caregivers a priority (World Health
Organization, 2012). Currently, it is estimated that 500,000 Canadians have a clinical diagnosis
of Alzheimer’s disease (AD) or a related dementia and this number is expected to climb to over
a million by 2038, creating the projected demand of 847,000 beds in long-term care (LTC) and
the necessary formal caregiver staff required to provide standard daily care (Alzheimer Society
of Canada, 2010a). AD is the most common form of all dementias (accounting for
approximately 60-80% of all cases (Thies & Bleiler, 2012) and is characterized as a progressive
neurodegenerative disease that impacts multiple cognitive domains, causing significant
impairments in an individual’s previous social, occupational, and functional capacity
(Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR, American Psychiatric
Association, 2000). Deterioration in memory, orientation, language, executive functioning,
visual processing, and praxis all play a role in the declining functional ability of individuals with
AD, which in turn, lead to the need for caregiver assistance during activities of daily living (ADLs). Communication is a fundamental component of the functional and relational aspects of a dyad, which, in this case, consists of a caregiver and an individual with AD that is established to facilitate the completion of ADLs. Unfortunately, prominent language declines associated with AD impact, first, word-finding abilities, category fluency, and verbal comprehension and, later as the disease progresses, speech content, and prosody (Karantzoulis & Galvin, 2011; Weiner & Lipton, 2009), which can lead to communication breakdowns during a variety of ADLs (Small, Geldart, & Gutman, 2000) and contribute to caregiver stress (Savundranayagam, Hummert, & Montgomery, 2005; Williamson & Schulz, 1993).

Several recommended communication strategies for caregivers interacting with individuals with AD can be found in the clinical literature. For example, as part of their study, Small and colleagues (2003) surveyed the AD caregiver literature and reported 10 strategies that were found to reoccur including, but not limited to, using one direction at a time, speaking slowly, using verbatim or paraphrased repetition, using closed-ended questions over open-ended questions, and using short simple sentences (Small, Gutman, Makela, & Hillhouse, 2003). However, while the empirical literature supports the use of some of these strategies (e.g., verbatim or paraphrased repetition (Small, Kemper, & Lyons, 1997) and providing one instruction at a time (Rochon, Waters, & Caplan, 1994; 2000)), research does not lend support for others. For example, sentence comprehension of individuals with AD has been examined, with findings indicating that the number of propositions, and not syntactic complexity, had a significant impact on sentence comprehension performance of individuals with mild to moderate AD (Rochon et al., 1994; 2000). In addition, slowing down one’s speech rate has been shown to
be an ineffective strategy to improve sentence comprehension in individuals with mild to moderate AD (Small, Andersen, & Kempler, 1997; Small, Kemper et al., 1997). Finally, individuals with severe AD have been shown to respond appropriately to open-ended questions, particularly when personally relevant (Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997).

While a few communication strategies have been individually examined for effectiveness during the context of discourse production (e.g., question type) (Small & Perry, 2005; Tappen et al., 1997), and some have reported on caregivers’ perceived effectiveness of communication strategies (e.g., Beach & Kramer, 1999; Savundranayagam, Ryan, Anas, & Orange, 2007, Wilson, Rochon, Leonard, & Mihailidis, in press), much of the literature surrounding communication strategies has focused on evaluating the efficacy of communication training programs for formal caregivers (e.g., Bourgeois, Dijkstra, Burgio, & Allen, 2004; Dijkstra, Bourgeois, Burgio, & Allen, 2002; McCallion, Toseland, Lacey, & Banks, 1999; Ripich, Wykle, & Niles, 1995; Tappen, Williams, Barry, & DiSesa, 2001). Although these training programs have reported benefits, these studies are limited in that they include several communication strategies, some of which may not be empirically supported. Within the context of ADL completion, some research has examined caregivers’ use of communication strategies with individuals with AD (Small et al., 2003; Wilson, Rochon, Mihailidis, & Leonard, 2012). For example, Small et al. (2003) found that family caregivers assisting individuals with mild to moderate AD during ADLs frequently employed the strategies of paraphrased repetition, giving one instruction or asking one question at a time, using closed-ended questions and using short,
simple sentences, with only the latter two being associated with fewer breakdowns during the tasks.

In the long-term care (LTC) setting, formal caregivers are responsible for the direct daily care of residents with moderate and severe AD, and thus have first-hand knowledge of a variety of techniques that are helpful in the completion of daily care routines, including the use of communication strategies. However, little is known about which communication strategies are actually utilized by formal caregivers during their care practice, which communication strategies are effective, and which communication strategies are best suited for individuals with moderate as compared to severe AD. Recently, we (Wilson et al., 2012) were the first to address this gap in the literature by examining formal caregivers’ actual use of task-focused communication strategies during the successful completion of handwashing, a complex basic ADL. In our study, formal caregivers assisted residents with AD (n = 12 caregiver-resident dyads) during handwashing. Results indicated that caregivers frequently employed a sub-set of task-focused verbal and nonverbal strategies that included providing the residents with one instruction, direction, or question at a time, using closed-ended questions, paraphrased repetition, encouraging comments and using the resident’s name. However, while this study provided insight into formal caregivers’ use of communication strategies with individuals with AD, it was limited in that the majority of resident participants had severe AD and communication strategies were examined within the context of a single ADL.

Building upon this work, therefore, the present investigation examined the communication strategies used by caregivers to assist individuals with moderate and severe AD to brush their teeth. Toothbrushing, a basic ADL, was chosen as the representative task for a
number of reasons: Firstly, toothbrushing is a multi-step task that individuals with moderate and severe AD have difficulty completing independently (Beck, Heacock, Rapp, & Mercer, 1993; Tappen, 1994); secondly, oral care practice is vital to the oral health of residents with AD (Chalmers & Pearson, 2005); and thirdly, the use of effective communication strategies can support caregivers assisting residents with oral care (Chalmers, 2000). Good oral health is essential to overall health (Haumschild & Haumschild, 2009) and optimal oral health can be supported by caregivers’ inclusion of a standard oral care practice in their daily routine (e.g., as outlined by the Registered Nurses’ Association of Ontario practice guidelines: www.rnao.org/bestpractices). Unfortunately, poor oral health is a central concern in the LTC setting because frail, functionally dependent residents with dementia are at risk for receiving inadequate levels of oral care, leading to poor oral health (Chalmers & Pearson, 2005; Chalmers, 2004). Moreover, inadequate oral care has been associated with several negative consequences on the health and wellness of residents with dementia including, poor oral health (e.g., oral disease, dentate loss, oral infections), oral pain and associated behavioural problems in those unable to communicate, poor nutrition and hydration, several serious health illnesses (e.g., aspiration pneumonia, cardiovascular disease, diabetes), and changes in social participation that can contribute to social isolation and low self-esteem (Chalmers & Pearson, 2005; Chalmers, 2004). While there is an increasing understanding of the importance of oral care in the LTC setting, caregivers have identified several barriers to providing regular oral care to residents with dementia, including the time to complete the task and breakdowns between the caregiver –AD dyad during the task (Chalmers, 1996; Sonde, Emami, Kiljunen, & Nordenram, 2011).
Study Aims and Hypotheses

To summarize, the purpose of this study was to examine formal caregivers’ (e.g., professional support workers or registered nurses) use of communication strategies while assisting residents with moderate and severe AD during the completion of a basic ADL, specifically toothbrushing. This extends our previous research (Wilson et al., 2012) to include residents with moderate AD and a new representative ADL. Based on our previous research, we hypothesized that caregivers assisting individuals with severe AD would utilize a subset of task-focused verbal (i.e., one proposition at a time, closed-ended questions, paraphrased repetition, verbal praise, and use of the resident’s name) and nonverbal (i.e., guided touch, pointing to an object, demonstrating an action and handing an object to the resident) communication strategies during the completion of toothbrushing, as has been found with handwashing (Wilson et al., 2012). Also, we anticipated that caregivers would reduce their rate of speech when interacting with AD patients during the ADL. Finally, we expected that there would be observed differences in caregivers’ use of task-focused communication strategies during task completion as a function of AD severity.

Method

Research Design

This study employed a cross-sectional systematic observational (group comparison) design. Standard methodology established for the quantitative content analysis research technique, traditionally used to examine content from recorded communication (Berelson, 1971; Kolbe & Burnett, 1991; Lombard, Snyder-Duch, & Bracken, 2002), was employed to examine
caregivers’ communication behaviour during the completion of oral care. The systematic observational method allows for the collection of data occurring naturally in the context of normal care routines conducted in the LTC setting. The quantitative content analysis method supports the use of the scientific method to make replicable and valid inferences from data to their context (Krippendorf, 2004b; Neuendorf, 2002).

**Ethics Approval**

Ethics approval was granted by the University of Toronto Research Ethics Board (REB) and by Toronto Rehabilitation Institute REB, which is affiliated with one of the participating LTC facilities. Oral and written information was provided to caregivers and written informed consent was provided to the substitute decision makers of the residents with AD. Consent was obtained from all caregivers and residents (via proxy) in this study. All participants and substitute decision makers were informed that participation in this study was voluntary and that one could withdraw at any time.

**Participants**

A non-probability purposive sampling (criterion-based) procedure was employed to select the participants (i.e., caregivers and residents with AD) from two LTC facilities in the Toronto area, as this sampling procedure is suitable for the comprehensive study of a phenomenon of interest based on knowledge and practice of experts in the field (Tongco, 2007). A total of 13 residents with AD (female = 10) and 15 caregivers (female = 14) specialized in dementia care participated in this study (personal support worker (PSW) = 14; registered nurse = 1). Each of the 13 residents with AD and their caregiver(s) (non-randomly assigned), referred
to as caregiver-resident dyads in this paper, completed six toothbrushing sessions. The attained sample size is comparable to previous research that examined naturally occurring communicative interactions (Watson, Chenery, & Carter, 1999; Orange, Lubinski, & Higginbotham, 1996; Wilson et al., 2012).

**Residents with AD**

All participants had a diagnosis of moderate or severe AD documented by a medical professional in their medical records, had at least one natural tooth (dentate), had a confirmed need for assistance during oral care, and understood English. Exclusion criteria included unspecified dementia or another dementia type specified in their medical chart (e.g., vascular dementia), a history of stroke, depression, psychosis, alcoholism, or drug abuse, uncorrected sensory deficits, or physical aggression towards caregivers.

Residents from the two facilities were comparable on years of education, length of time residing at the LTC facility, and age. As such, data from residents were collapsed across settings. Cognitive impairment level based on the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), ranged from moderate (score between 10-20) to severe (score less than 10) AD (average MMSE score out of 30 was 9.15 ($SD = 7.35$, range $0 – 20$). See Table 3-1 for resident characteristics. The two groups were comparable on all basic demographic characteristics. As anticipated, ADL functional capacity, as measured by the Activities of Daily Living Inventory – Severe Impairment Version (ADCS-ADL –SIV) (Galasko et al., 1997) differed significantly between the two severity groups: $U = 1.0; z = -2.90, p = .002$, with residents with moderate AD having significantly higher functional capacity score ($Mdn = 15, SD = 6.0$) than those in the severe group ($Mdn = 6, SD = 3.5$).
Table 3-1

*Characteristics of Participating Residents Grouped by AD Severity Level (N = 13)*

<table>
<thead>
<tr>
<th></th>
<th>Moderate AD Group (n = 6)(Female = 5)</th>
<th>Severe AD Group (n = 7)(Female = 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (Range)</td>
<td>SD</td>
</tr>
<tr>
<td>Age (years)</td>
<td>84.6 (71-92)</td>
<td>7.64</td>
</tr>
<tr>
<td>Education (years)</td>
<td>13.8 (10-23)</td>
<td>4.67</td>
</tr>
<tr>
<td>Stay at LTC facility (years)</td>
<td>3.51(.08-7)</td>
<td>2.41</td>
</tr>
<tr>
<td>MMSE score (/30)</td>
<td>15.8 (11-20)</td>
<td>4.072**</td>
</tr>
<tr>
<td>ADCS-ADL –SIV score (/54)</td>
<td>16.2 (9-25)</td>
<td>6.014*</td>
</tr>
</tbody>
</table>

Note. MMSE = Mini Mental State Exam; ADCS-ADL –SIV = Activities of Daily Living Inventory – Severe Impairment Version.

* p = .002. ** p = .001

**Formal caregivers**

Eight personal support workers (PSWs) and a registered nurse recruited from Location 1 and six PSW’s recruited from Location 2 participated in this study. All caregivers worked the day shift and were responsible for the daily care of the participating residents with AD. Further, to be included in this study, caregivers had to speak English comfortably and have at least one year working with individuals with AD. The average age of the caregiver participants was 45.4 years (SD = 11.66, range 26 - 62), 14 of the caregivers were female, and caregivers, on average, had 12 years experience interacting with individuals with AD. In terms of communication training to assist people with AD and dementia, 100% of the caregivers reported participating in in-service training and 73.3% reported receiving additional training (e.g., courses sponsored by...
the Alzheimer Society of Ontario). Caregivers from the two locations were comparable on age, years of education, and years in the profession. See Table 3-2 for caregiver characteristics.

Table 3-2

*Characteristics of Formal Caregiver Participants Grouped by AD Severity Level (N = 15)*

<table>
<thead>
<tr>
<th></th>
<th>Moderate AD Group (n = 7)(Female = 7)</th>
<th>Severe AD Group (n = 8)(Female = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (Range)</td>
<td>SD</td>
</tr>
<tr>
<td>Age (years)</td>
<td>47.4 (26-62)</td>
<td>13.3</td>
</tr>
<tr>
<td>Education (years)</td>
<td>14.4 (12-18)</td>
<td>2.22</td>
</tr>
<tr>
<td>Years in profession</td>
<td>17.3 (2-40)</td>
<td>14.6</td>
</tr>
<tr>
<td>Years of experience working with residents with AD</td>
<td>13.3 (2-25)</td>
<td>9.99</td>
</tr>
</tbody>
</table>

Procedure

*Observation of toothbrushing sessions*

Each of the 13 caregiver-resident dyads was observed during the completion of six separate toothbrushing sessions (n = 78) during their daily morning care routine over the span of two weeks. Based on our experience (Wilson et al., 2012), six sessions allows for sufficient opportunity for caregivers to generate a variety of communication behaviours. Video-recordings
(with audio) of each toothbrushing session were collected by either the first author or a trained research assistant using a hand-held camera. At the beginning of each toothbrushing session, a visual diagram, with text, outlining the nine steps of toothbrushing (adapted from the Refined Activities of Daily Living (ADL) Assessment Scale (Tappen, 1994)) was displayed at the sink area. Also, at the beginning of each session caregivers were instructed to use any verbal and nonverbal communication that they typically use to assist the resident participant successfully through all 9 steps of the task. Variations on the ordering of steps involved in toothbrushing were permitted.

At the end of the first toothbrushing session the following data were also collected: 1) a baseline video representing each caregiver’s normal communicative style, in which caregivers described the typical steps involved when assisting an individual with AD during the task of toothbrushing and how he/she would help a resident to complete the task; 2) the caregiver’s basic demographic information; and 3) an MMSE assessment of the resident.

Finally, as part of a larger project, some participating caregivers (n = 5 at each LTC location) completed two focus group interviews. Details and findings from the focus group interviews are reported elsewhere (Wilson et al., in press).

**Transcription**

All toothbrushing sessions and baseline videos were orthographically transcribed verbatim by a professional transcription service and each transcript was checked for accuracy by the first author. All toothbrushing session transcripts and baseline videos were then imported into a software program, Systematic Analysis of Language Transcripts, Research Version 9 (SALT RV9) (Miller & Chapman, 2009), for further coding and analysis. All dialogue occurring
during each toothbrushing session was segmented into utterances based on phonological units, which is defined by the completion of a thought. Two factors outlined in SALT RV9 conventions were used to help identify the completion of a thought: (1) rising and falling intonation that reflects a statement or a question and (2) the presence of a pause. Further, utterance segmentation was framed around the context of the task: completion of a thought that was aimed towards the resident to assist them in a step of the task. Duration of each toothbrushing session was also recorded.

