

DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION: INCREASING RURAL  
ACCESSIBILITY FOR DEMENTIA CARE

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By

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## Abstract

This dissertation contributes to knowledge on digital and remote methods of dementia education, which are methods that are accessible for rural residents. Education for informal caregivers (who are typically unpaid family members) may improve caregiver wellbeing, increase self-efficacy in caregiving, and prolong time at home for persons with dementia, and remote methods make this education accessible for rural dwelling families. Similarly, rural primary care professionals face challenges in dementia care related to unique aspects of rural living, such as work isolation and reduced access to specialized services and learning opportunities. Provision of continued education to primary care practitioners plays a vital role in improving patient care by reducing knowledge disparities and diagnostic doubt, thereby assisting patients in receiving a timely diagnosis. Over the course of the first two studies, the dissertation will develop an evidence-based delivery strategy for evaluating digitally-delivered dementia education for informal caregivers and rural primary care providers, which that is feasible and acceptable. This evidence will serve as a foundation for the third study, a pilot study for rural primary care providers.

Study 1 investigates and documents technology-based modes of remote dementia education for informal caregivers via a systematic review and meta-analysis of the impact on caregivers based on the intervention literature. Study 2 investigates and documents technology-based modes of remote dementia education for healthcare providers via a systematic review, which is used to inform the third study. Study 3 explores feasibility and acceptability of dementia education delivered via a smart phone application with selective reminding (research has shown that education can be enhanced with intermittent prompts to boost use of newly acquired concepts in everyday practice). We postulate that this form of remote education will be flexible (i.e., able to be distributed over shorter time intervals), tailored to care provider needs, and highly accessible.

The dissertation findings will determine a model of dementia education best suited to the needs of rural caregivers (informal and formal) and will be used to determine next steps in developing and piloting of an educational program aimed at the understudied population of rural primary care providers.

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## **General Introduction**

In this dissertation I examined the feasibility of an empirically supported digital mode of educational dementia delivery accessible for rural caregivers; including informal caregivers who are typically unpaid family members (herein referred to as ‘caregivers’) and one group of formal caregivers, specifically rural primary healthcare providers. The intent was to examine the evidence base of digital educational methods for dementia care aimed at increasing accessibility for rural dementia care via systematic reviews of remote dementia education aimed at informal care providers and education aimed at healthcare providers. While individuals who are diagnosed with dementia were a consideration for the study, there is research which shows that there are differences in perceived needs of people with dementia, their informal caregivers and healthcare providers (Hancock et al., 2003; Miranda-Castillo et al., 2013; Orrell et al., 2008; van der Roest et al., 2009). A study examining perceived needs among the three populations found that people with dementia reported more needs related to psychological distress whereas caregivers and healthcare providers reported needs with dementia education and support with daytime activities (Miranda-Castillo et al., 2013). Several theories were formed around this finding. One theory posits that people with dementia ignore their difficulties to deal with perceived threat of autonomy (Steeman et al., 2006). Another theory posits that people with dementia as time progresses, begin to lack awareness and insight into problems and rate their quality of life as higher (Trigg et al., 2011). For the purposes of this study, I chose to focus on needs of informal caregivers and healthcare providers as these needs tend to be the most similar in type and quality and focus on dementia education. Two reviews were carried out to identify existing digitally-based dementia education for caregivers and healthcare providers. The two reviews revealed different findings for these two groups: a copious body of research on digitally-based dementia education programs for caregivers, which allowed for a meta-analysis, but few digitally-based dementia education programs for rural primary healthcare providers. This finding guided us to focus on rural primary healthcare providers in the third study and evaluate the feasibility and acceptability of an educational intervention aimed at this unique and understudied population. The dissertation is written in manuscript style, with the first study composed of manuscript-style

systematic review and meta-analysis, followed by the second study which is also a systematic review and lastly, a feasibility study building on the findings of the two systematic reviews.

Study 1 presents recent research on digitally-based, remotely delivered dementia educational interventions with an emphasis on studies with pre and post measures. Study 2 presents recent research on digitally-based remotely delivered dementia education for rural healthcare providers. Study 3 explores acceptability and feasibility of a digital education tool with rural primary healthcare professionals and serves as the basis for potential development of a remote dementia educational tool. Although general evidence suggests acceptability of digital and remote dementia educational tools for healthcare providers (Broughton et al., 2011; Cobbett et al., 2016; Harvey et al., 2006; Jones & Moyle, 2016; Ruiz et al., 2006; Waldorff et al., 2009), I argue that an approach implemented with consultation of a prospective user of the educational materials (someone to whose professional demographic the educational tool is targeted - primary healthcare; (Degryse et al., 2009; Fahey-McCarthy et al., 2009; Scott et al., 2015) is likely to optimize feasibility and acceptability. Implementations of digital tools for continued medical education have great benefits for remote and rural delivery (Kosteniuk et al., 2016), and are thus favorable methods for dementia education and may be particularly well-suited to a population of primary care health professionals practicing in a rural area such as Saskatchewan. The general introduction is intended to provide a broader, general conceptualization of dementia in the world and Canada, including current diagnostic practices and barriers to diagnosis, which are provided to situate and establish a framework for study rationalization.

### **Dementia Incidence and Prevalence**

Dementia is characterized by cognitive decline which includes memory loss, difficulties with communication and reasoning, behavioral and psychological symptoms, and sometimes a change in personality, all of which depend on concomitant factors such as etiology of dementia, age of onset, timing of diagnosis, and implementation of a management and treatment plan (Derby et al., 2017 & Hall, 2017; Fiest et al., 2016; Langa, 2015; Pink et al., 2018). Dementia diagnosis has an outward ripple effect that not only impacts persons living with dementia, but also impacts others in these individuals' lives, such as immediate and extended family members, healthcare providers, healthcare systems, insurance providers, communities and in the long run, whole nations (Akerjordet et al., 2018; Alzheimer Society of Canada, 2016; Alzheimer's Association, 2010; Eley, 2018; Matthews et al., 2016; McDougall, 2017). Dementia represents a

logistic as well as emotional strain on families and support systems (Akerjordet et al., 2018; Alzheimer Society of Canada, 2010; Alzheimer's Association, 2010), with progressively increased projected burden in the decades subsequent to onset of dementia (Langa, 2015).

Dementia prevalence signifies the proportion of individuals with dementia in a defined population, and dementia incidence signifies the occurrence of new cases of dementia over a determined period of time (e.g., a decade; (Wu et al., 2017)). Dementia prevalence and incidence have been noted to change over time (Derby et al., 2017; Fiest et al., 2016; Kokmen et al., 1993; Kokmen et al., 1988; Langa, 2015; Rocca et al., 2011; Rorsman et al., 1986; Satizabal et al., 2016; Schrijvers et al., 2012) with decreasing rates of incidence among higher income countries, and increasing rates in middle to low-income countries (Niu et al., 2017; Satizabal et al., 2016; Wu et al., 2017). Studies on dementia prevalence have been less clear, with some suggesting stable or declining prevalence of dementia (Niu et al., 2017; Wu et al., 2017), and some indicating increasingly higher prevalence in North America than South America and Europe (Fiest et al., 2016), as well as steadily increasing prevalence in East Asian countries such as Japan, South Korea, Hong Kong, Taiwan and China (Wu et al., 2017). Regardless of these trends, prevalence of dementia generally remains higher among females (Fiest et al., 2016; Niu et al., 2017). There seems to be a general discrepancy among rising trends in dementia incidence and fluctuating trends in dementia prevalence (Derby et al., 2017; Fiest et al., 2016; Langa, 2015; Niu et al., 2017). Some explanations of this discrepancy in incidence and prevalence of dementia across countries include postulated reductions in social inequalities, improvements in living conditions, better access to education, improved healthcare, which mitigates risk factors related to physical, mental and cognitive health (Satizabal et al., 2016; Wu et al., 2017), and a decreasing number of cardiovascular events due to more effective treatment of stroke and heart disease (particularly impactful for vascular type dementia; (Derby et al., 2017; Satizabal et al., 2016). While earlier studies found no significant changes in dementia incidence through the 1980's to early 1990's (Kokmen et al., 1993; Kokmen et al., 1988; Rorsman et al., 1986), studies conducted in a more recent period (Rocca et al., 2011; Satizabal et al., 2016; Schrijvers et al., 2012) have indicated that incidence is decreasing in the United States and Western Europe, thus supporting the observed pattern in dementia incidence as not stable, and therefore difficult to estimate.

Factors contributing to increased prevalence of dementia are a rapidly aging population (World Health Organization, 2015), and a significant association between older age and dementia prevalence (Fiest et al., 2016; Livingston et al., 2017). Some of the factors contributing to varied rates of incidence are higher rates of detection and better dementia education (Wancata et al., 2003; World Alzheimer Report, 2018; World Health Organization, 2015), where continuing dementia education for healthcare providers has been shown to influence earlier diagnosis, suggesting that clinicians are becoming better at diagnosing dementia (World Alzheimer Report, 2018; Wu et al., 2017). In North America, there is a trend indicating increasing mean age at diagnosis from 80 to 85, indicating later onset of dementia (Satizabal et al., 2016). However, despite the age-specific trend in diagnosis, and some potential stabilization in prevalence (Niu et al., 2017; Satizabal et al., 2016), the world-wide burden of dementia is expected to increase as the average life expectancy grows (Langa, 2015; Satizabal et al., 2016). Training programs in medicine in the United States do not require geriatric training, even though many of these professionals are specializing in areas likely to include work with older populations such as cardiology, oncology, and emergency medicine (Lichtenberg & Hegde, 2009). Additionally, in the United States, the accreditation council for medical education does not require geriatrics training (Lichtenberg & Hegde, 2009). Existing healthcare education is typically limited to a series of clinical placements that are time limited and fail to deliver a deeper understanding of chronic conditions such as dementia (Banerjee et al., 2017). One way to counteract a lack of dementia training is to enhance existing dementia education in medical and healthcare university programs (Alushi et al., 2015). Another way would be to provide ongoing medical training and education for practicing healthcare professionals (Hvalic-Touzery et al., 2018). Lack of dementia education for healthcare providers translates into lack of education provided to family caregivers after diagnostic appointments or check-ins for the carees whom most of the day-to-day caregiving duties fall. This outlines the importance of dementia education for healthcare providers. This is also acknowledged in the new national dementia strategy for Canada, which advocates for integration of a dementia lens within existing curricula for healthcare providers (Public Health Agency of Canada, 2019).

