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iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

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

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Abstract

Electronic conversational memory notebooks, a more current application of previous hardcopy versions, consist of personally relevant photographs and accompanying sentences. The notebooks help persons with dementia access memories during conversations. Person-centred communication (PCC) recognizes the individual, accommodating for personal beliefs and intentions. The purpose of the current study was to determine whether persons with dementia and their family caregivers could be educated and trained to use PCC while using an iPad-based electronic conversational memory notebook. Seven persons with mild to moderate dementia and their family caregiver completed the six-week study. Participants were educated and trained to use PCC while conversing on 40 family photos uploaded to iPads. Results showed that persons with dementia and their family caregivers significantly increased PCC use post education and training. The findings indicate that conversing on family photos using an electronic conversational memory notebook can elicit PCC between persons with dementia and their family caregivers.

Keywords: Dementia, family caregivers, electronic conversational memory notebook, person-centred communication

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Chapter 1: Introduction

Dementia Defined

Dementia is a syndrome of progressive cognitive impairment that results from neurochemical and structural changes leading to neuronal loss and shrinkage of brain volume (Denning & Sandilyan, 2015). The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) categorizes dementia as a major or minor neurocognitive disorder depending on the severity of the symptoms. The severity of symptoms is dependent on both the type and clinical stage of dementia. Alzheimer's dementia is the most common subtype of dementia accounting for up to 75% of all cases (Qiu, Kivipelto & von Strauss, 2009). Subtypes of dementia are distinguished based on a combination of: a) the time course, b) the cognitive domains affected, and c) the associated symptoms of the condition (American Psychiatric Association, 2013). There are three clinical stages of dementia including mild, moderate and severe. The symptoms of these stages range from mild memory deficits to more severe cognitive impairments resulting in decreased functional abilities to complete activities of daily living (Hoe & Thompson, 2010). To be diagnosed clinically with dementia, there must be significant and objective measures showing cognitive declines from previous levels of abilities in one or more of the following cognitive domains: a) complex attention, b) executive function, c) learning and memory, d) language, perceptual-motor skills, and e) social cognition (American Psychiatric Association, 2013). Additionally, a significant other, such as family members or relatives of persons with dementia, also must report changes in mental abilities, behaviours and functions in persons with dementia, often before a clinical diagnosis of dementia is made (Strivens & Craig, 2014). The definitive diagnosis of dementia is made only

after pathological autopsy examination. Dementia mainly affects older adults and is not a normal part of healthy aging (Wong, Gilmour & Ramage-Morin, 2016).

Prevalence of Dementia

As the world's population continues to age the rates of dementia rise due to the syndrome's later life onset (Astell et al., 2010). Particularly with an aging baby boom generation and increasing rates of longevity, the prevalence of dementia will be higher than ever before (Sabat, 2012). In 2016, it was estimated that 46.8 million people were diagnosed with dementia, and this number will reach 131.5 million by 2050 (World Alzheimer Report, 2016). Currently, 564,000 Canadians live with dementia (Alzheimer Society of Canada, 2016). By 2031 it is estimated that this number will increase to 937,000 (Alzheimer Society of Canada, 2016). In 2016, the combined health-care system costs and out-of-pocket caregiver costs amounted to \$10.4 billion (Alzheimer Society of Canada, 2016). Cost for caring for persons with dementia is expected to rise by 60% before 2031, resulting in \$16.6 billion being spent (Alzheimer Society of Canada, 2016). Rates of dementia will continue to rise in the absence of any form of cure or preventative measures, while bringing immense financial and emotional costs to our health care system and care providers (Sabat, 2012).

Characteristics of Dementia

Dementia is characterized by symptoms showing a decline in mental functions that, in turn, affect social functioning. These symptoms include memory problems, difficulty focusing and paying attention, poor reasoning abilities, disorientation, and delusions (Wong et al., 2016). Dementia also is characterized by decreased life expectancy due to physical disability, institutionalization, and decreased quality of life (Qiu et al., 2009). Further, while dementia is identified by a decline in memory and cognition, language and communication problems also are

a well-recognized clinical component that are present in almost all cases (Orange & Colton-Hudson, 1998). Language and communication impairments associated with dementia vary across all three clinical stages (Tomoeda & Bayles, 1993). During the mild clinical stage, persons with dementia experience subtle word-finding problems, and difficulty using or expressing complex language such as metaphors or similes (Tomoeda & Bayles, 1993). During the moderate clinical stage, persons with dementia begin to show more pronounced word-finding difficulties, particularly to express their feelings or their needs (Tomoeda & Bayles, 1993). During the late clinical stage, persons with dementia show a wide range of difficulties including limited verbal output, problems understanding spoken and written language, restricted vocabulary, reiterative problems (i.e., repeating themselves or others), and difficulty understanding simple grammar (Tomoeda & Bayles, 1993). People with dementia often experience communication breakdowns, particularly when interacting with others as a result of these language and communication problems (Orange & Colton-Hudson, 1998). Persons with dementia may be unable to communicate their needs due to language deterioration, therefore reducing their well-being and heightening their distress (Alsawy, Mansell, McEvoy & Tai, 2017). Deteriorating communication has also been shown to contribute to an increase in both stress and mortality (Ekström, Ferm & Samuelsson, 2017).

Communication Predicaments in persons with Dementia

Research has shown repeatedly that the ability to initiate interaction and to maintain communication with other people declines as dementia progresses (Ekström et al., 2017). Conversational partners of persons with dementia often lack awareness of the symptoms of dementia, of the specific changes in communication that occur with people with dementia, and of supportive methods to achieve functional and rewarding communication (Delfino, Komatsu,

Komatsu, Neri & Cachioni, 2017). Persons with dementia need supportive and stimulating interpersonal environments to help them overcome the changes in their communication skills. However, instead of receiving this support they often can experience additional communication predicaments as a result of extra barriers imposed by their conversational partners (Ryan, Meredith, Maclean & Orange, 1995). Communication predicaments often begin when conversational partners first encounter persons with dementia, quickly recognizing them based on their age-related features. (i.e., grey hair, vision and hearing impairments, cognitive impairments) Recognition based on age-related features evokes stereotyped expectations of the performances of older adults (Ryan et al., 1995). Communication predicaments mean that conversational partners automatically lower their standards relative to the intellectual and productive competence of persons with dementia (Ryan et al., 1995). Inappropriate communication accommodation occurs toward persons with dementia through speech modification. The occurrence of secondary baby talk, patronizing speech or elderspeak is common as a result of these stereotyped modifications (Ryan, Bourhis & Knops, 1991). Elderspeak consists of a slower rate of speech, simplified syntax, vocabulary restrictions, and exaggerated intonation, among other features. It is associated with communication problems and lower rates of communication competency (Corwin, 2017). Elderspeak often is judged by older adults to be patronizing because it assumes they are cognitively impaired (Kemper & Harden, 1999). Elderspeak often results in social isolation and cognitive decline (Corwin, 2017).

Confinement of Identity

The use of elderspeak is demeaning towards persons with dementia and often results in putting them at risk of malignant social positioning among other negative outcomes (Sabat, 2006). Malignant social positioning means “being positioned in a negative or undesirable way by

others” (Sabat, 2006). For persons with dementia malignant positioning is especially problematic due to cognitive, verbal, social and functional limitations that undermines their ability to re-position themselves in positive ways. Their inabilities often are due to word-finding issues, syntactic problems, and other communication concerns. Moreover, persons with dementia view themselves in progressively more defective terms and lose a sense of self-worth (Sabat, 2006). Their social identity is restricted to “the patient’s” role in this situation, and instances of appropriate behaviour often are interpreted incorrectly as being pathological (Sabat & Gladstone 2010). Malignant positioning often turns into a negative cycle, whereby the capacity of persons with dementia to deviate from this negative view is compromised fully (Sabat, Napolitano & Fath, 2004). Subsequently, the functional and verbal abilities of persons with dementia become more defined by their impairments and less validated by their capacities (Sabat et al., 2004). Such personally degrading assertions towards persons with dementia impose constraints on opportunities for interaction, leading to hindered physical and psychological activity (Ryan et al., 1995). The communication difficulties of persons with dementia contribute further to this negative representation, leading to a “loss of self” (Ryan, Byrne, Spykerman & Orange, 2005). A “loss of self” in persons with dementia refers to their compromised self-worth and self-identity, often due to losses in cognitive abilities and declines in functional autonomy (Ryan et al., 2005). Further reduction in communication and interaction with others can occur when conversation partners confine the person’s identity to their disorder (Savundranayagam, Dilley, & Basting, 2011). Therefore, an overall lack of engagement and interaction will continue to impact negatively the person with dementia’s well-being, leading to a continuous downward spiral towards depersonalization (Ryan et al, 1995).

Caregiver Burden

Communicative interactions based on negative stereotypical views commonly result in inadequate care and feelings of marginalization for both persons with dementia and their family caregivers (Watson, Aizawa, Savundranayagam & Orange, 2013). Ineffective communication between persons with dementia and their caregivers can trigger behavioural problems such as resisting care and caregiver dissatisfaction (Savundranayagam & Lee, 2017). Not only will persons with dementia feel isolated and personally degraded, but the caregiver will face feelings of being disconnected from their family members (Watson et al., 2013). Different forms of caregiver burden will result from patronizing communication when caregiving techniques to resolve communication breakdowns are applied improperly (Savundranayagam & Orange, 2011). Firstly, caregivers will face stress burden defined as a negative emotional impact on their well-being. Secondly, they will face relationship burden defined as the extent to which care for the person with dementia is perceived to be overly demanding. Finally, they will face objective burden defined as how the support they are providing infringes on other aspects of their lives (Savundranayagam, Hummert & Montgomery, 2005). Unfortunately, as dementia progresses responsive behaviours increase such as agitation, restlessness, and wandering, while at the same time communication skills continue to degrade (Savundranayagam et al., 2005). Greater burden is placed on the family caregivers as a result of problem behaviours and communication problems, impacting all three levels of burden. (Savundranayagam et al., 2005). Self-reports by caregivers show that dyadic-based communication difficulties often lead to declines in the quality of family dyadic interactions and relationships (Savundranayagam et al., 2005). The relationship between persons with dementia and family caregivers will be impacted negatively

without supportive communication, leading to further feelings of marginalization and disconnect (Savundranayagam et al., 2005).

Need for Collaboration

A growing body of literature suggests that engaging dementia-related caregivers and care recipients simultaneously in interventions may be especially promising to improve their respective well-being (Ingersoll-Dayton et al., 2013). It is important to develop collaborative activities and opportunities for communication between persons with dementia and their family caregivers in order to promote positive social interaction and preserve self-identity (Savundranayagam et al., 2011). There will be an increased likelihood of follow through and success during the interaction when persons with dementia are actively involved in developing strategies for such communication that is well-matched to their unique situations (Ryan et al., 1995). Collaboration on these decisions will help to preserve both the personal and the relational identities of each member of the dyads. With proper support and collaboration, persons with dementia will be able to engage in meaningful conversation, despite their impairments (Ryan et al., 2005). Family caregivers need to act as the conversation facilitator for persons with dementia and must obtain both the skills and attitudes to relate to their relatives with dementia rather than with the disease (Ryan et al., 2005). Avoiding a biomedical view means close emotional bonds will remain intact or will re-form within the dyad, leading to a strong sense of relationship value and self-identity (Smebye & Kirkevold, 2013).

Communication Enhancement Model

Communication education and training interventions can help to increase family caregivers' understanding of the normal aging process, thereby providing them with a new set of skills to use when interacting with persons with dementia (Ryan et al., 1995). It is important for

family caregivers to have an understanding of the large range of variables that influence the health of persons with dementia, while at the same time addressing the person's expectations and wishes (Ryan et al., 1995). The Communication Enhancement Model (CEM) (Ryan et al., 1995) is a useful model that can be used to support education and training interventions which seek to optimize communication with persons with dementia. The CEM framework helps researchers and clinicians target strategies that can be used to maximize positive and appropriate interaction between caregivers and persons with dementia (Savundrayanagam et al., 2011). Effective interaction strategies can help overcome biases and barriers to communication, while at the same time establish a structure for productive exchange of personally meaningful conversation between persons with dementia and their family caregivers (Ryan et al., 1995). When applying the CEM, it is important that caregivers use accommodated/adjusted communication that matches the personal and specific needs of persons with dementia. Optimal accommodation is done through the recognition of individual cues from persons with dementia based on their specific individual needs (Ryan et al., 1995). The CEM includes topics such as: a) optimizing on residual communication abilities of individuals with dementia, b) capitalizing on communication strengths and problem solving skills of the family caregivers, c) targeting challenging behaviours in individuals with dementia that are communication related, d) responding to changes in language, communication, and cognition over the course of the disease, and e) making adjustments to the physical and psychosocial environments that support communication (Orange & Colton-Hudson, 1998). These modifications in communication can optimize the well-being and competence of persons with dementia, while at the same time maximize opportunities for meaningful engagement and collaboration between persons with dementia and their family caregivers (Ryan et al., 1995). A sense of autonomy and competence in individuals with

dementia will be reinforced by appropriately adjusting these areas to accommodate to individual communication needs between the dyad (Savundranayagam et al., 2011).

Personhood

Kitwood's (1997) personhood aligned approach to communicating with persons with dementia greatly complements the CEM (Savundranayagam et al., 2011). Kitwood defines personhood as "a standing or status that is bestowed upon one human being by others in the context of relationships and social being. It implies recognition, respect, and trust." (Kitwood, 1997, p. 8). Sabat further states that there are three aspects of the self that forms an individual's personhood. The three elements include a) the self of personal identity, meaning the identification of a person as an individual being, b) the self of physical and mental attributes, meaning the characteristics that describe this individual being, and c) the self of multiple social identities that the person constructs with the necessary cooperation of others (Sabat, 2005). Unfortunately, persons with dementia often are negatively positioned by others, making it difficult for them to uphold these three aspects in a positive sense (Hedman, Hellström, Ternstedt, Hansebo & Norberg, 2014). Without caregivers acknowledging all three levels of the self in persons with dementia, the identity of persons with dementia becomes restricted to the role of the "dysfunctional patient" thereby resulting in a loss of personhood (Sabat, 2005). There needs to be recognition of person's needs, wants, emotions, personality, relationships, and life story in order to acknowledge these aspects of selfhood (Palmer, 2013). Negative pre-existing beliefs about aging and dementia can be dispelled as caregivers are educated and exposed to the personhood of the individuals they care for (Mileski et al., 2018). However, more often caregivers' perceptions of levels of personhood in individuals with dementia will change and diminish during severe cognitive decline (Palmer, 2013). This loss in a sense of personhood by

the person with dementia is largely due to the way that they are treated by others, with a focus shifted away from the person with dementia to the syndrome they are facing (Perry, 2005). Authors of case studies have shown that persons with dementia are still able to possess an intact social identity as well as construct new social identities with proper support from their family caregivers (Sabat, 1998). Engagement in social interaction with family caregivers can help persons with dementia construct valued and worthy social identity (Sabat, 1998). However, persons with dementia often become more defined by their impairments and less validated by their capacities despite their abilities to communicate verbally and to interact with family caregivers (Sabat et al., 2004). A negative view such as this leads to depersonalization and a loss of selfhood in persons with dementia (Sabat & Gladstone, 2010). Enhancing communication strategies that involve the acknowledgement of personhood are needed in order to enhance persons with dementias' well-being in order to avoid this loss of self-identity (Sabat, 1998).

Meaningful Engagement

It is important to promote meaningful engagement and opportunities for communication between persons with dementia and their family caregivers in order to advocate for positive interaction, to minimize communication-related burdens and to avoid loss of self-identity (Savundranayagam et al., 2011). Engagement in personally meaningful activities are an important determinant for successful aging and quality of life in older adults (Han, Radel, McDowd & Sabata, 2016). Unfortunately, persons with dementia often lack opportunities for meaningful engagement (Han et al., 2016). Lack of opportunity for persons with dementia can be due to decreased cognitive abilities, increased psychological and behavioural symptoms, perceived stigma of persons with dementia, and caregivers' perceptions of what is meaningful to persons with dementia (Han et al., 2016). Often caregivers will focus on activities that help to

maintain persons with dementias' functional abilities, rather than considering individual preferences and values (Han et al., 2016). For example, family caregivers may believe it is important to organize social activities with other older adults for persons with dementia, when persons with dementia would prefer to spend time with their family. As a result, persons with dementia have fewer opportunities to engage in activities of their choosing, leading to increased risk for depression, social isolation and further functional decline (Phinney & Moody, 2011). By understanding the perceptions of what is meaningful to persons with dementia, caregivers will better be able to support engagement in activities of their choice (Han et al., 2016). By engaging in activities of their choice, persons with dementias' psychosocial needs as well as quality of life can be maintained and/or improved (Han et al., 2016). Additionally, by minimizing social stigma towards persons with dementia, family caregiver-dementia dyads can engage in more meaningful interaction and form stronger relationship ties (Phinney & Moody, 2011).

Conversational Memory Notebooks

A common way to promote meaningful engagement and opportunities for communication between persons with dementia and their family caregivers is through a conversational memory notebook. Conversational memory notebooks contain pictures and sentences of personally relevant stimuli that help persons access content in semantic and episodic memories to use in conversation (Benigas & Bourgeois, 2011). Semantic memory involves the storage of conceptual and categorical knowledge, while episodic memory involves the storage of the detail and context of a particular experience (Mohanty, Naveh-Benjamin & Ratneshwar, 2016). Conversational memory notebooks can help access and retrieve information from both types of memory resulting in better communication between the person with dementia and caregiver (Bourgeois, Dijkstra, Burgio & Allen-Burge, 2001). Persons using conversational memory books look at both

the photo depicted in the notebook, as well as the simple active declarative sentence (e.g., The dog barked.) that corresponds to and explains what is depicted in the photo. The photo and sentence work in complimentary and compensatory ways for persons with dementia, helping to facilitate recall of the stated facts and other related information (Bourgeois, 2014).

Compensatory strategies such as memory notebooks are beneficial for individuals with cognitive impairments because they reduce demands placed on impaired abilities while also reinforcing preserved abilities (Lanzi, Wallace & Bourgeois, 2018). Memory notebooks capitalize on the remaining strengths of individuals with dementia such as reading and visual processing abilities, while reducing cognitive demands on memory (Lanzi, Burshnic & Bourgeois, 2017). By mediating these memory deficits, memory notebooks can lead to more meaningful interaction between persons with dementia and their family caregiver (Bourgeois, 2014). Researchers suggest that these memory aids increase the number of on-topic statements, decrease off-topic utterances, improve conversational turn-taking, and decrease physical agitation in persons with dementia (Benigas & Bourgeois, 2011). By including photos in the memory notebook that are connected to positive emotions, persons with dementia will recall what is occurring in the photo more often as well as experience those memories with greater intensity (van Dulmen, Smits & Eide, 2017). Memory notebooks also help to support the relationship between persons with dementia and their family caregivers by providing opportunity for enjoyable and meaningful engagement between members of the dyad (Mcallister, Dayton, Oprescu, Katsikitis & Jones, 2017). Overall, conversational memory notebooks help to increase the quality of living in persons with dementia because they act as a cognitive support for functional independence and more coherent conversations with others (Bourgeois, 2014).

Conversation based on Reminiscence Therapy

Reminiscence therapy is a psychosocial intervention commonly used for persons with dementia and involves the discussion of past activities, experiences, and events of another person or group of people (Gonzalez, Mayordomo, Torres, Sales & Meléndez, 2015). Reminiscence therapy is recognized for possessing positive impacts and therapeutic benefits towards persons with dementia (Melendez, Torres, Redondo, Mayordomo & Sales, 2017). Reminiscence therapy promotes feelings of comfort as well as reduces challenging behaviours in persons with dementia (Mileski et al., 2018). Reminiscence therapy often elicits positive effects on persons with dementias' communication and behavioural abilities (Bejan et al., 2018). It has also been found to benefit persons with dementias' cognition, personal identity and quality of living (Bejan et al., 2018). Participating in reminiscence therapy provides persons with dementia with increased opportunities to socialize (Alm et al., 2007). Conversation based on reminiscence is a useful way to structure social interaction in order to maximize positive conversation contributions by persons with dementia (Alm et al., 2007). Even though persons with dementia often suffer from working memory impairments, their long-term declarative memory is slightly more functional. By engaging in reminiscence therapy, persons with dementia are able to take advantage of their preserved long-term memory, thereby taking a more active role in conversation (Alm et al., 2007). Socializing with others allows persons with dementia to use their existing social and cognitive skills, while at the same time participate as equals in social situations (Fels & Astell, 2011). Reminiscing with others leads to a shared sense of meaning and supports putting a lifetime of experiences into meaningful perspectives (Fried-Oken et al., 2015). Conversation based on reminiscence helps to acknowledge, affirm, and place value upon life experiences, even for persons with dementia who suffer cognitive-linguistic abilities (Fried-Oken et al., 2015). The

use of prompts such as photographs of familiar events from the past are commonly used in reminiscence therapy, which can be incorporated into a memory notebook (Gonzalez et al., 2015). The content of memory notebooks can range from only a few concepts to a wide variety of different ones such as daily schedules, family history, personal care needs, or general information about individuals (Bourgeois, 2014). However, targeting personally relevant content and using this to reminisce on is one of the most common approaches to selecting the content of memory notebooks (Gonzalez et al., 2015). Reminiscence therapy also can be used as a method to help maintain self-identity and self-concept in persons with dementia, while at the same time stimulate conversation with others (Karlsson, Axelsson, Zingmark, Fahlander & Sävenstedt, 2014). When persons with dementia and their caregivers participate in reminiscence therapy together, a natural transition towards a person-centred approach to conversation often occurs (Mileski et al., 2018). By applying this therapy to memory notebooks, persons with dementia will be easily prompted to discuss past events in their lives that are important to them, allowing for meaningful communication with their caregivers and others around them (Johnson, 1997).