**Data coding**

In each toothbrushing session, caregivers’ utterances that were directed towards the resident during completion of the task were systematically quantified using our multidimensional observation coding scheme (MOCS). The MOCS was developed based upon a coding scheme previously used in our research that investigated task-focused communication between formal caregivers and residents with AD during the completion of handwashing (see Wilson et al., 2012). In the present study, we included all task-focused communication strategies examined in Wilson et al., 2012, while also expanding the previous coding scheme to capture additional task-focused communication strategies (i.e., introduction of task and negotiation) and to include the social communication that occurs during completion of ADLs. Similar to Wilson et al.’s, (2012) previously developed coding scheme, the current MOCS was informed by the empirical literature (e.g., Small et al., 2003; Rochon et al., 1994; 2000; Wilson et al., 2012). Furthermore, the MOCS includes strategies outlined in the positive care interactions discussed in the theoretical literature on dementia care (Kitwood, 1998).
Table 3-3 provides a detailed description of the MOCS. The MOCS codes consisted of three dimensions: (1) task-focused communication strategies; (2) social communication strategies; and (3) miscellaneous (MISC). Within the task-focused dimension, communication strategies were coded as either verbal or nonverbal. Verbal strategies were further subcategorized into number of propositions, repetition type, question type, and others, with each of these sub-categories being mutually exclusive. Nonverbal strategies were further subcategorized into mutually exclusive tactile and visual types. Social communication codes were applied to utterances that occurred during the toothbrushing session that were not task-focused. Note, however, social communication codes could be used in combination with task-focused codes. Finally, MISC codes were used for utterances that did not fit under the two main dimensions. Importantly, to capture the natural complexity and the multiple functions of caregivers’ communication content, as well as to include all data, utterances had the potential to be coded for multiple communication strategies. This technique, as opposed to the typical coding technique of reducing an utterance to a single category (i.e., mutually exclusive coded units of analysis), was employed to avoid the loss of valuable insights into caregivers’ use of communication strategies during ADL completion.
### Table 3-3

*Codes Included in the Multidimensional Observation Coding Scheme (MOCS)*

<table>
<thead>
<tr>
<th>MOCS codes</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dimension 1: Task-focused communication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Verbal strategies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number of propositions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One proposition</td>
<td>Single direction, request, or instruction present in caregiver's utterance to assist resident during steps of the task</td>
<td>&quot;Please turn on the water.&quot;</td>
</tr>
<tr>
<td>Two propositions</td>
<td>Two directions, requests, or instruction present in caregiver's utterance to assist resident during steps of the task</td>
<td>“Please get the towel and dry your hands.”</td>
</tr>
<tr>
<td><strong>Repetition type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbatim repetition</td>
<td>Caregiver repeats previous message (all content words or entire utterance) within same utterance or in immediate next utterance (task related)</td>
<td>“Turn the tap on, turn the tap.”</td>
</tr>
<tr>
<td>Paraphrased repetition</td>
<td>Caregiver restates previous message for clarification (related to steps of the task)</td>
<td>“Turn the taps on. Turn the taps to get some water.”</td>
</tr>
<tr>
<td><strong>Question type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closed-ended question</td>
<td>Caregiver’s question can be answered with yes or no response</td>
<td>“Can you turn the water on?”</td>
</tr>
<tr>
<td>Open-ended question</td>
<td>Caregiver's question allows for a more elaborate response</td>
<td>“How do you brush your teeth?”</td>
</tr>
<tr>
<td>Simple-choice question</td>
<td>Caregiver provides response options for resident to choose to answer question</td>
<td>“Do you want to rinse your mouth or turn off the water?”</td>
</tr>
<tr>
<td>Verification question</td>
<td>Caregiver clarifies, verifies, or interprets resident’s request or response that is related to the task</td>
<td>“Are you telling me you’re done?”</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Introduce task</td>
<td>Caregiver indicates to the resident that they are going to brush their teeth (at beginning of toothbrushing session)</td>
<td>“We are going to brush your teeth now.”</td>
</tr>
<tr>
<td>Explanation of actions</td>
<td>Caregiver explains what they are going to do with the resident during steps of the task</td>
<td>“I am going to help you turn the water on now.”</td>
</tr>
<tr>
<td>Use of resident’s name</td>
<td>Caregiver addresses resident by their first or last name during steps of the task to gain their attention</td>
<td>“Ms. X, here is the toothbrush”</td>
</tr>
<tr>
<td>Negotiation</td>
<td>Dialogue between the dyad to reach an agreement or understanding focused on the task</td>
<td>“Okay, after we finish brushing, I will get you a cup of tea.”</td>
</tr>
<tr>
<td>Encouraging comments</td>
<td>Verbal praise, reassurance, optimism directed toward resident while</td>
<td>“You’re doing a good job!”</td>
</tr>
<tr>
<td>Nonverbal strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td><strong>Tactile</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand object to the resident</td>
<td>Caregiver provides object to resident as a tactile prompt for the resident</td>
<td>Caregiver hands towel to the resident</td>
</tr>
<tr>
<td>Guided touch</td>
<td>Caregiver uses physical touch to guide resident through a step of the task</td>
<td>Caregiver guides resident’s hand to the toothbrush</td>
</tr>
<tr>
<td>Comfort touch</td>
<td>Caregiver uses touch to indicate support or reassurance during a step of the task</td>
<td>Caregiver touches the resident’s shoulder</td>
</tr>
<tr>
<td>Attention touch</td>
<td>Caregiver uses touch to gain or regain the attention of the resident when “off-task”</td>
<td>Caregiver touches the resident’s hand to indicate that it is time to begin brushing</td>
</tr>
<tr>
<td><strong>Visual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstration gesture</td>
<td>Caregiver illustrates, with action, how to perform a step of the task</td>
<td>Caregiver demonstrates how to brush teeth</td>
</tr>
<tr>
<td>Pointing</td>
<td>Caregiver visually indicates direction of an object necessary for the step of the task</td>
<td>Caregiver points to the location of the toothpaste</td>
</tr>
</tbody>
</table>

**Dimension 2: Social communication**

| Greet resident | Caregiver greets resident upon initial contact | “Hello Ms. X, how are you today.” |
| Compliment resident | Caregiver compliments resident, building rapport or validating resident | “You look nice today.” |
| Caregiver responds to resident | Caregiver acknowledges, agrees, shows empathy or responds to a comment, request, or statement made by the resident | “I know you are looking forward to lunch today.” |
| Habitual social expressions | Habitually used expression that acts as conversation fillers | “Alright.” “Okay.” “Uh uh.” |
| Social conversation | Caregiver makes small talk or short comment: e.g., personal remark, states opinion, jokes, or shows concern, social talk | “You’re like me, I like to dance too!” |
| Closing remarks | Caregiver thanks the resident for participating in the task | “We are all done now, thank you.” |

**Dimension 3: MISC**

| Full physical assistance | Caregiver uses full physical assistance during the step of the task | Caregiver brushes the resident’s teeth |
| Redirection             | Caregiver redirects resident to keep on task | Caregiver guides resident to water instead of towel |
| Uncategorized utterance | Caregiver’s utterance cannot be categorized by any codes in the MOCS |  |
| Unobservable            | Nonverbal behaviour occurred but view was obstructed in video-recording |  |
**Task success**

In addition to the coding of caregiver utterances, the success of each toothbrushing session was determined by coding for the resident’s participation and completion of the steps of the task. Specifically, each of the nine steps of toothbrushing were categorized as follows: (1) the resident completed the step; (2) the resident did not complete the step when given the opportunity to participate (e.g., resident did not respond to caregiver’s prompts); (3) the caregiver completed the step without providing an opportunity for the resident to participate; (4) the step was skipped; or (5) the step was unobserved. As in our previous research (Wilson et al., 2012), task success rate for each dyad, was calculated to be the proportion of the completed six sessions that were entirely successful (i.e., resident completed all steps of the task in which he/she was given the opportunity to participate).

**Reliability of the Observations**

**Transcription**

A professional transcription service provider transcribed all toothbrushing sessions using phonological units to segment utterances (SALT conventions). The first author independently transcribed a random selection of 20% of the toothbrushing sessions to calculate inter-observer agreement for word and utterance segmentation. Total percent (point-by-point) agreement was computed as follows: $A / (A + D) \times 100$, which is the total number of agreements divided by total number of agreements and total number of disagreements multiplied by 100 (see for review House, House, & Campbell, 1981). Acceptable agreement was demonstrated for both word (84.27%) and utterance segmentation (80.04%).
Multidimensional observation coding scheme (MOCS)

The first author and a trained research assistant independently applied the MOCS to a random selection of 20% of the toothbrushing sessions (total units of analysis = 525 utterances) in order to establish an inter-coder reliability measure for the MOCS. However, before doing so, a training process was initiated in which three transcripts were randomly selected, from the 20% of transcripts selected for inter-coder agreement analysis, to train the research assistant on the MOCS. During training, inter-coder agreement was assessed informally until 100% agreement between the two coders was achieved. During this time, any need for clarifications was noted and addressed by making the necessary modifications to the organization of the observation scheme, coding procedures, code definitions, and code examples. Further, during this training period, the need for the addition of two other codes was identified (habitual social expression and uncategorized utterance) to ensure that all caregiver utterances were coded, thereby meeting the exhaustive criteria for observation schemes used following methods of content analysis.

Following training, no new codes were added to the MOCS. Inter-coder agreement was assessed after coding half of the transcripts (n = 175 utterances) originally selected for inter-coder agreement analysis, with the purpose of identifying any issues regarding the definitions of the codes. During this time, four codes were identified as having poor agreement: paraphrased repetition; verbatim repetition; guided-touch; and full physical assistance. Further refinements were made to the definitions to ensure that the codes were mutually exclusive, which led to the resolution of disagreement on those codes.

To establish reliability of the communication codes defined in the MOCS, we measured the extent to which two trained coders agreed on the behaviours observed across 525 units of
analysis (from a random 20% of total transcripts). Cohen’s Kappa statistic was calculated to measure inter-coder reliability for the application of the MOCS coding scheme on this random twenty percent of the transcripts. Only those communication strategies that occurred in more than 20% but less than 80% of the units of analysis were included in the calculation as high frequency (greater than 80%) and low frequency behaviours (20% or less) can produce inaccurate agreement coefficients (House, House, & Campbell, 1981).

No single MOCS code had a high rate of occurrence in the transcripts sampled. For communication strategies with a low prevalence rate (10-20%) we report percent agreement indices (occurrence agreements/ occurrence agreements + disagreements X 100), following suggested guidelines (House et al., 1981; Suen, 1989). This approach is widely reported in the transcription literature (Cucchiarini, 1996) and in content analysis research (Lombard et al., 2002).

All inter-coder agreement calculations (i.e., Cohen’s Kappa and percent agreement) were made using www.dfreelon.org and Table 3-4 provides a summary of the computed inter-coder agreement coefficients. As can be seen, all communication strategies demonstrated acceptable agreement coefficients: 70% or greater for occurrence percent agreement and .60 or greater for chance corrected Cohen’s Kappa coefficient (House et al., 1981; Krippendorff, 2004a; Landis & Koch, 1977; Lombard et al., 2002; Neuendorf, 2002).
Table 3-4

Summary of Inter-coder Agreement Indices for Codes Included in the MOCS and for Coding of the Completion of Steps in the Task (n = 525 utterances)

<table>
<thead>
<tr>
<th>Codes (n = 33)</th>
<th>Occurrence percent agreement</th>
<th>Cohen’s kappa</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MOCS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Task-focused: Verbal strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One proposition</td>
<td></td>
<td>.80</td>
</tr>
<tr>
<td>Paraphrased repetition</td>
<td>72.1</td>
<td></td>
</tr>
<tr>
<td>Closed-ended question</td>
<td>80.2</td>
<td></td>
</tr>
<tr>
<td>Encouraging comments</td>
<td>80.7</td>
<td></td>
</tr>
<tr>
<td>Use of resident’s name</td>
<td>96.7</td>
<td></td>
</tr>
<tr>
<td>Task-focused: Nonverbal strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand object to resident</td>
<td>75.9</td>
<td></td>
</tr>
<tr>
<td>Guided touch</td>
<td>72.1</td>
<td></td>
</tr>
<tr>
<td>Social Conventions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver responds</td>
<td>75.5</td>
<td></td>
</tr>
<tr>
<td>Step completion</td>
<td></td>
<td>.90</td>
</tr>
</tbody>
</table>

**Task success**

For the same 20% sample of transcripts, we also calculated inter-coder agreement for step completion which was used to measure task success and it was found to be excellent (see Table 3-4). The remainder of all toothbrushing sessions were coded by the first author.

**Data Analysis**

The method of quantitative content analysis was used to collect and organize the data (Krippendorff, 2004b; Neuendorf, 2002) and all descriptive and non-parametric statistical analyses were done using IBM SPSS Statistics software (version 20). Friedman’s ANOVA
indicated that caregivers in each AD severity group produced utterances containing communication strategies similarly across the six (6) sessions (moderate group: \( \chi^2 (5) = 4.2, p = .52 \); severe group \( \chi^2 (5) = 1.26, p = .94 \)), thus data were collapsed across sessions for all analyses.

The frequency of occurrence of caregivers’ use of communication strategies during toothbrushing for each severity group was determined as follows: For each dyad, the percentage of caregiver utterances that contained each communication strategy (e.g., one proposition) was calculated by dividing the total number of a given communication strategy produced by the total number of utterances produced and multiplying by 100. We also compared differences in caregivers’ use of communication strategies and task success as a function of disease severity using the Mann-Whitney U Test (p < .05, two-tailed). In addition, speech-rate measures (words/minute) during the baseline task and each caregiver’s mean speech-rate during the toothbrushing task (across sessions) were compared using a Wilcoxon Signed Rank Test as a function of severity.

Results

In total, 78 toothbrushing sessions were recorded producing 5.6 hours of discourse while completing the task. Across all sessions, caregivers produced 2,627 utterances and residents produced 698 utterances. All caregiver utterances were coded utilizing the MOCS, which identified caregivers’ total production of communication strategies as follows: 3,785 (85%) task-focused communication strategies (verbal = 3,218; nonverbal = 567); 463 (10%) social strategies; and 202 (5%) MISC strategies.
Overall use of Communication Strategies and Strategy use as a Function of Disease Severity

In total, the moderate AD group completed 36 toothbrushing sessions, with caregivers producing a total of 1074 utterances. The severe AD group completed 42 toothbrushing sessions, and caregivers produced a total of 1553 utterances across sessions. Table 3-5 displays the discourse summary of an average dyad during a toothbrushing session while assisting individuals with moderate and severe AD. There were no significant differences between severity groups in terms of the number of utterances produced by caregivers, duration of the task, and words produced by caregivers per minute. Further, there were no group differences in the total number of verbal, nonverbal, and social strategies produced.

In order to investigate which communication strategies caregivers utilize while assisting individuals with moderate and severe AD during oral care, we calculated the percentage of utterances containing each type of communication strategy within each dimension (see Table 3-6).
Table 3-5

Representative Discourse of Caregivers and Residents During a Toothbrushing Sessions

Grouped by AD Severity Level

<table>
<thead>
<tr>
<th></th>
<th>Moderate AD Group</th>
<th></th>
<th>Severe AD Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 6)</td>
<td></td>
<td>(n = 7)</td>
</tr>
<tr>
<td>Duration (Mins)</td>
<td>4.65</td>
<td>1.45</td>
<td>4.12</td>
</tr>
<tr>
<td>Caregiver utterances</td>
<td>29.83</td>
<td>23.71</td>
<td>36.96</td>
</tr>
<tr>
<td>Resident utterances</td>
<td>15.0</td>
<td>13.56</td>
<td>3.76</td>
</tr>
<tr>
<td>Caregiver utterances per mins</td>
<td>6.24</td>
<td>3.86</td>
<td>9.07</td>
</tr>
<tr>
<td>Caregiver words per mins</td>
<td>35.79</td>
<td>23.85</td>
<td>34.57</td>
</tr>
</tbody>
</table>

Note. Caregiver utterances per mins were calculated based on utterances produced during toothbrushing.

Task-focused communication strategies

The top task-focused verbal strategies used by caregivers interacting with individuals with severe AD were: 1) use of one proposition at a time (54.1%); 2) use of the resident’s name (16.9%); 3) use of encouraging comments (14.6%); 4) use of paraphrased repetition (12.9%); and use of closed ended questions (12.2%). The top strategies used by caregivers interacting with individuals with moderate AD were: 1) use of one proposition at a time (40.4%); 2) use of the closed ended questions (15.7%); 3) use of paraphrased repetition (8.2%); 4) use of two propositions (6.7%); and 5) use of verifying questions (6.2%) and encouraging comments (6.2%). Caregivers for both groups were also found to introduce the task quite frequently (severe: 78.6% of sessions; moderate 66.7% of sessions).

Table 3-6 shows the percentage of utterances containing task-focused verbal communication strategies for each severity group. In terms of differences in strategy use as a function of disease severity, while, as just indicated, both groups used one proposition and
introduced the task most often, with respect to the use of one proposition, caregivers in the severe group did so significantly more often than the moderate group ($U = 2.0, z = -2.71, p = .005$). In addition, caregivers assisting individuals with severe AD used paraphrased repetition ($U = 2.5, z = -2.67, p = .006$) and the resident’s name ($U = 0.0, z = -3.0, p = .001$) significantly more often than those assisting individuals with moderate AD and the use of verbatim repetition approached significance ($U = 9.0, z = -1.74, p = .092$). As well, caregivers assisting residents with moderate AD tended to use verifying questions more frequently than those assisting individuals with severe AD (with this difference approaching significance: $U = 8.5, z = -1.81, p = .073$).

Table 3-6 shows the percent use of task-focused nonverbal communication strategies. While there were no significant group differences in terms of strategy use, the top three strategies used by caregivers assisting individuals with both moderate and severe AD were: 1) the tactile prompt of handing an object to the resident (severe: 7.2%; moderate 7.6%); 2) guided touch (severe: 5.6%; moderate 5.8%); and 3) pointing (severe: 4.4%; moderate 6.2%).