The Canadian rural population is primarily older than the urban population, where approximately 20% of the rural population versus 16% of the urban population are aged 65 years and older (Statistics Canada, 2016). Saskatchewan has a high percentage of older adults living in



rural areas; approximately 15.4 % of the rural population is aged 65 and older (Census of Canada, 2016). In 30 years, it is estimated that 2.3% of the Saskatchewan population will be living with dementia (Alzheimer Society of Canada, 2010). Of this population, an estimated 65% will be women (Alzheimer Society of Canada, 2010). As noted earlier, incidence of dementia is generally more likely for older age groups (aged 65 to 84 years and aged 85 or older; (Derby et al., 2017; Kosteniuk et al., 2016; Satizabal et al., 2016)). Diagnosis also tends to be generally higher among females (31% higher among females than males; (Derby et al., 2017; Fiest et al., 2016; Kosteniuk et al., 2016; Niu et al., 2017)), and a greater proportion of dementia cases are identified in more populous areas (Russ et al., 2012).

### **Financial Impact of Dementia**

The global cost of dementia care in 2015 was estimated at 818 billion (Eley, 2018). Seventy percent of this estimated cost is attributed to two specific regions: North America and Western Europe (World Health Organization, 2015). Costs of dementia care exceed the costs of caring for those diagnosed with cancer, heart disease, and other chronic conditions (Alzheimer's Association, 2018; Grand et al., 2011; Hurd et al., 2013; Jutkowitz, Kuntz, et al., 2017; Jutkowitz, MacLehose, et al., 2017; Kelley et al., 2015; Mayeux & Stern, 2012; Quentin et al., 2010; Samuel, 2010; Taylor et al., 2001). The costs of dementia care in Canada are estimated at five and a half times higher for individuals diagnosed with dementia compared to individuals diagnosed with other health conditions, with home care and long-term care representing the largest fraction of these costs (Alzheimer Society of Canada, 2016). Cost of care for individuals aged 70 or older, who passed away between 2005 and 2010 in the United States incurred approximately 287,038 dollars for private medical insurers in the United States, such as Medicare ("Dementia has 'crushing' financial burden," 2016). A large proportion of the estimated costs of care in dementia in the U.S. also include expenditures for physician visits and drug prescriptions (Chen et al., 2009).

Higher financial cost of dementia care is more prevalent in affluent countries (Eley, 2018), with higher costs attributed to higher spending on social care and healthcare (Bremer et al., 2017; Hsu & Willis, 2013; World Health Organization, 2015). The cost of caring for people with dementia in low-income countries was estimated at a much lower financial point, and accounts for only 1% of overall estimated global cost. Comparably lower financial cost of care in less affluent countries is hypothesized to correspond to a greater reliance on informal care,

underdeveloped infrastructure and health care systems (World Health Organization, 2015), and a growing aging population in developed countries (Zweifel et al., 1999). While higher-income countries are purported to have a better structure for handling of dementia diagnosis, education, care and management, the healthcare systems are still fragmented, and are generally unresponsive and uncoordinated in terms of immediate patients' and families' needs (Kelley et al., 2015; Mason et al., 2018; Mayeux & Stern, 2012; Murante et al., 2017; Taylor et al., 2001; Thorpe et al., 2015; World Alzheimer Report, 2018).

In Canada and Saskatchewan, the cost of care for individuals diagnosed with dementia, and number of unpaid care hours contributed by informal caregivers is expected to rise (Alzheimer Society of Canada, 2010, 2014, 2016). The Canadian government has invested 23 billion dollars toward dementia initiatives, with 236 million invested toward dementia research through Canadian Institutes of Health research (Alzheimer Society of Canada, 2014), and as part of a new Canadian strategy, 50 million dollars were announced, which will be invested toward a new dementia strategy (Public Health Agency of Canada, 2019).

An ability to provide a timelier diagnosis, implement proper management, and offer necessary care, has shown to increase the impact of efforts to slow dementia progression (Alzheimer Society of Canada, 2016; Alzheimer's Association, 2010; Mason et al., 2018). The Alzheimer's Association (2010) determined that if such efforts were vested in a well-timed manner in the U.S., the number of those over the age 65 diagnosed with dementia (advanced stage) would decrease from 2.4 to 1.1 million in 2020; in the same manner, estimated insurer costs would drop from an estimated 117 billion in 2050, to 62 billion. Thus, implementation of timely diagnosis, treatment, and management could not only reduce strains on individuals and caregivers, but also decrease the overall financial burden incurred on healthcare systems and health insurance providers (Alzheimer Society of Canada, 2016; Hsu & Willis, 2013; Hurd et al., 2013; Jutkowitz, MacLehose, et al., 2017; Mason et al., 2018; Murante et al., 2017; Quentin et al., 2010).

### **Financial Impact of Caregiving for Dementia**

Out-of-pocket expenditures by informal caregivers are estimated at an average \$61,522 ("Dementia has 'crushing' financial burden," 2016). In the United States, everyday yearly costs of caring for patients with dementia – which includes individual care, nursing home care, and costs incurred on Medicare, Medicaid, and other private medical insurers for a sample of 10,000

individuals – were reported between \$41,689 and \$56,290 (Matthews, 2013). In Canada, the cost associated with Alzheimer’s and other dementias, exceeded the cost of other neurodegenerative conditions and brain injuries (Public Health Agency of Canada, 2019). A similar trend of exceedingly high care costs, associated with caring for dementia patients, was also reported in the United Kingdom (U.K.; (Eley, 2018; Mason et al., 2018; Samuel, 2010)). While the National Health Service in U.K. allows for free care for chronic conditions such as cancer, stroke, and heart disease, dementia is not covered under this plan; costs typically not covered by medical insurance (such as costs affiliated with dementia care), fall on informal caregivers (regarded as out-of-pocket costs) and are estimated to account for three-fifths of overall care cost (Eley, 2018). Calculated into these expenditures are also costs attributed to lost wages by carers who contribute a significant amount of time to care and consequently less time to paid work (Eley, 2018; Hsu & Willis, 2013; Murante et al., 2017; Thorpe et al., 2015).

Demands of caregiving tasks typically increase with time, both in complexity, and number of needed tasks, with an eventual assumption of comprehensive daily household duties and finances by informal carers (Hsu & Willis, 2013; World Health Organization, 2015). This takes a toll on informal carers not only physically, but also psychologically and emotionally (Bremer et al., 2017; Thorpe et al., 2015; World Alzheimer Report, 2018). For informal caregivers (herein referred to as caregivers or informal caregivers), assuming household finances and protecting against mismanagement by a cognitively impaired spouse may involve additional tasks such as assigning power of attorney, establishing trusts, and taking over former financial responsibilities of the spouse (Hsu & Willis, 2013). Additionally, caring for aging individuals typically carries the possibility of caring for other comorbid health conditions, which when paired with cognitive decline, translate to an even greater need for a more comprehensive oversight and care (World Health Organization, 2015). Furthermore, if a caregiver has a cognitive, mobility, or health limitation, this adds burden and limitations in access to other necessary health services (Thorpe et al., 2015). Shifting resources toward better education on dementia diagnosis and management for caregivers, may alleviate some of the financial burdens, and re-direct efforts toward earlier diagnosis, and generally better care (Bremer et al., 2017; Grand et al., 2011; Jutkowitz, Kuntz, et al., 2017; Jutkowitz, MacLehose, et al., 2017; Mayeux & Stern, 2012; Murante et al., 2017; Quentin et al., 2010; Taylor et al., 2001; Thorpe et al., 2015). Creating a shift toward community-based services can also re-direct care efforts toward

resources that are ready to handle the complexity of demands and extent of costs (Hurd et al., 2013; Kelley et al., 2015; World Alzheimer Report, 2018). Additionally, it may be more financially advantageous to divert diagnosis and management away from specialists, toward management-focused primary care, to reduce overall expenditures on unnecessary neuroimaging tests and specialist costs (Alzheimer Society of Canada, 2016; Mason et al., 2018; World Alzheimer Report, 2018).

### **Emotional and Health Impact of Dementia on Caregivers**

Caregivers of individuals diagnosed with dementia face unknowns about the extent of their new role and caregiving requirements and a sudden shift in the relationship with the caree (Biegel & Schulz, 1999; Braithwaite, 1992; Brodaty & Donkin, 2009; Mioshi et al., 2013; Pearlin et al., 1990; Riedijk et al., 2006). Some caregivers may initially care only a few hours per week; however, this time commitment can change and extend up to 40 hours per week (Biegel & Schulz, 1999) or more for live-in caregivers. This sudden shift may induce feelings of burden, which is defined as awareness of the condition, unpredictability of progression, shifts in the relationship with the caree (e.g., from partner or child to caregiver), and a perceived lack of free choice (Braithwaite, 1992; Pearlin et al., 1990). As impairment continues to progress, this leads to increasing levels of dependency for meeting basic care needs (Pearlin et al., 1990). This sudden shift may also have a sudden impact on re-structuring of the previous relationship. Caregiving, which is an initial component of relationships, may now expand to the point where it comprises the entirety of the relationship (Pearlin et al., 1990). Additionally, as the number of care responsibilities grows, so does the time devoted to care, at which point there are indirect costs that occur due to loss of earnings previously obtained outside the home, and now devoted to informal care (Brodaty & Donkin, 2009). Role stressors are hypothesized to be rooted in needs or demands of the individual diagnosed with dementia, and the perceived caregiving repertoire of needs (Pearlin et al., 1990).

The range and magnitude of impairment arising out of memory loss, communication, and recognition difficulties, affect perceived caregiver stress and burden (Pearlin et al., 1990).

Studies show that various types of dementia and the severity of disease presentation may also affect perceived caregiver burden (Mioshi et al., 2013; Riedijk et al., 2006). A study by Mioshi and colleagues (2013) found that caregivers caring for individuals diagnosed with semantic dementia, prefrontal dementia, and Alzheimer's disease showed similar amounts of perceived

burden. However, caregivers of individuals diagnosed with frontotemporal dementia showed higher burden than caregivers of individuals diagnosed with Alzheimer's disease (Mioshi et al., 2013). Another study by Riedijk and colleagues (2006) found that caregivers of individuals diagnosed with frontotemporal dementia reported increased burden and decreased quality of life. These authors advocated for interventions targeted to increased support of caregivers of individuals with frontotemporal dementia as well as more education on coping strategies (Riedijk et al., 2006). These findings indicate that perceived presentation of each dementia variant may have a differing effect on caregiver ability to provide care, as well as affecting perceived quality of life reported by caregivers.