Electronic Conversational Memory Notebooks

Interest in technology for older adults is beginning to grow along with societies' continuous technological advances (Schulz et al., 2015). There is strong support to show that technological advances can play an important role in enhancing quality of living and independence of individuals facing illness and aging (Schulz et al., 2015). In particular, consumer electronics can be used to increase social interaction and communication for older adults (Schulz et al., 2015). Many researchers have documented that as adults age, they experience social isolation from friends and family members resulting in feelings of loneliness, depression, anxiety and loss of self-esteem (Delello & McWhorter, 2017). Persons with dementia

are at even greater risk of these negative consequences of aging due to their problems communicating (Small, Geldart & Gutman, 2000). Technology is becoming commonly used in dementia care with interventions focusing mainly on health monitoring as well as safety and security measures to provide reassurance to caregivers (Smith & Astell, 2018). However, many of these technological advances do not address the needs and priorities of persons with dementia specifically. Technologies are mainly being built on the premise of the traditional medical model (Smith & Astell, 2018). There is a need to include persons with dementias' preferences and needs in future technological compensatory systems (Smith & Astell, 2018). The majority of researchers to date who examined the use of memory notebooks in persons with dementia focused on hard copy versions (Oriani, 2003). Literature that addresses the use of an electronic form of a memory notebook versus a hard copy version indicates many benefits regarding the use of electronic versions. Electronic versions facilitate access to and retrieval of pictures stored on the device as well as pictures from the internet. This feature is beneficial because not everyone has personal photographs that they can use to remind them of events from their past. Given the embedded camera in the majority of recent electronic devices, new pictures can be taken at any point in time and added to the notebook. Further, use of technology allows persons to use or to share their stories at their own convenience, while at the same time add on to the stories and to share them with others (Park, Owens, Kaufman & Liu, 2017). Many electronic devices offer the option of audio recording a simple declarative sentence instead of just typing or writing it out, providing the added benefit of auditory inputs (Critten & Kucirkova, 2017). Persons with dementia often face age- and disease-related changes in sensory skills. It is important to have the ability to modify written and visual supports (Bourgeois, Brush, Douglas, Khayum & Rogalski, 2016). Electronic conversational memory notebook permit modifications

of written and sensory information in order to accommodate for sensory impairments (Bourgeois et al., 2016). If persons with dementia face visual impairments, the font size of the written sentences on the notebook can be increased. Additionally, if persons with dementia face auditory impairments, volume on the notebook can be increased (Bourgeois et al., 2016). Even though many people question older adults' abilities to use such devices due to the "digital divide", researchers actually find that older adults are very open to learning about using new technologies (Delello & McWhorter, 2015). Technology also can reduce challenging behaviours in persons with dementia such as anxiety, restlessness, agitation, sleep disturbances and disorientation (Imtiaz, Khan & Seelye, 2018). Researchers found that despite cognitive deficits, persons with dementia are still able to learn new information (Delello & McWhorter, 2015). However, without new stimuli and targeted cognitive interventions to learn from, their life may begin to feel empty and purposeless, leading to even further cognitive decline (Delello & McWhorter, 2015). Tablet computers such as Apple's iPad often are associated with simplicity of use due to the touch screen interface. Apple iPad simplicity provides potential for persons with dementia to use tablet computers as a part of their everyday living, particularly for those who have little or no computer experience (Lim, Wallace, Luszcz & Reynolds, 2013). Additionally, Apple iPads are quite portable and accessible. Cohen-Mansfield and colleagues (2005) noted that 73% of older adults prefer electronic memory aids to be small and compact (Cohen-Mansfield et al., 2005). Overall, digital memory notebooks can be an effective method for communication because it allows for multiple ways of conveying information (Park et al., 2017). Persons with dementia have the ability to link various items to create a dynamic and flexible communication tool (Ekström et al., 2017). With collaboration from a caregiver, electronic conversational memory notebooks can be

put together easily, learned to use and implemented with persons with dementia to facilitate conversations.

Person-Centred Communication

An additional technique that often is used to promote more meaningful dyadic conversation between persons with dementia and their family caregivers is the use of person-centred care strategies (Savundranayagam & Moore-Nielson, 2015). Person-centred communication focuses on individualized care, whereby persons with dementias' motivation and capacity are assessed, and their environment is adjusted to optimize their strengths (Savundranayagam & Lee, 2017). Person-centred care prioritizes persons with dementias' well-being first, beyond physical and custodial care (Tay et al., 2018). For persons facing complex medical conditions such as dementia, care focused on individual preferences results in more satisfactory care (Douglas, Brush & Bourgeois, 2018). Communication plays an integral role in person-centred care because it permits an understanding of and responses to the needs of persons with dementia (Williams et al., 2018). Person-centred strategies enable caregivers to gather information from persons with dementia, prompts self-disclosure by persons with dementia, and provides empathetic acknowledgement towards persons with dementia (Williams et al., 2018). Person-centred communication recognizes the individual as a person, accommodating for individual beliefs, intentions, and roles while bridging individual differences and unique qualities of the person (Williams et al., 2018). Person-centred communication puts emphasis on the desires, feelings, and needs of persons with dementia, while focusing on collaboration between carers and care receivers (Forsgren, 2017). Person-centred strategies lead to the development and maintenance of rewarding relationships that are characterized by supportive social interaction (Savundranayagam & Moore-Nielson, 2015). By engaging in person-centred communication, the

recognition of “the self” persists despite the cognitive impairments in persons with dementia, thereby supporting their levels of personhood (Kontos & Naglie, 2007). When person-centred strategies are paired with other compensatory techniques (i.e., conversational memory notebooks) they optimize individuals’ remaining functional, emotional and cognitive abilities (Lanzi et al., 2017).

Four key strategies are relevant to conversational interaction within the context of person-centred communication between persons with dementia and their family caregivers. They include: recognition, negotiation, facilitation, and validation (Ryan et al., 2005). Recognition involves identifying the person as a unique individual, for example calling them by their preferred name. Negotiation involves consulting the person with dementia on their needs and preferences, such as serving them their favourite meal for dinner. Facilitation enables the use of the person’s remaining abilities, for example helping them on a walk outside of the home. Finally, validation involves accepting the reality of another, even during misconceptions (Ryan et al., 2005). More meaningful opportunities for engagement will become available by applying these objective, conversation-based strategies to communication between persons with dementia and their caregivers. Both personal and relational identity between the dyad will be preserved (Savundranayagam et al., 2011).

Statement of the Problem

Published studies to date address how conversational memory notebooks help improve communication between persons with dementia and their family caregivers. Moreover, researchers have found that reminiscence therapy elicits positive effects on communication abilities of persons with dementia. Finally, the literature shows how the use of person-centred care strategies improves the care of older adults with dementia. However, researchers have yet to

examine the overlap between these concepts, and whether reminiscing on photos in a conversational memory notebook, specifically an electronic version, could help preserve personhood, and lead to more meaningful communication between members of a dyad, one of whom has dementia.

Aims and Research Questions

The current research study addressed four aims. The first aim was to determine whether the use of an electronic conversational memory notebook could increase the use of person-centred communication between persons with dementia and their family caregivers. The second aim was to determine whether previous knowledge and familiarity with using iPads could impact participants' abilities to apply person-centred communication to their conversations. The third aim was to determine whether participants perceived that their knowledge of person-centred communication increased after completing the study. Finally, the fourth aim was to receive an overall evaluation of the study through verbal feedback from the participants.

The following research questions were examined:

- 1) Does the collaborative use of an electronic conversational memory notebook increase the use of objective, conversation-based measures of person-centred communication in dementia family caregiver dyads?
- 2) Does previous knowledge and familiarity with using iPads impact dementia family caregiver dyads' abilities to apply person-centred communication strategies to their conversation?
- 3) Do participants perceive that their knowledge of person-centred communication increased after completing the study?

Hypotheses

The following three hypotheses were posed for the current study:

1. The collaborative use of an electronic conversational memory notebook will increase the use of objective, conversation-based measures of person-centred communication in dementia family caregiver dyads.
2. Familiarity and experience with an iPad will not impact dementia family caregiver dyads' abilities to apply person-centred communication strategies to their conversations.
3. Participants will perceive their knowledge of person-centred communication to increase after completing the study.

Chapter 2: Method

Participants

Ethics approval for the current study was obtained from Western University's Ethics Board in accordance to the Declaration of Helsinki (HSREB file number: 109725; see Appendix A). Participants included 7 dyads consisting of persons diagnosed clinically with mild or moderate clinical stage Alzheimer's dementia (AD) and a family caregiver (i.e., spouse or adult child). Participants were asked to read a letter of information and to sign a consent form if they agreed to participate in the study (see Appendices B and C). The letters of information provided a detailed breakdown of what was required to be completed by the participants during each week of the study. If persons with dementia were not able to provide their own consent, their family caregivers were able to sign for them.

The clinical diagnosis of AD was made by the attending physician of the person with AD. The sample size of the current study mirrors that of previous similar studies on memory

notebooks which showed significant results on enhanced communication (Bourgeois, 1990; 1992; 1993; 1996). Persons with a diagnosis of dementia other than AD were excluded to optimize homogeneity in participants' communication and behavioural patterns (Albert, 2008). AD is the most common form of dementia, consisting of up to 75% of all cases (Qiu et al., 2009). All participants were monolingual English speakers and writers to avoid influences of multiple languages on outcome measures.

A family caregiver also was recruited alongside their relative with AD. Family members were either a spouse or an adult child. The family member must have been directly involved in daily communication with the person with AD over the previous 12-months. Previous researchers found that spouses and adult-children comprise the majority of informal caregivers for persons with AD (Grill, Monsell & Karlawish, 2012). The participants with AD and their family caregivers were community dwelling and were recruited from the geographic areas of London and Middlesex counties of Southwestern Ontario. Participants were recruited by representatives from McCormick Home Dementia Services. Participant demographics are listed in Table 1.

Table 1.

Participant Demographics

PWD	Age (yrs)	Gender	Education (yrs)
1	52	M	12
2	79	F	14
3	67	M	12
4	83	M	12
5	58	F	12
6	86	M	11
7	63	M	15
M (SD)	69.7 (13.1)		12.6 (1.4)
FC	Age (yrs)	Gender	Education (yrs)
1	57	F	12
2	81	M	15
3	73	F	12
4	78	F	18
5	56	M	12
6	64	F	19
7	56	F	18
M (SD)	66.4 (10.8)		15.1 (3.2)

Note. PWD= Person with dementia; FC= Family caregiver

Week 1 of the study consisted of the screening the participants to confirm eligibility. The Montreal Cognitive Assessment (MoCA) was administered to participants by the researcher (KAD) directly from the iPad to screen their memory, language, and visuospatial abilities (Nasreddine, 2003). The MoCA possesses acceptable psychometric properties to screen for cognitive impairment in older adults. The MoCA demonstrates high reliability ($r = 0.92$), high concurrent validity ($r = 0.87$) and high internal consistency ($\alpha = 0.83$) (Nasreddine et al., 2005). The MoCA was administered to both persons with AD and to their family caregivers to help determine the clinical stage of the syndrome in persons with AD, as well as to screen whether the family caregivers had non-age-related cognitive impairments (see Appendix D). Participants with AD had to score below 23/30 to be considered cognitively impaired (Nasreddine, 2003).

Participants classified with mild clinical stage AD showed MoCA scores ranging from 14/30 to 23/30 (Chang et al., 2012). Participants with moderate clinical stage AD exhibited MoCA scores ranging from 8/30 to 13/30 (Chang et al., 2012). MoCA scores vary based on education levels (Chang et al., 2012). The ranges of MoCA scores for mild and moderate listed above were appropriate for the years of education of the participants. The MoCA is best at detecting mild levels of AD and has been found to be too difficult for those persons in the more severe stages of AD (Lucza et al., 2015). Family caregivers had to score at or above 26/30 on the MoCA to be eligible for the study. Participants who had completed MoCA testing within the previous six months of participating in this study did not have the MoCA re-administered. The most recent MoCA score within the previous six months was used to determine their clinical stage. Additionally, if participants had completed the Mini Mental Status Exam (MMSE) (Folstein, Folstein & McHugh, 1975) in the past 6 months, this score also was accepted and was compared to MoCA scores in order to confirm eligibility. None of the participants had completed a MoCA or MMSE within the previous 6 months.

Participants were screened for vision impairments using the logMAR Visual Acuity Chart (Bullimore, 2015). The logMAR Visual Acuity Chart is one of the five vision tests contained in the Western Regional Commemorative Vision Test (Bullimore, 2015). The logMAR Visual Acuity chart is based on the Bailey-Lovie Visual Acuity Chart. The chart is used routinely as a vision screening tool directly on electronic devices (Bullimore, 2015). The participants were asked to complete the vision screening directly on the iPad or on a MacBook Pro version 10.10.5 (see Appendix E). The participants were asked to wear their glasses if they were prescribed for reading purposes. Participants were asked to sit/stand exactly 5 feet away from the iPad/MacBook Pro 10.10.5. They then were asked to read aloud the letters on the chart.

Study eligibility required participants to read letter size 25 at a distance of 5 feet in order to be eligible to participate in the study. Letter size 25 at a distance of 5 feet corresponds to a visual acuity score of 4/20. Visual screening ensured participants' ability to see and to read from the iPad during the study.

Participants' hearing also was screened based on a commonly used and empirically based hearing screening protocol (American Speech-Language-Hearing Association, 2012) (see Appendix F). Sufficient hearing was defined as either: a) the ability to detect a 25 dB HL signal 1000, 2000, and 4000 Hz in at least one ear on a recently calibrated GSI18 portable air conduction audiometer, b) the use of a hearing device including one's own hearing aids, or c) study-provided personal amplification device (Pocket Talker Pro) for the duration of the assessment (American Speech-Language-Hearing Association, 2012). Hearing screening ensured that participants' hearing did not prevent them from engaging successfully in conversations with their family caregiver.

Participants were screened for depression based on two different standardized measures; one for the person with AD and one for the family caregiver. Persons with AD were screened using the Cornell Scale of Depression in Dementia (Alexopoulos, Abrams, Young & Shamoian, 1988). The Cornell Scale of Depression in Dementia (see Appendix G) is used to score the depression-like symptoms in persons with dementia that are observed by their family caregivers (Korner et al., 2006). It possesses acceptable psychometric properties for detecting depression in persons with dementia. The Cornell Scale of Depression demonstrates high concurrent validity ($r = 0.80$ or greater) high reliability (total scale $K_w = 0.67$) and high internal consistency ($\alpha = 0.84$) (Alexopoulos et al., 1988). Family caregivers were screened using the Caregiver Self-Assessment Questionnaire (American Medical Association, 2015). The Caregiver Self-

Assessment Questionnaire (see Appendix H) is used for the family caregiver to help determine their own levels of depression (Epstein-Lubow, Gaudiano, Hinckley, Salloway & Miller, 2010). It possesses acceptable psychometric properties for detecting depression in caregivers. The Caregiver Self-Assessment Questionnaire demonstrates high reliability ($\alpha = 0.78$), high concurrent validity ($r = 0.807$) and high internal consistency ($\alpha = 0.82$) (Epstein-Lubow et al., 2010).

Participants were asked to complete a short, three-item questionnaire developed by the researcher and her supervisor (JBO) regarding the participants' previous experiences with using an iPad. The questionnaire also contained questions that asked the participants about their previous knowledge of person-centred communication (see Appendix I). The questionnaire helped the researcher to understand how much previous experience the participants had regarding the study's main areas of focus.

Measures of relationship harmony between the dyads also were taken in order to confirm their quality of relationship. For spousal dyads the Dyadic Adjustment Scale (see Appendix J) was administered to and completed by the couple (Spanier, 1976). For child-parent dyads the Parent Adult-Child Questionnaire (PACQ) (see Appendix K) was administered and completed by the dyad (Peisah, Brodaty, Luscombe, Kruk & Anstey, 1999). Both measures possess acceptable psychometric properties. The Dyadic Adjustment Scale demonstrates high construct validity ($r = 0.93$), and high reliability ($\alpha = 0.96$) (Spanier, 1976). The Parent Adult-Child Questionnaire demonstrates high concurrent validity on all scales ($r = 0.71$ or greater) and high reliability on all scales ($r = 0.77$ or greater) (Peisah et al., 1999). Participants scoring in the normal or acceptable ranges on both measures ensured that the persons with AD and their family caregiver have close emotional bonds, could work well together and did not have marital or

relationship harmony that would influence negatively the integrity of the conversational data.

Participant screening scores are listed in Table 2.

Table 2.

Participant Screening

Participant	MoCA (max 30)	CS (max 18)	CSA (max 30)	DAS (min 107)	PACQ (min 8)	HA	VA
Person with Dementia							
1	22	6	N/A	136	N/A	pass	pass
2	16	8	N/A	142	N/A	PTP needed	pass
3	11	3	N/A	135	N/A	pass	pass
4	8	3	N/A	132	N/A	hearing aids	pass
5	10	11	N/A	117	N/A	PTP needed	pass
6	21	4	N/A	N/A	14	PTP needed	pass
7	20	0	N/A	132	N/A	pass	pass
M (SD)	15.4 (5.8)	5 (3.7)		132.3 (8.4)	14 (0)		
Family Caregiver							
1	26	N/A	9	137	N/A	PTP needed	pass
2	26	N/A	2	120	N/A	hearing aids	pass
3	28	N/A	5	108	N/A	PTP needed	pass
4	30	N/A	2	130	N/A	pass	pass
5	28	N/A	9	120	N/A	pass	pass
6	29	N/A	4	N/A	14	pass	pass
7	28	N/A	4	114	N/A	pass	pass
M (SD)	27.9 (1.5)		5 (2.9)	121.5 (10.5)	14 (0)		

Note. MoCA= Montreal Cognitive Assessment; CS= Cornell Scale of Depression;

CSA= Caregiver Self-Assessment Measure; PACQ= Parent Adult-Child Questionnaire;

DAS= Dyadic Adjustment Scale; VA= Vision Assessment; HA= Hearing Assessment;

PTP= Pocket Talker Pro

Materials

The most current version of a 2017 Apple iPad was used as the hardware platform on which the electronic conversational memory notebooks were based. The iPad was equipped with a working audio recording device to record an audio version of the written simple active declarative sentences printed beneath their matching photos. A software application called “Pictello” (AssistiveWare, 2016) was used on to the iPad to upload participants’ photos into high

resolution digital files to be used in a slideshow format, simulating the hardcopy versions of conversation memory notebooks used in previous studies by Bourgeois (Bourgeois, 1990; 1992; 1993; 1996). The Pictello software application enables photos to be uploaded in a slideshow format with a plain white background and black typed text, thus providing a clear visual for the participants (Bourgeois, 2014). Additionally, the Pictello application permits text to be audio recorded while being read, and later replayed aloud. The audio recording feature is often used for persons facing communication and language difficulties. The audio feature provides both visual support for speeches as well as to cue speech output when needed (Hoover & Carney, 2014).

Forty family photos were selected collaboratively by the persons with AD and their family caregiver. Members of each dyad selected photos based on what they considered to be meaningful personally and on what they enjoyed reminiscing the most. Previous researchers found that it is important for the family members themselves to choose the topics they would find the most enjoyable on which to reminisce (Fried-Oken et al., 2015). Twenty photos were used for the baseline phase, and 20 photos were used for the intervention phase of the study. Photos were randomized to the baseline and to the intervention phases by the researcher using a random numbers chart. Previous researchers have shown that 15 to 30 photos are optimal to create conversation based on reminiscence between members of a dyad (Bourgeois, 1990; 1992; 1993; 1996).