Table 3-6 shows the percentage of combined communication strategies. It was found that caregivers interacting with individuals in the severe group used significantly more multiple verbal strategies than those interacting with individuals in the moderate group ($U = 1.5, z = -2.08, p = .003$).
### Table 3-6

**Caregivers’ Use of MOCS Communication Strategies as a Function of AD Severity**

<table>
<thead>
<tr>
<th>Communication strategies</th>
<th>No. times strategy used</th>
<th>Percentage of utterances containing strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Moderate AD (n = 6)</td>
<td>Severe AD (n = 7)</td>
</tr>
<tr>
<td>1. Task-focused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One proposition</td>
<td>483</td>
<td>841</td>
</tr>
<tr>
<td>Two proposition</td>
<td>72</td>
<td>67</td>
</tr>
<tr>
<td>Verbatim repetition</td>
<td>49</td>
<td>176</td>
</tr>
<tr>
<td>Paraphrased repetition</td>
<td>88</td>
<td>200</td>
</tr>
<tr>
<td>Closed-ended question</td>
<td>169</td>
<td>190</td>
</tr>
<tr>
<td>Open-ended question</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Verify question</td>
<td>67</td>
<td>18</td>
</tr>
<tr>
<td>Simple-choice question</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Introduce task</td>
<td>24</td>
<td>33</td>
</tr>
<tr>
<td>Explanation of actions</td>
<td>38</td>
<td>67</td>
</tr>
<tr>
<td>Use of resident’s name</td>
<td>49</td>
<td>262</td>
</tr>
<tr>
<td>Negotiation</td>
<td>16</td>
<td>43</td>
</tr>
<tr>
<td>Encouraging comments</td>
<td>67</td>
<td>227</td>
</tr>
<tr>
<td>Nonverbal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand object to the resident</td>
<td>82</td>
<td>113</td>
</tr>
<tr>
<td>Guided touch</td>
<td>62</td>
<td>87</td>
</tr>
<tr>
<td>Comfort touch</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Attention touch</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>Demonstration gesture</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>Pointing</td>
<td>66</td>
<td>69</td>
</tr>
<tr>
<td>Combined</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple verbal strategies</td>
<td>247</td>
<td>587</td>
</tr>
<tr>
<td>Verbal and visual strategies</td>
<td>74</td>
<td>89</td>
</tr>
<tr>
<td>Verbal and tactile strategies</td>
<td>145</td>
<td>238</td>
</tr>
<tr>
<td>2. Social</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greet resident</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Compliment resident</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Caregiver responds to resident</td>
<td>249</td>
<td>55</td>
</tr>
<tr>
<td>Habitual social expression</td>
<td>17</td>
<td>25</td>
</tr>
<tr>
<td>Social conversation</td>
<td>20</td>
<td>41</td>
</tr>
<tr>
<td>Closing remarks</td>
<td>16</td>
<td>28</td>
</tr>
<tr>
<td>3. MISC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full physical assistance</td>
<td>-</td>
<td>166</td>
</tr>
<tr>
<td>Redirect resident</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>Uncategorized utterance</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>Unobservable</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*Note.* †Denotes strategies (i.e., introduce task, greet resident, and closing remarks) that were calculated based on the number of times strategy occurred out of the total number of sessions completed (moderate = /36; severe = /42).

* p < .05. ** p < .01. † p < .10.
Social communication strategies

Table 3-6 shows the percentage of social communication strategies used by caregivers. Only the strategy of responding to a resident’s request resulted in a significant group difference ($U = 0.0, z = -3.02, p = .001$) with caregivers interacting with residents with moderate AD doing so more often than those interacting with individuals with severe AD.

MISC communication

Finally, as outlined in Table 3-6, the only strategy used that was categorized as miscellaneous that was significantly different between caregivers interacting with individuals in the moderate versus severe group was that of providing full assistance to the resident ($U = 9.0, z = -2.09, p = .036$), with those in the severe group needing it more than those in the moderate group.

Participation in the task and task success

On average, across the two groups of severity, residents were invited to participate in 49% of the steps of toothbrushing and residents completed an average of 45% of these steps. On average, caregivers completed 46% of the steps of the task and only 5% of the steps were skipped entirely during task completion. Getting the toothbrush and toothpaste and turning the water on/off were most often completed by the caregiver.

Task success was rated as either: (1) entirely successful, in which the resident completed all steps of the task in which he/she was given the opportunity to participate; (2) marginally successful, in which the resident completed at least half of the steps, but not all steps of the steps, in which he/she was given the opportunity to participate; or (3) unsuccessful, which
indicated the resident completed less than half of the steps of the task when given the opportunity to participate. Overall, 67% of the toothbrushing sessions were categorized as entirely successful, 23% as marginally successful, and 10% as unsuccessful. All unsuccessful sessions occurred while caregivers assisted individuals with severe AD and the majority of the unsuccessful sessions (75%) took place in a single caregiver-resident dyad.

**Task success rate**

For each severity group, task success rates (number of sessions in which residents completed all steps in which they were given the opportunity to participate/ total number of sessions) were calculated. Although caregivers assisting individuals with moderate AD had a higher overall mean percentage task success rate (79%), than those assisting individuals in the severe group (57%), this difference was not significant ($U = 11.0, z = -1.49, p = .183$).

**Speech rate**

Speech rate was assessed both within and between groups. At baseline and during task completion there was no significant difference in the speech rate of caregivers assisting individuals with moderate AD as compared to those assisting individuals with severe AD. However, the groups did show a significant difference between their respective baseline and task conditions such that both slowed their speech during the toothbrushing task (median for moderate group: 158 words/min at baseline vs. 42 words/min during task [$z = -2.02, p = .043$]; median for severe group: 98 words/min at baseline vs. 40 words/min during task [$z = -2.37, p = .018$]).
Discussion

This study was the first to compare formal caregivers’ use of a variety of task-focused and social communication strategies while assisting residents in LTC with moderate and severe AD during the completion of an ADL: toothbrushing. Of particular interest was whether we could replicate the findings from our previous study (Wilson et al., 2012) which used a different ADL: handwashing. As an extension of our earlier research we also sought to determine whether caregivers utilized different strategies when assisting residents with moderate AD as compared to residents with severe AD during completion of the task. The existing literature has examined patient-caregiver communication strategies in a number of contexts including family caregivers’ use of communication strategies while assisting spouses with mild to moderate AD during ADLs involving conversations (e.g., Small et al., 2003; Small & Perry, 2005); caregivers’ perceived use of communication strategies (e.g., Beach & Kramer, 1999; Richter, Roberto, & Bottenberg, 1995), and the benefits of caregiver communication training programs (e.g., Bourgeois et al., 2004; Dijkstra et al., 2002). However, relatively little is known about formal caregivers’ actual use of specific types of communication strategies produced while assisting residents in long term care with AD to complete ADLs (e.g., Wilson et al., 2012). Further, to our knowledge, no research has examined the differential use of communication strategies during the completion of ADLs, as a function of disease severity.

Overall, the results from this study support our previous findings (Wilson et al., 2012). We found that communication strategies used by caregivers assisting residents with severe AD during toothbrushing were similar to those used by caregivers assisting residents with severe AD during handwashing (Wilson et al., 2012). In the present study, when caregivers assisted
residents with severe AD, the most frequently used communication strategies were using one proposition at a time, using the resident’s name, verbal praise, paraphrased repetition, closed-ended questions, and, finally verbatim repetition. In Wilson et al. (2012), the majority of residents were identified as having severe AD (n = 9) (mean MMSE score = 6/30), and caregivers most frequently utilized one proposition at a time, followed by the use of closed-ended questions, encouraging comments, paraphrased repetition, and the use of the resident’s name. Furthermore, the use of paraphrased and verbatim repetition were negatively correlated with MMSE score (disease severity). Interestingly, when participating caregivers in the current study also rated their perceived effectiveness of 9 task-focused communication strategies during a focus group interview (results reported elsewhere Wilson et al., in press), they indicated that the most effective verbal strategies for both moderate and severe AD included the use of encouraging comments, using the resident’s name, and giving one instruction at a time.

The results of this study also extend our previous work in examining the communicative strategies used when interacting with individuals with moderate AD. Interestingly, we found that some communication strategies were similarly utilized by caregivers across disease severity. For instance, it was found that when assisting residents with moderate AD caregivers most frequently used the strategies of one proposition, closed ended questions, paraphrased repetition, and encouraging comments (i.e., verbal praise). These strategies are very similar to those used with residents with severe AD, although the rank order of their use is somewhat different. The use of nonverbal communication strategies by caregivers was also similar across disease severity as was the use of most of the social communication strategies. In addition, caregivers reduced their rate of speech when communicating with both groups of residents.
However, some differences in strategy use as a function of disease severity did emerge. For instance, although caregivers of both severity groups most frequently employed the communication strategy of providing only one proposition (i.e., one direction, instruction, or idea at a time), the caregivers of individuals with severe AD used this strategy significantly more often than those of individuals with moderate AD. This likely reflects the increased support residents with severe AD require during each step of the task. This finding is supported by research on sentence comprehension in AD (Rochon et al., 1994; 2000) and by the work of Small et al. (2003) who found that family caregivers of individuals with mild-moderate AD frequently employed this strategy during all activities measured. It should also be noted that the use of one proposition is a common clinical recommendation suggested for use by caregivers of individuals with AD (e.g., Lee, 1991; Small et al., 2003).

Other communication strategies for which significant differences emerged between the two severity groups were the use of paraphrased repetition, using the resident’s name, and provision of full assistance. As with the use of only one proposition, these strategies were used more often when assisting individuals with severe AD. In contrast, caregivers interacting with residents with moderate AD demonstrated the social communication strategy of responding to residents’ requests significantly more often than when interacting with residents with severe AD. This might simply reflect increased interaction between caregivers and residents with moderate AD.

One might speculate that caregivers’ differential use of some communication strategies as a function of disease severity may correspond to an adjustment of their communication behaviour to capitalize on residents’ residual neuropsychological abilities. For example, it has
been reported that individuals with moderate AD have the capacity to sustain attention (particularly when verbal information is supported by visual information) (Lines et al., 1991); follow two-step commands (Hopper, Bayles, & Kim, 2001); have relatively preserved procedural memory (Rösler et al., 2002; Van Tilborg, Kessels, & Hulstijn, 2011; Zanetti et al., 1997); participate in social conventions (Williams & Tappen, 2008); and comprehend sentences with fewer propositions (Rochon et al., 2000) (see also Hopper, Bayles, & Kim, 2001 for review).

While research on the communicative abilities of individuals with severe AD is limited, research suggests that some communicative abilities of these individuals remain relatively intact. For instance, Kim and Bayles (2007) found that the majority of the participants with severe AD in their study responded appropriately to the social convention of greeting the examiner, and also recognized his/her name when spoken to, and correctly responded to simple yes-no questions. The authors also found that the participants produced more intelligible words during a language assessment than was originally anticipated. Based on these results, Kim and Bayles (2007) suggested that caregivers should avoid the tendency to reduce the number of opportunities available to individuals with severe AD to participate in communicative interactions. Overall, findings from our study suggest that formal caregivers recognize the importance of this. We found that caregivers of individuals with severe (and moderate) AD incorporated a variety of communication strategies when interacting with the residents during toothbrushing. This finding suggests that caregivers acknowledge the possibility that residents may be able to respond to communication attempts and participate, with assistance, in their own self-care.
Clinical Implications

The results of this study contribute to furthering our understanding of formal caregivers’ use of effective communication strategies when assisting residents with moderate and severe AD during the completion of daily tasks. Providing caregivers with information regarding a variety of effective evidence-based communication strategies that meet the individual needs of residents under their care has at least two potential benefits for the resident with AD: (1) to support the participation of the resident in his/her own self-care, thus promoting independence; and (2) to improve the caregiver-resident relationship during the completion of daily tasks, contributing to improved quality of care. With respect to potential benefits to caregivers, these findings could be used to inform the development of evidence-based communication guidelines to be used in caregiver training programs, thus providing caregivers skill-building tools to improve knowledge and job satisfaction. Similarly, these findings could assist speech-language pathologists working in LTC settings in the provision of services and advocacy for residents with moderate and severe AD, as well as in the education of both formal and informal caregivers.

Limitations and Future Directions

Before concluding, a couple of caveats are in order. Firstly, it is acknowledged that the relatively small sample size for each comparison group may have precluded the detection of significant differences between the two severity groups with respect to caregiver strategy use. Secondly, as the sampling procedure was not random, generalization of findings to other caregivers should be done with caution.
While this study provides a comprehensive overview of the many communication strategies caregivers employ while assisting residents with moderate and severe AD, future research is needed to further delineate which task-focused and social communication strategies effectively repair a communication breakdown. This information, in addition to the current findings, could inform the development and testing of evidence-based communication guidelines that support person-centred dementia care (Kitwood, 1997). In addition, these results could help to inform the development of communication assistive technology designed to support individuals with AD and their caregivers (e.g., Mihailidis, Boger, Craig, & Hoey, 2008).

**Conclusion**

Overall, the findings of this study showed that the majority of residents, irrespective of disease severity, successfully completed toothbrushing with the support of caregiver assistance. Further, results demonstrated that formal caregivers’ discourse was dominated by task-focused communication strategies (verbal and nonverbal), with a minority of social communication strategies also being used. For the most part, the communicative strategies used by caregivers interacting with individuals with AD did not differ across disease severity; however some differences were identified. These results add to the emerging literature on the use of effective communication strategies by formal caregivers during interactions with institutionalized individuals with AD during the completion of daily tasks.
Acknowledgements

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CHAPTER 4

FORMAL CAREGIVERS’ PERCEPTIONS OF EFFECTIVE COMMUNICATION STRATEGIES WHILE ASSISTING RESIDENTS WITH ALZHEIMER’S DISEASE DURING ACTIVITIES OF DAILY LIVING

At the time that this dissertation was submitted, this manuscript was accepted for publication. This chapter is excerpted from the accepted manuscript in its entirety.


Abstract

This article describes caregivers’ perceptions of communication strategies that are useful in their care practice when assisting individuals with moderate and severe Alzheimer’s disease (AD) during the completion of activities of daily living (ADLs). A total of 10 formal caregivers participated in one-hour semi-structured focus group interviews (FGIs) conducted at two different long-term care (LTC) locations (n = 5 at each location). To identify the strategies caregivers perceived to be effective, content analysis was the primary method used to examine the FGI data. Particular attention was given to identifying the frequency and extensiveness in which caregivers made reference to communication strategies during the FGIs. Caregivers discussed a total of 33 strategies that they perceived to be useful when assisting residents with
moderate and severe AD during the completion of ADLs. The majority of the communication strategies discussed (64%) were task-focused and the most frequently mentioned strategies included the use of negotiation and explaining one’s actions to the resident. Greeting the resident was the most frequently discussed social strategy. In addition, two emergent themes containing a total of 12 strategies were identified, with the most frequently mentioned being establishing eye contact, familiarity with the resident, and postponing the task. Caregivers’ perceived use of communication strategies indicates that person-centred dementia care is a central aspect to facilitating the completion of ADLs.

Introduction

Alzheimer’s disease (AD) is a progressive neurodegenerative disease and is the leading cause of dementia, accounting for 63% of all dementias diagnosed in Canada (Alzheimer Society of Canada, 2010). AD is clinically diagnosed with the criterion of having an insidious onset that leads to the development of multiple cognitive deficits that worsen with disease progression. More specifically, the hallmark clinical symptoms of AD are memory impairment coupled with disturbances in language, executive functioning, and motor activity that significantly impact an individual’s social and occupational functioning (Diagnostic and Statistical Manual of Mental Disorders 4th ed., text rev (DSM-IV-TR)(American Psychiatric Association, 2000). Memory and language declines affect the communication abilities of individuals with AD. For instance, semantic problems, including word finding difficulties, reduced verbal fluency, and comprehension impairments are well documented (Appell, Kertesz, & Fisman, 1982; Karantzoulis & Galvin, 2011; Kempler, 2005; Kempler, 1991; Weiner & Lipton, 2009) and these impairments impact the capacity to communicate. In addition to social participation, communication is a fundamental component to completing instrumental activities
of daily living (IADLs) (e.g., managing finances or planning activities). Moreover, as AD progresses, managing the completion of basic activities of daily living (ADLs) becomes problematic, creating the need for caregivers to become increasingly involved in supporting individuals during routine daily tasks (e.g., personal hygiene). Unfortunately, given the characteristic cognitive deficits that manifest in AD, communication difficulties inevitably arise and ensuing breakdowns in communication can strain the relationship between caregivers and individuals with AD (Savundranayagam, Hummert, & Montgomery, 2005; Williamson & Schulz, 1993).