Caregivers of individuals diagnosed with dementia generally report higher levels of perceived stress, depression, lower general wellbeing, greater physical health consequences, and lower levels of perceived self-efficacy compared to noncaregivers (Pinquart & Sorensen, 2003). The perceived stress may also have an impact on caregiver mental health by increasing depression and anxiety (Brodaty & Donkin, 2009). Additionally, the time now devoted to the caree is allocated to care from pleasurable self-care activities such as engagement with social contacts and supports, and pursuit of leisure activities and hobbies. This reduction in pleasurable activities and engagement with social supports and family members may further negatively affect caregiver mental health (Brodaty & Donkin, 2009). Caregiver symptoms of depression also have higher correlates with physical health than behavioral problems or intensity of caregiving tasks (Pinquart & Schonbrodt, 1997). Other factors affecting physical health are identified as higher caregiver age, lower socioeconomic status, and lower levels of perceived support (Pinquart & Schonbrodt, 1997). Other studies have shown impact of the new caregiving role and forfeiting of self-care activities, which negatively affected physical health and manifested as increased cardiovascular problems, lower immunity, slower healing, and increased presence of chronic conditions (Baumgarten et al., 1992; Haley et al., 1987). The impact on caregivers also includes more visits to the physician, greater use of prescription medication, lower self-rated health, less engagement in healthy behaviors such as exercise, and increased likelihood of smoking, drinking, and poorer sleep habits (Baumgarten et al., 1992; Haley et al., 1987; Schulz & Martire, 2004). These findings enforce the inter-linked nature of higher needs and responsibilities, and their effect on caregiver mental and physical wellbeing.

Receiving a timely dementia diagnosis can affect the wellbeing of the patient by slowing the progression of the disease and in helping to maintain a higher quality of life for a longer time (Bradford et al., 2009; Cattell et al., 2000; Lohle et al., 2014; van Vliet et al., 2013). However, the making of the diagnosis depends on several factors such as the stage and severity of the cognitive decline, whereby diagnosis is more likely to be made in the later stages of progression (Bartfay et al., 2014), and the age of onset, whereby younger age of onset was related to a timelier diagnosis (van Vliet et al., 2013). Timely dementia diagnosis also has vast implications for caregivers, because caregivers are asked to suddenly step into a brand new and unknown role (Ducharme et al., 2012). Earlier diagnosis allows for caregivers to better plan for future care, utilization of new coping strategies, better knowledge of available services, and lower emotional distress (Ducharme et al., 2012). Caregivers who were asked to share the benefits of obtaining a dementia diagnosis in a Rural and Remote Memory Clinic indicated they felt more acceptance, access to treatment, guidance, and knowledge of what to expect after their caree received the diagnosis (Morgan et al., 2014). Furthermore, six months later the same caregivers indicated that the diagnosis had provided them with a sense of validation, improved access to care, and a greater sense of relief (Morgan et al., 2014). Therefore, timelier dementia diagnosis can impact both the wellbeing of the caregiver and the caree (Bradford et al., 2009; Cattell et al., 2000; Ducharme et al., 2012; Lohle et al., 2014 2014; Morgan et al., 2014; van Vliet et al., 2013).

### **Caregiver Burden**

Research posits that two kinds of caregiver burden may arise, namely subjective burden and objective burden (Braithwaite, 1992). Subjective caregiver burden occurs when the caregiver appraises their ability to handle the burden (including the emotional and physical impact of burden) and availability of supporting resources (Braithwaite, 1992; Brodaty & Donkin, 2009). Objective burden relates to the perceived caree behavioral issues and the level of dependency (Brodaty & Donkin, 2009). However, environmental antecedents may influence the perceived level of burden (Lazarus & Folkman, 1987). There are potential mediating factors which may influence the perceived level of burden such as quality of the relationship prior to onset of disease (Kramer, 1993), acceptance of the situation and ongoing implications (Lloyd et al., 2016), and cultural influences (e.g., filial relationships in the family) (van Wezel et al., 2016; Yu et al., 2016), all of which may enable the caregivers to commit to their new role, and draw upon personal strengths and create more meaningful opportunities to interact with their caree (Nolan et

al., 1996). A finding by Ownsworth (2010) indicates that finding and relying on caregiver strengths can create more effective coping and support strategies for caregivers. The quality of the relationship between the caregiver and the caree may enhance feelings of accomplishment through a greater sense of self efficacy and increase caregivers' self-reported wellbeing (Carbonneau et al., 2010).

A study investigating the effect of perceived hassles and uplifts in everyday caregiving found that both have a direct impact on caregiver's social and psychological wellbeing (Kinney & Stephens, 1989). The authors noted that caregivers who are more intensely involved in care would benefit from uplifts via assistance with activities of daily living and respite (Kinney & Stephens, 1989). A study by Rapp and Chao (2000) found that appraisals of strain and gain in the caregiving role can also result in negative affect or positive affect in caregivers. This has an important implication for caregiving as it suggests that stress is an important mediating factor in appraisal of the caregiving role, which may also affect the ability to care and perceived burden and stress. Appraisal of stress and the ability to cope with the new role directly affects perceived levels of burden (Braithwaite, 1992; Brodaty & Donkin, 2009; Carbonneau et al., 2010; Lazarus & Folkman, 1987; van Wezel et al., 2016; Yu et al., 2016).

### **Stress Appraisal and Coping**

One model used to explain why the perceived stress results in negative affect causing anxiety and depression is the Stress Coping Model (Biegel & Schulz, 1999). This model assumes that as chronic illness progresses toward physical disability, this process is stressful for both the caregiver and the caree. When caregivers face these stresses, they make an evaluation of whether their caregiving abilities or capacity exceeds the caregiving need. When the need is perceived as heavier than the coping resources and capacity, then the caregiver perceives himself or herself to be under stress (Biegel & Schulz, 1999). Appraisals of past coping experiences whilst caring for someone may also impact appraisal of present caregiving abilities and stress (Chwalisz, 1996). If the caregiver had a previous positive caregiving experience that imposed a demand and was met with adequate coping ability, these place the present appraisal of potential stress as less threatening (Chwalisz, 1996). Another mediating factor has been identified as finding meaning in the caregiver role, where finding meaning may serve as a positive predictor of caregiver wellbeing (Farran et al., 1991).

Appraisal of caregiving burden does not always go hand in hand with appraisal of gain (Rapp & Chao, 2000). There is research demonstrating that there are also positive aspects to caregiving, which are not necessarily on the opposite end of the burden on a continuum, but may reflect another aspect of caregiving (Boerner et al., 2004). Positive appraisal can enhance caregiver wellbeing despite the existing challenges (Lawton et al., 1991). Positive aspects of caregiving may protect against burnout and reduce negative aspects such as perceived burden, anxiety, depression, identity loss, and perceived role captivity (Blume, 1999; Morano, 2003; Walker et al., 2016). Reduction of burden via implementation of strategies and finding meaning in the caregiver role may enhance caregiving skills (Butcher & Buckwalter, 2002) and improve the ability to rely more on personal empowerment (Cohen et al., 2002; Morano, 2003; Walker et al., 2016).

### **Positive Aspects of Caregiving**

Self-efficacy is an important factor in caregiving (Cheng et al., 2012; Cheng et al., 2015). A study by Cheng and colleagues (2012) found that perceived self-efficacy in the caregiving role had a direct impact on depression. Self-efficacy was defined by the ability to respond to disruptive behaviors, ability to secure respite, and perceived ability to intercept negative thinking. The results of this study showed the effect of positive perceived aspects on caregiver wellbeing and the perceived role in the caregiving relationship (Cheng et al., 2012). Other examples of positive aspects constructed by caregivers (and influencing the caregiving relationship) include committing to the role, finding gratification in the caregiving role, finding increased patience/tolerance, letting go of things, feeling useful (Cheng et al., 2015; Cohen et al., 1994), feeling a personal sense of accomplishment, effective emotional regulation, and finding a sense of personal growth (Sanders, 2005; Yu et al., 2018). Finding positive aspects in caregiving has also been associated with lower depression and perceived burden (Cohen et al., 2002). While positive aspects are not on the other end of the continuum of burden, positive aspects may simply reflect a dimension which may improve the caregiving experience (Boerner et al., 2004). A study by Pinqart and Sorensen (2003) noted that psychosocial interventions focusing on enhancing positive aspects of caring could serve as a strong protective factor against perceived burden, mental and physical difficulties, and could enhance the positive aspects of the caregiving experience (Carbonneau et al., 2010; Pinqart & Sorensen, 2003)



## **Lack of Dementia Knowledge Among Caregivers**

Caregiving for individuals diagnosed with dementia presents unique challenges for caregivers, including lack of information regarding management and care (James & Paulson, 2019), which carry unique implications for care during the progression of disease e.g., lack of knowledge regarding increased levels of care and respite needed further along progression of disease (Bonner et al., 2015), management of emotional and behavioral challenges (Ali & Bokharey, 2016; Lee et al., 2015), and availability of support services (James & Paulson, 2019). Caregivers identify several gaps in knowledge such as education aimed at everyday caregiving tasks (Bonner et al., 2015), financial counselling (James & Paulson, 2019), management of own emotional needs (reactivity and self-neglect) (Ali & Bokharey, 2016; Peterson et al., 2016 et al., 2016), information regarding the course and progression of disease (Peterson et al., 2016), and availability of existing dementia information and resources (Lee et al., 2013).