The photos were uploaded electronically on to the iPad using the “Pic Scanner: Scan Old Photos” application (App Initio Limited, 2018). The application takes a high quality, electronic picture of the hard copy photo to simulate the photo being scanned. Two different Pictello presentations were created, each containing 20 randomly selected photos. One Pictello presentation of 20 randomly selected photos was used for the baseline phase, and another

Pictello presentation of the other 20 randomly selected photos were used for the intervention phase.

A digital audio recording device (TasCam Dr-05) external from the iPad was used to record all dyadic conversations during all data collection sessions. Family caregivers were instructed by the researcher and provided with written instructions on how to set-up and to activate the digital audio recorder. The researcher collected weekly digital audio samples from each dyad and transferred them electronically to the Western University ITS networked research computer located in the International Consortium for Communication, Aging and Neurodegeneration (ICCAN) laboratory in Room 2595 at Elborn College.

Design

The current study followed a within-participants, prospective design whereby the participants' baseline phases were compared to their intervention phases. Within-participants design permitted the researcher to control for individual differences such as age or levels of cognitive decline. Multiple baseline phases were taken to obtain a profile of performance variability and to demonstrate experimental control and sufficient baseline stability.

Week 1 of the study included obtaining consents, screening vision, hearing and cognition, and collecting depression and marital or family harmony scores. Week 2 of the study included collecting baseline conversations from participants. Weeks 3, 4, 5 and 6 corresponded to the intervention phase of the study. All data were collected from participants while they were in their own homes. Figure 1 gives a breakdown of the timeline participants followed while completing the study.

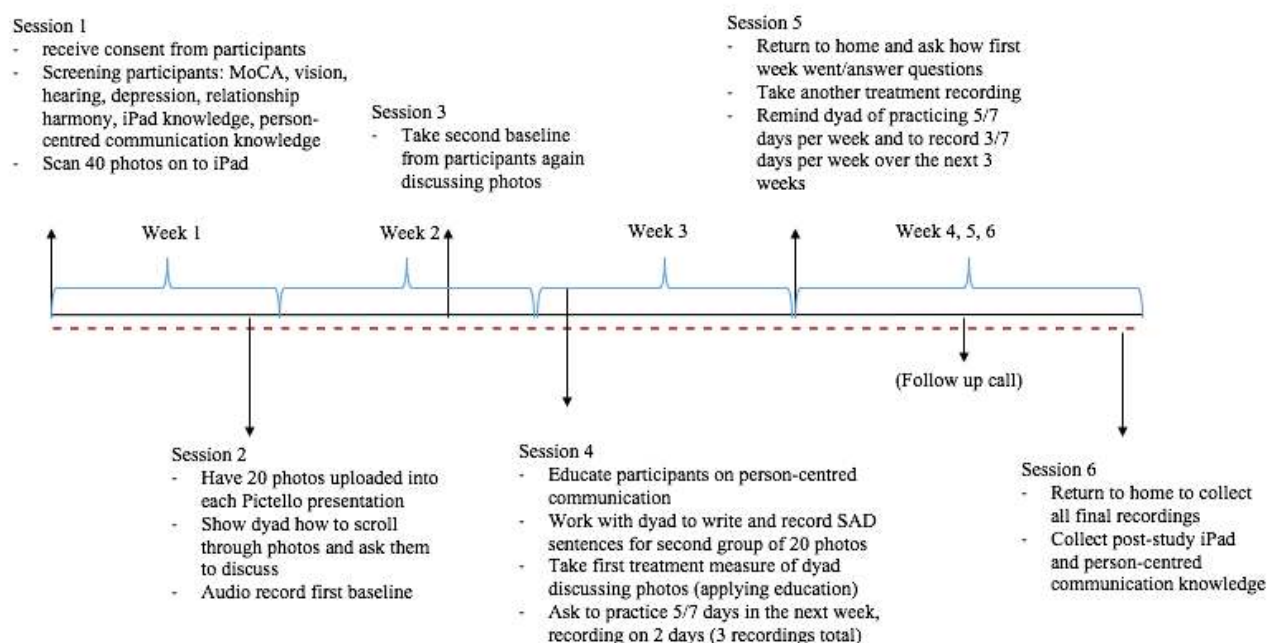
Figure 1. Study Timeline

Figure 1. Study ran over a 6-week period. Week 1 consisted of participant screening. Week 2 consisted of the baseline phase. Weeks 3 to 6 consisted of the intervention phase.

Procedure

Baseline phase.

During Week 2 of the study participants selected 40 photos from their personal photo collections depicting past life events of the person with AD and/or of the family caregiver. Eligibility criteria for the selected photos were that they had to be a minimum of 10 years from the start of the study, depicted memorable events in the lives of the participants, and at least one member of the dyad was in each photo. The 40 photos were scanned and uploaded onto the iPad using the “Pic Scanner: Scan Old Photos” software application. Twenty randomly selected photos were uploaded into the first Pictello presentation, and the other 20 photos were uploaded into the second Pictello presentation.

The researcher showed the participants how to scroll through the photos on the iPad using the Pictello software application. The participants demonstrated to her their accurate and consistent abilities to do so. The researcher also provided the participants with a written handout that included step-by-step instructions on how to use the iPad (see Appendix L). The participants then were instructed to discuss the photos with one another. The Tascam digital audio recorder was provided to the participants. The participants also were taught how to use the digital audio recorder and were given a detailed instructional handout on how to use it (see Appendix M).

The initial conversation between members of the dyad was digitally audio recorded by the researcher using the digital audio recorder. The researcher left the room while the dyad discussed the photos. The conversations lasted approximately 20 minutes or until the dyad completed discussing all 20 photos. At the end of the first baseline conversation, the researcher asked the participants to digitally audio record one (the first three dyads) or two (the last four dyads) more baseline conversations while viewing the first set of 20 photos. Two or three baseline sessions provided sufficient data to reflect the variability in participants' day-to-day conversations, and to compare performances to intervention sessions. The researcher returned at the beginning of the following week to start the intervention phase of the study.

Intervention phase.

Starting Week 3 of the study, the researcher provided a 30- to 40-minute scripted education and training session on person-centred communication, reminiscence therapy and conversational memory notebooks. The education and training session was consistent in content and format for all seven dyads. Approximately 10 to 15 minutes were allotted to each of the three topics. The researcher followed a set of PowerPoint (PP) slides during the education session (see Appendix N). The participants were given a hardcopy version of the PP slides so that they could

follow along with the researcher. Person-centred communication strategies, defining features of reminiscence therapy and the concept of memory notebooks were explained verbally by the researcher and presented in the PP slides. The education session involved both verbal explanations and examples of person-centred communication. The session provided a review of the written material in the handout that outlined defining features of the communication strategies and offered written examples (see Appendix O). The four defining features of person-centred communication outlined in the handout and measured in the study included: recognition, negotiation, facilitation, and validation (see Appendix S). The concepts of reminiscence therapy and memory notebooks also were explained by the researcher. A handout explaining the concept of reminiscence therapy and memory notebooks was reviewed with the participants and provided to them for future reference (see Appendix O). Adult learning strategies were used during the educational sessions to confirm attainment of information by the participants. For example, participants were asked to use strategies such as metacognitive monitoring, summarization and role playing to help their learning (Hock & Millard, 2011). Metacognitive monitoring involves thinking about what you have just learned, and mentally checking to see if it makes sense (Hock & Millard, 2011). Summarization involves paraphrasing main ideas and important details that were just read and/or learned (Hock & Millard, 2011). Role playing involves simulating what was just learned back to the educator in order to actively engage in the concept (Mezirow, 1997). The researcher confirmed that the participants understood the information based on using these adult learning strategies.

After the education session was completed, the second Pictello presentation was opened containing the other 20 randomly selected photos that were not used in the baseline phase of the study. For this second group of photos, simple active declarative sentences (SAD) were co-

created by the members of the dyad and the researcher for each photo. SAD sentences are best to use for persons with AD because they facilitate reading comprehension, while at the same time limit sentence length (Bourgeois, 2014). By the later stages of AD, memory loss can lead to persons forgetting the beginning of a sentence by the time they read to the end of the sentence (Bourgeois, 2014). Readers are able to understand better sentences that contain a single subject, verb and object (Bourgeois, 2014). Each SAD sentence was typed out and placed beneath each photo on the iPad screen. The SAD sentences were digitally audio recorded by the person with AD or by their family caregiver reading them aloud. There also was an alternative option to have a computerized voice within the app itself to read the sentences out loud. However, this was the less preferred option and was never used by any of the participants. A minimum font size of 24 using Arial (san serif) font type was used for the SAD sentences but was increased in size if participants stated that they experienced difficulties reading the sentences.

Once the electronic conversational memory notebook was set-up with twenty typed and digitally audio recorded SAD sentences located below each photo, the participants were asked to implement this Pictello slideshow into their conversations. The participants were instructed to apply the education they received on person-centred communication and reminiscence therapy to their conversation using the electronic conversational memory notebook. The researcher digitally audio recorded the first conversation without the researcher in the room. After 20 to 25 minutes, the researcher then returned to the room and asked the participants to practice using their electronic conversation memory notebook 4 more times that week (5/7 days), while randomly recording two of the four sessions (recording 3/5 practice sessions per week). The participants recorded on days of their choosing and were instructed to apply the person-centred communication strategies into their conversations. The participants were asked to record the date

and length of time they spent practicing using their electronic conversational memory notebook on a calendar provided to them (see Appendix P).

The researcher returned one week later (i.e., Week 4) to ask participants how their conversations went during the preceding week, to retrieve digital audio recordings, to answer any questions about the study, and to optimize continued participation. The researcher reminded participants to (1) continue to use their electronic conversational memory notebook at least 5 times/week over the next three weeks (i.e., Weeks 4, 5 and 6), (2) to record 3 of 5 conversations/week, and (3) to mark the dates and length of time they practiced on their calendars provided. The researcher called the participants 1.5 weeks later (i.e., part-way through Week 5) to follow up on how practice was going and to confirm the date and time the researcher would come to pick up all final data. At the end of Week 6, the researcher returned to collect all final recordings. The researcher asked the participants to fill out a second questionnaire asking them whether their knowledge of iPads improved, as well as whether their knowledge of person-centred communication improved. Additionally, the participants were asked to record in writing what they found to be most beneficial about the study, as well as what they found least beneficial (see Appendix Q).

The five conversational data collection sessions (i.e. baseline conversations, immediately after education and training, 1-week post education and training, 2-week post education and training, 3-weeks post education and training) were implemented to differentiate the immediate and interim effects of the interventions.. Participants were required to practice their person-centred communication skills 5 out of 7 days per week over the 4 weeks of intervention.

Transcriptions of conversations.

All digitally audio recorded conversations from the dyads (i.e., 2 or 3 baseline, 3 intervention sessions/week for 4 weeks=12) were transcribed orthographically and coded by the researcher. The conversations were segmented into utterances (Rzeczyk, 2001; Shewan, 1988) (see Appendix R) and coded by the researcher for instances of the four mutually exclusive person-centred communication strategies (see Appendix S for coding definitions). Due to technical difficulties, some participants failed to complete the requested number of audio recordings. Of the 7 dyads who enrolled in and completed the study, a total of 98 recordings were received out of a possible 102.

Tests of intra-rater and inter-rater agreement were conducted (% point-by-point agreement) to confirm that the transcriptions were valid and that the codings were being applied consistently (LeBreton & Senter, 2008). For intra-rater agreement, the researcher re-transcribed 15% of the total number of audio recordings. The researcher also segmented and coded another 15% of the total number of audio recordings to confirm consistent utterance segmentation and coding. Fifteen percent of the total number of audio recordings required the researcher to transcribe and segment 15/98 randomly chosen recordings. The researcher then coded a second set of 15 randomly chosen recordings. Two external, trained research assistants (RA) (one in undergraduate level psychology, one in 1st year master's of speech-language pathology) completed inter-rater agreements for the study. The first trained RA (undergraduate in psychology) transcribed 15 randomly selected audio recordings. The second trained RA (master's in speech-pathology) segmented and coded another 15 randomly selected audio recordings. By randomly selecting two different sets of 15 audio recordings for the two trained RA, 15% of all audio recordings were checked for transcription, segmenting, and coding. The

researcher then compared the independent transcriptions using point-by-point percent agreement scores to confirm that transcribing, segmenting and coding were judged to be similar. Agreement analysis was then calculated by dividing the total number of agreements by the total number of agreements and disagreements. Acceptable point-by-point percent agreement scores normally should range between 85 and 100% (McHugh, 2012). All inter-rater scores fell between the 85 to 100% range (see Table 3).

Table 3

Inter-rater and Intra-rater Agreements Scores

Recording	Intra-rater agreement			Inter-rater agreement		
	Transcriptions	Segmenting	Coding	Transcriptions	Segmenting	Coding
1	94	98	92	96	99	86
2	96	95	93	98	99	90
3	95	97	91	98	99	89
4	96	98	95	96	99	85
5	95	96	92	97	98	89
6	95	98	95	98	99	88
7	94	98	88	97	99	93
8	98	98	85	98	99	91
9	97	99	91	98	93	90
10	98	98	96	96	98	91
11	98	98	91	98	95	86
12	97	98	90	98	100	88
13	97	98	94	98	97	92
14	97	99	92	98	99	88
15	97	97	93	97	94	87
M(SD)	96(1.3)	98(1)	92(2.7)	97(0.8)	98(2)	89 (2)

Note. Numbers represent percentage of agreement for each transcript

Data analysis.*Aim 1, research question 1 and hypothesis 1.*

Comparisons were made between baseline scores vs. intervention scores for each of the four person-centred communication strategies. A linear mixed effects model was used to explore the change in strategy usage over the course of the study, with group (person with dementia vs.

caregiver), and time entered as fixed effects. Participant ID, Trial, and Dyad were entered as random effects. A linear mixed effects model was deemed appropriate for these analyses because it reduced concerns regarding missing data on the dependent variables (i.e., the analysis uses all available data without the need for interpolation). Additionally, linear mixed effects models are robust against violations of the assumptions of normality (Gelman & Hill, 2007). Linear mixed effects models do not pool the variance when testing for significant differences between groups. Therefore, error is acknowledged directly within group comparisons (Gelman & Hill, 2007). Three separate models (i.e., null, main effects only, and interaction) were tested for each subscale in order to distinguish the model-of-best-fit for the data. The null model consisted of the dependent variable (i.e., proportion of utterances that represented strategy usage) predicted by error (both participant ID and trial number). The main effects model tested the ability of group membership and time separately to predict self-efficacy for each subscale. The interaction model accounted for differential effects of group across time.

All statistical analyses for Research Question 1 were performed using the statistical freeware called R (R Core Team 2017), with linear mixed effects analyses conducted using the lme4 (Bates et al. 2015) and lmerTest (Kuznetsova, Brockhoff & Christensen, 2017) packages. All possible comparisons among the time periods were assessed using the lsmeans package (Lenth, 2016). An alpha level was set at 0.05.

Aim 2, research question 2 and hypothesis 2.

Descriptive comparisons were made between pre- and post- iPad knowledge scores based on participants' questionnaire reports as shown in Appendices I and Q. The Likert scale question regarding participants' previous knowledge with using an iPad from Appendix I was compared descriptively to the post-iPad knowledge Likert scale question as shown in Appendix Q. The

Likert scale question asking participants how comfortable they were with using iPads from Appendix I was used to see how much iPad training would be needed. The iPad comfortability question was not used in data comparison for study aim 2. Median scores of Likert scale data based on pre- and post-iPad knowledge were compared descriptively to see whether there was an obvious change in iPad knowledge. Descriptive comparisons were made for the persons with dementias' pre-and post-intervention scores as well as the family caregivers' pre- and post-intervention scores. Median score descriptive comparisons were deemed appropriate for this analysis because this is most accurate way of analyzing ordinal data derived from a Likert scale (Sullivan & Artino, 2013). This analysis permitted the researcher to determine whether there were any obvious differences and/or changes in iPad knowledge pre-and post-intervention. Any large changes in iPad knowledge could have potentially impacted participants' abilities to apply person-centred communication strategies to their conversations. The researcher operationalized iPad knowledge by describing the margin of change from pre-to post-intervention. The Likert scale questions included 7 rank-ordered options regarding level of iPad knowledge. A small change in median score from pre-to post-intervention represented a one-point change. A one-point change equaled $1/7$ or a 14.3% difference from pre-to post-intervention. A medium change in median score from pre-to post-intervention represented a two-point change. A two-point change equaled $2/7$ or a 28.6% difference from pre-to post-intervention. A large change in median score from pre-to post-intervention represented a 3 or more-point change. A three or more-point change equaled a minimum of $3/7$ or 42.9%.

Aim 3, research question 3 and hypothesis 3.

Descriptive comparisons were made between pre- and post-intervention perceived person-centred communication knowledge scores based on participants' questionnaire scores as

shown in Appendices I and Q. Median scores of Likert scale data were compared descriptively to see the change in perceived person-centred communication knowledge after completing the study. Descriptive comparisons were made for the persons with dementias' pre- and post-intervention scores as well as the family caregivers' pre- and post-intervention scores. Median score comparisons were deemed appropriate for this analysis because this is most accurate way of analyzing ordinal data derived from a Likert scale (Sullivan & Artino, 2013). This analysis permitted the researcher to determine whether participants perceived that their knowledge of person-centred communication changed largely. The researcher operationalized person-centred communication knowledge by describing the margin of change from pre-to post-intervention. The Likert scale questions included 7 rank-ordered options regarding level of person-centred communication knowledge. A small change in median score from pre-to post-intervention represented a one-point change. A one-point change equaled $1/7$ or a 14.3% difference from pre-to post-intervention. A medium change in median score from pre-to post-intervention represented a two-point change. A two-point change equaled $2/7$ or a 28.6% difference from pre-to post-intervention. A large change in median score from pre-to post-intervention represented a 3 or more-point change. A three or more-point change equaled a minimum of $3/7$ or 42.9%.

Chapter 3: Results

Aim 1, Research Question 1 and Hypothesis 1

Data setup.

Research question 1 asked whether the use of an electronic conversational memory notebook increases the use of person-centred communication between persons with dementia and their family caregivers. It was hypothesized that the collaborative use of an electronic

conversational memory notebook would increase the use of objective, conversation-based measures of person-centred communication in dementia family caregiver dyads.

There were five time points (i.e., one baseline, four interventions), with participants digitally audio recording 1 to 3 conversations during each week of the study. The total number of utterances in conversations were coded for each of the following person-centred communication strategies: Facilitation, Negotiation, Recognition, Validation. Each of the total number of strategy occurrences was converted into a proportion by dividing the number of occurrence by the total utterances for each participant. For example, if Participant 1 produced 400 utterances, and 50 of them were coded as “facilitation”, Participant 1’s score for this variable is $50/400 = 0.125$. A composite variable was created that represented an aggregate of all of the strategies. In other words, the values for each strategy for each participant were calculated to determine the number of times a person-centred strategy was used in conversation. Similar to the individual person-centred communication strategies, the composite variable was converted to a proportion by dividing it by the total number of utterances for that individual.

Data analysis.

Descriptives for outcome variables.

Means and standard deviations for the average proportions of use for the four person-centred communication strategies, as well as overall person-centred communication strategy use, are presented in Table 4, separated by time and participant group.

Table 4.

Average Proportions of Strategy Use Among Persons with Dementia and Caregivers Over Time

Strategy M(SD)	Time									
	Baseline		Week 1		Week 2		Week 3		Week 4	
	PWD	FC	PWD	FC	PWD	FC	PWD	FC	PWD	FC
Facilitation	0.05(0.04)	0.09(0.04)	0.05(0.04)	0.11(0.07)	0.05(0.05)	0.13(0.06)	0.05(0.04)	0.12(0.06)	0.05(0.02)	0.13(0.08)
Negotiation	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)	0.00(0.00)
Recognition	0.28(0.12)	0.38(0.13)	0.29(0.12)	0.37(0.11)	0.31(0.12)	0.38(0.11)	0.34(0.14)	0.40(0.10)	0.35(0.15)	0.36(0.08)
Validation	0.06(0.05)	0.06(0.03)	0.08(0.06)	0.05(0.03)	0.07(0.06)	0.06(0.03)	0.07(0.05)	0.06(0.04)	0.06(0.05)	0.07(0.04)
PCC total	0.40(0.10)	0.53(0.10)	0.42(0.13)	0.54(0.09)	0.43(0.11)	0.57(0.09)	0.46(0.12)	0.58(0.11)	0.45(0.14)	0.56(0.07)

Note. Table 4 represents the proportion of each person-centred strategy participants used over the course of the study, as well as a collapsed proportion of all 4 strategies. The table separates persons with dementia and family caregivers. The table also shows the increase in strategy use from baseline to intervention. PWD = Person with dementia; FC = Family caregiver; PCC = Person-centred communication

Testing the model.