At the moderate to severe stages of AD, placement in long-term care (LTC) often becomes necessary to manage the complex care requirements of individuals with declining cognitive and functional abilities. Formal caregivers (e.g., personal support workers [PSW]) are directly responsible for ensuring that the daily care needs of residents with AD are met. Given the declines in memory, language, attention, executive functioning, and visuospatial skills, formal caregivers experience many challenges (e.g., breakdowns during the steps of a task) when assisting individuals with AD in tasks that depend on these capacities. Further, communication is fundamental to fostering co-operative care during the caregiver-AD dyad interaction; however, the declining language skills in residents with AD further complicate the cognitive and functional declines. To help caregivers achieve their care practice goals and to help residents experience optimal quality of care, several recommended communication strategies have been made available to caregivers as guidance during caregiver-AD resident encounters (e.g., Alzheimer Society of Canada, 2010; Hopper, 2001; Lee, 1991; Ripich, Wykle, & Niles, 1995; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997; Zientz et al., 2007). Some typical recommended communication strategies reported in the caregiving
literature include the use of short-simple sentences, speaking slowly, asking one question or giving one instruction at a time, using yes/no questions or simple-choice questions, using verbatim repetition, giving time to respond, establishing eye contact and eliminating environmental distractors (e.g., Lee, 1991; Sheldon, 1994; Small, Gutman, Makela, & Hillhouse, 2003). Some of these strategies have been individually examined and have been shown to support the caregiver-AD communication dyad. For example, improved sentence comprehension in individuals with AD has been documented when paraphrased or verbatim repetition was provided (Small, Kemper, & Lyons, 1997) and the use of one proposition at a time has been shown to improve comprehension as compared to the use of multiple ideas in a sentence (Rochon, Waters, & Caplan, 1994; Rochon, Waters, & Caplan, 2000). Further, the use of closed-ended questions has been investigated while observing conversations between caregivers and individuals with AD, with findings demonstrating that this strategy supports successful discourse (e.g., Small & Perry, 2005; Tappen et al., 1997). However, to date, few studies have examined effective communication strategies best suited for the procedural discourse (i.e., discourse focused on how to do something) occurring between family caregivers and spouses with AD during the completion of ADLs (Small et al., 2003) and between formal caregivers assisting residents with moderate to severe AD during the completion of ADLs (e.g., Hammar, Emami, Engström, & Götell, 2011; Wilson, Rochon, Mihailidis & Leonard, 2012).

With respect to communication strategies examined in the LTC setting, several communication training programs have been developed and have demonstrated effectiveness (e.g., Burgio et al., 2001; Dijkstra, Bourgeois, Burgio, & Allen, 2002; McCallion, Toseland, Lacey, & Banks, 1999; Ripich et al., 1995); however, these training programs have some limitations. For instance, the training programs contain some communication strategies that
have yet to be examined individually for effectiveness. In addition, some of these studies evaluating training programs include residents with dementia without a confirmed diagnosis of probable AD. Importantly, dementia is an umbrella term used to describe acquired cognitive impairment (Weiner, 2009) and there are several causes of irreversible dementia, each with distinguishable language and cognitive characteristics. For example, in vascular dementia, the second leading cause of dementia (Hebert et al., 2000), less impaired language function with greater executive functioning impairments, and less impaired memory as compared to individuals with AD has been observed (Looi & Sachdev, 1999). Conversely, in semantic dementia, language deficits occur in the absence of significant cognitive impairments and these language impairments are slowly progressing (Maxim & Bryan, 2006). Thus, findings from studies that include residents with dementia may not be applicable to the language and functional impairments typical of individuals with dementia of the AD type. Additionally, the training programs have not been examined in the context of assisting residents with moderate to severe AD specifically during the completion of ADLs.

Research has been done to examine communication between LTC staff (e.g., nurses or PSWs) and residents (e.g., Caris-Verhallen, 1998; Caris-Verhallen, Kerkstra, & Bensing, 1999), with findings indicating that caregivers and residents participate in more task-focused communication as compared to socio-emotional communication, during which they utilize eye contact and affective touch to establish communication interactions. Only a few studies have examined communication between formal caregivers and residents with moderate to severe AD (e.g., Williams & Tappen, 1999; Tappen et al., 1997). For instance, Williams & Tappen (1999) examined conversations between caregivers and residents with moderate to severe AD to explore the possibility for the development of therapeutic relationships in advanced AD.
Findings from this study indicated that, despite advanced disease progression, therapeutic relationships were fostered during conversations between caregivers and individuals with AD.

In terms of perception of effective communication strategies, some research has explored the viewpoints of family and formal caregivers’ experiences around communicating with individuals with AD (e.g., Richer, Roberto, & Bottenberg, 1995), with findings indicating the importance of individualized interventions. Others have focused on the perceptions of formal caregivers when assisting LTC residents (e.g., Medvene & Lann-Wolcott, 2010) or when communicating with persons with AD (e.g., Beach & Kramer, 1999; Savundranayagam, Ryan, Anas, & Orange, 2007). For example, Medvene and Lann-Wolcott (2010) explored nurses aides’ communication behaviours when working with LTC residents by interviewing nurses aides to examine which communication strategies caregivers discussed using in their care practice. Findings indicated that “giving positive regard” was the most frequently discussed strategy and was used by all participating nurses aides. While this study explored nurses aides’ perceptions of effective communication strategies for LTC residents, the discussions were not specific to assisting residents with AD. To our knowledge, no studies have examined caregivers’ perceptions of effective communication strategies with a specific focus on assisting residents with moderate and severe AD during the completion of ADLs; and yet, the completion of ADLs comprises the bulk of caregiver-resident interactions in the LTC setting.

The purpose of this research was to describe formal caregivers’ perceptions of communication strategies that are effective when assisting individuals with AD residing in LTC, at the moderate and at the severe impairment levels, during the successful completion of ADLs. This research was conducted as part of a larger observational comparison study designed to investigate communication strategies employed by formal caregivers assisting residents with
moderate and severe AD during the completion of an activity of daily living (Wilson, Rochon, Mihailidis, & Leonard, manuscript submitted). The data presented in this paper are complementary to the larger observational study and provide the opportunity to help clarify or explain the observational data. The specific aims of this article were: (1) to identify which task-focused communication and social strategies, defined a priori, caregivers consider useful when assisting individuals with AD; and (2) to report any emergent themes, consisting of strategies that caregivers perceive to be effective, that were not included in the previously developed coding scheme.

Method

Research Design

A descriptive study design was employed to examine caregivers’ perceptions of the communication strategies that they utilize while assisting residents with moderate and with severe AD during completion of daily tasks. To address the purpose of this research, formal caregivers participated in a one-hour semi-structured focus group interview (FGI). FGI is a useful method to collect qualitative data, which can be quantified, on a topic of interest (McLafferty, 2004). A non-probability criterion-based purposive sampling procedure was implemented to select formal caregiver participants, as this sampling procedure is suitable for the comprehensive study of a phenomenon of interest that is supported by the deliberate choice of participants because of their expert knowledge (Creswell & Plano Clark, 2007; Forman, Creswell, Damschroder, Kowalski, & Krein, 2008; Tongco, 2007). All participating formal caregivers were responsible for the direct care of individuals with moderate to severe AD, thus were deemed expert care providers of individuals with AD who could contribute to the
understanding of effective communication strategies for this client population. All caregivers who participated in an FGI also participated in our larger observational study (Wilson et al., manuscript submitted).

**Participants and Setting**

A total of 10 formal caregivers (personal support worker (PSW) = 9; registered nurse = 1) from two different LTC settings participated in a single one-hour semi-structured FGI. Five other caregivers had consented to participate in the FGIs; however, four could not attend due to scheduling conflicts and one caregiver had taken a health-related leave of absence after consent was obtained. At each LTC location, five caregivers participated in the FGIs, which is considered an appropriate sample size to generate data (McLafferty, 2004; Rabiee, 2004). Across the two LTC locations, formal caregivers did not significantly differ on age, years of education, years in current professional title, and years working with residents with AD.

Table 1 summarizes the characteristics of the participants. Nine of the caregivers were female, all caregivers worked the day shift, and all were responsible for the daily care of residents with moderate and severe AD. Further, to be included in this study, caregivers had to speak English comfortably and have worked with individuals with AD for at least one year. All caregivers involved in the FGIs were recruited as participants in a larger project which measured caregivers’ actual use of task-focused (verbal and non-verbal) and social-focused communication strategies while assisting individuals with moderate and severe AD during the completion of an ADL -- toothbrushing.
Table 4-1

*Characteristics of Formal Caregivers Participating in the Focus Group Interviews (N = 10)*

<table>
<thead>
<tr>
<th>Professional Title</th>
<th>Years in Current Professional Title</th>
<th>Years Working with Individuals with AD</th>
<th>Years of Education</th>
<th>Age (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSW</td>
<td>2</td>
<td>2</td>
<td>13</td>
<td>30</td>
</tr>
<tr>
<td>PSW</td>
<td>5</td>
<td>5</td>
<td>17</td>
<td>37</td>
</tr>
<tr>
<td>PSW</td>
<td>25</td>
<td>25</td>
<td>18</td>
<td>62</td>
</tr>
<tr>
<td>RN</td>
<td>32</td>
<td>24</td>
<td>13</td>
<td>57</td>
</tr>
<tr>
<td>PSW</td>
<td>25</td>
<td>25</td>
<td>15</td>
<td>52</td>
</tr>
<tr>
<td>PSW</td>
<td>40</td>
<td>22</td>
<td>12</td>
<td>58</td>
</tr>
<tr>
<td>PSW</td>
<td>7</td>
<td>4</td>
<td>16</td>
<td>34</td>
</tr>
<tr>
<td>PSW</td>
<td>11</td>
<td>3</td>
<td>15</td>
<td>35</td>
</tr>
<tr>
<td>PSW</td>
<td>14</td>
<td>8</td>
<td>15.5</td>
<td>43</td>
</tr>
<tr>
<td>PSW</td>
<td>7</td>
<td>7</td>
<td>18</td>
<td>38</td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td><strong>16.82 (12.9)</strong></td>
<td><strong>12.51 (10.1)</strong></td>
<td><strong>14.7 (1.7)</strong></td>
<td><strong>44.6 (11.6)</strong></td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td>2 - 40</td>
<td>2 - 25</td>
<td>12 - 18</td>
<td>30 - 62</td>
</tr>
</tbody>
</table>

*Note.* PSW = Personal support worker. RN = Registered nurse. There was no difference between caregivers on their overall references made to strategies when grouped by years of experience working with individuals with AD: Group 1 = ten years or less experience (n = 6) and Group 2 = 20 years plus experience (n = 4), $U = 10.5$, $z = -.32$, $p = .75$.

**Ethics Approval**

Ethics approval was granted by the University of Toronto Research Ethics Board (REB) and by Toronto Rehabilitation Institute REB, which is affiliated with one of the participating LTC facilities. Oral and written information was provided to caregivers. Written consent was signed by all caregivers in this study. All participants were informed that participation in this
study was voluntary and that one could withdraw at any time without any impact on their work status.

Procedure

Data collection

Two one-hour on-site FGIs were conducted with participant caregivers, one FGI at each LTC facility. FGIs were conducted after completion of data collection for our observational study (Wilson et al., manuscript submitted). To ensure consistency, each FGI was led by the same externally hired professional moderator who had experience conducting FGIs in the health care setting (e.g., biotechnology and life sciences research) and each FGI was also attended by the first author to take field notes. The FGIs followed a semi-structured interview format consisting of a pre-determined question guide comprised of open-ended questions and their probes. The question guide was structured to focus caregivers to generate a discussion based on which communication strategies caregivers perceive as useful when assisting individuals with moderate and severe AD during completion of ADLs. The FGIs started with an introduction to the purpose of the discussion and a general knowledge question to begin the discussion: “What comes to mind when you think about your experience communicating with individuals with AD during your daily care routine?” Following the introduction, two main broad questions were posed to participants in each FGI: (1) “Which verbal and non-verbal communication strategies come to mind that you think are useful, or effective, when assisting individuals with AD during daily care tasks?” and (2) “Do you think that there are some communication strategies that may be better suited for individuals with moderate AD and for those individuals with severe AD?” Across both FGIs, the aforementioned broad questions were posed to the caregivers. However,
in instances where the moderator felt it necessary, probes were given to explore or clarify participant discussion that was deemed important to the study and if the caregivers requested an example of a daily task, toothbrushing was the ADL suggested as a guide to their discussion. Following the discussion of the guided questions, caregivers were asked to rate the effectiveness of nine communication strategies that were previously found to frequently occur while formal caregivers assisted residents with AD during the successful completion of handwashing (Wilson et al., 2012). Using a 10-point scale, 1 being the least effective, 5 being moderately effective, and 10 being very effective, caregivers rated the following strategies for residents with moderate and severe AD: (1) present one idea or instruction at a time, (2) use closed-ended (yes/no) questions, (3) use paraphrased repetition, (4) use the resident’s name, (5) use encouraging comments (verbal praise), (6) point to objects relevant to the task, (7) demonstrate the step of the task using gestures, (8) hand objects to the resident (tactile prompt), and (9) use guided touch. The FGIs were video-recorded (but participants’ faces were not visible, at their request). Data collection for this research project took place between September 2010 and February 2011.

Data Analysis

Transcription and data coding

The FGIs were orthographically transcribed verbatim by a professional transcription service and each transcript was checked for accuracy by the first author. Also, all field notes were typed out for later interpretation. To address the primary aim of this research, directed content analysis was deemed the appropriate method (Hsieh & Shannon, 2005). Hsieh and Shannon (2005) describe this approach to content analysis as having the goal of extending or
validating existing research and this approach has been used to explore nurses aides’ perceived communication behaviours with nursing home residents (Medvene & Lann-Wolcott, 2010). Following the review of discussions relevant to the research aims, each of the caregiver’s statements in these discussions was segmented based on a reference or, in some instances, multiple references made to a communication strategy (units of analysis) in a given discussion. Following unitization of each of the caregiver’s comments, a multidimensional observation coding scheme (MOCS) was used to identify communication strategies discussed by the caregivers. MOCS is a comprehensive coding scheme that was developed based on the current empirical literature regarding communication and individuals with AD (e.g., Rochon et al., 2000; Small et al., 1997; Small et al., 2003) and was adapted from a coding scheme used to examine which task-focused communication strategies formal caregivers employ during the completion of an activity of daily living (Wilson et al., 2012; Wilson et al., manuscript submitted). MOCS was also utilized for the quantitative content analysis of the observational data collected as part of the larger study that preceded this research. MOCS consists of three dimensions that contain specific communication strategies that may be utilized during the completion of ADLs: (1) task-focused communication strategies, (2) social communication strategies, and (3) miscellaneous (MISC) categories. The task-focused communication strategies dimension contains a total of 19 communication strategies falling under one of two sub-categories, verbal and non-verbal body language (e.g., gestures and touch). Six communication strategies were classified as social in nature and four codes were included in the MISC dimension. See Table 2 for a detailed description of the communication strategies included in the MOCS, which were described by caregivers during the discussion stemming from guided questions provided to them. Examples provided in Table 2 relate to the task of
toothbrushing and these examples were generated from the larger observational study. All
decisions regarding MOCS codes and code definitions were made a priori.

To summarize, the first step of the analysis involved segmenting the transcripts to
include the discussion surrounding caregivers’ perceived use of communication strategies while
assisting individuals with AD. The next step in the analysis was coding each of the relevant
statements with the predetermined codes outlined in the MOCS. Finally, any communication
strategy that did not fall under MOCS dimensions was coded as a strategy that fell under
emergent themes.