Caregivers indicate barriers to care which include a lack of general dementia knowledge and education regarding symptoms and everyday care management, especially with regards to behavioral symptoms of dementia (Peterson et al., 2016). The bulk of the dementia education is typically shared via healthcare professionals in form of print materials and community and Internet resources; however, this has been deemed insufficient by caregivers (James & Paulson, 2019; Jensen et al., 2015; Lee et al., 2016a; Peterson et al., 2016). Caregivers generally express a need for education on dementia and request information on numerous topics such as behavioral management (Ali & Bokharey, 2016; Lee et al., 2015), management of daily tasks (Peterson et al., 2016), access to community programs and respite care (James & Paulson, 2019), financial counselling for increasing needs and eventual admission to long-term care (James & Paulson, 2019), and access to other community and online educational resources (Elmståhl et al., 2012; Lee et al., 2015). Their healthcare providers are not, however, able to provide this education for caregivers, due, at least in part, to the lack of dementia education aimed at healthcare providers (Cahill et al., 2008; Gove et al., 2017; Peterson et al., 2016; Phillips et al., 2012; Tang et al., 2018). Also, it has been noted that information in the form of letters, pamphlets, and online resources supplied by the healthcare providers has been well received but deemed largely insufficient by caregivers (James & Paulson, 2019; Jensen et al., 2015; Lee et al., 2015; Peterson et al., 2016).

## **Benefits of Dementia Education for Caregivers**

Provision of education for caregivers of those diagnosed with dementia has been shown to reduce burden and increase satisfaction with caregiving (Carbonneau et al., 2011; Elmståhl et al., 2012 & Nordell, 2012), delay admission to long-term care (Warrick et al., 2018), improve coping and resilience after a loss (Somers et al., 2016), close information gaps among caregivers with lower educational attainment (Brown et al., 2013), reduce anxiety and depressive symptoms (Blom et al., 2015 Cujpers, & Pot, 2015), increase confidence and self-efficacy in caregiving (Ducharme et al., 2011), and increase efficacy in management of challenging behaviors (Guest et al., 2015; Terayama et al., 2018). Studies on dementia education for caregivers have demonstrated both a high need and positive effect of dementia education on experience of caregiving (Ali & Bokharey, 2016; Elmståhl et al., 2012; James & Paulson, 2019; Lee et al., 2015; Peterson et al., 2016). Educational courses for caregivers of persons diagnosed with dementia have also been noted as successful in achieving their educational goals and are generally well-received by caregivers (Blom et al., 2015 Cujpers, & Pot, 2015; Carbonneau et al., 2011; Ducharme et al., 2011; Elmståhl et al., 2012; Guest et al., 2015 2005; Terayama et al., 2018). A course designed for caregivers was delivered over a duration of two months with two 90-minute lectures delivered by healthcare professionals such as physicians and nurses (Terayama et al., 2018). This course included information regarding how to address common dementia questions regarding the progression and preparation for long-term care, and management of comorbid medical issues (Terayama et al., 2018). The course was successful in improving symptoms of depression, a sense of burden among caregivers, and psychological symptoms of dementia among the care recipients (Terayama et al., 2018). Another 5-session course divided across five 1.5-hour training installments was designed to address everyday challenges of care such as communication, activities of daily living, and challenging behaviors (Guest et al., 2015). Caregivers who attended this course indicated improved understanding of dementia, better recognition of symptoms, and better management of challenging behaviors (Guest et al., 2015). A program consisting of 90-minute individual sessions distributed over seven weeks was designed to convey information regarding preparedness to deal with caregiving situations, planning for anticipated needs of the care recipient, knowledge of available community support resources, and proper use of coping strategies (including targeted problem solving, and cognitive thought re-framing; (Ducharme et al., 2011)). Caregivers who participated

in this program noted they felt more efficacious in their caregiving roles and had improved knowledge and efficacy in care provision (Ducharme et al., 2011). Regardless of the manner of delivery, length of program, and informational format, the caregivers noted increased knowledge and satisfaction with the caregiving experience, demonstrating usefulness of educational programs for caregivers.

### **Dementia Education in Transition to Role of Caregiver and Benefits of Digital Dementia Education**

Becoming a caregiver of someone who was diagnosed with dementia involves a process of learning and getting accustomed to a new role (Ducharme et al., 2011; Mittelman et al., 2006 ; Warrick et al., 2018). During this time, stress is very common (Alzheimer's Association, 2018; Canadian Electronic Library & Canadian Institute for Health Information, 2010), as well as worries about the future including possible transition to long-term care (Cepoiu-Martin et al., 2016) and access to community services (Ducharme et al., 2011; James & Paulson, 2019). Some of the common responses to this shift are depression (Mitchell et al., 2011) and perceived increased care burden (Warrick et al., 2018). During such transitions, programs allowing caregivers to immerse themselves in new information have been shown to alleviate burden (Jensen et al., 2015; Mitchell et al., 2011), depression (Mitchell et al., 2011 2011; Terayama et al., 2018), and even improve the wellbeing of patients with dementia (Brown et al., 2013; Jensen et al., 2015; Vickrey et al., 2006). Introducing practical strategies for self-care has also been shown to increase coping ability among caregivers and improve the relationship with their loved one (Bonner et al., 2015 ; Somers et al., 2016).

A successful transition to a caregiver role can allow caregivers to be better prepared and equipped to deal with uncertainties and tasks of their new roles (Elmståhl et al., 2012; Somers et al., 2016). Education aimed at easing that transition can foster this transition (Carbonneau et al., 2011). A study by Ducharme and colleagues (2011) examined the effectiveness of an educational program with a group of caregivers that was designed to introduce new coping strategies, improve communication, and enhance knowledge of services as well as community service access. The findings of this study indicated that caregivers expressed greater confidence in daily caregiving tasks, felt like they were better prepared for their transition, and reported an increased sense of confidence in their caregiving self-efficacy. The caregivers also noted accessing coping strategies more easily, as well as utilizing better problem-solving skills (Ducharme et al., 2011).

Programs aimed at increasing dementia knowledge including the progression of the disease, and cognitive symptoms have also been shown to improve caregiver knowledge of dementia (Bonner et al., 2015). A course designed to educate caregivers on signs and symptoms of dementia was reported to increase caregiver's understanding of dementia, signs, and symptoms, and improve management of daily tasks (Guest et al., 2015). Even educational programs aimed at increasing satisfaction during leisure activities among caregivers and care recipients have shown to increase caregiver's perceived sense of wellbeing, as well as the perceived satisfaction with the caregiving role (Carbonneau et al., 2011). Clearly, the benefits of educational programs for caregivers are wide reaching and multifaceted.

Digitally-based or remotely delivered educational programs for caregivers have shown to have equivalent benefits for caregivers as face-to-face programs (Blom et al., 2015; Lee et al., 2015). Also, with the increased use of technology, digitally-delivered education has become even more accessible to caregivers and can be easily incorporated into daily routines (Lee et al., 2015). A study composed by Lee and colleagues (2015) examining usage of smartphone and computers among caregivers of individuals diagnosed with dementia found that most of the caregivers in the study sample reported some use of smartphone communication through social media apps and email. A study by Blom and colleagues (2015) examined the effectiveness of an Internet-based educational intervention for caregivers aimed at enhancing dementia education. This study found that caregivers post intervention reported lower symptoms of depression as indicated on a Center for Epidemiologic Studies Depression Scale, and lower anxiety levels as indicated in a Hospital Anxiety and Depression Scale. Thus, use of digitally-based delivery modes of dementia education for caregivers can be a valuable and practical option for delivery of educational materials.

### **Dementia Diagnostic Practice and Care**

Western nations have developed consensus documents on what constitutes primary symptoms of dementia, what steps should be taken in order to achieve a reliable diagnosis, and steps needed to develop an adequate care plan (Cummings et al., 2002; De Lepeleire et al., 2008; Delrieu et al., 2009; Hogan et al., 2008; Iliffe et al., 2009; Musicco et al., 2004; National Institute for Health and Clinical Excellence, 2007; Perry et al., 2010; Segal-Gidan et al., 2011; Villars et al., 2010; Waldemar et al., 2007; Zilkens et al., 2009). Common evidence-based, best practice recommendations for most Western nations include noting the early signs and symptoms of

dementia, composing a multidimensional evaluation, practicing sensitivity toward patient needs, being mindful of patient and family reaction during disclosure, collaborating with the patient and caregivers in establishing a care plan, and establishing an ongoing plan for monitoring and management as patient and caregiver needs evolve (Aminzadeh et al., 2012). A Canadian report by the Institute for Clinical Evaluative Sciences and the Canadian Institute of Health Information also recommends a close collaboration with alternate level of care services and long-term care institutions for these patients with a greater focus on later stages, requiring palliative care (Bronskill et al., 2011; Canadian Institute for Health Information, 2011).

Western guidelines for dementia diagnosis and care differ in agreement regarding need for specialist consultation and referral for symptomatically ‘typical/uncomplicated’ cases of dementia (Alzheimer Society of Canada, 2016; Aminzadeh et al., 2012; Mason et al., 2018). Some international guidelines favor a specialist referral, but Canada differs in this regard (Aminzadeh et al., 2012). The Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (Ismail et al., 2020; Moore et al., 2014) states that diagnosis for typical presentations of dementia should be made by the primary care physicians and should be made earlier on in the progression of disease. This could be established via clinical evaluation, cognitive testing, basic laboratory results, and structural imaging (Moore et al., 2014). Canadian guidelines, much like other international guidelines (Europe and the United Kingdom), suggest that primary care providers should be divested of the diagnostic burden of more complicated presentations of dementia, and diagnostic responsibility should be moved toward multidisciplinary teams of healthcare specialists. This would assure less pressure on primary care physicians and would provide more time for specialists to focus on atypical/complex dementia presentations. These guidelines also advocate for greater collaboration with community agencies and greater utilization of community supports (Callahan et al., 2009; Hogan et al., 2008; Moore et al., 2014; Waldemar et al., 2007). With movement toward interdisciplinary teams for diagnosing and management, Western and European guidelines also recommend better coordinated ongoing management, dementia training for all members, standardized testing tools and protocols for diagnosing, better access to technology resources, and regular monitoring and follow-ups (Austrom et al., 2006; Callahan et al., 2006; Cherry et al., 2009; Chodosh et al., 2006; Reuben et al., 2010; Vickrey et al., 2006).