The main effects model was significant, $\chi^2(5) = 20.78$, $p = 0.00089$. However, the interaction model was not significant when compared with the main effects model $\chi^2(4) = 1.18$, $p = 0.8812$. The results show that while there are statistically significant differences on the main effects of Group or Time, there is no significant difference between the Groups in terms of their performance over Time.

Given that the main effects model is statistically significant, further analyses were conducted to determine where the significant differences occurs. Group was examined as the simplest main effect because it consists of only two levels (i.e., persons with dementia and family caregivers). The main effect of group was statistically significant, $t(12.03) = 2.82$, $p =$

0.0154. Persons with dementia used significantly fewer person-centred communication strategies than did family caregivers.

The same type of analysis was conducted to evaluate the effects of the intervention over Time, averaged across the persons with dementia and family caregivers. Each intervention time (i.e., Intervention weeks 1, 2, 3, and 4) was compared with the baseline. Findings showed that all times from Time 2 onwards are significantly greater than baseline. Week 2 was significantly different than baseline $t(176.4) = 2.18, p=0.0307$. Week 3 was significantly different than baseline $t(176.2) = 3.25, p = 0.0014$. Week 4 was significantly different than baseline $t(174.4) = 2.6, p = 0.0101$.

None of the pairwise comparisons between times are statistically significant (see Table 5). The pairwise findings show that all of the statistically significant gains in technique usage are in place by Week 2, and performance plateaus at that point.

Table 5.

Pairwise Comparisons of Week-to-week Person-centred Communication Strategy Use

Comparison	P-Value
Baseline - Week 1	0.8772
Baseline - Week 2	0.1925
Baseline - Week 3	0.0121
Baseline - Week 4	0.749
Week 1 - Week 2	0.7018
Week 1 - Week 3	0.1241
Week 1 - Week 4	0.4134
Week 2 - Week 3	0.8139
Week 2 - Week 4	0.99
Week 3 - Week 4	0.9755

Note. P-value adjustment- tukey method for comparing 5 estimates

Figure 2. Participant use of Person-centred Communication Strategies over Time

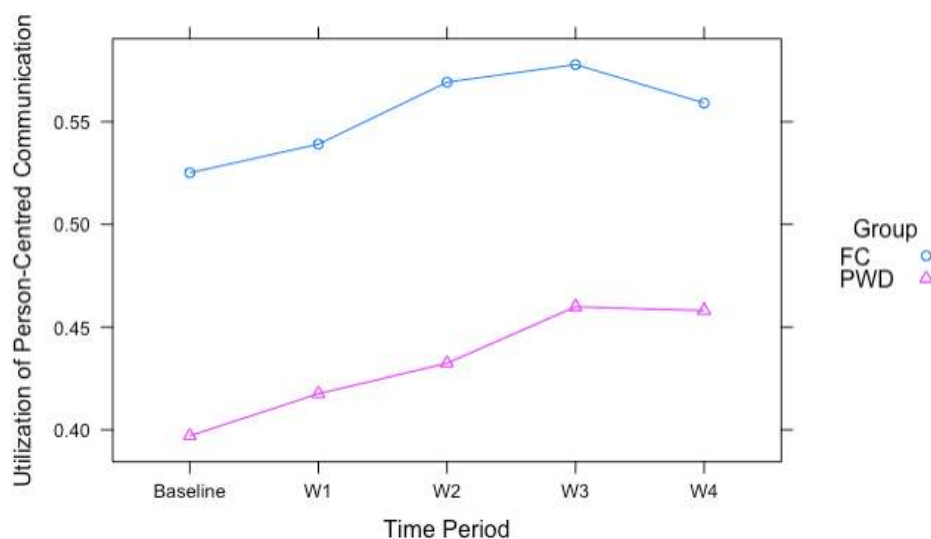


Figure 2. Proportion of utterances representing person-centred communication strategies used by persons with dementia and family caregivers over 5-week period. (baseline to Week 4 intervention). W = week.

Figure 2 illustrates that both persons with dementia and family caregiver increase their use of person-centred communication strategies over the course of the intervention. In addition, Figure 2 shows that both groups change their use of person-centred communication strategies in a similar pattern over time. Finally, Figure 2 illustrates the substantial difference in strategy use between groups (i.e., family caregivers use substantially more person-centred communication strategies).

Overall, hypothesis 1 is supported based on the findings. The collaborative use of an electronic conversational memory notebook resulted in a significant increase in the use of objective, conversation-based measures of person-centred communication in dementia family caregiver dyads.

Differences in Strategy Use

It is useful to note the differences in person-centred strategy use when comparing the four main categories. Based on the proportion values outlined in Table 4 you can see that recognition was the most commonly used person-centered strategy. This may be due to the fact that conversations often focused on the person's family, life and situational context. Facilitation and validation also contributed to the total proportion of person-centred strategy use. Facilitation was used in dyad conversations to enable conversations to continue. Facilitation was used by family caregivers to support their family member with dementia to continue talking. Validation was used throughout the conversations when members of the dyad acknowledged or supported the other persons' feelings about the photo. Validation was particularly obvious when conversations focused on family members. Based on the proportions outlined in Table 4, negotiation proportions were 0. Out of all 98 conversations, the 7 dyads only used the negotiation person-centered strategy for only a combined total of 60 times over the entire study. This particularly low use may be due to the fact that negotiation is very task oriented and therefore is not as applicable to conversations based on family photos. Additionally, all family members participating in the study had strong relationship ties. There may have been a reduced need to consult or to negotiate with each other regarding needs and preferences if family members already had strong understandings of one another's individual qualities. Examples of each person-centred strategy obtained from participants' conversations are shown in Table 6.

Table 6.

Transcript Examples of Person-Centred Communication Strategies used by Persons with Dementia (PWD) and Family Caregivers (FC)

Person-centred communication Strategy	Example
Recognition	This is at your mom's house. (PWD) That's dad's second youngest sister. (FC) That's her boyfriend Dan. (FC)
Facilitation	Didn't we go visit Paige and Baylee when we went there? (FC) Is that the mountains back there? (PWD) What was your favourite part about our wedding? (FC)
Negotiation	Okay shall we go to the next picture? (PWD) Do you want me to get your glasses? (FC) You turn the page when you're ready. (FC)
Validation	That is a nice picture. (PWD) I always look forward to visiting the grandchildren. (FC) Everybody looks good.(PWD)

Note. Randomly selected examples of person-centred communication use directly from the participant transcripts. Names do not represent actual participants.

Aim 2, Research Questions 2 and Hypothesis 2

Research question 2 asked whether previous knowledge of and familiarity with using iPads could impact participants' abilities to apply person-centred communication to their conversations. It was hypothesized that familiarity and experience with an iPad would not impact dementia family caregiver dyads' abilities to apply person-centred communication strategies to their conversations.

Participants were asked to complete a study-specific measure of their knowledge of using an iPad pre- and post-intervention (see Appendices I & Q). Table 7 shows participants pre- and post-intervention scores.

Table 7.

Pre- and Post-Intervention iPad use Knowledge and Person-centred Communication Knowledge

<u>Participant.</u>	<u>Pre</u>		<u>Participant</u>	<u>Post</u>	
PWD	iPad knowledge	PCC knowledge	PWD	iPad knowledge	PCC knowledge
1	7	4	1	4	7
2	4	3	2	5	6
3	3	2	3	4	5
4	1	1	4	4	4
5	2	4	5	4	4
6	1	2	6	7	6
7	5	2	7	6	5
Median (SD)	3 (2.2)	2 (1.1)	Median (SD)	4 (1.2)	5 (1.1)
<u>Participant</u>	<u>Pre</u>		<u>Participant</u>	<u>Post</u>	
FC	iPad knowledge	PCC knowledge	FC	iPad knowledge	PCC knowledge
1	3	3	1	4	5
2	3	2	2	5	6
3	5	2	3	5	6
4	1	1	4	6	6
5	6	4	5	4	5
6	5	3	6	4	5
7	6	1	7	4	7
Median (SD)	5 (1.9)	2 (2.1)	Median (SD)	4 (0.8)	6 (0.8)

Note. PWD = Person with Dementia, FC = Family Caregiver,

PCC= person-centred communication

Data analysis.

Participants' pre- and post-intervention iPad knowledge scores did not largely change based on median score descriptive comparisons. Both persons with dementia and family caregivers' median iPad knowledge scores changed by 1-likert point from pre-to post-

intervention. As shown in Table 7, persons with dementias' median score increased by 1, and family caregivers' median score decreased by 1. Therefore hypothesis 2 was supported.

Familiarity and experience with an iPad did not largely influence dementia family caregiver dyads' use of person-centred communication strategies.

Research Question 3 and Hypothesis 3

Research question 3 asked whether participants perceived that their knowledge of person-centred communication increased after completing the study (see Appendices I & Q). It was hypothesized that participants would perceive that their knowledge of person-centred communication increased after completing the study. Table 7 shows participants pre- and post-intervention scores.

Data analysis.

Participants' person-centred communication knowledge pre- and post-intervention scores were largely different based on median descriptive comparisons. Persons with dementia showed a large increase in person-centred communication knowledge, with the median increasing by 3 Likert points. Family caregivers also showed a large increase in person-centred communication knowledge, with the median increasing by 4 Likert points. Therefore, hypothesis 3 is supported. Participants perceived their knowledge of person-centred communication increased as a result of participating in the study.

Study Aim 4

The fourth aim of the current study was to obtain feedback from participants regarding their overall impression of the study. Participants were asked what they found to be the most beneficial and the least beneficial of the study.

Positive participant reports.

Participants reported both verbally and in writing that they enjoyed using the electronic conversational memory notebook during the study. They stated that they did not find the iPad difficult to use and were open to learning new technology. Participants also found the electronic version to be very accessible, keeping photos organized in a concise manner. Participants found the technology to be beneficial by including both the visual of the photo as well as the audio of the simple active declarative sentence. Participants reported that they found the simple active declarative sentence written beneath each photo helpful to prompt their memory. The majority of the participants reported that they found the audio of the simple active declarative sentence being read aloud helpful to jog their memory and promote conversation. Participants noted that they preferred viewing the photos in an electronic format rather than in hard copy versions. Specifically, participants found the Pictello software simple to use. Many participants took interest in using similar software to organize their family photos in the future. Overall participants reported that electronic versions of memory notebooks should be used for future studies.

Participants reported that they enjoyed viewing the photos on the iPad with one another. Viewing the photos on the iPad enabled the family members to spend quality time together, while giving them the opportunity to reminisce on events from the past. Participants found that by viewing the photos, multiple topics for conversation would arise, allowing for long and enjoyable conversations. Participants also reported their relationship with their family member felt closer (i.e. improved bonding) as a result of holding conversations about the photos. Finally, participants reported that they found the topic of person-centred communication to be beneficial

and interesting to learn about. Participants enjoyed working with their family member while practicing to apply the strategies together.

Negative participant reports.

Participants most commonly reported that too few photos were used. Participants found the 40 photos to become quite repetitive after continuous practice. Participants especially found the second group of 20 photos that were used during the intervention phase to be quite repetitive. Family caregivers reported that they often had low motivation to practice using the photos in the latter weeks of the study. However, the family caregivers also stated that once they began viewing and discussing the photos, their low motivation dissipated. Finally, participants reported a difference in ease of conversation depending on what is depicted in the photo being viewed. Photos that depicted action events (i.e., family vacations) provided more conversational context. Photos only depicting people (i.e., posed family portrait) were more difficult for participants to discuss between one another over a long period of time.

Chapter 4: Discussion

Aim 1, Research Question 1 and Hypothesis 1

The first aim of the study was to determine whether the use of an electronic conversational memory notebook increased the use of person-centred communication strategies between persons with dementia and their family caregivers. It was hypothesized that the collaborative use of an electronic conversational memory notebook would increase the use of objective, conversation-based measures of person-centred communication in dementia family caregiver dyads.

Main effects model.

The findings of this study support the use of electronic conversational memory notebooks to increase the use of person-centred communication strategies. Hypothesis 1 was supported. Both persons with dementia and their family caregivers increased their use of person-centred communication over time using the electronic conversational memory notebook. The results suggest that educating and training dyads on person-centred communication and asking them to apply the strategies they learned to their conversations using an electronic device is beneficial. Previous evidence shows that opportunities for more meaningful engagement and positive dyadic conversation among persons with dementia and their caregiver can arise when using person-centred communication strategies (Savundranayagam & Moore-Nielson, 2015).

Positive dyadic conversations emerged for the participants in this study because conversations became more person-centred over time. Person-centred communication strategies help optimize communication with persons with dementia (Murray & Boyd, 2009). By engaging in person-centred communication, family caregivers are able to prioritize persons with dementias' well-being while also promoting their strengths and values (Tay et al., 2018). Recognition of self-identity persists when prioritizing persons with dementias' well-being (Kontos & Naglie, 2007). Recognizing the self-identity of persons with dementias is integral to reducing their identity within the "patient role" (Kontos & Naglie, 2007). Stereotypical "patient roles" can be diminished by engaging in person-centred communication which, in turn, increases levels of personhood among persons with dementias (Kitwood, 1997).

Additionally, memory notebooks capitalize on the remaining strengths of individuals with dementia while simultaneously reducing cognitive demands on their memory (Lanzi et al., 2017). Memory notebooks support the relationship between persons with dementia and their

family caregivers by mediating memory deficits (McAllister et al., 2017). Persons with dementia in this study were able to recall information better by viewing the photos in the electronic conversational memory notebooks and by hearing and seeing a supportive simple active declarative sentence. Opportunities for meaningful engagement emerged due to the reduced visual and auditory cognitive loads placed on the participants with dementia and on their family caregivers.

The finding that both members of the dyad were able to increase their use of person-centred communication while using an electronic conversational memory notebook further suggests that persons with dementia should be included in education and training programs alongside their family caregivers. This finding supports previous reports by Delello and McWhorter (2015) who found that despite cognitive deficits, persons with dementia are still able to learn new information. Additionally, a growing body of literature suggests that simultaneously engaging the caregiver and care recipient in interventions may improve both persons' well-being (Ingersoll-Dayton et al., 2013). The benefits of involving persons with dementia in education and training were proven in this study due to both members of the dyads' abilities to engage in person-centred communication. Particularly, Ryan and colleagues (1995) stated that there is an increased likelihood of success when persons with dementia are actively involved in developing conversation strategies. The current study focused directly on communication strategies that would benefit both persons with dementia and their family caregivers. By involving persons with dementia in the education and training sessions, members of the dyad were able to work together, while adapting to each other's specific conversational needs and preferences.

An additional implication related to the main effects model finding is the resulting impact on caregiver burden. Family caregivers often face burden when dealing with

conversational difficulties (Watson et al., 2013). However, if persons with dementia also are able to adopt person-centred communication strategies and apply them to conversations with their caregiver, burden may be reduced. To be person-centred is to focus on collaboration between the carer and the care receiver (Forsgren, 2017). If both persons with dementia and family caregivers are able to apply person-centred communication strategies to their conversation, more meaningful engagement can occur, and stronger relationship ties can form. Further, strong relationship ties between persons with dementia and their family caregivers help to reduce caregiver burden (Tough, Brinkhof, Siegrist & Fekete, 2016).

Note. Randomly selected examples of person-centred communication use directly from the transcripts. Names do not represent actual participants.

Group differences.

Results showed that persons with dementia did apply significantly fewer person-centred communication strategies than did their family caregivers. This finding aligns with the fact that family caregivers play the primary role of assisting to maintain persons with dementias' levels of personhood (Kitwood, 1997). Family caregivers are to act as the conversation facilitators in order to support persons with dementias' well-being (Ryan et al., 2005). By engaging in person-centred communication the recognition of "the self" persists despite the cognitive impairments that persons with dementia face (Kontos & Naglie, 2007). The results from this study show that family caregivers aligned with their roles and were able to apply person-centred communication strategies successfully within their conversations. As family caregivers used a larger portion of person-centred strategies than persons with dementia, it is likely that family caregivers did in fact support the personhood of their family members with dementias. However, considering that persons with dementia also were able to apply person-centred communication strategies to their

conversation, it is important note that they did have an impact on improving conversation within their dyad.

The finding that family caregivers used more person-centred communication strategies than persons with dementia provides insight to the study's relationship with the Communication Enhancement Model. Kitwood's (1997) personhood aligned approach to communicating with persons with dementia greatly complements the Communication Enhancement Model (Savundranayagam et al., 2011). By applying person-centred communication to conversations, family caregivers can elicit a positive cycle of interaction as noted by Ryan and colleagues (1995). The Communication Enhancement Model states the importance of the family caregiver using appropriate accommodation of communication that matches the needs of the person with dementia. Optimal accommodation is reached through recognizing individual cues from the person with dementia, and making specific adjustments based on individual needs (Ryan et al., 1995). Person-centred communication strategies support this positive cycle because of the focus on the individual person. Recognition involves identifying the person as a unique individual, thereby supporting the autonomy of persons with dementia. Negotiation involves consulting persons on their needs and preferences, allowing persons to take part in their own decision making. Facilitation enables the use of persons with dementias' remaining abilities, which is useful to help modify communication and assist in conversation continuation. Validation acknowledges the reality of persons with dementias' emotions, which can in turn authenticate what is being said and therefore maximize feelings of support (Ryan et al., 2005). Once family caregivers are able to apply these strategies within their conversation, a positive feedback loop can occur (Ryan et al., 1995). The feedback loop will, in turn, lead to optimized communication and well-being for persons with dementia. The positive feedback loop can continue by having

family caregivers continue to apply person-centred communication to their conversation with persons with dementia.

Finally, family caregivers participating in the study did not face obvious cognitive impairments. All family caregivers were screened as normal, age-appropriate on the MoCA before beginning the study (see Table 2). Therefore family caregivers had cognitive advantages over persons with dementia and were expected to be able to apply person-centred strategies to their conversation at a higher rate.

Time differences.

The finding that significant increases in person-centred communication strategy use were found over time, especially in place by week 2, has important implications for future education and training programs. Based on these results, persons with dementia and family caregivers were able to learn and to use person-centred communication strategies successfully within their conversations following a short-term practice period. Participants were asked to practice applying person-centred communication strategies to their conversation 5 times per week over a 4-week period. However, participants were able to maximize their ability to use the strategies by the second week suggesting that they are able to learn and apply the strategies quite quickly. This finding is beneficial for future studies because it is useful to know that persons with dementia and family caregivers are able to apply person-centred communication with a short-term length of practice. However, quick ability to apply person-centred strategies may be due to the way the education and training session was completed. Adult learning strategies were used throughout the education and training sessions. The strategies used included metacognitive monitoring, summarization and role-playing. Metacognitive monitoring involved asking participants to think about what they had just learned, and mentally checking to see if it made sense (Hock &

Mellard, 2011). Participants also were asked to summarize main ideas that were taught (i.e., the four person-centred communication strategies). Finally, participants were asked to simulate what was learned back to the researcher through role-playing in order to confirm active engagement in the concept (i.e., practice using the 4 person-centred strategies) (Mezirow, 1997). By facilitating the participants to actively engage in the education and training they received, their learning became more self-directed. Adult learning tactics such as described were beneficial for both persons with dementia and family caregivers. All dyads were able to engage quickly in the material being provided to them. If the researcher had used a lecture styled learning tactic, participants may not have been able to apply the person-centred communication strategies as efficiently.

Participants used high levels of person-centred communication strategies during baseline phases. Of the utterances produced by family caregivers, 53% were person-centred during baseline. Of the utterances produced by persons with dementia, 40% were person-centred during baseline. The baseline statistics provide support that the participants in this study already conversed with one another in highly person-centred ways. All participants consisted of family caregivers (6 spouses, 1 daughter) who had quite harmonious relationships. All participants met relationship-harmony screening requirements in order to be eligible to participate in the study (see Table 2). Person-centred communication involves both focusing on the individual, while focusing on collaboration between the caregiver and the care receiver (Forsgren, 2017). Being person-centred is likely simpler for persons who already have close relationship ties due to the ease in ability to collaborate and focus on one another's individual qualities. Harmonious relationships could explain further why participants plateaued on ability to apply person-centred communication skills by Week 2. With participants already using high rates of person-centred

strategies during baseline phases, it would be difficult for them to continuously increase strategy use over the next four weeks. When comparing relationship levels to formal caregivers such as nurses and personal support workers, formal caregivers do not have the advantage of already having a strong relationship with the care receiver. Persons with dementia and family caregivers may have advantages in their abilities to apply person-centred communication strategies to their conversations as a result of their relationship closeness.