Table 4-2

Caregivers’ Perceived Use of Communication Strategies Included in the Multidimensional
Observation Coding Scheme (MOCS)

<table>
<thead>
<tr>
<th>Communication strategies</th>
<th>Definition</th>
<th>Example: toothbrushing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dimension 1: Task-focused</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One proposition</td>
<td>Single direction, request, or instruction present in caregiver’s utterance to assist resident during steps of the task (e.g., step-by-step instructions)</td>
<td>&quot;Please turn on the water.&quot;</td>
</tr>
<tr>
<td>Verbatim repetition</td>
<td>Caregiver repeats previous message (all content words or entire utterance) within same utterance or in immediate next utterance (task related)</td>
<td>“Turn the tap on, turn the tap on.”</td>
</tr>
<tr>
<td>Paraphrased repetition</td>
<td>Caregiver restates previous message for clarification (related to steps of the task)</td>
<td>“Turn the taps on. Turn the taps to get some water.”</td>
</tr>
<tr>
<td>Introduce task</td>
<td>Caregiver indicates to the resident that they are going to brush his or her teeth</td>
<td>“We are going to brush”</td>
</tr>
<tr>
<td>Non-verbal strategies</td>
<td>Caregiver provides object to resident as a tactile prompt for the resident</td>
<td>Caregiver hands towel to the resident</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Hand object to the resident</td>
<td>Caregiver uses physical touch to guide resident through a step of the task</td>
<td>Caregiver guides resident’s hand to the toothbrush</td>
</tr>
<tr>
<td>Guided touch</td>
<td>Caregiver uses touch to indicate support or reassurance during a step of the task</td>
<td>Caregiver touches the resident’s shoulder</td>
</tr>
<tr>
<td>Comfort touch</td>
<td>Caregiver uses touch to gain or re-gain the attention of the resident when “off-task”</td>
<td>Caregiver touches the resident’s hand to indicate that it is time to begin brushing</td>
</tr>
<tr>
<td>Attention touch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dimension</td>
<td>Description</td>
<td>Example</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>---------</td>
</tr>
<tr>
<td>Demonstration gesture</td>
<td>Caregiver illustrates, with action, how to perform a step of the task</td>
<td>Caregiver demonstrates how to brush teeth</td>
</tr>
<tr>
<td>Pointing</td>
<td>Caregiver visually indicates direction of an object necessary for the step of the task</td>
<td>Caregiver points to the location of the toothpaste</td>
</tr>
<tr>
<td>Dimension 2: Social</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greet resident</td>
<td>Caregiver greets resident upon initial contact</td>
<td>“Hello Ms. X, how are you today.”</td>
</tr>
<tr>
<td>Compliment resident</td>
<td>Caregiver compliments resident, building rapport or validating resident</td>
<td>“You look nice today.”</td>
</tr>
<tr>
<td>Caregiver responds to resident</td>
<td>Caregiver acknowledges, agrees, shows empathy or responds to a comment, request, or statement made by the resident</td>
<td>“I know you are looking forward to lunch today.”</td>
</tr>
<tr>
<td>Dimension 3: MISC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full physical assistance</td>
<td>Caregiver uses full physical assistance during the step of the task</td>
<td>Caregiver brushes the resident’s teeth</td>
</tr>
<tr>
<td>Redirection</td>
<td>Caregiver redirects resident to keep on task</td>
<td>Caregiver guides resident to water instead of towel</td>
</tr>
</tbody>
</table>

*Note.* The complete set of codes (n = 33) included in the MOCS is reported in Wilson, Rochon, Mihailidis, and Leonard (manuscript submitted for publication). “Quantitative Analysis of Formal Caregivers’ Use of Communication Strategies while Assisting Residents with Alzheimer’s disease During Oral Care”. This Table only includes the codes that were referred to by at least one caregiver during the FGIs.
Transcription and MOCS agreement

As part of the larger study, agreement analysis was performed on all transcripts. The first author independently transcribed a random selection of 20% of the transcripts. Total percent (point-by-point) agreement was computed as follows: \( \frac{A}{A + D} \times 100 \), which is the total number of agreements divided by total number of agreements and total number of disagreements multiplied by 100 (see for review House, House, & Campbell, 1981). Acceptable agreement was demonstrated for words (84.3%) and utterance segmentation (80.0%). After agreement for transcript content was established, the first author and a trained research assistant (clinical speech-language pathology student) independently coded the segments containing caregivers’ references to communication strategies that they use in their care practice. Codes applied to these segments were either the communication strategies defined in the MOCS or those that were novel strategies reported by caregivers. The agreement analysis was performed on half of the total number of segmented units caregivers produced (\( n = 51 \) utterances). MOCS codes and strategies categorized within the emergent themes demonstrated an acceptable 88.2 percent occurrence agreement (occurrence agreements/occurrence agreements + disagreements X 100) between the two coders.

Results

An analysis of the transcripts derived from the FGIs indicated that formal caregivers discussed a variety of communication strategies that they perceive to use in their care practice. Specifically, caregiver guided interviews generated narratives that were segmented into a total of 102 units (each unit referring to one or more strategy) that contained a total of 137 references made to strategies that caregivers perceived to be useful when assisting residents. Importantly,
with respect to our research aims, 83 (60.6%) of the total references made to strategies were contained within MOCS and 54 (39.4%) of the total references made were categorized under one of the two emergent themes: general communication strategies and general care strategies. Moreover, the references caregivers made to strategies were identified by a total of 33 strategy codes, with 64% of these coded strategies (n = 21) defined in the MOCS. In the subsequent sections, the results are presented with respect to our research aims. In addition, the findings regarding caregivers’ perceived use of strategies as a function of disease severity and caregivers’ effectiveness ratings for a set of task-focused communication strategies are presented.

**Communication Strategies Defined by MOCS**

Of the total segments (n = 102 units) that were derived from the FGI narratives, over three-quarters (81.4%) contained at least one strategy that was defined *a priori* in MOCS. Broken down further, 65.7% of these strategies were identified as falling under the dimension of task-focused communication strategies, 11.8% were categorized as social strategies, and 3.9% were categorized as MISC. With respect to the strategies identified utilizing the MOCS (n = 83), the majority of strategies were categorized as verbal task-focused communication strategies (55.4%), while 25.3% were task-focused non-verbal strategies, 14.5% were social strategies, and 4.8% were MISC. The task-focused verbal communication strategies that caregivers most frequently discussed were: (1) using negotiation, (2) explaining their actions to the resident, and (3) using the resident’s name to gain their attention. With reference to negotiation, caregivers perceived this strategy to be essential to their care practice and indicated that negotiation is intimately linked to understanding a resident’s preferences, needs, and personal history. In addition, supplying residents with their preferred food choices was a
common method of negotiation. The most frequently discussed non-verbal task-focused communication strategies were: (1) using visual demonstration, and (2) handing an object to the resident (tactile prompt). Finally, the most frequently used social strategy was greeting the resident. Table 3 provides examples of caregiver narratives pertaining to the most frequently discussed task-focused and social communication strategies identified with the MOCS. These narrative examples were generated in response to the guided questions presented to the caregivers during the FGIs.

In terms of the extensiveness of references made to the communication strategies defined in advance (i.e., the number of individual caregivers that express the use of the same communication strategy), the strategies that exhibited the greatest level of extensiveness during the FGIs were the use of negotiation (90%), the caregiver explaining their actions to the resident (60%), the caregiver demonstrating or gesturing an action to the resident (50%), and the caregiver greeting the resident (60%). In addition to individual references each caregiver made to communication strategies during the FGIs, there were also instances of group consensus during the FGIs whereby all caregivers agreed that the strategy was useful. The six communication strategies that were identified in this way were: (1) negotiation, (2) use the resident’s name, (3) paraphrased repetition, (4) verbatim repetition, (5) greet the resident, and (6) respond with empathy to the resident’s requests, statements, or needs. Table 4 summarizes the findings for the communication strategies formal caregivers commented on that were identified utilizing the MOCS.
Table 4-3

Examples of Caregivers’ Comments Pertaining to the Most Frequently Discussed Communication Strategies

<table>
<thead>
<tr>
<th>Communication strategy</th>
<th>Narrative example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task-focused Negotiation</td>
<td>You use it to bargain or negotiate with them. [For example] we tell them “okay brush your teeth and afterward we’ll go for coffee and get you some treats.”</td>
</tr>
<tr>
<td>Explanation of actions</td>
<td>Tell every instruction you will do. [For example] like every instruction you got to do, you just tell them.</td>
</tr>
<tr>
<td>Use of resident’s name</td>
<td>When you start, just call them by their last name.</td>
</tr>
<tr>
<td>Demonstration gestures</td>
<td>What I noticed, working with residents, I find the non-verbal because of the language barrier…that doing demonstration. [For example] wanting them to brush their teeth you do the demonstration and when you put the socks on or whatever, I give a demonstration on myself for what I want them to.</td>
</tr>
<tr>
<td>Hand object to the resident</td>
<td>…. I will have to do the brushing of the teeth or I put the brush in the hand and ask them to do it. Right away you know [their severity level].</td>
</tr>
<tr>
<td>Social Greet resident</td>
<td>We always greet them when we go into their rooms in the morning</td>
</tr>
</tbody>
</table>
Table 4-4

*Frequency and Extensiveness of Formal Caregivers’ Perceived Use of Communication Strategies*

<table>
<thead>
<tr>
<th>Communication strategies</th>
<th>Frequency</th>
<th>Relative Frequency (%)</th>
<th>Extensiveness (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Task-focused Verbal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One proposition</td>
<td>3</td>
<td>3.6</td>
<td>20</td>
</tr>
<tr>
<td>Verbatim repetition</td>
<td>2</td>
<td>2.4</td>
<td>10†</td>
</tr>
<tr>
<td>Paraphrased repetition</td>
<td>2</td>
<td>2.4</td>
<td>10†</td>
</tr>
<tr>
<td>Introduce task</td>
<td>2</td>
<td>2.4</td>
<td>20</td>
</tr>
<tr>
<td>Explanation of actions</td>
<td>9</td>
<td>10.8</td>
<td>60</td>
</tr>
<tr>
<td>Use of resident’s name</td>
<td>4</td>
<td>4.8</td>
<td>20†</td>
</tr>
<tr>
<td>Negotiation</td>
<td>17</td>
<td>20.5</td>
<td>90†</td>
</tr>
<tr>
<td>Encouraging comments</td>
<td>2</td>
<td>2.4</td>
<td>20</td>
</tr>
<tr>
<td>Multiple verbal strategies</td>
<td>5</td>
<td>6</td>
<td>40</td>
</tr>
<tr>
<td><strong>Non-verbal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand object to the resident</td>
<td>4</td>
<td>4.8</td>
<td>20</td>
</tr>
<tr>
<td>Guided touch</td>
<td>3</td>
<td>3.6</td>
<td>20</td>
</tr>
<tr>
<td>Comfort touch</td>
<td>2</td>
<td>2.4</td>
<td>20</td>
</tr>
<tr>
<td>Attention touch</td>
<td>3</td>
<td>3.6</td>
<td>30</td>
</tr>
<tr>
<td>Demonstration gesture</td>
<td>5</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Pointing</td>
<td>2</td>
<td>2.4</td>
<td>20</td>
</tr>
<tr>
<td>Verbal and visual strategies</td>
<td>2</td>
<td>2.4</td>
<td>20</td>
</tr>
<tr>
<td><strong>2. Social</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greet resident</td>
<td>8</td>
<td>9.6</td>
<td>60†</td>
</tr>
<tr>
<td>Compliment resident</td>
<td>1</td>
<td>1.2</td>
<td>10</td>
</tr>
<tr>
<td>Caregiver responds to resident</td>
<td>3</td>
<td>3.6</td>
<td>10†</td>
</tr>
<tr>
<td><strong>3. MISC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full physical assistance</td>
<td>3</td>
<td>3.6</td>
<td>10</td>
</tr>
<tr>
<td>Redirect resident</td>
<td>1</td>
<td>1.2</td>
<td>10</td>
</tr>
</tbody>
</table>

*Note.* Relative frequency is the total frequency of a given communication strategy relative to the total number of communication strategies commented on by the formal caregivers included in the MOCS (total = 83). Extensiveness refers to how many of the participating caregivers commented on the use of the same communication strategy in their care practice. †Denotes that a group consensus was expressed regarding the usefulness of a given strategy.
Emergent Themes

Data from the FGIs led to the identification of two main emergent themes, which, combined, contained a total of 12 strategies that caregivers perceived to be useful in their care practice when assisting individuals with moderate to severe AD during the completion of ADLs. The two emergent themes were: (1) general communication strategies, and (2) general care strategies. General communication strategies were classified as communication strategies caregivers discussed that that were not included in the MOCS and that were considered to be applicable to all circumstances of communication, thus not necessarily task-driven (e.g., giving time for resident to respond). General care strategies were classified as strategies that caregivers discussed that were applicable to their general approach to care, which they use across contexts and are not specific to communicating with residents. Further, general care strategies may indirectly support the completion of ADLs (e.g., knowing the resident’s preferences). For each strategy, Table 5 provides a definition and an example of a segment of the narrative that made reference to the emergent strategy during the discussion generated when the guided questions were presented to the caregivers. Caregivers made a total of 54 references to these strategies and at least one of these strategies was present in 52.9% of the unitized segments. Of these novel strategies, 20.6% were categorized in the emergent theme of general communication strategies and 32.3% were categorized in the emergent theme of general care strategies.

The general communication strategy that was most frequently commented on in the FGIs was the use of eye contact, while the most frequently mentioned general care strategies were (1) familiarity and (2) postpone the task/ repeated attempts. Moreover, caregivers indicated that establishing eye contact is always the first strategy they use to communicate with a resident with AD and that residents with cognitive impairments still respond to a familiar
face. In terms of familiarity, caregivers expressed that this is an essential component to their care practice, as knowing a resident’s preferences helps the caregiver to select the best approach (i.e., implement an effective communication strategy) to support a resident during the completion of ADLs. Caregivers also discussed postponing completion of a task when the resident is non-compliant or indicates that they want to participate at a later time, as a strategy that acknowledges and validates the resident’s needs.

With respect to the notion of extensiveness, postponing the task was discussed by 40% of the caregivers. Though not initially expressed by each caregiver as being a strategy that she used, all caregivers agreed that the following three strategies are useful during the completion of ADLs: (1) eye contact, (2) interpret non-verbal communication, and (3) familiarity. Table 6 reports the frequency and extensiveness of the strategies in detail.
Table 4-5

*Emergent Themes Caregivers Perceived to be Useful While Assisting Residents with AD during the Completion of ADLs*

<table>
<thead>
<tr>
<th>Strategies (n = 12)</th>
<th>Definition</th>
<th>Narrative example</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General communication strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be patient</td>
<td>Provide time for the resident to respond to request, instruction, or general communication attempt</td>
<td>“Be patient with them and give them time [to respond].”</td>
</tr>
<tr>
<td>Focus the resident</td>
<td>Gain the resident’s attention and use strategies (e.g., proximity) to help maintain his or her focus during the activity</td>
<td>“The more cognitively impaired the resident is, the harder it is to get their attention, we have to try to put ourselves in front of the resident, get him to look at me and get their attention.”</td>
</tr>
<tr>
<td>Environmental cues</td>
<td>Use stimulation available in the resident’s environment as cues to support participation in the activity</td>
<td>“I’d go in [to the resident’s room] and say good morning, good morning, I’d put the light on, just to let him feel like it’s the sunshine coming down.”</td>
</tr>
<tr>
<td>Eye-contact</td>
<td>Establish eye-contact to introduce yourself to the resident, connect with the resident, and gain the resident’s attention</td>
<td>“They see us on a daily basis and they will remember our face. They don’t remember anything else but they’ll remember your face. Look at them [eye contact] and as soon as they see you, they say <em>Oh it’s you again,</em>”</td>
</tr>
</tbody>
</table>
Para-verbal monitoring
Monitor the tone, pitch and pace of the voice when communicating with the resident
“[Be] calm [and] soft when you talk with them. Be caring and show empathy, so [when] you communicate, you talk to them gently and they [will] cooperate better.”

Interpret non-verbal communication
Be aware of a resident’s use of non-verbal communication (i.e., body language, such as gestures and facial expression), and help to interpret the message
“They’re responding non-verbally and you try to understand and respond verbally but it’s up to them, depending on their cognitive ability to get what you’re saying and actually respond back.”

2. General care strategies

Familiarity
Being familiar with the resident by knowing their personal preferences and personal history assists in meeting the resident’s needs and interpreting his or her behaviour
“This is where their personal history comes in. If the person was never a morning person, why even introduce mornings to this person when they’re never a morning person, and then oh this person never has supper, why would you introduce supper, You understand, You’re giving them things they don’t normally have.”