Unfortunately, dementia diagnosis is often made later in the course of the disease (Bamford et al., 2004; Boise et al., 2004; Bond et al., 2005; Boustani et al., 2003; Bradford et al., 2009; Connell et al., 2004; Iliffe et al., 2009; Koch et al., 2010; Schoenmakers et al., 2009; Waldemar et al., 2007; Wilkinson & Milne, 2003). Adding to the diagnostic delay are factors such as physician reluctance to disclose diagnosis (Iliffe et al., 2009; Waldorff et al., 2005) and delayed help seeking by the individual or their family/partner (Borson et al., 2007; Waldorff et al., 2005; Wilkinson & Milne, 2003). Primary care physicians generally struggle with recognition of early signs and symptoms of dementia (Bond et al., 2005; Canadian Institute for Health Information, 2016; Delrieu et al., 2009; Iliffe et al., 2009), express a low confidence in diagnosis (Cahill et al., 2006; Iliffe et al., 2009), and hold the perception that they have inadequate training regarding diagnosing dementia (Bond et al., 2005; Delrieu et al., 2009; Iliffe et al., 2009). For these reasons, many primary care physicians prefer to defer diagnosis to specialists (Bradford et al., 2009; Cahill et al., 2006; Iliffe et al., 2009). Additionally, many primary care physicians view presentation and progression of symptoms of dementia as more complex, as well as psychologically and biologically more sensitive than other chronic conditions (Harris et al., 2009; Pimlott et al., 2009). Other barriers to diagnosis include lack of confidence in therapeutic benefits of timely diagnosis (Bamford et al., 2004; Bradford et al., 2009; Constantinescu et al., 2018), higher priority given to other comorbid physical ailments (Bradford et al., 2009), and a perception that diagnosis may impose a strain on the medical system (Carpenter & Dave, 2004; Iliffe et al., 2009).

Primary care physician accuracy of dementia diagnosis varies based on stage of progression (Mazzocco & Hussain, 2012; O'Shea et al., 2015; Phillips et al., 2012; Pimlott et al., 2009; van den Dungen et al., 2012). A systematic review examining physician accuracy in diagnosis (sensitivity; correctly identifying cases with dementia and specificity; correctly identifying cases without dementia) revealed that both sensitivity and specificity increased for moderate to severe cases of dementia (van den Dungen et al., 2012). In cases of mild dementia and mild cognitive impairment, both sensitivity and specificity decreased (van den Dungen et al., 2012). Primary care physicians' ability to recognize cognitive impairment based on clinical judgment alone is more difficult with milder presentation of memory concerns (Bott et al., 2014; Leung et al., 2011; Mitchell et al., 2011). A meta-analysis of studies examining physician ability to recognize a range of cognitive impairment using clinical judgment, revealed that 73.4% were

able to recognize dementia correctly; 62.8% were able to recognize cognitive impairment correctly; and 44.7% were able to recognize mild cognitive impairment correctly (Mitchell et al., 2011). This generally shows that while potentially more severe types of impairment such as more advanced or progressed stages of dementia are easier to detect for physicians, more subtle variations of early-stage symptoms are more difficult to detect. Additionally, certain sub-types of dementia such as frontotemporal dementia (FTD) may present with psychiatric symptoms that resemble FTD symptomatology, which may contribute to misclassification (Bott et al., 2014).

Other barriers to dementia diagnosis identified by physicians include a reported lack of confidence (Phillips et al., 2012; Tang et al., 2018), worries about stigma associated with applying a dementia label (Cahill et al., 2008; Gove et al., 2017; Phillips et al., 2012), lack of comprehensive diagnostic tools (Mazzocco & Hussain, 2012), subjective patient ambiguity regarding initial symptoms (Leung et al., 2011), presence of other co-morbid psychiatric or neurologic disorders (Bott et al., 2014; Coebergh, 2014), comorbid chronic mental illness and language barriers (Coebergh, 2014), perceived difficulty in coordinating supportive services (Tang et al., 2018), and a lack of knowledge about dementia (Barczak, 2018; Tang et al., 2018). Frequently overlooked symptoms of dementia occur in palliative care (O'Shea et al., 2015); successful dementia management requires early detection, timely pharmacological treatment, ongoing support and oversight, and the right type of support befitting level of need (Bremer et al., 2017; Grand et al., 2011; Massoud et al., 2010; Quentin et al., 2010; Thorpe et al., 2015). Massoud and colleagues (2010) recommend two levels of specialized care approach, with secondary referrals to memory disorders clinics that can diagnose complex cases of dementia. More recent popular approaches to diagnosis include use of predictive models such as the stepwise logistic regression proposed by Mazzocco and colleague (2012) to diagnose dementia; however, some findings suggest that supporting physicians and carers by providing adequate education on dementia is sufficient in reducing diagnostic delay (Barczak, 2018; Bott et al., 2014; Innes et al., 2014; Leung et al., 2011; Phillips et al., 2012; Tang et al., 2018).

### **Dementia Best Practice Guidelines**

Best practice guidelines for dementia diagnosis and management do not always translate to same level of adherence by medical healthcare professionals (Sivananthan et al., 2013). A systematic review of literature used to examine consistency between medical care practice and best practice guidelines revealed that there is a variation in adherence (Sivananthan et al., 2013).

Even though pharmacological intervention is clearly important, a delay in diagnosis can mean worse consequences for management including a lack of monitoring and lack of home supports (Sivananthan et al., 2013). Sivananthan and colleagues (2013) reviewed 12 studies and found that nine out of these studies found a general lack of physician adherence to best practice guidelines. They noted that physicians did not always follow the recommendations for diagnosis and management such as memory testing, imaging, bloodwork, referrals to counseling, community services, and specialists. Failing to complete important tasks included in best practice guidelines translate into varied quality of care for patients (Alzheimer Society of Canada, 2016; Mason et al., 2018; Moore et al., 2014). Encouragingly, the review by Sivananthan and colleagues (2013) found that more recently published studies reported higher numbers of physicians adhering to some guideline recommendations, such as making referrals to secondary supports such as counseling services, community supports, and specialists. This trend may reflect a more recent push toward change in physician practice and scope of knowledge regarding dementia.

Best practice guidelines change as new research identifies gaps and inefficiencies in current practice (Moore et al., 2014). However, it may be difficult to maintain knowledge of new evolving needs. A systematic review by Durepos (2016) found that most international guidelines lack a palliative care component. More notably, there is less focus on spiritual end-of-life care and a lack of content on dealing with grief (Durepos et al., 2016). Considering that many dementia related best practice guidelines identify the need for ongoing follow-ups and implementation of supports to meet every stage in progression of dementia (Aminzadeh et al., 2012; Massoud et al., 2010), it seems important to merge some of the later evolving needs with palliative care. Best practice guidelines for adults with dementia and learning disabilities are also at the forefront of much needed reform (Strydom et al., 2016). Adults with Down syndrome are at an increased risk of dementia (Strydom et al., 2016). Strydom and colleagues (2016) note that screening and diagnosis in such cases are largely dependent on information from carers. In these cases, baseline assessments become immensely important. The earlier on they are established, the easier the monitoring and follow-ups, which would mean shorter delays to diagnosis.

A more concerning finding regarding best practice guidelines is the lack of ethical guidelines for dementia care (Knüppel et al., 2013). Knüppel and colleagues (2013) researched national clinical guideline databases for countries such as Australia, Austria, the United



Kingdom, France, Germany, Malaysia, Scotland, Singapore, Switzerland, and the United States, and found missing or insufficiently addressed ethical issues in diagnosis and management of dementia. The guidelines varied considerably in terms of which ethical issues were broached and which were not. For example, some guidelines did not specify how to approach existing advance directives in decision making and implementation of monitoring techniques, nor how to address suicidality (Knuppel et al., 2013). Other aspects which were lacking were an explicit approach to ethical issues, absence of recommendations for specific ethical issues, inclusion of a rationale and references used to support each recommendation, and level of detail used in explaining the rationale behind each ethical issue recommendation (Knuppel et al., 2013). Inclusion of ethical guidelines in best practice guidelines could have a positive impact on diagnostic disclosure (Cahill et al., 2008; Gove et al., 2017; O'Shea et al., 2015; Phillips et al., 2012), and enhance patient and carer satisfaction with the disclosure process (Innes et al., 2014).

Australian best practice guidelines for dementia are highlighted here because they are up-to-date, multifaceted, and designed to address a variety of settings and healthcare professions (Laver et al., 2016). Australian guidelines address care of individuals in residential care and community settings, and are formatted to assist medical staff, nurses, aged care workers, and other allied health professionals (Laver et al., 2016). The guidelines also include information for researchers, educators, and policy decision makers (Laver et al., 2016). There is a strong emphasis on a need for timely diagnosis at the outset of symptoms, and a need for medical attention given to early complaints. Additionally, the guidelines emphasize a thorough systematic approach to assessment which includes history gathering, cognitive assessment, medical examination, blood work, and imaging tests. The guidelines advise healthcare professionals not to rely on potential biomarkers of dementia in their diagnosis, and in this respect are very similar to Canadian guidelines (Sivananthan et al., 2013). Furthermore, Australian guidelines emphasize a need for regular review after diagnosis at 6- or 18-month intervals. The guidelines also recommend an assessment of other comorbid psychiatric features such as depression or anxiety. Lastly, the guidelines advocate for an integration of a palliative approach to care, sensitivity to increasing required supports by the patient and their caregivers (level of support corresponding to patient needs), inclusion of caregivers in management planning (inclusion of caregivers is thought to increase quality of life for both caregiver and patient), and caregiver education (Laver et al., 2016).

Canadian guidelines similarly address necessary components of diagnosis and care including gathering of health and mental health history, physical examination, and stressing the need for cognitive testing (Ismail et al., 2020). Canadian guidelines also stress the need for laboratory tests and structural or functional neuroimaging and advise against use of potential dementia biomarkers (Ismail et al., 2020). According to Canadian guidelines, clinical evaluation should entail gathering of patient medical history, a family interview (composed separately from patient interview to capture additional information and assist in gathering external evidence of memory issues, functional issues, changes in behavior, and daily functioning), physical examination to gather present medical functioning, and a brief cognitive assessment to determine severity of cognitive impairment. The physicians are advised to examine aggregated evidence and determine if the patient meets criteria for dementia (Alzheimer Society of Canada, 2014, 2016; Mason et al., 2018). Having established a diagnosis, physicians are advised to focus on differentials in which other laboratory investigations and medical imaging may serve a purpose (Ismail et al., 2020). Canadian guidelines also make a case for risk and prevention through better management of vascular risk factors such as hypertension and avoidance of high doses of estrogen, and support provisions for individuals at a higher genetic risk (Ismail et al., 2020). The more recent recommendations from the National Institute for Health and Care Excellence (NICE) advocate for inclusion of caregivers in the diagnostic and care management process, as well as education for caregivers (Pink et al., 2018). Lastly, the guidelines advocate for continuity in care, so that the medical professional who makes the diagnosis remains involved in care, oversees quality of care, remains in charge of oversight of care, and continues to coordinate care in the long-term (Pink et al., 2018).