An additional explanation for why both persons with dementia and family caregivers use high amounts of person-centred communication strategies to begin with could be due to the conversation topics. Participants were asked to view family photos on iPads and reminisce on topics that came to mind based on the photos. Reminiscing on family photos already is a very person-centred task due to specific discussion about family and friends in the photos. In particular, there were high levels of the person-centred strategy “recognition”. Recognition is defined as acknowledging a person, the persons family, their life, their day, or their situational context. Participants’ family photos consistently brought up conversational topics that involved the persons’ lives, family, and situation contexts (e.g., vacations). The requirement to reminisce on family photos for the study may support why levels of person-centred communication began so high during baseline phases, resulting in non-significant week-by-week comparisons.

Interaction effects model.

There were no significant differences between persons with dementia and family caregivers in terms of their use of person-centred communication strategies over time. The interaction effects model showed us that although persons with dementia used substantially fewer person-centred communication strategies (i.e., baseline started at a much lower proportion)

they were able to make a steady increase in strategy use over the course of the study. This finding supports the hypothesis that both persons with dementia and family caregivers would be able to apply the education and training they received to their conversations. It was expected that family caregivers would be using higher proportions of person-centred communication strategies. It was expected that family caregivers would do so in order to fulfill their role of helping to preserve their family member with dementia's level of personhood (Kitwood, 1997). Additionally, family caregivers participating in the study did not face substantial cognitive impairments and therefore had the advantage to learn and to apply more easily the person-centred communication strategies. It was promising to find that persons with dementia also were able to increase the use of the person-centred communication strategies at a steady rate following an education and training session. Persons with dementia face the added challenge of cognitive impairments when trying to apply person-centred communication strategies. Persons with dementia were expected to use a lower proportion of person-centred strategies at baseline and were expected to increase the proportion of person-centred communication strategies over time. The study findings support the fact that persons with dementia are still able to learn new information, despite their cognitive impairments (Delello & McWhorter, 2015).

Both persons with dementia and family caregivers being able to increase their use of person-centred communication strategies further supports the assertion that persons with dementia should be included in communication enhancement education and training programs. Without new stimuli and targeted cognitive interventions for persons with dementia to learn from, their life may begin to feel empty and purposeless, leading to further cognitive decline (Delello & McWhorter, 2015). The exclusion of persons with dementia from education and training contradicts the idea of person-centred care. Being person-centred is based on the premise

that personhood is formed in relation to others (Kitwood, 1997). To be person-centred is to put emphasis on the person with dementia's preferences, feelings, and needs, while focusing on collaboration between the carer and the care receiver (Forsgren, 2017). By providing education to both persons with dementia and family caregivers in the study, dyads were not only able to increase their use of person-centred strategies at similar, steady rates, but also were able to work collaboratively.

Aim 2, Research Question 2 and Hypothesis 2

The second aim of the study was to determine whether previous knowledge and familiarity with using iPads could impact participants' abilities to apply person-centred communication to their conversations. Hypothesis 2 was supported. Familiarity and experience with iPads did not impact dementia family caregiver dyads' abilities to apply person-centred communication strategies to their conversations.

The finding that iPad knowledge did not impact participants' abilities to apply person-centred communication to their conversation is an important result. The aim of using an electronic conversational memory notebook version over a hard copy version was simply to test new technological advances in the field of dementia and communication (Bourgeois, 2014). Using an iPad as the memory notebook hardware platform could distract participants and impact their ability to apply the person-centred communication techniques to their conversation. However, after meeting with the participants, the majority of them had some prior experience with using iPads. There was no statistical significance pre- and post-intervention relative to iPad knowledge. Thusly, the electronic version of a conversational memory notebook did not impact person-centred communication strategy use among participants in this study.

Aim 3, Research Question 3 and Hypothesis 3

The third aim of this study was to determine whether participants perceived that their knowledge of person-centred communication increased after completing the study. Hypothesis 3 was supported. Participants perceived their knowledge of person-centred communication to increase as a result of participating in the study.

An increase in self-perceived person-centred communication knowledge was expected following the education and training session that was provided to all participants. Additionally, an increase in self-perceived person-centred communication knowledge was expected due to the time period over which the participants were asked to practice applying the strategies using their electronic conversational memory notebook.

Participants' increase in perceived knowledge and abilities to apply person-centred communication strategies was an important finding for this study. It is beneficial that participants were not only able to increase their use of person-centred strategies from baseline to intervention (as per hypothesis 1), but also perceived that their knowledge of person-centred communication increased (as per hypothesis 3).

The findings supporting hypothesis 1 and 3 suggest that person-centred education can be provided to informal family caregivers living at home. Previous researchers have focused on providing person-centred education sessions to formal caregivers in long-term care settings. However, the family caregivers in this study reported that they were able to learn and to apply the person-centred communication strategies provided to them. The family caregivers' reports supports the assertion that informal caregivers also can aim to make their conversations more person-centred directly at home. Additionally, participants diagnosed with dementia reported that their knowledge of person-centred communication increased after completing the study. This

novel finding also supports the position that persons with dementia can play an integral role enhancing communication within the home.

Study Aim 4

Participants' reports on their overall impressions of the study were important to help identify the main strengths and limitations of the protocol. Participants were asked to identify what they liked about the study as well as what they did not like. Written reports from the participants regarding strengths and limitations have important implications for future studies that look at the use of electronic conversational memory notebooks and/or person-centred communication. Participant reports are summarized in the strengths and limitations sections below.

Strengths

Participants enjoyed using the electronic conversational memory notebook and did not find it difficult to use during the study. These findings support the fact that older adults as well as adults facing cognitive impairments are able to learn and to adapt to the use of new technologies (Delello & McWhorter, 2015). Even though many people question older adults' abilities to use electronic devices such as iPads due to the "digital divide", results from this study prove that electronic devices can be beneficial for enhancing communication among persons with dementia and their family caregivers. Participants reported that they found the technology to be beneficial especially using digital displays of the photos and the audio recordings of the simple active declarative sentences. The digital photos and the audio sentences working as a compensatory system to prompt memory supports previous findings by Bourgeois (2014). Participants preferred viewing the photos in an electronic format rather than in hard copy versions due to their neat and concise layout. Participants liked the way in which photos were organized within

the Pictello software in particular. Reports of concise layout align with previous researchers who have shown the benefits of electronic photo formats, including organization and easy accessibility (Park et al., 2017). Further, participants enjoyed viewing the photos on the iPad with one another. Viewing the photos on the iPad permitted the family members to spend quality time together, while also giving them a reason and the opportunity to reminisce on personally-relevant events from their past. These findings suggest that prompts such as photographs are beneficial to help support conversation based on reminiscence (Gonzalez et al., 2015).

Participants found that by viewing the photos, multiple topics for conversation arose, supporting lengthy and enjoyable conversations. The majority of the participants found the audio recording playback option of the simple active declarative sentence helpful to jog their memory and to prompt conversations. Auditory playback options within the electronic conversational memory notebook were beneficial for participants because it permitted accommodation for sensory and cognitive (i.e., working memory) impairments (Bourgeois et al., 2016). The addition of auditory playback options for electronic conversational memory notebooks further supports the concept of both audio and visual inputs working together to assist persons with dementia viewing (and listening to) the photos (Critten & Kucirkova, 2017). Participants enjoyed viewing and conversing on the photos because it allowed for the dyad to work on a task together that did not involve basic activities of daily living. Participants stated that as a result of bonding over the photos, their relationship felt closer. Feelings of relationship closeness emphasize the importance of promoting meaningful engagement between persons with dementia and family caregivers (Savundranayagam et al., 2011). By promoting meaningful interaction, stronger relationship ties can begin to form (Phinney & Moody, 2011). Overall participants agreed that electronic versions of conversational memory notebooks should be used for future studies due to the benefits

described above. Finally, participants' reports on the concept of person-centred communication also were positive. Participants enjoyed practicing to apply the strategies to conversation with their family members. Enjoyment of time spent together further supports the importance of collaboration between caregivers and care receivers (Savundranayagam et al., 2011). By working together on applying person-centred communication strategies conversations, opportunities for more meaningful engagement occurred for all participants.

Limitations

A limitation that was not reported by participants but was noted by the researcher was the small sample size. It is difficult to generalize results with this size of sample. Statistical power is also limited with this size of a sample. A larger sample size would increase statistical power (Lin & Lucas, 2013). However, previous researchers who have examined the use of memory notebooks with persons with dementia have used similar sample sizes (Bourgeois, 1990; 1992; 1993; 1996). The number of photos for participants to reminisce on was an additional limitation to the study. Participants found the 40 photos to be too few. Reminiscing on the same 40 photos become quite repetitive for the participants after continuous practice. Participants especially found the second group of 20 photos that were used during the intervention phase to be quite repetitive, particularly after 4 weeks of practice. Previous researchers in this field reported that 15 to 30 photos are optimal to create conversation based on reminiscence (Bourgeois, 1990; 1992; 1993; 1996). However with advances in technology it may be easier for persons to access family photos now than it did in the early 1990s as per Bourgeois' previous work. The issue of the repetitiousness of the photos was reported mainly by the family caregivers. Reports of repetition by persons with dementia ranged depending on the severity of their dementia. Persons who scored in the mild clinical stages of AD reported that the photos were repetitive. However,

participants with AD who were rated as being in the moderate clinical stage did not report this. This may be due to their lack of recall of viewing the same photos on several occasions. Family caregivers specifically reported that they often lacked motivation to practice using the photos in the latter weeks of the study. Lack of motivation by family caregivers again relates to the issue of photo repetition. However, the family caregivers also stated that once they began viewing and discussing the photos, their lack of motivation declined. Finally, participants reported a difference in ease of conversation depending on what is depicted in the photo being viewed. Photos that depicted action events (i.e., family vacation) provided more conversational context. Photos only depicting people (i.e., posed family portrait) were more difficult for participants to discuss between one another over a long period of time. Future studies could specify that photos used in the memory notebook are to contain more action-oriented events. More elaborate memories could be prompted within members of the dyad by specifying the type of photo, thereby allowing for ease in conversation.

Future Implications

The findings of this study support the hypothesis that electronic conversational memory notebooks can be used to increase the use of person-centred communication strategies between members of family-based dementia dyads. This is the first study to overlap the use of a conversational memory notebook with the use of person-centred communication strategies between persons with dementia and their family caregivers. More specifically, this is the first investigation to study an electronic conversational memory notebook format using Pictello software (AssistiveWare, 2016). Future studies should examine electronic forms of conversational memory notebooks in further detail. For example, electronic conversational memory notebooks could be implemented in long-term care settings. Formal caregivers could

use electronic conversational memory notebooks to gain a better understanding of persons with dementias' individual qualities. Person-centred care strategies could emerge from recognizing individual qualities of the persons with dementia. Videos could be implemented into electronic conversational memory notebooks. For example, a video showing the person with dementia's grandchildren could be uploaded into the notebook. A simple active declarative sentence depicting what is occurring in the video should also be included. Electronic conversational memory notebooks could be used to assist persons with dementia regarding basic activities of daily living. For example, photos could include depictions of their home, what grocery store they like to shop at, or what types of food they like to eat. Based on participant reports, an electronic version is preferred over a hard copy version. With societies continuous advances in technology, photographs are being viewed electronically more often than in hard copy. It is integral for researchers to look further into the use of electronic conversational memory notebooks for future generations to come, who solely rely on electronics. Finally, this is the first study to apply the use of person-centred communication strategies directly to in-home family caregivers. The use of person-centred communication strategies including: facilitation, negotiation, recognition, and validation have, to date, only been studied using formal caregivers in long-term care studies. Results of this study provided evidence that both persons with dementia and family caregivers living at home were able to learn and to apply person-centred communication strategies in their conversations. The dementia-family caregiver dyads' conversations were enhanced by doing so. Future studies should look further into the use of person-centred communication strategies directly with in-home family caregivers. Long-term effects of the education and training should be examined. Researchers should examine how long continuous use of person-centred communication can be achieved (i.e. 2 months later). Future studies should also examine the

impact of electronic conversational memory notebooks and person-centred communication strategies on caregiver burden. Meaningful engagement in conversation between persons with dementia and family caregivers may be able to provide caregivers with reduced stress. The impact on depression levels and quality of life in both persons with dementia and family caregivers should also be examined. Meaningful engagement in conversation may decrease levels of depression in persons with dementia and family caregivers, as well as increase their quality of living. Future studies should consider the impacts of this intervention on persons with more severe stages of dementia. Communication interventions similar to the current study may provide positive benefits to persons facing more severe stages. Future studies should explore the impact of the intervention on dyads who do not have strong relationship ties to begin with. Results of the intervention could vary depending on dyads' levels of relationship harmony. Future studies should also examine dyadic conversations for examples of missed person-centred communication opportunities and instances of elderspeak. Identifying missed opportunities could help shape future education and training programs that target avoiding depersonalized communication. Finally, future studies should examine different mechanisms to achieve person-centred communication. For example, persons with dementia and their family caregivers could engage in different collaborative activities each day. Collaborative activities could involve cooking a meal together, painting together, or having a cup of coffee together. By comparing a variety of collaborative activities, researchers could expand options to elicit person-centred communication other than through electronic conversational memory notebooks.

Conclusion

As the prevalence of dementia increases worldwide, communication problems among persons with dementia are becoming better recognized (Lanzi et al., 2017). There is an increased

need for person-centred care to ensure the best quality of life possible for individuals with dementia (Lanzi et al., 2017). Identification of evidence-informed strategies to help reduce communication difficulties between persons with dementia and their caregivers is crucial to maintain well-being and reduce caregiver distress (Alsawy et al., 2016). The current study found that both persons with dementia and family caregivers are able to increase their use of person-centred communication strategies while viewing and reminiscing on photos using an electronic conversational memory notebook.

Memory notebooks have beneficial effects on communication between persons with dementia and family caregivers (Bourgeois, 2014). External memory aids such as memory notebooks help to maintain the independence of persons with dementia, thereby improving their quality of living (Lanzi et al., 2018). Memory notebooks increase conversational turn-taking and topic maintenance, reduce partner prompting and conversation dominance, and reduce repetitive questioning (Bourgeois, 1992). More specifically, electronic conversational memory notebooks have the potential to enhance conversation by providing both auditory and visual support to persons with dementia (Lanzi et al., 2017) The current study was the first to apply the useful features of Pictello software directly to an electronic conversational memory notebook on an iPad. Findings showed that dual sensory support (visual and auditory) was beneficial for persons with dementia. By including both the visual of the photo/sentence as well as an audio recording of the sentence being read aloud, persons with dementia had an easier time retrieving memories about the photos. It is well documented that as dementia progresses sensory skills decline (Lanzi et al., 2017). The Pictello software used in this study supported modifications both visually and auditorily to accommodate for declining abilities often observed among persons with dementia and sometimes seen in older adults who do not have dementia or cognitive impairment.

Participants reported that they enjoyed reminiscing on the photos in the electronic conversational memory notebook. Conversations about the photos led to quality time spent together between the dyads in the study. Reminiscence therapy is known to elicit various positive activating effects on persons with dementia and their caregivers (Bejan et al., 2018). Activating effects can include things such as positive emotional effects on interest, interaction and mood as well as reduced unwanted behaviours (Bejan et al., 2018). Reminiscence therapy in turn can generate beneficial impacts on cognition, identity and quality of life for persons with dementia and family caregivers (Bejan et al., 2018). Findings from the current study support that reminiscing on photos can exert a positive impact on persons with dementia and family caregivers in multiple ways.

Finally, participants in the current study were able to learn and to implement person-centred communication strategies into their conversations. Person-centred communication plays an integral role in recognizing persons with dementia as individual persons, accommodating for their preferences, feelings or needs (Williams et al., 2018). There is a need to expand the use of person-centred communication strategies outside of formal caregiving in long-term care facilities. Person-centred strategies can be implemented anywhere within the community. Specifically, this study has shown that person-centred strategies can be implemented at home between persons with dementia and family caregivers who already have strong social bonds. It is integral that researchers continue to look for further ways in which communication strategies can be implemented between persons with dementia and family caregivers. Person-centred communication emphasizes the inherent personhood, autonomy, and dignity of human beings, regardless of cognitive impairments (Douglas et al., 2018). Persons with dementia need to be recognized as individuals who no longer are defined by their syndrome (Perry, 2005).

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Appendix A

Research Ethics Board Approval



**Western
Research**

Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice

Research Ethics

Principal Investigator: Dr. Joseph B. Orange
Department & Institution: Health Sciences/Communication Sciences & Disorders, Western University

Review Type: Delegated
HSREB File Number: 109725
Study Title: iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

HSREB Initial Approval Date: December 01, 2017
HSREB Expiry Date: December 01, 2018

Documents Approved and/or Received for Information

Document Name	Comments	Version Date
Revised Western University Protocol		2017/08/29
Letter of Information & Consent	Participants - Dementia	2017/08/29
Caregiver Letter of Information & Consent		2017/08/29
Other	Timeline of Study	2017/08/23
Instruments	The Parent Adult Child Relationship Questionnaire	2017/08/23
Instruments	Dyadic Adjustment scale	2017/08/23
Instruments	The caregiver self-assessment measure	2017/08/23
Instruments	Cornell Scale of Depression	2017/08/23
Instruments	Hearing screening protocol	2017/08/23
Instruments	LapMax Visual Screening tool	2017/08/23
Instruments	Montreal Cognitive Assessment, Cognitive	
Instruments	The Perception of Conversation Index- Dementia of the Alzheimer's Type	2017/08/23
Data Collection Form/Case Report Form	Demographic form	2017/08/23
Data Collection Form/Case Report Form	Participant Record Keeping	2017/08/23
Other	References	2017/08/23
Instruments	Education handout for participants	2017/12/29

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH 25 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 05003942.

Appendix B

Letter of information/Consent Form- Family Caregiver



Health and Rehabilitation Sciences

Project Title: iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

Principal Investigator:

JB Orange, PhD, Western University, School of Communication Sciences and Disorders.

Co-Investigators:

Kelsey Dynes, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

Conflict of Interest

We do not have any conflict of interest in this study. We are not receiving and funding from any companies to complete this study.

Letter of Information – Family Caregiver of Individual with Dementia

Invitation to Participate

You are being invited to participate in a research study. The use of the word “you” refers to you, the caregiver of the person with dementia participating in the study. The study explores the use of an iPad to improve conversations between you and your family member with dementia. You have been referred by executive director Ms. Karen Johnson, of the McCormick Home Dementia Care Services. This is a student project that is part of the requirements for Ms. Kelsey Dynes to complete her master’s degree at Western University. You are being asked to participate in this

study because you are the family member/caregiver of a person diagnosed with mild to moderate clinical stage dementia.

You do not need to have an iPad to join this study. An iPad will be provided to you by the investigators to use during the study. However, the iPad must be returned immediately to Ms. Kelsey Dynes when your segment of the study is completed.

Purpose of the Letter

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

Purpose of this Study

The purpose of this study is to determine whether viewing and discussing photos on an iPad increases the use of person-centred communication between persons with dementia and their family caregivers. You and your relative with dementia will be educated on how to use person-centred communication using your family photos that are loaded on the iPad. You also will be educated on how to reminisce on your family photos.

Person-centred communication is a conversation strategy. The strategy includes using words that are related directly to a person (e.g., use of person's name, her/his current/former roles/positions in society [treasurer, coach, volunteer], her/his personal qualities/traits [patient, kind, fast talker, etc.], etc.). These person-centred words are used to support the communication and language of a person with dementia in conversation.

Reminiscing is a conversation strategy that involves remembering events from the past and talking about them. This is often done by looking at old family photos.

Inclusion Criteria

Family members/caregivers of individuals with dementia who meet the following criteria are eligible to participate in this study:

Family Caregiver:

- Speak English
- Either a spouse or adult-child caregiver
- Have been communicating with family member with dementia a minimum once a day over the past 12 months
- MoCA score above 26/30
- Pass vision, hearing, depression, strength of relationship screening
- Have a minimum of 40 family photos to be used in the study
 - Must contain at least you or your family member with dementia in them
 - Must have taken place at least 10 years in the past

Exclusion Criteria

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

Study Design

This is a longitudinal study that will last approximately 6 weeks.