Interpret behaviour
Be aware of a resident’s actions to verify that they are
“You check their understanding [and] if they are compliant to
<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess mood</td>
<td>At the beginning of each encounter, assess the resident’s mood and decide the best action to take following his or her response</td>
<td>“You need to check how their mood is in the morning. [For example] when you greet you will know, when you say good morning, they might say go away or get out of my room.”</td>
</tr>
<tr>
<td>Assess for resistiveness</td>
<td>At the beginning of each encounter, assess for any restive behaviour and consider the management of aggressive responses</td>
<td>“For example, at first you see that a resident is very aggressive, so right away we know you have to tender him.”</td>
</tr>
<tr>
<td>Request assistance</td>
<td>Ask for assistance from another caregiver because the resident may respond to a different person</td>
<td>“They might say yes to someone else, and then you go back [to finish the task].”</td>
</tr>
<tr>
<td>Postpone / repeated attempts</td>
<td>When communication or non-compliance difficulties arise, postpone completing the task and repeat the attempt to complete the task at a later time</td>
<td>“We usually leave them and go somewhere else and come back, and if we have to we’d just leave and postpone again.”</td>
</tr>
</tbody>
</table>
Table 4-6

*Frequency and Extensiveness of Formal Caregivers’ Perceived Use of Strategies Included in the Emergent Themes*

<table>
<thead>
<tr>
<th>Strategies (n = 12)</th>
<th>Frequency</th>
<th>Relative Frequency (%)</th>
<th>Extensiveness (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General communication strategies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be patient</td>
<td>2</td>
<td>3.7</td>
<td>20</td>
</tr>
<tr>
<td>Focus the resident</td>
<td>3</td>
<td>5.6</td>
<td>10</td>
</tr>
<tr>
<td>Eye-contact</td>
<td>8</td>
<td>14.8</td>
<td>30†</td>
</tr>
<tr>
<td>Environmental cues</td>
<td>2</td>
<td>3.7</td>
<td>10</td>
</tr>
<tr>
<td>Para-verbal monitoring</td>
<td>3</td>
<td>5.6</td>
<td>20</td>
</tr>
<tr>
<td>Interpret non-verbal communication</td>
<td>3</td>
<td>5.6</td>
<td>30†</td>
</tr>
<tr>
<td>2. General care strategies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familiarity</td>
<td>11</td>
<td>20.4</td>
<td>30†</td>
</tr>
<tr>
<td>Interpret behaviour</td>
<td>1</td>
<td>1.9</td>
<td>10</td>
</tr>
<tr>
<td>Assess mood</td>
<td>5</td>
<td>9.3</td>
<td>30</td>
</tr>
<tr>
<td>Assess for restiveness</td>
<td>4</td>
<td>7.4</td>
<td>30</td>
</tr>
<tr>
<td>Request assistance</td>
<td>3</td>
<td>5.6</td>
<td>30</td>
</tr>
<tr>
<td>Postpone task / repeated attempts</td>
<td>9</td>
<td>16.7</td>
<td>40</td>
</tr>
</tbody>
</table>

*Note. Relative frequency = total frequency of a given emergent strategy/ total number of strategies (n = 54). † Denotes that a group consensus was expressed regarding the usefulness of a given strategy.*

**Differences in Strategies Used with Moderate and Severe AD**

During the FGIs, caregivers were asked to respond to the following question: Do you think that there are some communication strategies that may be better suited for individuals with moderate AD and for those individuals with severe AD? Specific to this guided FGI discussion, 70% of the caregivers provided input. In general, caregivers commented that they
use a variety of strategies, with the selection of verbal or non-verbal strategies being based on each individual’s cognitive level, needs, and personal preferences. Caregivers also indicated that, regardless of the cognitive severity level, they utilize the following approach to completing ADLs with residents: (1) greet the resident, (2) introduce the task, (3) explain their actions, and (4) repeat instructions when necessary. However, caregivers did make some distinction between strategies that were considered to be more useful during the completion of ADLs depending on the patient’s level of cognitive impairment. With respect to moderate AD, caregivers identified four strategies that they perceive to be best suited for this severity group: (1) familiarity, (2) handing an object to the resident, (3) giving one instruction at time, and (4) using negotiation. Also, caregivers indicated that more challenges arise (e.g., non-compliance) when assisting these individuals during ADLs because in some instances the resident will respond with non-compliance to the caregiver’s requests and in some encounters there is little to no response to the caregiver’s attempts to help with a given task. Interestingly, caregivers indicated that providing closed-ended questions (yes-no response) is not helpful to their care practice because, when a resident responds “no”, they would then have to find alternative ways to encourage the resident to participate in a given task. Caregivers also expressed that negotiation, supported by knowing the person’s history and preferences, is a key strategy that is used to complete daily tasks.

Conversely, when assisting individuals with severe AD, postponement of the task (repeated attempts), interpreting non-verbal behaviour, using the resident’s name, and employing full assistance were identified as more appropriate strategies. Also, caregivers agreed that they continue to verbalize their actions, greet residents, and talk generally (e.g., social communication) to residents with severe AD even when residents no longer have the
capacity to respond. However, caregivers discussed the difficulty in gaining the attention of individuals with severe AD. They indicated that an increased reliance on non-verbal behaviour when interacting with these individuals was important. Such non-verbal behaviours included positioning themselves in front of the resident and establishing eye contact. Caregivers also discussed relying less on negotiation as a strategy of choice as the disease progressed. Instead, they noted that postponement of the task was the main strategy they used when assisting residents with severe AD, particularly when a resident demonstrated resistive (i.e., non-verbal non-compliance) or aggressive behaviour, which was noted to be most problematic when assisting residents with severe AD. Finally, caregivers indicated that assisting individuals with severe AD is less difficult than assisting those with moderate AD because they generally have to provide full-assistance to these residents and verbalized non-compliance rarely occurs.

**Effectiveness Ratings**

Formal caregivers were asked to rate, on a scale of 1 to 10 (10 = most effective), the effectiveness of nine task-focused communication strategies (verbal = 5 and non-verbal = 4) that have been previously reported as frequently used when caregivers assist individuals with moderate and severe AD during an ADL (Wilson et al., 2012). Medians are reported in this section, as the median is the more appropriate statistic to report for ordinal scales and for non-parametric tests (Field, 2009). The highest ranked verbal strategies for both severity groups were the use of encouraging comments (moderate: $Mdn = 9.5, IQR = 1.0$; severe: $Mdn = 8.5, IQR = 2.0$), using the resident’s name (moderate: $Mdn = 8, IQR = 2.0$; severe: $Mdn = 9.5, IQR = 2.3$), and giving one instruction at time (moderate: $Mdn = 8.5, IQR = 2.3$; severe: $Mdn = 9, IQR = .2.0$). For the moderate group, the verbal strategy for which caregivers provided the lowest rating was using closed-ended questions ($Mdn = 7, IQR = 2.3$) and the lowest rated
verbal strategy for the severe group was the use of paraphrased repetition ($Mdn = 7.5$, $IQR = 2.0$).

Overall, caregivers rated the effectiveness of non-verbal strategies lower than verbal strategies. In terms of assisting residents with both moderate and severe AD, caregivers provided the highest rating for the strategy of guided touch (moderate: $Mdn = 7$, $IQR = 2.3$; severe: $Mdn = 5.5$, $IQR = 2.0$). Further, when assisting residents with severe AD, caregivers rated handing an object to the resident ($Mdn = 3$, $IQR = 1.5$), pointing to an object ($Mdn = 4$, $IQR = 4.5$), and demonstrating ($Mdn = 4$, $IQR = 2.3$) as least effective.

In order to examine differences between caregiver ratings for each strategy when assisting those with moderate versus severe AD, a Mann Whitney U test was conducted. There was no significant difference in caregivers’ effectiveness ratings for all the verbal strategies. However, significant differences were present for caregivers’ ratings of non-verbal strategies. Caregivers rated the following non-verbal strategies as significantly more effective when assisting individuals with moderate AD than when helping those individuals with severe AD during ADLs: (1) pointing ($Mdn = 6.5$, $IQR = 2.3 > Mdn = 4$, $IQR = 4.5$; $U = 5$, $z = -2.1$, $p = .037$); (2) demonstrating ($Mdn = 6$, $IQR = 2.3 > Mdn = 4$, $IQR = 2.3$; $U = 2$, $z = -2.8$, $p = .013$); and (3) handing an object to the resident ($Mdn = 6.5$, $IQR = 1.5 > Mdn = 3$, $IQR = 1.5$; $U = 1.5$, $z = -2.8$, $p = .004$).

**Discussion**

The purpose of this study was to elucidate the perceptions of formal caregivers with respect to which communication strategies they find effective when assisting residents with moderate and severe AD during the completion of ADLs. While previous investigations have
focused on examining formal caregivers’ use of a selection of communication strategies during conversation with individuals with moderate to severe AD (e.g., Savundranayagam et al., 2007; Tappen et al. 1997), the present study provides a detailed description of formal caregivers’ perceived use of a variety of strategies, the majority of which were task-focused, specific to the completion of ADLs. A key finding was that, in addition to task-focused and social communication strategies, caregivers incorporate broader communication and care strategies than originally reported in the literature that has examined caregivers’ use of communication strategies when assisting individuals with AD during the completion of ADLs (Small et al., 2003; Wilson et al., 2012). For instance, while the use of a variety of task-focused communication strategies has been previously observed during the communication occurring between caregivers and individuals with AD during the completion of ADLs (e.g., provide one instruction at a time), findings from this study bring added value to this literature, as caregivers highlighted the importance of the broader care context surrounding communication during ADLs (e.g., being familiar with the resident). That is, the strategies that caregivers discussed appear to fall along a continuum, with some of these strategies representing more of a “micro” approach to communication during daily care routines (i.e., strategies specific to completing ADLs) and some of the strategies representing more of a “macro” approach to communication and care (i.e., general communication strategies (e.g., eye-contact) and general care strategies (e.g., postponement)). These two approaches appear to be intimately connected in the sense that strategies that caregivers report using in their general care practice provide underlying support for the implementation of individual communication strategies. A striking illustration of this finding is caregivers’ reference to the general care strategy of familiarity, or knowing the resident’s preference and personal history, and the selection of strategies individualized to the resident’s needs. Negotiation was the most frequently discussed task-focused strategy and being
familiar with the resident and understanding their needs is essential to employing this particular strategy effectively.

The results indicated that caregivers perceive that they use numerous task-focused communication strategies, some of which have been previously reported in the empirical literature. For example, formal caregivers ranked highly the use of one proposition (i.e., one instruction or idea) at a time with residents with moderate and with severe AD. They also indicated with a consensus that paraphrased repetition and verbatim repetition were useful strategies when assisting residents with AD during the completion of ADLs. Of note, while paraphrased repetition was the lowest ranked verbal strategy for individuals with severe AD, the ranking of this strategy was still moderately high (Mdn = 7.5). Importantly, reduced number of propositions (Rochon et al., 1994) and repetition (Small et al., 1997) have been shown empirically to increase comprehension in individuals with AD). In addition, the most frequently mentioned non-verbal strategy was the use of demonstrating gestures to support the verbal message. The use of gestures was investigated by Pashek and DiVenere (2006), who showed that gestures enhance comprehension of verbal messages in individuals with mild to moderate AD. During the FGIs, the most common strategies that formal caregivers discussed as being useful when assisting residents with AD included: (1) negotiation; (2) familiarity; (3) explaining their actions to the resident; (4) postponing completing the task when difficulties arise; (5) greeting the resident; and (6) establishing eye contact with the resident. These findings indicate that caregivers perceive that a combination of task-focused, general communication strategies, and general care strategies is an effective approach to assisting residents with moderate and severe AD during the completion of ADLs.
Negotiation was the strategy that caregivers most frequently discussed and was often commented on in relation to being familiar with the resident. This notion appears to incorporate the idea of coaxing in order to achieve a mutually satisfactory solution (see also Small & Montoro-Rodriguez, 2006). Beach and Kramer (1999) also reported that caregivers perceived compliance gaining strategies, which included negotiation and understanding the resident’s preferences, as a core communication strategy useful when interacting with residents with AD. Further, being familiar with a resident’s personal history and preferences, and acknowledging their individual needs have been shown to be essential components to enhancing relationships between care providers and residents in LTC (McGilton, 2002; McGilton et al., 2003; Richter et al., 1995). Furthermore, therapeutic relationships with residents with moderate to severe AD can be created (Williams & Tappen, 1999), which has the potential to improve residents’ quality of care (Anderson, Taha, & Hosier, 2009; Bowers, Esmond, & Jacobson, 2000; Nakrem, Vinsnes, & Seim, 2011), and improve job satisfaction for LTC staff assisting individuals with dementia (Moyle, Murfield, Griffiths, & Venturato, 2011).

Another communication strategy that may reinforce interpersonal relationships is the use of positive feedback during caregiver-resident interactions. Caregivers in this study referred to the use of encouraging comments and providing sufficient time for residents to respond. Indeed, Medvene and Lann-Wolcott (2010) explored experienced nurses aids’ perceived communication behaviours in the LTC setting and reported the key finding that giving what they call “positive regard” to residents was the most frequently utilized strategy. Furthermore, investigations into the effects of caregiver communication training intervention on conversation content in the LTC setting supports caregivers’ use of positive statements, providing simple instructions, and making conversational content personally relevant to the
resident (e.g., Bourgeois, Dijkstra, Burgio, & Allen, 2004; Burgio et al., 2001; Dijkstra et al., 2002; McGilton et al., 2009) as effective strategies when communicating with residents with AD. For example, Dijkstra and colleagues (2002) reported that caregivers’ use of one instruction at time, positive feedback, giving sufficient time for the residents to respond, and individualizing the content of the conversation benefited individuals with moderate and severe AD. Together, reported findings on the use of communication strategies during conversation support key findings in this current study, indicating that there may be a similarity between communication strategies used during the completion of ADLs (i.e., task-driven communication) and those used during conversation.

When assisting residents with moderate as compared to severe AD, formal caregivers in this study indicated a perceived distinction between the effectiveness of a sub-set of the strategies. Interestingly, the distinction may reflect caregivers’ knowledge and experience with the declining cognitive and functional abilities that are apparent with the progression of AD (Appell et al., 1982; Bayles & Tomoeda, 1994; Bayles, Tomoeda, & Trosset, 1992; Bayles & Tomoeda, 1991). In terms of interacting with residents with moderate AD, caregivers commented on a larger selection of strategies that are useful in their care practice, including task-focused verbal strategies (e.g., using negotiation and providing one instruction at a time), task-focused non-verbal strategies (e.g., handing an object to the resident) and general care strategies (e.g., familiarity). Conversely, although caregivers agreed that verbalizing with residents should continue when assisting individuals with severe AD, caregivers discussed the usefulness of only a few strategies when assisting residents with severe AD, outside of full assistance. Specifically, the general care strategy of postponing the task and repeating at a later
time, the general communication strategy of interpreting the resident’s non-verbal behaviour, and the task-focused verbal strategy of using the resident’s name were discussed.

Caregivers’ effectiveness ratings for task-focused non-verbal communication strategies indicated that the strategies of demonstrating or gesturing an action, pointing to an object, and handing an object to the resident were better suited for individuals with moderate AD, whereas full assistance for individuals with severe AD was the more typical approach discussed during the guided interviews. Taken together, caregivers’ ratings of effective communication strategies imply a perceived shift from non-verbal strategies that act as a prompt to complete the step (i.e., assume resident can participate with the assistance of the strategy) to full assistance and no independent participation of the resident. Of note, the fact that there were no significant differences found among the verbal strategies that were rated highly by the caregivers may be attributed to a ceiling effect. On the other hand, it must be noted that the strategies selected for rating were chosen from among those found to be frequently used in our previous work (Wilson et al., 2012), and thus a high rating for all these strategies was not unexpected. Finally, it is important to note that, while the frequency data and the effectiveness ratings appear to display divergent findings for the use of encouraging comments, providing one instruction at a time, and guided touch, it is possible that this finding reflects the nature in which the data were generated. That is, the frequency data were produced in response to open-ended questions, included in the semi-structured FGI, which allowed for a broad range of responses from the caregivers. In this scenario, the aforementioned communication strategies may not have readily came to the minds of the caregivers when they reflected on their care practices. Conversely, the effectiveness ratings placed caregivers in a situation where they were directly asked about a given strategy and had to reflect on their use of that specific strategy in their care practice.
Thus, it may be possible that a limitation associated with self-report data (e.g., failure to recall) during the semi-structured interview process, generated different information but not necessarily divergent findings.