A survey of national dementia strategies reviewed 29 countries and compared these with Canadian policies for key actions (Chow et al., 2018). Some commonalities among 18 countries (Australia, Czech Republic, England, Finland, Greece, Indonesia, Ireland, Israel, Luxembourg, Malta, Finland, Greece, Indonesia, Ireland, Puerto Rico, Switzerland, Taiwan, the United States, and Wales) in terms of strategies, were increasing awareness of dementia by providing more education and information to families and communities. Other similarities were implementation of efforts to reduce stigma surrounding dementia through awareness campaigns (for Cuba, Czech Republic, Ireland, Israel, Italy, Malta), identification of necessary support services needed to provide psychological support to caregivers, creation of peer or other support networks (for

Australia, Cuba, Czech Republic, England, Greece, Israel, Japan, Luxembourg, Northern Ireland, Norway, Scotland, the United States, Wales), and calling for improvement of quality of services by standardization of care and implementation of best practice guidelines for development of explicit care pathways and care management for patients (for Australia, Cuba, Czech Republic, England, Finland and France). Finland identified a need for provision of 24-hour care to patients by establishing dedicated health-care teams; England, Ireland, Israel, Japan, and Norway appointed specialized health care practices to lead quality improvement of services, and to coordinate dementia care; Australia identified a need to improve access to end-of-life and palliative care, by promoting advance care planning after diagnosis of dementia; the Czech Republic advocated to establish standardized rules for assessing ability of dementia patients to drive safely; and Norway advocated the need to conduct home visits for older adults to promote dementia prevention. A plan to improve training and education on dementia, and an increase in specialists by inclusion of geriatric training in graduate and undergraduate curricula for related specialties was noted in Cuba, Czech Republic, Mexico, Korea, and the United States. Cuba also advocated for refresher courses about dementia for healthcare specialists. Greece decided to offer research scholarships for dementia, and lastly, Israel implemented training of general practitioners on dementia diagnosis and management. Canada is woefully in need of the next dementia strategy (Public Health Agency of Canada, 2019).

### **Dementia From a Medical Aid in Dying Perspective**

In 2015, the Canadian province Quebec passed a law legalizing medical aid in dying (MAID) to individuals who meet the criteria (Bravo & Arcand, 2020). More recently, the federal government in Quebec is considering extending MAID to non-competent patients who made an advanced directive before losing capacity (Bravo et al., 2021). To qualify and demonstrate eligibility individuals must have an illness that leads to intolerable suffering and foreseeable death (Nakanishi et al., 2021). The argument surrounding accessibility of MAID to individuals with dementia raises complex issues surrounding individual's potential to adapt to effects of the disease through its progression and finding the correct moment to carry out directives, as well as uncertainty for healthcare providers in determining whether the individual still wishes to carry through with the potentially forgotten directive (Bravo et al., 2018). Furthermore, individuals with dementia may not fully understand what is occurring during the MAID process and may resist (Bravo et al., 2018). An interview with a physician discussing MAID in Netherlands shone

a light on this issue comparing provision of MAID without capacity and consent to an inhumane act akin to that carried out in veterinarian medicine (Sibbald, 2016). Present Canadian legislation excludes individuals who do not have capacity to consent, therefore people with dementia would be excluded from eligibility due to their inability to consent during the advanced stages of dementia where dementia can be characterized as a diagnosis with a foreseeable death, and during the early stage at which individuals could have the capacity to consent, dementia would not be classified as a reasonably foreseeable death (Nakanishi et al., 2021). The present MAID legislation if passed could allow individuals with dementia to access MAID by removing the foreseeable clause and by allowing individuals to make advance requests (AR) for MAID should a loss of capacity occur (Nakanishi et al., 2021).

In the United States aid in dying laws have two conditions; individuals who are terminally ill with a prognosis of six or less months to live may make a request, and at the time during which medically assisted death is carried out, the individual has to be competent to make the decision. In this case, advanced directive for a later time at which competence is in question could not be made (Steinbock & Menzel, 2018). Many individuals who have been diagnosed are more in fear of living with a disease to the time when they lose decision making capacity, and about preventing suffering and loss of dignity. The line is even more blurry when an individual specifies an advance directive e.g., expressing a want to carry out the directive at the time during which they are no longer living with dignity, during the later stages of dementia, this is no longer imperative, and the individual may have forgotten their directive. Also, the quality of life at the latter point may be defined differently by the same individual (Steinbock & Menzel, 2018). This occurs through two hypothesized venues; adaptation where the individual's desire diminishes or ceases as they adapt to their new reality, and changes of mind, where the individual with dementia may change their mind and realize the new life is worth living e.g., new circumstances are no longer deemed intolerable, and the individual may begin to enjoy simpler activities and hobbies (Steinbock & Menzel, 2018).

A study eliciting attitudes of 471 informal caregivers toward MAID used vignettes describing situations in which MAID was sought (Bravo et al., 2018). Two thirds (68%) of the caregivers found it acceptable for incompetent individuals with dementia in advanced stages who have previously made the request while competent, and 91% found it acceptable during the terminal stage of the disease (Bravo et al., 2018). More interestingly was that this finding

occurred in the sample of caregivers regardless of caregiver demographics (age, sex, race/ethnicity, country of origin, financial situation, and country of origin) (Bravo et al., 2018). Support among stakeholders in offering MAID to individuals diagnosed with dementia was also high where the bulk of the concern with AR revolved around incompetent patients, advanced directives, and concerns with eligibility to receive MAID when capacity is no longer present (Bravo & Arcand, 2020).

Support among healthcare providers, namely physicians is more varied (Nakanishi et al., 2021). Clinicians are more likely to be divided on this issue because ultimately, clinicians are the ones who are tasked with interpreting and enacting an advanced directive once the individual has lost their capacity to consent (Bravo et al., 2018; Nakanishi et al., 2021). Other issues concerning clinicians include ways to protect the future interests of individuals accessing MAID, and identifying signs around coercion, especially in situations in which individuals can no longer show a desire for MAID or appear at peace (Nakanishi et al., 2021). Most healthcare providers are concerned about similar concerns and anticipate that enacting MAID (especially AR), will be difficult logistically and ethically (Nakanishi et al., 2021). While these concerns exist, most clinicians, including specialists from family and geriatric medicine and psychiatry show some support for AR in MAID (Nakanishi et al., 2021). This support tends to be higher for cases where the patient is at the terminal stage of dementia (Bravo et al., 2018). In several studies examining the physician demographics and support of MAID, it was noted that physicians who were older, had religious beliefs, and had not previously received MAID requests had fewer positive attitudes toward MAID (Bravo et al., 2021; Ditommaso et al., 2018). In a study by Koksvik (2020) nine interviews were performed with physicians participating in patient end of life care. The physicians in the study seemed happy about their practice (ability to provide MAID). They noted that some of the benefits for patients included allowing them to get their affairs in order and have their farewell with loved ones. Despite feeling grateful for the ability to provide this service, some noted shock in cases where the patient did not seem to be dying, and where transition toward death appeared to be abrupt. Some noted losing their sense of confidence and gratitude for provision of this service (Koksvik, 2020). There are two situations in which physicians may change their mind regarding provision of MAID; these are conscientious objection and moral distress (Ditommaso et al., 2018). Moral distress arises from a violation of values and core beliefs, whereas conscientious objection allows the healthcare provider to refuse

the provision of a service that is not aligned with personal, moral, or scientific beliefs (Heilman & Trothen, 2020). A study of relational ethics in MAID by Heilman and colleagues (2020), noted that future policies aimed at allowing physicians to provide MAID should try to minimize the negative consequences of moral distress by cultivating moral resilience and allowing open communication to take place among team members and other healthcare providers. No matter what the future holds for provision of MAID for individuals with dementia, despite logistic and moral concerns around provision of such a service (especially in the case of AR), there seems to be support for MAID among caregivers (Bravo et al., 2018), healthcare providers (Nakanishi et al., 2021), and stake holders (Bravo & Arcand, 2020). Changes in legislation will have to address the remaining concerns including ones revolving around AR and ensuring the ability to reject provision where physicians do not feel comfortable. Although MAID is not presently considered in the context of dementia education for caregivers and healthcare providers, this is something which may have to be considered more closely especially in the case that the legislation surrounding provision of MAID to individuals with dementia is passed in Canada. This issue will likely become more central and relevant to dementia education.

### **Practitioner Approach to Disclosure of Dementia Diagnosis**

In everyday practice, primary care physicians indicate barriers to diagnosis of dementia, such as difficulties recognizing dementia symptoms (Tanner et al., 2006), difficulties differentiating normal aging from dementia symptoms (Cahill et al., 2006), lack of knowledge of assessment procedures (Cody et al., 2002 & Pope, 2002), negative attitudes toward diagnosis (Kissel & Carpenter, 2007), and concerns about referral sources (L. Boise et al., 1999 Rose, & Congleton, 1999). According to Boise et al. (1999) negative attitudes and time constraints were identified as the most impactful barriers to disclosure of diagnosis. While most physicians agree on the moral imperative of diagnosis, there is some variation in attitudes to disclosure of the diagnosis, depending on perceived utility of disclosure (Kissel & Carpenter, 2007). For example, in the Kissel and Carpenter (2007) study, where 10 physicians interviewed to determine barriers to disclosure of diagnosis, physicians reported a case-by-case disclosure depending on family dynamics, and progression of dementia (e.g., if progressed further, physicians were more likely to disclose; see also) (Hum et al., 2014). Another major barrier was uncertainty in diagnosis (or a lack of confidence), where physicians who are unsure about dementia diagnosis were less likely to make the diagnosis and share this with the patient and their families or make an appropriate

referral to another agency or a specialist (Cody et al., 2002). In another study by Hum et al. (2014) physicians indicated difficulties in access to secondary services and fragmentation of community resources as another decisive factor in referring clients to secondary supports. The physicians noted that improving collaboration among primary care providers, specialists, and community resources was essential in making diagnoses as well as putting in place appropriate resources for better management (Hum et al., 2014).