Study Procedures**Week 1- Testing**

If you agree to participate in this study, you will be tested for the following:

- thinking, memory and language skills (Montreal Cognitive Assessment Measure)
- Hearing testing (commonly used hearing protocol)
- Vision testing (LogMar Vision test)
- How well you get along in your marriage or family relations (Dyadic Adjustment Scale or Parent Adult-Child Relationship Questionnaire)
- Depression (Caregiver Self-Assessment Questionnaire)
- Perception of Conversation Index- Dementia of the Alzheimer's Type (PCI-DAT)
 - Measure of conversation patterns between persons with dementia and caregivers

Ms. Kelsey Dynes and Dr. JB Orange will both visit your family member with dementia's home and/or your home if you live together during Weeks 1 and 2. Ms. Kelsey Dynes will administer the tests to you, with Dr. JB Orange supervising. If you pass all testing measures, you will continue to take part in the study.

Week 2- Collecting Baseline Information

You will be asked to gather 40 family photos that include at least you or your family member with dementia in them. The photos must have taken place at least 10 years in the past. Ms. Kelsey Dynes will come to your family member with dementia's home and/or your home if you live together to scan and to upload the photos onto an iPad. Dr. JB Orange also will visit your family member with dementia's home/and or your home during Week 2 to assist Kelsey.

Once all 40 photos are loaded onto the iPad, Ms. Kelsey Dynes will separate the photos into two groups containing 20 photos each. You will be shown how to look through the photos on the iPad. You are asked not to share your photos with anyone other than your family member, with Ms. Kelsey Dynes and with Dr. Orange. You will be asked to talk about the first group of 20 of photos with your family member with dementia. Your conversation will be audio recorded using an external digital audio recorder. Two days later, Ms. Kelsey Dynes will return to your family member with dementia's home and/or your home. You will be again asked to talk about the group of 20 photos with your family member with dementia. The conversation will be audio recorded.

Week 3- Training

At the start of week 3, Ms. Kelsey Dynes will return to your family member with dementia's home and/or your home. Ms. Dynes will begin by educating you on ways to improve communication with your family member with dementia. She will explain the communication strategies in simple ways and provide you with specific examples. You also will be taught about the importance of remembering past events in photos. Remembering and talking about past memories can enhance conversations. A handout with what you will have learned will be provided to you. You can use and refer to the information on the handout anytime during the study.

Once your learning session is completed, the second group of 20 photos will be used. Ms. Kelsey Dynes will work with you and your family member with dementia to write a short sentence for each photo describing what is happening in it. This will help you and your family member with dementia to remember the past event occurring in the photo. You or your family member with dementia also will be asked to read the sentence out loud after it is written. The reading of the sentence will be recorded directly onto the iPad and listened to again. Whoever is the most comfortable with reading out loud can record the sentence.

Once all sentences are reviewed and read out loud, you and your family member with dementia will be asked to talk about this second group of 20 photos. You will apply what you have learned about communication strategies. This conversation will be audio recorded. Over the next week, Ms. Kelsey Dynes will ask you to practice using your iPad 4 more times on different days of the week (making 5 practice times in total). You also will be asked to audio record 2 of your practice times (making 3 recorded practice times). A calendar will be provided for you to record the date and the time you practiced and/or recorded your conversation using the iPad.

Week 4- Applying Training

Ms. Kelsey Dynes will return one week later (at the beginning of Week 3) to ask how the previous week of practice went. She will answer any questions that you have and collect audio recordings. You then will be asked to continue to practice talking about your iPad 5 times per week on separate days, and to record 3 of your practice times on days of your choosing.

Week 5- Applying Training Continued

You will continue to practice talking about your photos using the provided iPad 5 times per week on separate days, recording 3 of your practice times on days of your choosing. Ms. Kelsey Dynes will not be visiting your home this week.

Week 6- Applying Training Continued

You will continue to practice talking about your photos using the iPad provided 5 times per week on separate days, recording 3 of your practice times on days of your choosing. At the end of this week you will have completed all of the required practice sessions. Ms. Kelsey Dynes will return to collect the iPad and the digital audio recorder. She also will



administer the Perception of Conversation Index- Dementia of the Alzheimer's Type (PCI-DAT) survey for you to answer.

Audio Recordings

All of the weekly audio recordings that you completed are going to be typed up on a secure computer at Western University. Ms. Kelsey Dynes will compare your baseline conversations to your conversations after being educated on person-centred communication strategies. She then will be able to see if using the iPad increased person-centred conversation between you and your family member with dementia. Your typed up conversations will not have your name linked to them.

All of the typed conversations will not include your name on them and will be kept private. That is, all content that can be linked directly to you will be changed so that the information cannot be traced back to you.

There will be a total of 10 to 14 participants in this study. That is, there will be 5 to 7 individuals with mild to moderate dementia, and 5 to 7 family caregivers (spouse or adult-child).

Voluntary Participation

This study is voluntary. You may refuse to participate. Your decision will not impact your relations with McCormick Dementia Services. Your decision will not impact your current or future care.

Withdrawal from Study

You can withdraw from the study at any point in time. You have the right to not answer any questions that you do not want to or do not feel comfortable answering.

Possible Risks and Harms

There is a possible risk of feeling tired because the study takes place over 6 weeks. You can choose the time and the day when you practice using your iPad. All procedures including your practice sessions and your

teaching session will be completed in the comfort of your own home or the home of your relative with dementia.

There is a possible risk for stress or anxiety for some persons due to the use of audio recording equipment. Audio recording equipment will be placed where it will not bother you, as long as it is still able to record your conversation.

Possible Benefits

You may benefit directly from this study. For example, you may enjoy using the iPad to review family photos. You also will receive a personal learning session on communication strategies to use between you and your family member with dementia. Information from this study may provide benefits to society as a whole because results are expected to help us understand how to reduce communication problems between persons with dementia and their family caregivers. Reducing communication problems will help people live happier lives.

Compensation

You will not be paid or rewarded for your participation in this study. However, you will be able to learn, to practice and to use communication strategies that can improve everyday life between you and your family member with dementia.

Confidentiality

All data collected will remain private and accessible only to the investigators of this study. Participants will be encouraged to keep their discussions private and not to share the photos and sentences on the iPad. Anything that could identify you personally will be removed from the audio recordings.

The paper records of your data will be stored in the following way: locked in a filing cabinet in the locked, secured laboratory of Dr. Orange at Elborn College . Electronic records will be stored in the following way: firewall protected on the Western University network drive accessible only from a password-protected computer located in the International



Consortium on Communication in Aging and Neurodegenerative Disorders
Laboratory of Dr. Orange Elborn College at Western
University. Audio recordings will be reviewed only by members of the
research team. The typed up recordings will be destroyed after 7 years in
accordance with our professional college regulations for data management.

If the results of the study are published, your name and audio recordings
will not be used. If you choose to withdraw from this study, your data will be
removed and destroyed from our database.

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

Costs

This study has no cost. All required equipment for the study will be
provided by the researchers. However, the iPad must be returned to the
researchers once you have completed your segment of the study.

Contacts for Further Information/Questions about Study

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

- JB Orange, PhD:
- Kelsey Dynes, MSc candidate

If you have any questions about your rights as a research participant or the
conduct of this study, you may contact The Office of Research Ethics

**Publication**

If the results of this study are published, your name and audio recordings will not be used. The results of this study may be presented at research conferences or community meetings. The results of this study may be published in the form of research articles and the thesis of Ms. Dynes.

This letter is yours to keep for future reference.



**Consent Form – Family Member/Caregiver of Participant with
Dementia**

Project Title: iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

Principal Investigator:

JB Orange, PhD, Western University, School of Communication Sciences and Disorders.

Co-Investigators:

Kelsey Dynes, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

I consent to have my conversations audio recorded.

Participant's Name (please print)

Participant's Signature

Date

Person Obtaining Informed Consent (please print)

Signature

Date

Appendix C

Letter of Information/Consent Form- Person with Dementia



Health and Rehabilitation Sciences

Project Title: iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

Principal Investigator:

JB Orange, PhD, Western University, School of Communication Sciences and Disorders.

Co-Investigators:

Kelsey Dynes, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

Conflict of Interest

We do not have any conflict of interest in this study. We are not receiving funding from any companies to complete this study.

Letter of Information - Individuals with Dementia

Invitation to Participate

You are being invited to participate in a research study. The use of the word "you" refers to you, the person with dementia participating in the study. This study explores the use of an iPad to improve conversations between you and your family caregiver. You have been referred by executive director Ms. Karen Johnson, of the McCormick Home Dementia Services. This is a student project that is part of the requirements for Ms. Kelsey Dynes to complete her master's degree at Western University. You

are being asked to participate in this study because you are a person diagnosed with mild to moderate clinical stage dementia.

You do not need to have an iPad to join this study. An iPad will be provided to you by the investigators to use during the study. However, the iPad must be returned immediately to Ms. Kelsey Dynes when your segment of the study is completed.

Substitute decision makers should note that they do not need to take part in the study at any point in time unless they are the family caregiver directly participating in the study.

Purpose of the Letter

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

Purpose of this Study

The purpose of this study is to determine whether viewing and discussing photos on an iPad increases the use of person-centred communication between persons with dementia and their family caregivers. You and your family caregiver will be educated on how to use person-centred communication using your family photos that are loaded on the iPad. You also will be educated on how to reminisce on your family photos.

Person-centred communication is a conversation strategy. The strategy includes using words that are related directly to a person. (e.g., use of person's name, her/his current/former roles/positions in society [treasurer, coach, volunteer], her/his personal qualities/traits [patient, kind, fast talker, etc.], etc.). These person-centred words are used to support the communication and language of a person with dementia in conversations.

Reminiscing is a conversation strategy that involves remembering events from the past and talking about them. This is often done by looking at old family photos.

Inclusion Criteria

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

Person with dementia:

- Speak English
- Diagnosed with mild to moderate dementia
- MoCA score between 8/30 and 23/30
- Pass vision, hearing, depression, strength of relationship screening
- Have a minimum of 40 family photos to be used in the study
 - Must contain at least you or your family caregiver in them
 - Must have taken place at least 10 years in the past

Exclusion Criteria

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

Study Design

This is a longitudinal study that will last approximately 6 weeks.

Study Procedures

Week 1- Testing

If you agree to participate in this study, you will be tested for the following:

- thinking, memory and language skills (Montreal Cognitive Assessment Measure)
- Hearing testing (commonly used hearing protocol)
- Vision testing (LogMar Vision test)
- How well you get along in your marriage or family relations (Dyadic Adjustment Scale or Parent Adult-Child Relationship Questionnaire)
- Depression (Cornell Scale of Depression)

Ms. Kelsey Dynes and Dr. JB Orange will both visit your home during Weeks 1 and 2. Ms. Kelsey Dynes will administer the tests to you, with Dr.

JB Orange supervising. If you pass all testing measures, you will continue to take part in the study.

Week 2- Collecting Baseline Information

You will be asked to gather 40 family photos that include at least you or your family caregiver in them. The photos must have taken place at least 10 years in the past. Ms. Kelsey Dynes will come to your home to scan and to upload the photos onto an iPad. Dr. JB Orange also will visit your home during Week 2 to assist Kelsey.

Once all 40 photos are loaded onto the iPad, Ms. Kelsey Dynes will separate the photos into two groups containing 20 photos each. You will be shown how to look through the photos on the iPad. You are asked not to share your photos with anyone other than your family member, with Ms. Kelsey Dynes and with Dr. Orange. You will be asked to talk about the first group of 20 of photos with your family caregiver. Your conversation will be audio recorded using an external digital audio recorder. Two days later, Ms. Kelsey Dynes will return to your home. You will be again asked to talk about the group of 20 photos with your family caregiver. The conversation also will be audio recorded.

Week 3- Training

At the start of week 3, Ms. Kelsey Dynes will return to your home. Ms. Dynes will begin by educating you on ways to improve communication with your family caregiver. She will explain the communication strategies in simple ways and provide you with specific examples. You also will be taught about the importance of remembering past events in photos. Remembering and talking about past memories can enhance conversations. A handout with what you will have learned will be provided to you. You can use and refer to the information on the handout anytime during the study.

Once your learning session is completed, the second group of 20 photos will be used. Ms. Kelsey Dynes will work with you and your family caregiver to write a short sentence for each photo describing what is happening in it. This will help you and your family caregiver to remember the past event occurring in the photo. You or your family caregiver also will be asked to read the sentence out loud after it is written. The reading of the sentence

will be recorded directly onto the iPad and listened to again. Whoever is the most comfortable with doing so can record the sentence.

Once all sentences are reviewed and read out loud, you and your family caregiver will be asked to talk about this second group of 20 photos. You will apply what you learned about communication strategies. This conversation will be audio recorded. Over the next week, Ms. Kelsey Dynes will ask you to practice using your iPad 4 more times on different days of the week (making 5 practice times in total). You will also be asked to audio record 2 of your practice times (making 3 recorded practice times). A calendar will be provided for you to record the date and the time you practiced and/or recorded your conversation using the iPad.

Week 4- Applying Training

Ms, Kelsey Dynes will return one week later (at the beginning of Week 3) to ask how the previous week of practice went. She will answer any questions that you have and collect audio recordings. You then will be asked to continue to practice talking about your iPad 5 times per week on separate days, and to record 3 of your practice times on days of your choosing.

Week 5- Applying Training Continued

You will continue to practice talking about your photos using the provided iPad 5 times per week on separate days, recording 3 of your practice times on days of your choosing. Ms. Kelsey Dynes will not be visiting your home this week.

Week 6- Applying training continued

You will continue to practice talking about your photos using the iPad provided 5 times per week on separate days, recording 3 of your practice times on days of your choosing. At the end of this week you will have completed all of the required practice sessions. Ms. Kelsey Dynes will return to collect the iPad and the digital audio recorder.

Audio Recordings

All of the weekly audio recordings that you completed are going to be typed up on a secure computer at Western University. Ms. Kelsey Dynes will compare your baseline conversations to your conversations after being educated on person-centred communication strategies. She then will be

able to see if using the iPad increased person-centred conversation between you and your family caregiver. Your typed up conversations will not have your name linked to them.

All of the typed up conversations will not include your name on them and will be kept private. That is, all content that can be linked directly to you will be changed so that the information cannot be traced back to you.

There will be a total of 10 to 14 participants in this study. That is, there will be 5 to 7 individuals with mild to moderate dementia, and 5 to 7 family caregivers (spouse or adult-child).

Voluntary Participation

This study is voluntary. You may refuse to participate. Your decision will not impact your relations with McCormick Dementia Services. Your decision will not impact your current or future care.

Withdrawal from Study

You can withdraw from the study at any point in time. You have the right to not answer any questions that you do not want to or do not feel comfortable answering.

Possible Risks and Harms

There is a possible risk of feeling tired because the study takes place over 6 weeks. You can choose the time and day when you practice using your iPad. All procedures including your practice sessions and your teaching session will be completed in the comfort of your own home.

There is a possible risk for stress or anxiety for some persons due to the use of audio recording equipment. Audio recording equipment will be placed where it will not bother you, as long as it is still able to record your conversation.

Possible Benefits

You may benefit directly from this study. For example, you may enjoy using the iPad to review family photos. You also will receive a personal learning session on communication strategies to use between you and your family member. Information from this study may provide benefits to society as a whole because results are expected to help us understand how to reduce communication problems between persons with dementia and their family caregivers. Reducing communication problems will help people live happier lives.

Compensation

You will not be paid or rewarded for your participation in this study. However you will be able to learn, to practice and to use communication strategies that can improve everyday life between you and your family member.

Confidentiality

All data collected will remain private and accessible only to the investigators of this study. Participants will be encouraged to keep their discussions private and not to share the photos and sentences on the iPad. Anything that could identify you personally will be removed from the audio recordings.

The paper records of your data will be stored in the following way: locked in a filing cabinet in the locked, secured laboratory of Dr. Orange at Elborn College. Electronic records will be stored in the following way: firewall protected on the Western University network drive accessible only from a password-protected computer located in the International Consortium on Communication in Aging and Neurodegenerative Disorders Laboratory of Dr. Orange in Elborn College at Western University. Audio recordings will be reviewed only by members of the research team. The typed up recordings will be destroyed after 7 years in accordance with our professional college regulations for data management.



If the results of the study are published, your name and audio recordings will not be used. If you choose to withdraw from this study, your data will be removed and destroyed from our database.

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

Costs

This study has no cost. All required equipment for the study will be provided by the researchers. However, the iPad must be returned to the researchers once you have completed your segment of the study.

Contacts for Further Information/Questions about Study

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

- JB Orange,
- Kelsey Dynes,

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics

Publication

If the results of this study are published, your name and audio recordings will not be used. The results of this study may be presented at research conferences or community meetings. The results of this study may be published in the form of research articles and the thesis of Ms. Dynes.

This letter is yours to keep for future reference.

Consent Form – Participant with Dementia

Project Title: iPad use to Enhance Conversations between Persons with Dementia and their Family Caregivers

Principal Investigator:

JB Orange, PhD, Western University, School of Communication Sciences and Disorders.

Co-Investigators:

Kelsey Dynes, MSc candidate, Western University, Health and Rehabilitation Sciences Program.

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

I consent to have my conversations audio recorded.

Participant's Name (please print)

Participant's Signature

Date

I agree to allow my family member/legal charge,
_____, to participate in this study.

Name of the Legal Guardian of the Participant with dementia:

Signature of the Legal Guardian of the Participant with dementia:



Health and Rehabilitation Sciences

Date: _____

Person Obtaining Informed Consent (please print)

Signature

Date

Appendix D

Montreal Cognitive Assessment (MoCA)

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

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

VISUOSPATIAL / EXECUTIVE		Copy cube	Draw CLOCK (Ten past eleven) (3 points)	POINTS																		
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																			
MEMORY	Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.	<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		FACE	VELVET	CHURCH	DAISY	RED	1st trial						2nd trial						No points	
	FACE	VELVET	CHURCH	DAISY	RED																	
1st trial																						
2nd trial																						
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Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.	<input type="checkbox"/> FBACMNAAJKLBAFAKDEAAAJAMOF AAB	___/1																				
Serial 7 subtraction starting at 100	<input type="checkbox"/> 93 <input type="checkbox"/> 86 <input type="checkbox"/> 79 <input type="checkbox"/> 72 <input type="checkbox"/> 65	4 or 5 correct subtractions: 3 pts. 2 or 3 correct: 2 pts. 1 correct: 1 pt. 0 correct: 0 pt	___/3																			
LANGUAGE	Repeat: I only know that John is the one to help today. <input type="checkbox"/> The cat always hid under the couch when dogs were in the room. <input type="checkbox"/>	___/2																				
Fluency / Name maximum number of words in one minute that begin with the letter F	<input type="checkbox"/> _____ (N ≥ 11 words)	___/1																				
ABSTRACTION	Similarity between e.g. banana - orange = fruit <input type="checkbox"/> train - bicycle <input type="checkbox"/> watch - ruler	___/2																				
DELAYED RECALL	Has to recall words WITH NO CUE	<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td> <input type="checkbox"/> </td> <td> <input type="checkbox"/> </td> <td> <input type="checkbox"/> </td> <td> <input type="checkbox"/> </td> <td> <input type="checkbox"/> </td> <td> <input type="checkbox"/> </td> </tr> </tbody> </table>		FACE	VELVET	CHURCH	DAISY	RED	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Points for UNCUED recall only	___/5						
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© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30				TOTAL ___/30 Add 1 point if ≤ 12 yr edu																		

Administered by: _____

MoCA Screening cutoffs (Chang et. al. 2012)

Table 2. Montreal cognitive assessment scores in normal controls (NCs) and Alzheimer's disease (AD) patients based on educational level

Education level (years)	0 - 6 (n = 104)				> 6 (n = 131)			
	NC (n = 16)	Very-mild (n = 30)	Mild (n = 26)	Moderate (n = 32)	NC (n = 81)	Very mild (n = 22)	Mild (n = 22)	Moderate (n = 6)
Total score (30)	23.1 ± 3.8	14.9 ± 4.3 ^a	7.5 ± 3.5 ^{ab}	3.6 ± 2.1 ^{abc}	26.2 ± 2.9*	19.2 ± 4.5 ^a	11.2 ± 2.6 ^{ab}	4.7 ± 2.2 ^{abc}
Visuospatial-Executive (5)	3.3 ± 1.4	1.5 ± 1.6 ^a	0.7 ± 1.0 ^a	0.3 ± 0.6 ^{ab}	4.3 ± 1.1*	3.7 ± 1.2	1.1 ± 1.1 ^{ab}	0.5 ± 0.8 ^{ab}
Naming (3)	2.2 ± 1.0	1.3 ± 1.2 ^a	0.4 ± 0.7 ^{ab}	0.1 ± 0.4 ^{ab}	2.8 ± 0.6*	2.4 ± 0.9	1.6 ± 1.1 ^{ab}	0.7 ± 0.8 ^{abc}
Attention (6)	5.2 ± 1.1	4.0 ± 1.3 ^a	2.1 ± 1.5 ^{ab}	0.9 ± 0.7 ^{abc}	5.6 ± 0.9	4.9 ± 1.2	3.3 ± 1.5 ^{ab}	1.5 ± 1.0 ^{abc}
Language (3)	1.9 ± 0.9	1.1 ± 1.0 ^a	0.4 ± 0.8 ^{ab}	0.3 ± 0.5 ^{ab}	2.3 ± 0.8	1.2 ± 1.1 ^a	0.5 ± 0.7 ^{ab}	0 ± 0 ^{ab}
Abstraction (2)	0.8 ± 0.5	0.2 ± 0.4 ^a	0.1 ± 0.3 ^a	0.1 ± 0.2 ^a	1.4 ± 0.6*	0.8 ± 0.7	0.4 ± 0.5 ^{ab}	0 ± 0 ^{ab}
Delayed-recall (5)	2.9 ± 2.0	0.9 ± 1.4 ^a	0.1 ± 0.3 ^{ab}	0.1 ± 0.2 ^{ab}	3.3 ± 1.5	0.3 ± 0.8 ^a	0.2 ± 0.5 ^a	0 ± 0 ^a
Orientation (6)	5.4 ± 0.6	5.1 ± 1.2	2.6 ± 1.4 ^{ab}	1.0 ± 0.8 ^{abc}	5.9 ± 0.4*	5.1 ± 1.3 ^a	3.2 ± 1.0 ^{ab}	1.2 ± 1.0 ^{abc}

Values are expressed as mean ± standard deviation.