Across all strategies coded, the most frequently discussed strategies suggest formal caregivers incorporate a person-centred approach to dementia care (Kitwood, 1997) when assisting residents with AD during the completion of ADLs (see also Brooker, 2004). According to Kitwood’s theory of dementia care (1992; 1993; 1997), while individuals with AD exhibit declining cognitive abilities, they are also more than cognitive beings in that they maintain aspects of their emotional being and are apt to participate socially in relationships; thus, dementia care should emphasize recognition of personhood, (e.g., uniqueness of a person’s history and their need for relationships) during the cooperative reciprocal exchanges occurring during their care. Kitwood (1997) identifies five principle components of positive interactions in person-centred dementia care that has implications for communication: (1) recognizing the person as a unique individual; (2) negotiating by consulting an individual on preferences and choices; (3) validating an individual by acknowledging their emotions and responding with empathy; (4) collaborating by aligning oneself with an individual to engage in a task; and (5) facilitating by enabling the use of remaining abilities (see also Ryan, Bryne, Spykerman, & Orange, 2005). Interestingly, caregivers in this study employed strategies that support each of the key positive interactions identified in person-centred dementia care. With respect to recognition, caregivers identified that they always greet the resident and use the resident’s name at the beginning of every encounter. Caregivers also indicated that using eye contact and positioning themselves in front of the resident are an essential communication strategy in their care practices. Negotiation is another positive interaction approach in person-
centred dementia care and caregivers in this study reported using the strategy of negotiation during ADLs the most frequently. Further, being familiar with the resident’s needs and preferences maximizes the potential for successful negotiation. Caregivers’ use of postponing the task supports the positive interaction of validation. By postponing the task, typically in response to non-compliance or resistive behaviours, caregivers acknowledge the desires or needs of the residents with AD. Facilitation and collaboration are features of positive interactions in person-centred dementia care that are closely linked to the completion of ADLs. Caregivers commented on the use of a variety of task-focused (verbal and non-verbal) communication strategies that support residents’ participation in their own self-care. For example, caregivers frequently reported that they explain the steps of the task to residents, even in circumstances where residents do not have the cognitive capacity to respond, which supports their participation in the task. Caregivers also discussed the use of demonstration in conjunction with instructions as a useful strategy to help residents during the task, which is a strategy that supports the resident by assuming that they can use this strategy to initiate autonomous participation in the step of the task. Interestingly, caregivers’ overall effectiveness ratings for verbal task-focused communication strategies were higher than the effectiveness ratings provided for non-verbal strategies. This finding suggests caregivers still perceive verbal communication strategies as more effective, or necessary, in their care practice regardless of disease severity. This may relate to the person-centred approach to care, as caregivers’ continued use of verbal communication may indicate they understand the importance of treating the persons with AD as individuals and as social beings who interact with others primarily by means of verbal communication. Thus, relational communication is essential to the quality of care and quality of life for individuals with AD.
Additionally, caregivers’ perceived use of strategies appears to coincide with the framework outlined by the Communication Enhancement Model (Ryan, Meredith, MacLean, & Orange 1995; Orange, Ryan, Meredith, & MacLean, 1995). The Communication Enhancement Model provides a framework for a comprehensive approach to communicating with older adults with speech, language, or hearing impairments and has been applied as an intervention to enhance communication in individuals with AD (Orange & Colton-Hudson, 1998). This model emphasizes the importance of individuals’ interactions in their environment and how these interactions are important determinants of health care, health promotion and well-being. Further, the framework for this model, which includes offering a supportive environment (physical and social), meeting individual needs of the person with AD, and employing appropriate communication accommodations by avoiding over-accommodation (e.g., elderspeak, (Williams, Kemper, & Hummert, 2003; Williams, 2006; Williams, Herman, Gajewski, & Wilson, 2009)) has been used as part of a communication enhancement and training intervention for individuals with AD and their clinicians (e.g., Orange & Colton-Hudson, 1998). Caregivers in the current study commented on a variety of strategies (i.e., task-focused communication strategies, general care strategies, and general communication strategies) that they use to support communication with individuals with AD during the completion of ADLs. Moreover, as outlined by the Communication Enhancement Model framework, caregivers expressed the importance of being familiar with residents in order to understand their needs, which in turn helps caregivers to select strategies that are best suited to the individual needs of the residents. Finally, caregivers indicated that they distinguish between their use of communication strategies as a function of disease severity, indicating that they may be attempting to appropriately match communication accommodations to the individual’s cognitive status.
Before concluding, it must be acknowledged that possible limitations to the study exist, concerning the use of FGI data. Firstly, although a major advantage of self-report data is that participants can describe their own experiences rather than relying on inferences made from observational data alone, a disadvantage of self-report data is that participants may fail to recall (e.g., possibly under report the frequency of strategies used). Another disadvantage of self-report data is that social desirability effects may create the possibility that caregivers discuss particular strategies because they are more socially acceptable. Thirdly, it is recognized that this method of collecting data can be influenced by the dynamics of the group, such as individuals who tend to dominate a discussion and those who may be less inclined to speak in a group setting. In addition, although the caregivers were a homogeneous sample and the number of individuals per focus group (i.e., 5) that was used is considered an appropriate sample size to generate data, a total of three focus groups is preferable (McLafferty, 2004; Rabiee, 2004). Finally, we acknowledge that we could not examine whether different professional caregivers might have differed in their self reported use of strategies because the group was small and included only one nurse in comparison to nine PSWs. Future research could investigate this factor.

**Clinical Implications**

The results of this study provide further support for the importance and the use of targeted and individualized strategies that enhance communication between formal caregivers and individuals with AD. The results add to existing findings in that caregivers endorsed the use of previously reported strategies in the literature, many of which would be recommended by speech-language pathologists. Furthermore, other strategies that were previously unidentified in the literature emerged. Taken together the results provide direction for speech-language
pathologists to educate caregivers on how to optimize communication with individuals with AD during ADLs.

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CHAPTER 5

GENERAL DISCUSSION

The purpose of this dissertation was to address the following overall research questions:

1. Which communication strategies do formal caregivers actually use to assist residents with moderate and severe AD during the completion of an ADL?

2. Which communication strategies are related to successful task completion?

3. Is there a difference in caregivers’ use of communication strategies as a function of disease severity?

4. Which communication strategies do caregivers perceive to be useful in their care practice?

The beginning sections of this discussion outline the dissertation contributions and provide a review of the principle findings, with a focus on highlighting convergent and divergent findings reported in the three studies presented in the dissertation. After key results are reviewed, the relevance of these findings is discussed in relation to existing theory and frameworks for dementia care. Based on these findings, proposed evidence-based communication recommendations developed for caregivers assisting residents with moderate and severe AD are outlined. Finally, limitations of the studies are considered and future directions are proposed.
Summary of Dissertation Contributions

With the increasing numbers of older individuals residing in the community or in the long-term care setting and living with cognitive-functional impairments associated with AD, arises the need for tools to support communication between caregivers and persons with AD during care routines. This dissertation is comprised of three novel studies that addressed the need for empirically supported communication strategies best suited for formal caregivers assisting residents with moderate and severe AD during the completion of ADLs. In addition, this dissertation research sought to better understand which communication strategies caregivers frequently utilize when assisting residents with AD during their care practice in the LTC setting, as this information is currently limited in the literature. Chapter 2 presented findings from the first systematic study conducted as part of this dissertation, which identified the task-focused communication strategies formal caregivers use while assisting residents with moderate to severe AD during handwashing (also referred to as the handwashing study), and which identified the strategies that were related to task success. Chapter 3 presented findings from the toothbrushing study, which identified the task-focused and social communication strategies formal caregivers employed during a second ADL, toothbrushing, as a function of disease severity. Finally, Chapter 4 presented findings from a study describing formal caregivers’ perceived use of effective communication strategies when assisting residents with moderate and severe AD during the completion of ADLs.

Together, this dissertation was an innovative approach to investigating formal caregivers’ use of task-focused and social communication strategies specific to assisting residents with AD during the completion of ADLs. The observational research studies furthered
our understanding of which communication strategies were frequently employed during successful task completion and the crucial perspectives of the formal caregivers brought added value to the overall understanding of effective communication strategies, enriching the findings from the observational research. In addition, the focus group study shed light on general care practices and general communication strategies that supported the provision of task-focused communication strategies during oral care. Therefore, this research presents an important first step towards the development of evidence-based communication strategies that informs caregivers’ use of effective communication strategies in more advanced stages of AD. Caregivers’ utilization of empirically informed task-focused and social communication strategies has the potential to enhance communicative and functional aspects involved in the completion of basic ADLs, contributing to improved quality of care and quality of life for residents with AD (Anderson, Taha, & Hosier, 2009; Bowers, Esmond, & Jacobson, 2000), as well as improved caregiver work satisfaction (Moyle, Murfield, Griffiths, & Venturato, 2011). Finally, this research has the potential to contribute to computer-based intelligent assistive technologies designed to promote the autonomy of individuals with cognitive impairments resulting from dementia, as well as support informal and formal caregivers in their care practice by helping to alleviate the need for their presence during some daily activities (e.g., handwashing) (Mihailidis, Boger, Craig, & Hoey, 2008).

Summary of Principle Findings

Several convergent results were evident across the three studies, which included data collected while observing the completion of two different representative ADLs across three different LTC settings, in addition to the data gathered during the focus group interviews (FGIs).
In the LTC setting, formal caregivers use a variety of task focused verbal and nonverbal (e.g., visual and tactile prompts) communication strategies and, with continuous assistance, residents with moderate and severe AD were able to successfully complete the representative ADL for the majority of sessions involved in each of the observational studies. In addition, during the FGIs, caregivers discussed an array of communication strategies that they perceive to utilize often to effectively assist residents with AD during the successful completion of ADLs. Moreover, findings from this dissertation indicate that even residents with severe AD could benefit from caregivers’ use of communication strategies, demonstrating that, even with disease progression, residents retained some communicative and functional abilities that facilitated their participation in their own self-care. Together, these finding indicate that formal caregivers’ use of task-focused communication strategies may be an effective approach to support their care practice when assisting residents with moderate to severe AD during the completion of ADLs.

Importantly, findings across all three studies of this dissertation indicated that caregivers most frequently used a sub-set of task-focused verbal communication strategies. Moreover, findings from the two observational studies were supported by empirical literature. Specifically, findings supported our hypotheses that the use of one-proposition, paraphrased repetition, and closed-ended questions would be of benefit during the completion of the ADLs. Moreover, during the FGIs, caregivers ranked providing one instruction/direction at a time as one of the most effective communication strategies across disease severity. Further, all caregivers agreed that they thought they utilized paraphrased repetition in their daily care practice. Notably, in the toothbrushing study, caregivers provided one proposition at time and paraphrased repetition significantly more, as a proportion of their utterances, when assisting residents with severe AD as compared to assisting those with moderate AD. Further, we also found an association
between disease progression and the increased use of paraphrased repetition in the handwashing study. This finding likely reflects the increased support individuals with severe AD require when completing steps of ADLs. While our hypotheses stated that verbatim repetition would be beneficial during the completion of ADLs, this task-focused communication strategy did not fall within the top most frequently used strategies during successful task completion. However, caregivers did employ verbatim repetition and there was no significant difference between their relative use of paraphrased repetition and verbatim repetition. Further, during the FGIs, there was a consensus among caregivers that verbatim repetition was a communication strategy that they utilized during the completion of ADLs. Thus, while caregivers frequently employed paraphrased repetition, they also incorporated the use of verbatim repetition while assisting residents during the completion of ADLs. Together, these findings appear to indicate that formal caregivers frequently use a sub-set of communication strategies that are commonly found in the clinical recommendations and these strategies are supported by empirical findings.

In addition to the hypothesized task-focused communication strategies, caregivers’ frequently provided encouraging comments (e.g. verbal praise) and this finding was observed across the two ADL tasks studied. Further, caregivers perceived this strategy to be effective regardless of disease severity. This finding is supported by some studies that have examined communication training programs and reported the importance of positive regard in conversation between caregivers and residents with AD (e.g., Bourgeois et al., 2004; Dijkstra et al., 2002; McGilton et al., 2009). Additionally, using the resident’s name to gain their attention fell under the caregivers’ top most frequently utilized strategies in the handwashing study, which was comprised mostly of residents with severe AD, and this finding was also observed in caregivers assisting residents with severe AD in the toothbrushing study. Moreover, as a
proportion of caregivers’ utterances, this strategy was employed significantly more when caregivers assisted residents with severe AD as compared to residents with moderate AD. Further, during the FGIs, caregivers rated the use of encouraging comments, using the resident’s name, in addition to providing one instruction at a time, as the most effective communication strategies to employ across disease severity. Interestingly, while formal caregivers were both observed using and perceived using encouraging comments and using the resident’s name strategy in their care practice, these strategies have not been typically included in the clinical communication recommendations. Finally, consistent across the two observational studies, caregivers rarely or never used simple-choice questions and rarely used open-ended questions. Of note, the infrequent use of open-ended questions may reflect the limited opportunity for this question type to arise within the context of ADLs.

Also of note was that the findings indicated that formal caregivers often supplemented task-focused verbal communication strategies with task-focused nonverbal communication strategies. Particularly, the use of guided touch, handing an object to the resident, and pointing to an object relevant to the task, were the most frequently utilized task-focused nonverbal communication strategies and this was a consistent finding across the two observational studies. In addition, no significant differences in caregivers’ use of any of the nonverbal strategies were observed across disease severity levels. Moreover, caregivers perceived that the use of guided touch to assist a resident through steps of the task was an effective strategy when assisting residents with both moderate and severe AD. Interestingly, task-focused nonverbal communication strategies often co-occurred with the use of task-focused verbal strategies, with the most frequent combinations consisting of verbal and tactile strategies (e.g., one proposition and guided touch). Recognizing that caregivers rated the overall effectiveness of nonverbal
communication strategies lower than verbal strategies, together, the aforementioned findings appear to indicate that caregivers consider nonverbal communication strategies to be an important supplement to verbal prompts while facilitating participation of residents in their own self care, which is essential to the successful completion of ADLs.

While several findings were consistent across all three studies included in this dissertation, two task-focused communication strategies (i.e., introducing the task and negotiation) in addition to all social and MISC communication strategies were only included in the coding scheme for the toothbrushing study, following the completion of the handwashing study. However, there were relevant convergent findings regarding the communication strategies that were coded in the toothbrushing study and that were also discussed in the FGI study. That is, in the majority of toothbrushing sessions, across disease severity, caregivers introduced the task to the resident and during the FGIs caregivers referred to this strategy as an important step in their care approach. Specifically, caregivers discussed an agreed upon approach (i.e., steps) when assisting residents with AD, regardless of their severity level, during the completion of ADLs: (1) greet the resident; (2) introduce the task; (3) explain one’s actions; (4) repeat instructions when necessary. In addition to the task-focused strategies, responding to a resident’s remarks, requests or needs was one of the most frequently employed social communication strategies when caregivers assisted residents with moderate AD during the task. Indeed, it was found that caregivers used this social strategy significantly more when assisting residents with moderate AD compared to those with severe AD. Further, findings from the FGI study indicated that there was a consensus among caregivers that this strategy was useful in their care practice. Finally, greeting the resident was one of the most frequently used social strategies
when assisting residents with severe AD and caregivers were in agreement that this strategy is an important first step to their care approach during the completion of ADLs.

While several important convergent findings were identified across the three studies, there were a few divergent findings between the observed behaviour during the representative ADLs and caregivers’ perceptions of effective communication strategies that are noteworthy. Firstly, in relation to our hypothesis that residents would benefit from the use of closed-ended questions, we did observe, across disease severity, that caregivers frequently employed this strategy during the completion of an ADL. However, caregivers participating in the FGI study ranked the effectiveness of closed-ended questions lower in comparison to other verbal strategies, particularly for those with moderate AD. Interestingly, caregivers commented that the difficulty with this strategy is that residents with moderate AD may say “no” to the questions, leaving the caregiver trying to find an alternative method to encourage the resident to participate in a given task.

In terms of task focused nonverbal communication strategies, the use of demonstrating an action (e.g., co-verbal gesture) was inconsistent across the studies. Specifically, in the handwashing study (where the majority of residents had severe AD), demonstrating an action was one of the most frequently used nonverbal communication strategies; whereas in the toothbrushing study, this finding was not observed for either the moderate or the severe AD groups, inconsistent with work by Pashek and DiVenere (2006), which supports the use of co-verbal gestures when conversing with individuals with moderate AD. Moreover, in the FGI study, while caregivers ranked demonstrating an action as the least effective task-focused nonverbal strategy for residents with severe AD, they ranked it significantly higher for residents with moderate AD. These results suggest that more research examining the usefulness of co-
verbal gestures when communicating with individuals with AD may be warranted. Finally, there was an interesting discrepancy between caregivers’ observed use of explaining their actions and the use of negotiation and caregivers’ perceived use of these strategies in their care practice. Specifically, caregivers were observed to infrequently use these strategies while assisting residents with AD during the ADL; however, caregivers referred to their use of these two strategies most frequently, with the majority of caregivers discussing the relevance of these strategies in their care routines. They referred to negotiation as essential to their care practice and felt that this particular task-focused strategy is linked to understanding the needs and preferences of the individual; yet, this strategy was rarely used during the completion of toothbrushing. Together, findings indicate that caregivers’ actual use of some strategies and their perceived use may be inconsistent, indicating the need for further research to reconcile these divergent findings.

**Applying Findings to Existing Theory**

This dissertation addressed the following research questions: (1) Which communication strategies do caregivers actually use while successfully assisting residents with moderate and severe AD during the completion of an ADL? and (2) Which communication strategies do caregivers perceive to be useful when assisting residents with AD during an ADL? The strategies that emerged, both in terms of actual use and perceived use, suggest that formal caregivers incorporate a person-centred approach to dementia care when assisting residents with AD during the completion of ADLs. According to Kitwood’s theory of dementia care (1993; 1997), while individuals with AD exhibit declining cognitive abilities, they maintain aspects of their emotional being and are apt to socially participate in relationships. Therefore, dementia care should emphasize recognition of personhood (e.g., the uniqueness of the individual and the
need for relationships) as central to communication during the cooperative reciprocal exchanges that occur during care. Further, Kitwood (1997) identifies key positive interactions in person-centred dementia care that are relevant to communication, including recognition (recognizing the person as a unique individual), negotiation (the individual is consulted on preferences and choices), validation (acknowledging a person’s emotions and responding with empathy), collaboration (the caregiver aligns with the individual to engage in the task) and facilitation (enabling the use of remaining abilities).

Interestingly, across all the studies that comprise this dissertation, formal caregivers employed communication strategies that reflect each of the key positive interactions identified in person-centred theory of dementia care. For example, with respect to recognition, caregivers participating in the FGI study indicated that it is important to always greet the resident and use the resident’s name at the beginning of every encounter. Moreover, caregivers’ actual use of task-focused communication strategies reflects the importance of recognition, as using the resident’s name was one of the most frequently employed strategies when caregivers assisted residents with severe AD. Further, caregivers also referred to the importance of using eye contact and positioning themselves in front of the resident in their care practices. Negotiation is another positive interaction approach in person-centred dementia care and caregivers participating in the FGI study most frequently reported the use of this to assist in the successful completion of ADLs and deemed this strategy to be essential to their care practice. Further, being familiar with the resident’s needs and preferences also supported the individualized nature of negotiation. In addition, caregivers in the FGI study referred to the use of postponing the task when necessary, which supports the positive interaction labeled validation. By postponing the
task, typically due to non-compliance or resistive behaviours, caregivers are acknowledging the emotions of the residents with AD, thus responding to their needs.