### **Practitioner Beliefs Surrounding Dementia Diagnosis**

Other factors affecting physician beliefs regarding dementia diagnosis and disclosure of diagnosis are conceptualization of dementia as a stigmatizing condition (Kaduszkiewicz et al., 2008; Kissel & Carpenter, 2007), attitudes toward dementia treatment and care (Milne et al., 2005), previous dementia training (Ahmad et al., 2010; Kaduszkiewicz et al., 2008), and expectations regarding patient's ability to handle diagnostic disclosure (Connell et al., 2004). An online survey distributed among 1,011 general physicians in England collected information on physician attitudes, awareness, and practice regarding dementia diagnosis between physicians who qualified before the year 1990 and those who qualified after 1990 (Ahmad et al., 2010). A key finding indicated that seasoned physicians (who qualified before 1990) reported more confidence in diagnosis, advice giving, and management of dementia-related symptoms, however, they also exhibited more pessimism; they felt that making a dementia diagnosis was not beneficial, with few positive outcomes for patients, and felt that making a dementia diagnosis would result in a drain on the healthcare system. Conversely, younger physicians in the study (those who qualified after 1990), reported less confidence, yet indicated more positive attitudes toward dementia diagnosis. They believed that delivery of diagnosis can improve patient quality of life and enhance care management. This study hints at a potential generational shift in attitude in younger physicians (those who qualified later), or perhaps a factor of time practicing in the field.

Another study (Milne et al., 2005) comparing data from two studies conducted in 1997 and 2001 on physician attitudes toward dementia diagnosis also found that physicians in the more recent study (2001) exhibited more positive attitudes toward earlier diagnosis and benefits for patients than physicians in the 1997 study. This study may indicate a potential shift in training and emphasis on earlier diagnosis and care management in training for newer physician cohorts. Another study by Kaduszkiewicz and colleagues (2008) examined general physician,

and specialist attitudes and confidence in making a dementia diagnosis. Regardless of group (generalist or specialist), physicians who reported a more positive attitude toward diagnosis, and care for patients with dementia, also reported a belief in their ability to improve patient quality of life. These physicians were also more in favor of early detection and therapeutic response and were receptive to use of cognitive tests in assessment. The general findings indicated that interventions directed toward enhancement of competence in diagnosis and care and enhancing positive attitudes toward dementia are beneficial. While attitudes remain an important predictor of practice and care, a study by O'Connor, Melissa, and McFadden (2010) used qualitative mapping and factor analysis to develop a measurement scale for attitudes toward dementia among physicians as well as other healthcare professionals. This scale (Dementia Attitudes Scale: DAS) demonstrated excellent reliability and validity, as well as potential use for future measurement of physician attitudes in educational intervention evaluation. Another measure of dementia knowledge, Alzheimer's Disease Knowledge Scale, also showed great potential in assessment of healthcare professionals' dementia knowledge (Carpenter et al., 2009; Nordhus et al., 2012).

While physicians' negative attitudes toward dementia diagnosis and care can influence practice in detrimental ways (Ahmad et al., 2010; Kaduszkiewicz et al., 2008), and best practice guidelines are not always adequately utilized (Pimlott et al., 2009), enhancing knowledge, and changing attitudes have been shown to have positive effects on patient care and timely dementia diagnosis (Fortinsky, 2007). Furthermore, dementia education has not only been shown to change physicians' attitudes but also, other healthcare professionals' as well (Law, 2008). A study by Tanner and colleagues (2006) assessing training needs of general internists and geriatricians found that both types of professionals reported frustration with a lack of knowledge and lack of skill in caring for older adults, which increased negative attitudes. While a perceived lack of skill in dealing with patients with dementia may cause frustration and negative attitudes toward care for individuals with dementia, sometimes mere proximity and exposure to work with persons living with dementia may also impact attitudes in a positive manner. Kang, Moyle, and Venturato's (2011) study of Korean nurses' attitudes toward older individuals diagnosed with dementia in acute care found that nurses working in medical wards who had routine contact with older adults displayed more positive attitudes and were more attentive, friendly, and helpful



toward patients diagnosed with dementia than nurses employed in the surgical wards who had much less contact with such patients.

While physicians express a general interest (Robinson et al., 2001) and a need to learn more about dementia diagnosis and care (Meuser et al., 2004; Tanner et al., 2006), knowledge and confidence levels with regards to dementia vary across healthcare professions (Meuser et al., 2004). A study by Meuser and colleagues (2004) surveyed a sample of 834 healthcare professionals and found that specialists had highest scores on items relating to dementia practices. While all the health professionals indicated an interest in additional learning, rural physicians reported the highest interest and need. Healthcare professionals agreed on importance of early diagnosis and care management. Dementia training may not only be useful for primary care practitioners but also other primary healthcare staff (Kang et al., 2011; Law, 2008).

### **Lack of Dementia Knowledge Among Healthcare Providers**

Many healthcare practitioners (Gandesha et al., 2012a; Sakurai-Doi et al., 2014), including physicians (Allen et al., 2005; Boise, 2006; Sakurai-Doi et al., 2014; Turner et al., 2004), nurses (Fessey, 2007), and nursing students in training (Peres De Oliveira et al., 2013), indicate a need for ongoing professional training on dementia. A literature review conducted by Clevenger, Chu, and Hepburn (2012) of current practices of healthcare staff revealed that there is minimal guidance for healthcare providers of persons with dementia. The authors specifically indicated there is a need for more education on use of standardized cognitive screening measures, communication strategies with patients, and management of complications. A study by Allen and colleagues (2005) additionally found that physicians lack knowledge on pharmacological treatment and skills to discuss medico-legal issues regarding driving. There are also differences in amount of training available to various healthcare professions, for example Gandesha and colleagues (2012b) found that physicians typically report having received more adequate training on dementia than do nurses. Gandesha and colleagues (2012) also noted a need for additional training of healthcare staff who do not routinely interact with elderly patients, as their skill level and knowledge pertaining to dementia may be even lower. For healthcare staff working in long-term care with a geriatric specialty, dementia training has been also identified as an important topic in professional training. In addition to other important aspects such as pain management for persons with dementia (Barry et al., 2012), a study by Tousignant-Laflamme and colleagues (2012) in a survey of healthcare professionals working in long-term care, such as

physicians, pharmacists, physical therapists, and nurses, found that need for dementia training was ranked highest.

While many healthcare professionals indicate a need for ongoing education on dementia, and while for some general knowledge can be deemed adequate (Turner et al., 2004), there may be other obstacles such as difficulty and a lack of confidence in talking with patients about the diagnosis (Turner et al., 2004). A study by Turner and colleagues (2004) conducted with 20 clinics who participated in educational interventions of dementia diagnosis and management found that level of knowledge about dementia diagnosis and care was related to ratings of confidence and disclosure of diagnosis. Additionally, older physicians in the sample expressed more pessimistic attitudes toward dementia care. Thus time (years in practice) and a lack of information directly contributed to decisions on whether to disclose a diagnosis. Disclosure of diagnosis may be additionally complicated by uncertainty in presentation of symptoms (Werner et al., 2013). For example, a study by Werner and colleagues (2013) assessing physician familiarity with mild cognitive impairment found that physicians (70% of the sample where  $n = 197$ ) reported that they did not have enough knowledge or thought that mild cognitive impairment was a normal part of aging. The authors here concluded that more education on types of dementia may be useful in strengthening physician knowledge.

Provision of a timely diagnosis and inauguration of necessary supports in dementia does not only depend on healthcare staff knowledge and training, but also on informal care providers (Arai et al., 2008). A study by Arai and colleagues (2008) of 2,115 individuals found that there is a general lack of knowledge in the public about dementia and dementia symptoms. While older female respondents seemed to have more knowledge, forgetfulness was typically attributed to old age, rather than dementia. This knowledge gap in the general population may be a contributing factor to help-seeking behaviors and may contribute to prolonged time to diagnosis (Arai et al., 2008).

Education for healthcare providers has been shown to have beneficial effects on increasing skill levels (Lathren et al., 2013), confidence (Harvey et al., 2006), and knowledge of dementia (Bryans et al., 2003). A study by Bryans and colleagues (2003) found that prior to educational intervention, nurses' management knowledge of dementia was higher than knowledge pertaining to epidemiology of dementia, meaning nurses were better able to handle

care duties than recognize symptoms of dementia. Negative attitudes toward dementia care were also impacted by a reported lack of self-efficacy in care provision (Bryans et al., 2003).

Best practice guidelines may help in dementia diagnosis and management for physicians, however, providing healthcare providers with guidelines is not always sufficient (Allen et al., 2005; Boise, 2006). There are specific barriers that need to be addressed including difficulties in detection, diagnosis, management, and clinical practice time constraints (Boise, 2006). While effective education may encourage and assist in transmission of knowledge, dementia has been noted as a complex disease requiring additional considerations, including supports that extend beyond the physicians' office and beyond the limited time spent in a physician's office (15-20 minutes on average). Additional training may prove to be useful, especially considering that primary care physicians (with little or no training in geriatrics) are more likely to care for patients with dementia than geriatric specialists (Boise, 2006). Physicians in the Boise (2006) study indicated that there is not enough time to complete cognitive testing within the constraints of a patient's visit and identifying symptoms of dementia is complicated unless the symptoms are more obvious, which also unfortunately means that the patient has progressed further. Thus, education on epidemiology and symptomatology may prove to be fruitful.

### **Dementia Education for Healthcare Providers**

Dementia education modes vary and may include mixed modes of delivery (Cherry et al., 2009; Harvey et al., 2006), a single mode of delivery (Broughton et al., 2011), and modes including an in-person lecture component (Cherry et al., 2009; Prorok et al., 2015; Waugh et al., 2011). Modes of delivery such as DVD-based modes have been proven to be useful (Broughton et al., 2011). For example, Broughton and colleagues (2011) demonstrated effectiveness of a DVD-based dementia educational program (comprised of learning modules) for nursing home staff, which resulted in significant improvements in management strategies, as well as ratings of general dementia knowledge. A mixed mode of delivery which was developed with evidence-based practice guidelines included educational sessions, a theater troupe used to demonstrate proper response to patient needs, and an educational DVD on administration of a Mini Mental State Exam for physicians (Cherry et al., 2009). This intervention not only yielded improvements in dementia care but also client outcomes (Cherry et al., 2009). Another program developed by Cameron, Horst, Lawhorne, and Lichtenberg (2010) included academic detailing used to increase knowledge of early dementia detection in a sample of primary healthcare staff. This approach

consisted of 15-minute educational sessions and visits by trained teams comprised of a physician and representatives from the Alzheimer's Association. The healthcare staff rated these visits as useful and effective in enhancing their referrals to secondary agencies, as well as in changing their perception of assessment of patients. Other interventions that included a face-to-face component have also been successful in improving assessment and management of dementia for resident physicians (Prorok et al., 2015), increasing referrals to secondary support agencies (Reuben et al., 2010), and improving care for nurses (Waugh et al., 2011).