Number in parentheses following the task name = the maximum possible score

Scoring according to Nasreddine et al⁽¹⁾.

Very-mild AD indicated clinical dementia rating (CDR)=0.5, mild AD with CDR=1, moderate AD with CDR=2

* = p < 0.01 between 2 NC groups, a = p < 0.01 vs. educational matched controls, b = p < 0.01 vs. very-mild dementia, c = p < 0.01 vs. mild dementia.

MOCA SCORES

	Normal Controls (NC)	Mild Cognitive Impairment (MCI)	Alzheimer's Disease (AD)
Number of subjects	90	94	93
MoCA average score	27.4	22.1	16.2
MoCA standard deviation	2.2	3.1	4.8
MoCA score range	25.2 - 29.6	19.0 - 25.2	21.0 - 11.4
Suggested cut-off score	≥26	<26	<26 *ψ

* Nasreddine et al. J Am Geriatr Soc 53:695-699, 2005.

Appendix E

Visual Screening Acuity

Background

These iPad-based **logMAR** visual acuity charts are based on the Bailey-Lovie Visual Acuity Chart. The test uses the same 10-letter set as the Bailey-Lovie chart. The ten letters appear in a random order and have been shown to have similar visibility.

Unlike printed tests, these charts require no external lighting without need for special software or calibration. The test utilizes the high quality iPad screen to produce letters small enough to measure visual acuity at test distances as short as 6 feet or 2 m.

Test Procedure

The test should be performed with the screen brightness set at halfway and **Auto-Brightness** OFF. Room lights may be dimmed or left on, but care taken to avoid troublesome reflections

The main charts have ten lines of letters. The supplemental charts have two larger letters but the charts are not ideal for the assessment of severely visually impaired patients. At a test distance of 5 feet (1.5 meters) the largest letters will correspond to 20/200 (6/60).

Scoring

The test can be performed at any distance and the lowest line recorded. The Snellen fraction is then specified as test distance/lowest line read, e.g. 20/40 or 6/12. The letter sizes are given in both feet and meters (M units). Visual acuities taken at any distance can be transformed to 20/x or 6/x by simple math. For example a visual acuity of 8/25 corresponds to 20/63.

logMAR Scoring

The logMAR design of the chart may be leveraged to take more precise measurements. Credit may given for each individual letter read correctly (0.02 log units). This may be calculated by recording the logMAR value for the last line read completely and subtracting 0.02 for each subsequent letter read. Of course this requires that you know the logMAR value. On the last page, there is a table giving the logMAR values for each line for a number of test distances. A spreadsheet that will calculate logMAR based on the patient's responses for any test distance can be requested at ridgevue.com

Important Notes

- The letters display best on the Retina Display.
- They are scaled for the **full size iPad**.

For information about the test see this peer-reviewed paper:
[New Design Principles for Visual Acuity Letter Charts](#)

- For more information visit ridgevue.com

*Participants must be able to read size 24 Arial font at an arm's length distance in order to be eligible for this study.

Version 23/08/2017

Bullimore, M. (2015). LogMAR Visual Acuity Chart. In Ridgevue Vision, *Western Regional Conference Commemorative Vision Tests*. (pp. 7-11).

Appendix F

Auditory Screening Acuity

Overview: Screening for significant hearing impairments

Disease Groups: Core (all)

Materials: (1) GSI18 Portable Air Conduction Audiometer

STEP 1: Preparing the participant for the hearing screening – Task Instructions

1. Face the participant, and say: “I am going to screen your hearing. The test is only a screening and not a full hearing test.”
2. “I am now going to place these earphones over your ears. You will hear a variety of beeps - some high pitch, some low pitch, and at different volumes, even very soft. Whenever you hear, or you think you hear a series of sounds (‘beep, beep, beep’), raise your hand. Lower your hand when you no longer hear the sound. Remember that though some of the beeps will be easy to hear, others will become very faint. Therefore, you should listen very carefully and raise your hand whenever you think you hear the tone.
3. You may need to repeat or paraphrase the instructions until you are confident that the participant understands the hearing screening protocol.
4. Once you are sure the participant understands the procedure, position the participant so that her/his back is to the screening audiometer. S/he should not be able to see you pressing buttons on the audiometer or see your face during administration of the hearing screen.

STEP 2: Place headphones onto the ears of the participant:

1. Eliminate all obstructions between the headphones and the participant’s ear (e.g., push hair behind ears, ask to have her/him take off earrings, remove glasses, if necessary).
2. Place the headband solidly on the crown of the participant’s head.

STEP 3: Screen hearing

1. Test signal in each ear.
2. Select the ‘R’ button, set the intensity dial to 50 dB HL and the frequency or Hz dial to 1000. Press the presentation button for 5 seconds. Verify that the participant was able to hear the tone. “Did you hear that? Good. This is the sound that you are listening for although it will be quieter than what you just heard”.
3. Select the ‘L’ button, and say: “Now we are going to do your left ear.” Press the presentation button for 5 seconds. Verify that the participant was able to hear the tone. “Did you hear that? Good. This is the sound that you are listening for although it will be quieter than what you just heard. We are going to do your right ear first”
4. Select the ‘R’ button to test the right ear first.
5. Set the intensity dial to 25 dB HL.
6. Keep the frequency or Hz dial (i.e., frequency of the sound) at 1000.
7. Press the presentation button for 3 seconds. Wait 5 seconds for the participant response. Repeat.
8. Set the frequency or Hz dial to 2000.
9. Press the presentation button for 3 seconds. Wait 5 seconds for the participant response.

Version 23/08/2017

Repeat.

10. Set the frequency or Hz dial to 4000.

11. Press the presentation button for 3 seconds. Wait 5 seconds for the participant response.

Repeat.

12. Select the 'L' button to test the left ear. Say: "Now we are going to test your left ear."

13. REPEAT steps 6-11 with the left ear.

STEP 4: Scoring

1. If the participant does not respond at any frequency for either her/his R or L ear, it is considered a "Fail".

2. Sufficient hearing is defined as either: a) the ability to detect a 25 dB HL signal 1000, 2000, and 4000 Hz in at least one ear on a GSI18 portable air conduction audiometer, b) the use of a hearing device including one's own hearing aids, or c) study-provided personal amplification device (Pocket Talker Pro) for the duration of the assessment.

INCLUSION CRITERIA:

1. Participant must have pass all frequencies for both ears.

2. Indicate whether the participant passed or failed the Auditory Acuity screening, and required the Pocket Talker Pro during testing.

Version 23/08/2017

Appendix G

Cornell Scale for Depression in Dementia

Screening Tool: Cornell Scale for Depression in Dementia (CSDD)

Scoring System: a = unable to evaluate
0 = absent
1 = mild or intermittent
2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.

A. Mood-Related Signs

1. Anxiety anxious expression, ruminations, worrying	a	0	1	2
2. Sadness sad expression, sad voice, tearfulness	a	0	1	2
3. Lack of reactivity to pleasant events	a	0	1	2
4. Irritability easily annoyed, short-tempered	a	0	1	2

B. Behavioral Disturbance

1. Agitation restlessness, handwringing, hairpulling	a	0	1	2
2. Retardation slow movements, slow speech, slow reactions	a	0	1	2
3. Multiple physical complaints (score 0 if GI symptoms only)	a	0	1	2
4. Loss of interest less involved in usual activities (score only if change occurred acutely, i.e., in less than 1 month)	a	0	1	2

C. Physical Signs

1. Appetite loss eating less than usual	a	0	1	2
2. Weight loss score 2 if greater than 5 lb. in one month	a	0	1	2
3. Lack of energy fatigues easily, unable to sustain activities (score only if change occurred acutely, i.e., in less than 1 month)	a	0	1	2

D. Cyclic Functions

1. Diurnal variation of mood symptoms worse in the morning	a	0	1	2
2. Difficulty falling asleep later than usual for this individual	a	0	1	2
3. Multiple awakenings during sleep	a	0	1	2
4. Early-morning awakening earlier than usual for this individual	a	0	1	2

E. Ideational Disturbance

1. Suicide feels life is not worth living, has suicidal wishes or makes suicide attempt	a	0	1	2
2. Poor self-esteem self-blame, self-deprecation, feelings of failure	a	0	1	2
3. Pessimism anticipation of the worst	a	0	1	2
4. Mood-congruent delusions delusions of poverty, illness or loss	a	0	1	2

Scoring:

A score >10 probably major depressive episode
A score >18 definite major depressive episode

The scale is designed as a screening tool and is not diagnostic

Steps:

1. The investigator interviews the person with dementia's caregiver on each of the 19 items of the scale. The caregiver is instructed to base his/her report on observations of the person with dementia's behaviour during the week prior to the interview
2. The investigator briefly interviews the person with dementia

Total time of administration = approximately 30 minutes

The scale is valuable to demonstrate effectiveness of interventions, especially antidepressant treatment, when it is completed before the intervention and several weeks after.

Scoring:

1. Each question is scored on a two-point scale: 0 = absent; 1 = mild or intermittent; 2 = severe; n/a = unable to evaluate
2. The caregiver is asked to describe the person with dementia's behaviour observed during the week prior to the interview. Two items, "loss of interest" and "lack of energy" require both a disturbance occurring during the week prior to the interview and relatively acute changes in these areas occurring over less than one month. In these 2 items, the caregiver is instructed to report on the person with dementia's behaviour during the week prior to interview, then give the history of the onset of changes in these 2 areas that may have taken place at an earlier item.

3. The item "suicide" is rated with a score of "1" if the person with dementia has passive suicidal ideation, e.g. feels life is not worth living. A score of "2" is given to subjects who have active suicidal wishes, or have made a recent suicide attempt. History of a suicide attempt in a subject with no passive or active suicidal ideation does not in itself justify a score.
4. If there is a disagreement between the investigator's impression and the caregiver's report, the caregiver is interviewed again in order to clarify the source of discrepancy.
5. Older persons often have disabilities or medical illnesses with symptoms and signs similar to those of depression. Scoring of the Cornell scale on items as "multiple physical complaints", "appetite loss", "weight loss", "lack of energy", and possibly others may be confounded by disability or physical disorder.

Version 23/08/2017

Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry*, 23(3), 271-284.
doi:10.1016/00063223(88)90038-8

Appendix H

Caregiver Self-Assessment Questionnaire

During the past week or so, I have ...

- | | | | |
|--|--|---|--|
| 1. Had trouble keeping my mind on what I was doing.... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill (headaches, stomach problems or common cold)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed | <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. | _____ |
| 6. Felt lonely..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. | _____ |
| 7. Been upset that my relative has changed so much from his/her former self..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | Comments:
(Please feel free to comment or provide feedback.) | |
| 8. Felt a loss of privacy and/or personal time..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ | |
| 9. Been edgy or irritable..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ | |
| 10. Had sleep disturbed because of caring for my relative..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ | |
| 11. Had a crying spell(s)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ | |
| 12. Felt strained between work and family responsibilities... | <input type="checkbox"/> Yes <input type="checkbox"/> No | _____ | |

To determine the score:

1. Reverse score questions 5 and 15. (no counted as yes or yes counted as no)
2. Total the number of "yes" responses.

To interpret the score:

- If you answered "yes" to either or both questions 4 and 11
- If your total "yes" scores= 10 or more
- If your score on question 17 is 6 or higher
- If your score on question 18 is 6 or higher

Version 23/08/2017

Epstein-Lubow, G., Gaudiano, B. A., Hinckley, M., Salloway, S., & Miller, I. W. (2010). Evidence for the validity of the American Medical Association's caregiver self-assessment questionnaire as a screening measure for depression. *Journal of the American Geriatrics Society*, 58(2), 387-388.

Appendix I

Previous iPad and Person-centred Communication Knowledge

Protocol #109725

Participant Code: _____

Date: _____

iPad use to Enhance Conversation Between Persons with Dementia and their Family Caregivers

Kelsey Dynes, MSc candidate :

JB Orange, PhD:

Baseline

1. Based on your previous experiences, how knowledgeable are you about using iPads?

Very knowledgeable	Knowledgeable	Somewhat knowledgeable	Neutral	Somewhat not knowledgeable	Not knowledgeable	Not very knowledgeable
7	6	5	4	3	2	1

2. How comfortable are you with using iPads?

Very comfortable	Comfortable	Somewhat comfortable	Neutral	Somewhat uncomfortable	Uncomfortable	Very uncomfortable
7	6	5	4	3	2	1

3. How familiar are you with person-centred communication strategies?

Very familiar	Familiar	Somewhat familiar	Neutral	Somewhat unfamiliar	Unfamiliar	Very unfamiliar
7	6	5	4	3	2	1

Version 23/08/2017

Appendix J

Dyadic Adjustment Scale

	Always Agree	Almost Always Agree	Occa- sionally Disagree	Fre- quently Disagree	Almost Always Disagree	Always Disagreg
1. Handling family finances	5	4	3	2	1	0
NOTE: SCORING for Items 1-15 is the same						
2. Matters of recreation	5	4	3	2	1	0
3. Religious matters	5	4	3	2	1	0
4. Demonstrations of affection	5	4	3	2	1	0
5. Friends	5	4	3	2	1	0
6. Sex relations	5	4	3	2	1	0
7. Conventionality (correct or proper behavior)	5	4	3	2	1	0
8. Philosophy of life	5	4	3	2	1	0
9. Ways of dealing with parents or in-laws	5	4	3	2	1	0
10. Aims, goals, and things believed important	5	4	3	2	1	0
11. Amount of time spent together	5	4	3	2	1	0
12. Making major decisions	5	4	3	2	1	0
13. Household tasks	5	4	3	2	1	0
14. Leisure time interests and activities	5	4	3	2	1	0
15. Career decisions	5	4	3	2	1	0

	All the time	Most of the time	More often than not	Occa- sionally	Rarely	Never
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	1	2	3	4	5
17. How often do you or your mate leave the house after a fight?	0	1	2	3	4	5
18. In general, how often do you think that things between you and your partner are going well?	5	4	3	2	1	0
19. Do you confide in your mate?	5	4	3	2	1	0
20. Do you ever regret that you married? (<i>or lived together</i>)	0	1	2	3	4	5
21. How often do you and your partner quarrel?	0	1	2	3	4	5
22. How often do you and your mate "get on each other's nerves?"	0	1	2	3	4	5

	Every Day	Almost Every Day	Occasionally	Rarely	Never
23. Do you kiss your mate?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	All of them	Most of them	Some of them	Very few of them	None of them
24. Do you and your mate engage in outside interests together?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Laugh together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Calmly discuss something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Work together on a project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no)

	Yes	No	
29.	<input type="radio"/>	<input type="radio"/>	Being too tired for sex.
30.	<input type="radio"/>	<input type="radio"/>	Not showing love.

31. The circles on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please fill in the circle which best describes the degree of happiness, all things considered, of your relationship.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Which of the following statements best describes how you feel about the future of your relationship?

- I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.
- I want very much for my relationship to succeed, and *will do all I can* to see that it does.
- I want very much for my relationship to succeed, and *will do my fair share* to see that it does.
- It would be nice if my relationship succeeded, but *I can't do much more than I am doing now* to help it succeed.
- It would be nice if it succeeded, but *I refuse to do any more than I am doing now* to keep the relationship going.
- My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

	Every Day	Almost Every Day	Occasionally	Rarely	Never
23. Do you kiss your mate?	4	3	2	1	0
	All of them	Most of them	Some of them	Very few of them	None of them
24. Do you and your mate engage in outside interests together?	4	3	2	1	0

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas	0	1	2	3	4	5
26. Laugh together	0	1	2	3	4	5
27. Calmly discuss something	0	1	2	3	4	5
28. Work together on a project	0	1	2	3	4	5

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no)

	Yes	No
29. Being too tired for sex.	0	1
30. Not showing love.	0	1

31. The circles on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please fill in the circle which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Which of the following statements best describes how you feel about the future of your relationship?

- 5 I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.
- 4 I want very much for my relationship to succeed, and *will do all I can* to see that it does.
- 3 I want very much for my relationship to succeed, and *will do my fair share* to see that it does.
- 2 It would be nice if my relationship succeeded, but *I can't do much more than I am doing now* to help it succeed.
- 1 It would be nice if it succeeded, but I *refuse to do any more than I am doing now* to keep the relationship going.
- 0 My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

*Must score above 107 to be considered a non-distressed couple and to be eligible for the study

Version 23/08/2017

Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15–28.

Appendix K

Parent Adult-Child Relationship Questionnaire

The Parent Adult-Child Relationship Questionnaire

This form contains a number of statements about relationships between adults and their parents. Please read each statement carefully, and decide how well it describes your relationship with your mother and your father as it has been over the *last* year. Please circle the most appropriate response of the four possible responses.

Very true

Tick if you feel that the statement describes your relationship with your parent accurately.

Moderately true

Tick if you feel that the statement describes your relationship with your parent for the most part.

Somewhat true

Tick if you feel that the statement describes your relationship with your parent to a small extent.

Not true at all

Tick if you feel that the statement does not describe your relationship with your parent at all.