Facilitation and collaboration are features of positive interactions in person-centred dementia care that are closely linked to communication during the completion of ADLs. When it came time to complete the representative task (either handwashing or toothbrushing), caregivers aligned themselves with the residents (collaboration) and were observed using a variety of task-focused verbal and nonverbal communication strategies. Moreover, caregivers adjusted their use of strategies to the individual as well as to the disease severity level, enabling the participation of residents with AD in their self-care (facilitation). For example, caregivers most frequently provided one instruction or direction at a time and paraphrased repetition when assisting residents with AD, but also provided significantly more of these prompts with disease progression. Furthermore, in the FGI study, caregivers frequently reported that they explain the steps of the task to the resident, even in circumstances where the resident does not have the cognitive capacity to respond, which supports their participation in the task. Caregivers also discussed the use of demonstration in conjunction with instructions as a useful strategy to help residents during the task, which is a strategy that supports the resident by assuming that they can use this strategy to initiate autonomous participation in the step of the task.

In addition to caregivers employing a variety of communication strategies that demonstrated a person-centred approach to dementia care, it was also apparent that caregivers’ practice appeared to support the Communication Enhancement Model (Ryan et al., 1995). Specifically, caregivers in the FGI study indicated that they approach every encounter with an awareness of the individual’s needs, desires, and preferences and they utilize this information to
support their encounters (e.g., selection of communication strategies) with residents with AD during the completion of daily tasks. Further, caregivers appeared to adjust and modify their use of particular communication strategies depending on disease severity. Moreover, caregivers perceived that some strategies were more beneficial when assisting different disease severity levels. Thus, findings indicated that caregivers sought to understand the resident’s unique needs and made the necessary communication modifications for successful task completion that, in turn, may have supported the empowerment and well-being of both the residents and the caregivers.

In sum, formal caregivers assisting residents with AD in the LTC setting utilize a variety of strategies that support person-centred dementia care theory, which places a strong emphasis on recognizing the social and relational being that persists in the midst of declining cognitive abilities. In addition, caregivers appear to utilize the Communication Enhancement Model framework in their care practice. For instance, caregivers provided a supportive environment through the selection of communication strategies that were appropriate for the resident’s abilities, such that they enabled the resident’s participation in completion of their own self-care.

**Proposed Evidence-based Communication Recommendations**

The aim of this dissertation was to systematically examine formal caregivers’ use of optimal communication strategies. In turn, the findings were to be used to develop evidence-based communication recommendations for formal caregivers assisting residents with moderate and severe AD during the completion of ADLs. In addition to including communication strategies supported by empirical research, evidence-based communication recommendations should also be delivered in a manner that promotes personhood, autonomy, empowerment, well-
being, and positive behaviours during the caregiver- care recipient dyad, while minimizing imposed limits on residents’ abilities and communicating in a manner that would be deemed patronizing and that would reinforce negative stereotypes of incompetency in individuals with AD. Thus, communication recommendations should strike a balance between employing effective strategies that facilitate successful completion of daily activities while, at the same time, not limit opportunities for individuals with AD to participate in their own self care (i.e., avoid over-accommodation). Further, communication strategies are support tools that caregivers can utilize to enhance their person-centred care approach, which includes recognizing the unique attributes, personalities, values, and history of the resident with AD.

Importantly, the person-centred care approach has recently received increased attention in the resources available to caregivers of individuals with AD. For example, the Alzheimer Society of Canada has updated their caregiver communication tips to include a person-centred approach to communication. The updated communication tips stress that it is essential for caregivers to understand the nature of the disease and how it impacts functional and communication abilities, understand that communication is possible at all stages of AD, focus on retained abilities, and accept the reality of the individual living with dementia (Alzheimer Society of Canada, 2010b). Included in these updated communication tips are strategies such as the use of simple sentences, closed-ended questions, verification questions, using the resident’s name, encouragement, avoiding the use of patronizing speech, using eye-contact, showing and talking, and encouraging expression of emotions. Indeed, this dissertation addressed the need for effective communication strategies, with findings supported by empirical research, as well as a person-centred dementia care framework, that holds positive communication interactions
between residents with AD and their caregivers to be of the highest importance. Based on the findings from the studies that comprise this dissertation, proposed evidence-based communication strategy recommendations have been developed and are listed in Table 5-1.

Table 5-1

<table>
<thead>
<tr>
<th>Proposed Evidence-based Communication Strategy Recommendations</th>
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<tr>
<td>Communication strategy recommendations for assisting residents during activities of daily living (ADLs)</td>
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<tr>
<td>1. Across AD severity level (moderate and severe)</td>
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<tr>
<td>a. Task-focused verbal communication strategies</td>
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<tr>
<td>1. Provide simple instructions (i.e., one direction, instruction, or question at a time).</td>
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<tr>
<td>2. Use closed-ended questions</td>
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<td>3. Use paraphrased repetition</td>
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<td>4. Provide encouraging comments (e.g., verbal praise; positive feedback)</td>
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<td>5. Introduce the task</td>
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<td>6. Explain actions to the resident</td>
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<td>7. Use negotiation</td>
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<tr>
<td>b. Task-focused nonverbal communication strategies</td>
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<tr>
<td>1. Hand object to the resident</td>
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<td>2. Use guided touch</td>
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<tr>
<td>3. Point to an object</td>
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<tr>
<td>c. Social communication strategies</td>
</tr>
<tr>
<td>1. Greet the resident</td>
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<tr>
<td>2. Respond to resident</td>
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<tr>
<td>3. Make closing remarks</td>
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<tr>
<td>d. General communication strategies</td>
</tr>
<tr>
<td>1. Make eye-contact</td>
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<tr>
<td>2. Be patient</td>
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<tr>
<td>3. Focus the resident</td>
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<tr>
<td>4. Use environmental cues</td>
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<tr>
<td>e. General care strategies</td>
</tr>
<tr>
<td>1. Be familiar with the resident</td>
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<tr>
<td>2. Interpret behaviour</td>
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</tbody>
</table>
3. Assess mood
4. Assess for resistive behaviour
5. Request assistance

2. Additional suitable communication strategies when assisting residents with moderate AD

a. Task-focused verbal communication strategies
   1. Use two propositions
   2. Use verification questions

3. Additional suitable communication strategies when assisting residents with severe AD

a. Task-focused verbal communication strategies
   1. Use the resident’s name
   2. Increase use of simple instructions and paraphrased repetition

b. General communication strategies
   1. Interpret nonverbal behavior
   2. Monitor paralinguistic (para-verbal) aspects of communication (e.g., monitor the tone, pitch, and pace of voice)

c. General care strategies
   1. Postpone task/repeat attempt to complete the task at a later time

Limitations and Future Directions

The primary purpose of the studies presented in this dissertation was to examine formal caregivers’ use, as well as their perceived use, of effective communication strategies while assisting residents with moderate and severe AD during the completion of ADLs. Thus, observational designs (i.e., the handwashing and toothbrushing studies) and descriptive design (i.e., the FGI study) were the approaches taken to answer the research questions outlined in this dissertation. Together, the observational studies provided extensive data sets on the phenomenon of interest, permitting a deeper understanding of formal caregivers’ use of communication strategies within the context of care during the completion of ADLs. Further, the descriptive research supplemented our observational findings, allowing for a comprehensive
understanding of effective communication strategies within the context of care practices in the LTC setting. Major strengths of this dissertation research were the systematic approach taken to examine formal caregivers’ communication behaviours and the implementation of similar methods across both the handwashing and the toothbrushing studies. The toothbrushing study strengths included the inclusion of more residents with moderate AD in the toothbrushing study and the addition of coding for social communication strategies in the toothbrushing. The use of a second representative ADL meant that the replication of findings pertaining to task-focused communication strategies was possible. In addition, because we observed similar findings across the representative tasks, results may be generalized across basic ADLs. Moreover, this research had high ecological validity and was a useful starting point to generate future hypotheses regarding the effectiveness of task-focused verbal and nonverbal communication strategies. The descriptive study, which addressed caregivers’ perceived use of effective communication strategies also had strengths. For instance, this study allowed for the involvement of caregivers in the research process, providing a forum for caregivers to share their experience and expertise with the researchers. The in-depth discussions produced during the FGIs allowed for a greater appreciation and understanding of caregivers’ approach to communication during the completion of ADLs while assisting residents with moderate and severe AD. For example, real-world examples of communicating encounters provided valuable insight regarding caregivers’ use of general care and general communication strategies, and how these approaches support the choice of which task-focused communication strategies caregivers utilize with individual residents.

While the naturalistic examination of caregivers’ use of communication strategies across a large number of observed handwashing sessions (N=72) and toothbrushing sessions (N = 78)
was a major strength of the observational studies, there are a few limitations of each study that should be considered. Firstly, in the handwashing study, we aimed to have a representative sample of residents with moderate and severe AD to examine any possible difference in caregivers’ communication strategy use when interacting with differing severity levels; however, the sample in this study was limited to three individuals with moderate AD given the availability of individuals with a diagnosis of possible AD in their medical charts at the time of the study. Thus, all caregiver-resident dyads were treated as one group (moderate to severe AD) resulting in greater heterogeneity in severity levels than we initially anticipated and precluding analysis as a function of group. Further, participants in this study were not a random sample, but instead consisted of caregivers and residents of a single facility (i.e., a convenience sample). Caregivers worked on the floors in which residents with dementia were living. Although we did randomly assign AD residents to the caregivers, caregivers were familiar with the residents and previous experience with their assigned resident may have shaped the caregivers’ choice of communication strategies.

A second limitation of the handwashing study, and also applicable to the toothbrushing study, was the inability to examine caregivers’ use of four commonly recommended communication strategies that have been examined previously: (1) approach from the front; (2) maintain eye contact; (3) eliminate distractions; and (4) use simple sentences (i.e., syntactically simple). In our study, data collection began once caregivers-resident dyads were standing at the sink area and the caregiver was prepared to begin the session. Therefore, caregivers did not have the opportunity to approach residents from the front and there were no distractions in the washroom location that required elimination. Further, we could not measure eye contact via the video-recordings because (a) caregivers requested that their faces not be recorded and (b) we
made every possible effort to maintain the focus of the video camera on the sink area. Given the task driven nature of the interactions, we did not measure sentence structure because the majority of utterances provided were directive in nature and did not lend themselves to a wide variety of syntactic constructions, unlike utterances often observed during conversations.

Finally, the results of the handwashing study were descriptive and correlational, thus no causal relationships between communication strategy use and success of the task could be established. For example, we observed a significant relationship between verifying questions and poorer task performance; however, this may have been due to some other unmeasured characteristic, such as the clarity or quality of the request for clarification. While we did attempt to control for possible confounding variables (i.e., disease severity and years of experience working with residents with AD), we did not control for other potentially confounding variables that may have influenced caregivers’ choice of communication strategies, such as caregiver’s familiarity with the resident they were assisting, the quality of past experiences with residents (positive or negative), communicative ability of residents, or the communication style of the caregivers.

With respect to the toothbrushing study a notable limitation was the relatively small sample size and corresponding reduced statistical power for group comparisons. Also, the sampling procedure was not random, thus findings may not be generalizable to the caregiver population. Concerning the investigation of caregivers’ perceptions of effective communication strategies a possible limitation also relates to the relatively small number of participants used in the focus groups, thus limiting the generalizability of the findings. Also, it is acknowledged that the use of focus groups can be influenced by the dynamics of the group, such as individuals who tend to dominate a discussion and those who may be less inclined to speak in a group setting.
The studies presented in this dissertation represent the first steps in delineating formal caregivers’ use of task specific communication strategies when assisting residents with moderate and severe AD. While this dissertation research provides a comprehensive examination of the many communication strategies caregivers employ while assisting residents with moderate and severe AD, future research should build upon these findings by moving beyond descriptive and correlational analyses to examine the effectiveness of specific communication strategies on the comprehension of individuals with AD during completion of ADLs. Specifically, future research is needed to further delineate which task-focused and social communication strategies effectively repair a communication breakdown, which strategies may have no effect, and which strategies may actually hinder the repair of a communication breakdown during completion of ADLs. Linking the use of a specific communication strategy with a successful outcome (i.e., no breakdown in communication or successful repair of communication breakdowns) is essential to the final piece necessary for a thorough understanding of which communication strategies should be included in effective evidence-based communication guidelines for caregivers assisting individuals with AD. In addition, future research should explore caregivers’ use of nonverbal behaviour and the impact it has on the comprehension of individuals with moderate to severe AD, as this form of communication is used often during the completion of ADLs, yet little empirical research is available regarding the impact of nonverbal communication on the comprehension of individuals living with cognitive impairment. Following a greater understanding of exactly which communication strategies lead to fewer breakdowns in communication or which strategies successfully repair communication breakdowns during the completion of an ADL, the examination of the effectiveness of a comprehensive set of evidence-based communication recommendations is
warranted. Finally, an interesting application of findings from this dissertation is to the field of information and communication technologies (ICTs), with particular attention to technologies designed to support individuals with Alzheimer’s disease. Interest in ICTs has grown over the years, as these technologies have the potential to improve the quality of life for individuals with AD and their caregivers, while supporting individuals in the community through personal health care, which decreases burden on the healthcare system by delaying placement in institutional care settings (Dishman & Carrillo, 2007). Evidence-based communication strategies have the potential to help inform computerized prompting systems that have been designed to provide assistance to individuals with AD, which, in turn, support the autonomy of individuals with AD as well as relieve some of the burden of care from caregivers. Computerized prompting systems designed to support individuals with dementia during the completion of ADLs (e.g., handwashing) (Mihailidis et al., 2008) would benefit from the informed use of evidence-based communication prompts. That is, the system would select effective prompts while it helps to guide individuals with AD through a given task, as well as select optimal prompts that can repair a breakdown in one of the steps of the task.

Conclusion

Individuals with moderate and severe AD residing in long-term care experience a myriad of cognitive-linguistic impairments which affect their communication abilities, and which may, in turn, marginalize them and place them at risk of social isolation. Further, given the declines in memory, executive functioning, motor skills, visuo-spatial skills, and attention, the ability to complete basic ADLs is negatively impacted, creating the need for caregiver assistance. However, this dyad is challenged by communication declines associated with the progression of
AD, placing a heavy burden on caregivers to accommodate for cognitive-linguistic declines. Thus, there is a need for evidence-based communication strategies that will support formal caregivers in their care practices. The novel studies presented in this dissertation were the first necessary steps taken to systematically examine effective communication strategies used during the context of ADL completion. They have valuable clinical application and underscore the importance of employing communication strategies that reflect varying stages of the disease, while holding independence and participation as central to the caregiver-resident experience. Findings reported in the observational studies discussed in this dissertation supported our hypotheses, which were derived from empirical research, that the use of one proposition (i.e., one instruction or direction at a time), closed-ended questions, and paraphrased repetition would be of benefit to formal caregivers assisting residents with moderate and severe AD during the completion of ADLs. Moreover, caregivers frequently employed additional verbal strategies that reflect a person-centred approach to dementia care (e.g., encouragement and using the resident’s name) and often supplemented the verbal message with nonverbal forms of communication (e.g., pointing to an object). Further, data from the FGI study provide a deeper understanding of approaches formal caregivers take when assisting residents with moderate and with severe AD.

Findings from this dissertation have valuable clinical application. There is an emergent awareness that research is needed to understand which communication strategies are effective during ADLs, which communication strategies will promote participation of individuals with AD, and which communication strategies are best suited for various stages of AD. Furthermore, there is growing emphasis on striking a balance between the delivery of evidence-based communication strategies that facilitate successful completion of daily activities while
supporting a person-centred approach to dementia care. Specifically, it is important not to limit communication beyond what is necessary. Further, it is important to avoid over accommodations that could actually infringe on the independence of individuals with AD during task completion and limit their participation in meaningful communication experiences in their relationships. Findings from this dissertation indicate that formal caregivers utilize several empirically supported communication strategies and incorporate a person-centred approach to care. A striking example that supports enabling residents in their self care, regardless of disease severity, is found in this dissertation. Specifically, the population included this research consisted of residents with moderate and severe AD, yet with the provision of various communication strategies, residents were able to successfully complete the tasks at hand. This finding supports the notion that individuals with severe AD can participate in their own care and even those in late stages of AD demonstrate the ability and the interest to exchange in communicative interaction with others (Kim & Bayles, 2007). Indeed, it is appropriate to employ communication strategies that reflect varying stages of the disease, holding independence and participation central to the caregiver-resident experience.

In sum, findings from this dissertation contribute to the limited body of literature that addresses caregivers’ use of communication strategies during the successful completion of ADLs. Future research should address the effectiveness of individual communication strategies by examining caregivers’ use of communication strategies following a breakdown at different points of a task. This analysis will further characterize effective communication strategies during the completion of ADLs.
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