Relationship with Mother (PACQM)	Very true	Moderately true	Somewhat true	Not true at all
1. I look forward to seeing my mother	(3)	(2)	(1)	(0)
2. I feel responsible for my mother's happiness.	(III)	(II)	(I)	(0)
3. I feel that I should take care of my mother because she has suffered so much in her life.	(III)	(II)	(I)	(0)
4. My mother is my best friend.	(3)	(2)	(1)	(0)
5. My mother's difficulty in making decisions has been a burden on me.	(III)	(II)	(I)	(0)
6. My mother shows her appreciation of me.	(3)	(2)	(1)	(0)
7. I am the only one my mother can rely on.	(III)	(II)	(I)	(0)
8. My mother thinks I am good in a crisis so she calls on me all the time.	(III)	(II)	(I)	(0)
9. I respect my mother's opinion.	(3)	(2)	(1)	(0)
10. I feel that I have to protect my mother.	(III)	(II)	(I)	(0)
11. My mother relies on me too much.	(III)	(II)	(I)	(0)
12. I am glad to be able to repay my mother for all the love and care she gave me as a child.	(3)	(2)	(1)	(0)
13. I feel like I parent my mother.	(III)	(II)	(I)	(0)

Scoring: *Regard Scale* Arabic numerals
Responsibility Scale Roman numerals

Relationship with Father (PACQF)	Very true	Moderately true	Somewhat true	Not true at all
1. If I don't do things my father's way he will nag me.	(3)	(2)	(1)	(0)
2. I respect my father's opinion.	(3)	(2)	(1)	(0)
3. Something will happen to my father if I don't take care of him.	(III)	(II)	(I)	(0)
4. I feel that my father tries to manipulate me.	(3)	(2)	(1)	(0)
5. I look forward to seeing my father.	(3)	(2)	(1)	(0)
6. I feel responsible for my father's happiness.	(III)	(II)	(I)	(0)
7. My father tries to dominate me.	(3)	(2)	(1)	(0)
8. I feel that my father makes too many demands on me.	(3)	(2)	(1)	(0)
9. I know I can rely on my father to help me if I need him.	(3)	(2)	(1)	(0)
10. If I don't see my father for a week I feel guilty.	(III)	(II)	(I)	(0)
11. I don't discuss much with my father because I'm afraid of being criticized.	(3)	(2)	(1)	(0)
12. I don't mind putting myself out for my father.	(3)	(2)	(1)	(0)
13. My father thinks I'm good in a crisis so he calls on me all the time.	(III)	(II)	(I)	(0)

Scoring: *Regard Scale* Arabic numerals
Responsibility Scale Roman numerals
Control scale Italic Arabic numerals

Cutoff Scores:

TABLE 3. Normative data obtained in reliability and validity studies

PACQ scale (total score)	Test Time 1			Retest Time 2		Validity study		
	N	Mean	SD	Mean	SD	N	Mean	SD
PACQM^a								
Regard (15)	24	7.5	3.7	7.5	4.0	25	11.7	3.2
Responsibility (24)	24	4.7	4.8	4.6	4.9	25	5.6	5.7
PACQF^b								
Regard (12)	21	8.1	3.1	8.1	2.9	21	8.9	3.6
Responsibility (12)	21	1.1	1.6	1.3	1.4	21	2.1	2.4
Control (15)	21	2.3	3.2	2.1	2.9	21	3.1	4.7

^a PACQM refers to PACQ for mother. ^b PACQF refers to PACQ for father.

Version 23/08/2017

Peisah, C., Brodaty, H., Luscombe, G., Kruk, J., & Anstey, K. (1999). The parent adult-child relationship questionnaire (PACQ): The assessment of the relationship of adult children to their parents. *Aging & Mental Health*, 3(1), 28-38. doi:10.1080/13607869956415

Appendix L

iPad Instructional Handout



Health and Rehabilitation Sciences

iPad use to Enhance Conversation Between Persons with Dementia and their Family Caregivers

Protocol #109725

How to Use the iPad

Turning the iPad on:

- Press the home button
 - circle at the bottom centre (see picture)
- Type in the password 2595
- iPad should now open



Opening the slideshow of your family photos:

- Click on the button that looks like a photo album (see picture)
- The app will open to the home page showing your slideshow #1 and your slideshow #2
- Click on the slideshow you would like to view



Scrolling through the slideshow:

- Use the right arrow to move to the next photo
- To hear the sentence beneath the photo read out loud, tap the photo (NOTE: sentences beneath photos are only in slideshow #2)
- When finished scrolling through the photos click “back to library” to return to the home screen
 - You should now see slideshow #1 and #2 listed again

When finished with the iPad:

- Close the iPad case
- The iPad will lock automatically when the front cover is secure

**To charge the iPad:**

- **Plug the white cord provided into the bottom of the iPad**
- **You will see a small opening in the case where the plug goes**
- **Plug the other end of the cord into any outlet until the iPad is sufficiently charge**
- **The battery life is listed at the top right hand corner of the iPad, that way you will know when the iPad needs to be charged**

Please feel free to contact either Kelsey Dynes or JB Orange if you have any questions or concerns

Appendix M

Audio Recorder Instructional Handout



Health and Rehabilitation Sciences

iPad use to Enhance Conversation Between Persons with Dementia and their Family Caregivers

Protocol #109725

Contact Information:

JB Orange, PhD:

Kelsey Dynes, MSc candidate :

Turning the device on:

- Press and hold the **STOP ■** button that is labeled power/home until the screen lights up.
It will look like this:



Start recording:

- Press the Record **●** button twice
- After pressing the button for the first time the recorder will go into standby mode.
 - *The recording light will be flashing red at this time*
- Once you are ready to begin recording hit the button again.
 - *Now the light will stay lit up red. The light will stay on the entire time you are recording*

Stop recording:

- Press the **STOP ■** button. The recording is now complete. The file will automatically be saved on the recorder.

Turning off the device:

- Press and hold the STOP ■ button until the screen lights up showing the following image:



- The audio recorder will now go blank and is turned off.

If you accidentally stop the recording during your session or it shuts off:

- Start a new recording by following the previous instructions. Begin where you left off. The previous audio recording should have automatically been saved.

If the recorder does not turn back off:

- Try changing the batteries to the new set provided. Make sure the hold switch (on the side) has not accidentally been turned on.

Please feel free to contact either Kelsey Dynes or JB Orange if you have any questions or concerns

Appendix N

Participant Education Slideshow

iPad use to Enhance Conversation Between Persons with Dementia and their Family Caregivers

Information Booklet on Person-Centred Communication

Kelsey Dynes, MSc candidate
JB Orange, PhD
January to April 2018

Western HealthSciences

Page 1 of 11

#1- Memory Notebooks

- Include a picture and a one-idea sentence of what is occurring in the photo
- Personally relevant photos and sentences help people access their memories
- Help to draw on preserved memory and language skills
- Help prompt recall of long-term memories



Western HealthSciences

Page 2 of 11

Memory Notebooks

- Generally consist of biographical information, photos of family members, and descriptions of important events
- Can remind individuals of the topic of conversation thus enabling them to participate better in conversations
- Help to support the relationship between persons with dementia and their caregivers
- Provides opportunity for enjoyable and meaningful conversation

Western HealthSciences

Page 3 of 11

#2- Reminiscence Therapy

- A useful memory approach for older adults
- Helps recall "long forgotten", personal experiences
- Emphasis is placed on remembering life experiences for the pleasure of re-experiencing happy or satisfying occasions, and for sharing experiences
- Leads to a shared sense of meaning among the persons involved

Western HealthSciences

Page 4 of 11

Reminiscence Therapy

- The use of prompts such as photographs of familiar events from the past are commonly used in reminiscence therapy
- Reminiscence therapy along with a memory notebook (like iPads you are using)
- Helps maintain self-identity
- Reminder of who you are as a person
- Helps to start conversations

#3- Person-Centred Care

- Term used to describe the way a person with dementia should be treated and cared for
- Need to respect people and to treat them on an individual basis
- Focus on their needs, abilities, and achievements
- Value who they are, what they are interested in, and what they still can do
- Avoid the "medical" model of terminology
 - views the person based on the syndrome of dementia
- Need to care for the person, not the syndrome

Person-Centred Communication

- Helps to identify what the person wants or needs
- Puts an emphasis on the preferences, feelings and needs of people with dementia
- Focuses on collaborations between caregivers and care-receivers
- Characterized by supporting each other during social interaction
- Leads to the development and maintenance of rewarding relationships

Person-Centred Communication

4 main strategies:

1. **Recognition**- identifying the person as a unique individual
 - Example: Calling person by preferred name
 - Caregiver: "Hi John. How are you today?"
 - Example: Recognizing the persons family members
 - Caregiver: "Your daughter usually visits on the weekends, doesn't she?"
- Referring to unique qualities of a person allows you to relate on a personal level

Person-Centred Communication

2. **Negotiation**- asking the person with dementia directly about their needs and preferences
 - Example: Serving person's favourite meal for dinner
 - Caregiver: "John, would you like to have mashed potatoes with dinner tonight? I know mashed potatoes are your favourite."
 - Example: Asking what the person would like to do this evening
 - Caregiver: "Would you like to watch TV tonight or would you like to play a board game?"
- Giving choice leads to opportunity for the person to maintain control while acknowledging their preferences are important

Person-Centred Communication

3. **Facilitation**- support the person to use existing abilities
 - Example: helping person on a walk outside of home
 - Caregiver: "Hi John. Let's go for a walk together in the garden. It is nice and sunny in the garden."
 - Example: Showing interest in the person's life history
 - Caregiver: "When you were young, what were your hobbies?"
 - Example: Fulfilling the need of a person
 - Person with dementia: "I would like some coffee"
 - Caregiver: "I will make sure you get some coffee."
- Recognize when the person with dementia attempts an action or thought, then enabling them to respond, to initiate or sustain that action/thought

Person-Centred Communication

4. **Validation**- responding to the feelings of person with dementia
 - Example: Re-wording & confirming feelings
 - Person with dementia: "Where is Mary today?"
 - Caregiver: "Mary is at work today. Mary will be back to visit at 6:00 tonight. It is nice that you are concerned about her. Please do not worry. Mary is fine."
 - Involves expressing and understanding the feelings of the person with dementia
 - Validation statements are more feeling oriented
 - Vs. facilitation statements are more action oriented

Appendix O

Participant Education Handout



Health and Rehabilitation Sciences

Participant Handout

IPad use Increasing Conversation between Persons with Dementia and their Family Caregivers

Kelsey Dynes, MSc Student & JB Orange, PhD

Health and Rehabilitation Sciences, Western University

Person-centred communication

- Person-centred communication is an important communication strategy that helps caregivers to identify what a person with dementia wants or needs
 - Example: Are they hungry? Do they need to go to the bathroom?
- Person-centred communication helps caregivers gather personal information about the person with dementia
 - Example: They have two sisters named Betty and Mary
- It allows the caregiver to recognize persons with dementia as an individual
 - Example: They prefer to read a book before bed rather than watch TV
- Person-centred communication leads to the development of strong relationships
- Person-centred communication helps maintain strong relationships
- It is characterized by supporting each other during social interaction
- By applying person-centred strategies to communication between persons with dementia and their caregivers, more opportunities for positive interaction will become available
- Person-centred communication helps preserve the person with dementia's identity
- It will also help to preserve strong relationship bonds between persons with dementia and their caregivers

Person-centred communication contains 4 main strategies:

They include:

- 1) Recognition- identifying the person as a unique individual
 - Example: using person by their preferred name
 - Caregiver: "Hi John, how are you today?"
- 2) Negotiation- Asking the person with dementia directly about their needs and preferences
 - Example: serving them their favourite meal for dinner
 - Caregiver: "John, would you like to have mashed potatoes on the side with your dinner tonight? I know they are your favourite."
- 3) Facilitation- support using the person with dementia's best abilities
 - Example: helping them on a walk outside of the home
 - Caregiver: "Hi John. Why don't we go for a walk together out in the garden? It is nice a sunny outside today."

- 1) Validation- responding to the feelings of the person with dementia
 - Example: re-wording, confirming what has been said
 - Person with dementia (John): Where is Mary today?
 - Caregiver: "Mary is at work today John. She will be back to visit you at 6:00pm. It is nice that you have been worrying about her, but do not worry she is fine."

Reminiscence Therapy

- Reminiscence therapy involves the discussion of past activities, experiences, and events of a person
- Remembering events from the past has been found to be an extremely useful memory exercise for older adults
- This form of talk provides a sense of meaning between older adults
- Conversation based on reminiscence helps to place value on life experiences
- The use of prompts such as photographs of familiar events from the past are commonly used in reminiscence therapy
- Reminiscence therapy also is used as a method to help maintain person identity, while at the same time helps to stimulate conversation with others

Suggested Topics:

- talking about the person's childhood with them and where they grew up
- talking about old friends and the things they did together
- talking about their past career
- talking about vacations they've been on

Learning Strategies:

1. Think about what you have just learned, and check to see if it makes sense.
2. Summarize main ideas that were just read and/or learned.
3. Practice role playing or acting out what you have learned

Appendix P

Participant Record Keeping



Health and Rehabilitation Sciences

Participant Record Keeping

Please record the approximate length of time (in minutes) for each day you practice. Aim to practice 5 out of 7 days per week. Also please note which practice sessions were audio recorded. Place an "A" in the box for the day you audio recorded your practice session. Aim to audio record 3 of the 5 weekly sessions.

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 2	Time							
	Audio Recorded							
Week 3	Time							
	Audio Recorded							
Week 4	Time							
	Audio Recorded							
Week 5	Time							
	Audio Recorded							
Week 6	Time							
	Audio Recorded							

Western HSREB #109725

Appendix Q

Post iPad and Person-centred Communication Knowledge

Protocol #109725

Participant Code: _____

Date: _____

Post iPad Use

1. As a result of participating in this study, my knowledge of iPads is now:

A lot better	Better	Somewhat better	Neutral	Somewhat worse	Worse	A lot worse
7	6	5	4	3	2	1

2. As a result of participating in this study, my knowledge of person-centred communication is now:

A lot better	Better	Somewhat better	Neutral	Somewhat worse	Worse	A lot worse
7	6	5	4	3	2	1

3a. How many caregiver education sessions have you attended prior to starting this study?

0	1-3	4-6	more than 6
---	-----	-----	-------------

3b. Please describe the general topics discussed at these sessions:

Protocol #109725

Participant Code: _____

Date: _____

3c. Approximately how long ago did you take these sessions?

4. Please describe what you found most beneficial from participating in this study:

5. Please describe what you found least beneficial or helpful from participating in this study:

Appendix R

Utterance Definitions

1

Utterance (Rzepczyk, 2001)

Utterances are defined according to Shewan (1988). According to her definition, an utterance is a “complete thought, usually expressed in a connected grouping of words, which is separated from other utterances on the basis of content, intonation contour, and/or pausing” (p.124). The following guidelines apply:

- A change in content signals the beginning of a new utterance.
- A falling intonation contour signals the end of an utterance.
- A rising intonation contour signals the end of an utterance if it is a question.
- Pauses by themselves are not used to signal utterance boundaries. Pauses are interpreted in conjunction with content and intonation contours to signal the end of an utterance. Pauses longer than 1.0 second, in conjunction with a falling or rising contour and change in content localizes the end of an utterance.
- Tag questions or tag sentences are not segmented as separate utterances (e.g., It's cold in here, isn't it? = 1 utterance).
- Parenthetical remarks that are complete thoughts are segmented as separate utterances (e.g., I think that's right. = 1 utterance).
- Sentence starters and enders (e.g., okay, you know) will not be segmented as separate utterances when utterances follows unless the sentence starter or ender is accompanied by a falling or rising intonation contour and a distinct pause marking it as a separate utterance.
- Quotations are segmented as separate utterances (e.g., The father said [1 utterance]: 'Let's go children.' [1 utterance]).
- Utterances that are completely unintelligible will not be counted.
- Utterances that contain unintelligible components, but do have intelligible content are counted.
- For the purposes of this study, when an address is provided, the house/apartment number plus street name and then the city plus postal code are counted as separate utterances (e.g., 123 Rose Avenue [1 utterance] London N6H 4Y8 [1 utterance])

Appendix S

Person-Centred Communication Coding Chart

Person-centred Communication	Definition	Examples
Recognition (R)	To acknowledge a person, calling them by name, affirm them uniquely by incorporating their life story into conversation. Code when the persons family, life, day or situational context is referred to.	Hi Mr. Jones. How are you today? How many kids do you have? How is your husband doing? You daughter usually visits on weekends, doesn't she? Good morning Joe. There is your aunt Judy and Uncle John. That's just after we took the bus tour up the mountain.
Negotiation (N)	To consult the person on their preferences, desires and needs Often takes place over simple everyday issues.	Would you like to switch to the next picture now? Would you like to have lunch soon? Do you want to watch TV tonight or do you want to play a board game? Can you remind me of that later?
Facilitation (F)	To work together. To involve the person's initiative and abilities in a shared task, with definite aim in view. To enable to do what otherwise he/she wouldn't be able to do, by providing the missing parts of the action To enable interaction to get started, to amplify it and to help the person gradually fill it out with meaning To enable a person to sustain his or her action; to keep it from falling into the void because of memory failure To be ready to initiate or respond to the person, neither rushing in or too quickly or holding back for too long To enable the use of their remaining abilities by requesting To fill gaps in meaning and understanding To confirm information trying to be conveyed (often in question form) To request or provide specification (often providing an answer to a question or thought) To elaborate on the topic at hand. DO NOT code when asking who a person is, or asking if the person remembers.	What are you looking for Mr. Smith? Can I help? When you were young what was your favourite hobbies? P1: We didn't want to go to the mall so instead we um... P2: What happened then? (F) What was your favourite part of your vacation to Florida? Would you like me to get your glasses for you so you can see the photos better? P1: I saw my friend today P2: Did you see them this morning? (F) P1: I thought that was at Christmas P2: Yes it was Christmas of 2001 (F) P1: Why were we there? P2: We were visiting your sister (F)
Validation (V)	To acknowledge the reality of a person's emotions/feelings and give a response on the feeling level. To appreciate and respond to the desire or need that a person may be expressing; to help if necessary, to convert it to an intention. To use empathy and gain some sense of what a person may be experiencing To understand a person's definition of a situation. To respond sensitively to any signs that a person's definition of the situation is changing, and to move with any changes that occur. To express emotion about family, friends, life event or situational context.	Very good hon. You are right. P1: I can't figure this out. P2: Don't be upset Joe. You are doing well. You are doing your best. P1: Where is Mary now? P2: Mary lives in Toronto now. She is doing well. You have managed well this morning since you've been worried about Mary. Oh I really like that picture of you. You look great there. That vacation was so fun. I'm so glad we went. What a nice family picture. I love our children. That's right Good for you. Right I see what you are saying. We used to have so much fun. Everyone looks really happy.

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Savundranayagam, M. Y., & Moore-Nielsen, K. (2015). Language-based communication strategies that support person-centered communication with persons with dementia. *International Psychogeriatric*, 27(10), 1707–1718. doi:10.1017/S1041610215000903

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press: Maidenhead.

Curriculum Vitae

Kelsey Dynes

Education

Master of Science- Health and Rehabilitation Science

- Health and Aging
- Fall of 2016 to Fall of 2018
- International Consortium for Communication, Aging and Neurodegeneration

Bachelor of Arts- Honours Double Major Health Science and Psychology

- Brescia University College (Western University Affiliate), London, Ontario
- Fall of 2012 to Spring of 2016

Research Experience

Graduate Teaching Assistantship

September 2017 to December 2017

Western University, London, Ontario

- Course design for an e-campus funded diploma by the School of Health Studies
- Worked alongside content experts to research and design online courses

Research Assistant

Summer 2016

ICAAAN lab, Western University, London, Ontario

- International Consortium for Communication, Aging and Neurodegeneration
- Assist with data collection and transcription

Academic Teaching Skills

Teaching Assistant

January 2017 to May 2017

Western University, London, Ontario

- Health Sciences 4710B- Palliative and End of Life Care
- Helped facilitate weekly lectures regarding specific topics in palliative care
- Marking assignments, major essays, exams
- Assisted and answered course content questions to undergraduate students

Other Work-Related Experience

Scotiabank Customer Representative

March 2017 to present

Scotiabank Canada

- Helping customers with all banking and financial needs

Timbits Volleyball Coach/ Feed the Fire Coach

September 2015 to April 2017

London Volleyball Club, London, Ontario

- Helped coordinate volleyball related activities for young children

Conference and Workshop Participation

Speech-Language Audiology Canada Conference May 2018
Speech-Language Audiology Canada, Edmonton, Alberta

- 3-day research conference with leading researchers in the speech-pathology, audiology and other communication fields

Health & Rehabilitation Science Graduate Research Conference January 2018
Western University, London, Ontario

- Listened to fellow students present on their research

Communication Assistance Course January 2018
Communication Access Disabilities Canada

- Online course that focused on ways to assist persons who face speech and language impediments

Health & Rehabilitation Science Graduate Research Conference February 2017
Western University, London, Ontario

- Listened to fellow students present on their research

HRS Speaker Series October 2016 to May 2018
Health and Rehabilitation Sciences, Western University

- Attended multiple presentations from HRS alumni speakers

Primary Progressive Aphasia Rounds September 2016 to April 2018
Parkwood Institute, St. Joseph's Healthcare, London, Ontario

- Discuss case studies of persons with primary progressive aphasia

Montessori Spaced Retrieval Online Conference August 2016
American Speech-Language-Hearing Association (ASHA)

- Techniques to enhance communication interventions for individuals with dementia

Brain Exchange Online Conference September 2016
Alzheimer Society, Ontario

- Techniques for enhancing dementia care through knowledge exchange and translation

W.E. Mean Business- Women's Entrepreneurship Conference October 2015
Brescia University College, London, Ontario

- Learned the steps to starting and maintaining your own business and/or ideas

Honours and Achievements

- HRS Graduate Student Conference- Oral presentation award 2018
- Western Graduate Research Scholarship 2016, 2017
- Dean's Honour List 2013- 2016
- Brescia Entrance Scholarship for Academic Excellence 2012
- Therese Quigley TVDSB graduating volleyball player of the year 2012