Harvey and colleagues (2006) combined two modes of dementia education which included a memory loss tool kit and video conferencing. Video conferencing included ongoing case-based grand rounds surrounding patient cases. The grand rounds included group discussions on best course of action, and the tool kit included professional resources such as patient education materials, a clinical process guide (decision making guide), case studies, and other resources for brief assessment and evaluation. One resource included the Mini Mental Status Exam, which is frequently used in brief cognitive assessment (Chen et al., 2011). The combination of the two programs was useful in increasing knowledge and enhancing confidence. Another study by Lathren et al. (2013) examined impact of a one-day training program on physicians' and affiliated healthcare staff's care competency and referral patterns. The one-day training workshop which included discussion, case-based examples, and examples of cognitive assessment tools (administration and scoring) was successful in increasing use of cognitive screening tools, improved the healthcare staff's ability to convey relevant information to patients and caregivers, and resulted in increased referrals to community support services. It is noted, however, that education of healthcare staff may not be enough; another aspect which needs to be considered is vertical integration through buy-in from affiliated healthcare organizations (Chodosh et al., 2006). This buy-in may be instrumental in supporting continued practice with learned materials (Chodosh et al., 2006).

Dementia education uptake by intended healthcare population can be improved when the educational intervention suits the unique educational needs of healthcare providers (suits specific educational goals, is aligned with existing knowledge, and suits complexity of required skill level; Gandesha et al., 2012; Iliffe et al., 2012). With education better aligned to specific needs, there is higher potential to stimulate acceptance and adherence (Gandesha et al., 2012a; Iliffe et al., 2012). For example, Iliffe and colleagues (2012) developed and tested a tool for dementia

education needs of healthcare staff in five clinical practices. After completing the needs assessment, they piloted tailored programs suiting each practice and found that these tailored programs were better able to meet healthcare provider educational needs and reduce identified knowledge gaps. Dementia education for primary healthcare may also be supplemented by reliable online sources (Galvin et al., 2011; Iliffe et al., 2012) and printed sources (van der Steen et al., 2011). A study by Galvin and colleagues (2011) surveyed 373 physicians on use of online dementia resources and found that 75% of the sample reported using or visiting online sources on dementia. The same sample also indicated interest in reliable sources available in screening, treatment, patient education, and community resources. Another study by Van der Steen et al. (2011) found that physicians and nurses found a family booklet explaining possible complications in dementia care useful and helpful in provision of comfort care. Therefore, additional resources may also be useful in supplementing educational needs.

### **Rural Dementia Education for Caregivers and Healthcare Providers**

Rural areas are unique in that they signify geographical distance from major city centers (Greenway-Crombie et al., 2012). Other factors which deem such areas unique are associated with rural healthcare, for example, a heavy workload with restricted leave options for healthcare professionals, as well as limited access to professional development, and extended travel time (Greenway-Crombie et al., 2012). Similarly, rural caregivers also face unique challenges related to community service access and long-distance times to specialized services for their careers (Dal Bello-Haas et al., 2014; Jennings et al., 2015). Healthcare work in rural areas presents unique challenges such as professional isolation, lack of resources, and lack of access to up-to date information (Bellaver et al., 1999). Other unique challenges for both healthcare professionals and caregivers are inadequate community resources for management of patients with dementia, lack of access to specialists, long wait times for neuroimaging, distance to informal caregiver support (Kosteniuk et al., 2016; Kosteniuk et al., 2015), lack of knowledge of support services, lack of knowledge about dementia as a disease (Di Gregorio et al., 2015), and travel distance to specialists (Innes et al., 2014).

### **Remotely Delivered Dementia Education for Caregivers and Healthcare Providers**

Remotely delivered dementia education has the potential to address some of the rural healthcare professional and caregiver knowledge needs (Barth et al., 2018; Galvin et al., 2011; Shaw et al., 2011; Terayama et al., 2018). Learning may occur, and can be enhanced or

supplemented, through use of technology (Azad et al., 2012; Blom et al., 2015; Forducey et al., 2012; Raymond & Iliffe, 2013). For healthcare providers, use of online educational resources has been deemed both useful and reliable (Galvin et al., 2011) and has been received favourably by healthcare professionals (Shaw et al., 2011). Caregivers identify a similar need and levels of receptibility to remote dementia education (Cepoiu-Martin et al., 2016; Jensen et al., 2015; Somers et al., 2016)

Telemedicine has been noted as another useful venue for remote care delivery and education. A study by Azad, Amos, Milne, and Power (2012) found that use of telemedicine in a memory disorder clinic for patient check-ins and follow-ups with caregivers worked well, with 90% of physicians in the sample indicating that they would be willing to continue to use telemedicine with their patients. Other noted positive aspects of this study were timely access to specialists, fewer cancelled clinic dates, enhanced care between follow-up days, and primary care support for caregivers. While remote education may serve as a valuable alternative to face-to-face education, certain aspects of educational needs are unique to each rural area. There are likely certain aspects of remote or digitally-delivered education for healthcare providers and caregivers which would be more suitable, depending not only on needs but also on resources and learning considerations.

### **Summary**

Dementia diagnosis carries a heavy burden for patients and their families (Akerjordet et al., 2018; Alzheimer Society of Canada, 2010; Alzheimer's Association, 2010). Dementia also carries a heavy financial cost (Alzheimer's Association, 2018; Grand et al., 2011; Hurd et al., 2013; Jutkowitz, Kuntz, et al., 2017; Kelley et al., 2015), with healthcare costs in Canada exceeding those of other chronic conditions (Alzheimer Society of Canada, 2016). The increasing aging population means more diagnosed cases of dementia (World Alzheimer Report, 2018; World Health Organization, 2015), with 20% of the population in rural Canada aged 65 and older (Statistics Canada, 2016). Primary care physicians generally find the diagnostic process complex (Harris et al., 2009; Pimlott et al., 2009) and feel they have inadequate training (Bond et al., 2005; Delrieu et al., 2009; Iliffe et al., 2009). Physicians also generally prefer to refer to specialists when uncertain regarding a specific presentation (Bradford et al., 2009; Cahill et al., 2006; Iliffe et al., 2009). Caregivers of individuals diagnosed with dementia identify anxiety and fear with transition to a caregiving role (Ducharme et al., 2011; Guest et al., 2015;

Lee et al., 2016a), due to inadequate knowledge on dementia, and aspects of daily care (James & Paulson, 2019; Jensen et al., 2015).

For healthcare providers some of the identified barriers to diagnosis were low opinions on the utility of diagnosis (Kissel & Carpenter, 2007), lack of knowledge (Hum et al., 2014), and lack of confidence in management (Milne et al., 2005). Many healthcare practitioners including physicians express a need for ongoing professional training (Allen et al., 2005; Gandesha et al., 2012a; Sakurai-Doi et al., 2014). Healthcare providers indicate a need for more education, which has been shown to have positive effects on overcoming diagnostic barriers (Bryans et al., 2003) and in improving care (Gandesha et al., 2012a; Iliffe et al., 2012). For caregivers, some of the barriers were limited access to dementia information (Ali & Bokharey, 2016; Bonner et al., 2015; James & Paulson, 2019), relatively few sources of caregiving information (Jensen et al., 2015; Lee et al., 2016b; Peterson et al., 2016), and reliance on the healthcare professional to relay important information (Guest et al., 2015; Terayama et al., 2018).

Rural primary care providers face additional challenges to obtaining continuing education due to remoteness and long travel times (Kosteniuk et al., 2016; Morgan et al., 2011), and rural caregivers face a lack of access to specialized support services and dementia education programs (Dal Bello-Haas et al., 2014; Jennings et al., 2015). Remotely delivered dementia education can be used to overcome such barriers through remote and asynchronous delivery (Azad et al., 2012), with spaced education promising to increase information acquisition and retention (Kerfoot, 2010; Kerfoot & Baker, 2012; Minter, 2013; Tshibwabwa et al., 2017). While the Canadian guidelines on dementia diagnosis and care advocate for earlier diagnosis and a move of referrals for complicated cases of dementia to specialists (Callahan et al., 2009; Hogan et al., 2008; Moore et al., 2014; Waldemar et al., 2007), offloading some of the pressure on specialist care through remote dementia education may serve to educate rural healthcare providers and delay admission of patients to long-term care (Cepoiu-Martin et al., 2016; Warrick et al., 2018).

### **Overview of the Studies**

Study 1 and Study 2 will lay the foundation for Study 3. The objective of the studies is to conduct evidence-based and informed searches of current interventions on digitally-delivered dementia education for caregivers (Study 1) and healthcare providers (Study 2). These two studies serve as the foundation to inform Study 3, which entails the feasibility and acceptability piece, co-developed with an expert and a practitioner in the field. Study 3 will serve as a

foundation or a steppingstone to a pilot study for an educational intervention. The pilot study will not be included in the dissertation.

### **Statement on Intellectual Contribution**

To fulfill the requirements of a Ph.D. dissertation, I, Andrea Scerbe, have been responsible for the literature review, study design, systematic review data collection, data analysis, and manuscript preparation for the future manuscripts presented here. Dr. Megan O'Connell has been my research supervisor. As supervisor, she was consulted throughout the course of the research, has reviewed this document, and is a co-author on both studies. We had a team approach to data collection, which is also indicated in the co-author list. We agreed that I contributed 70% to the manuscripts presented here.



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## Study 1 Abstract

Continuing education on dementia has been shown to have positive effects on informal caregiver knowledge, dementia care, management, and caregiver physical and mental health. Technology-based dementia education has been noted to have equivalent effects as in-person, but with the added benefit of asynchronous and remote delivery, which increases accessibility. Using Cochrane review methodology, this study systematically reviewed the literature to compile a summary of technology-based dementia education for caregivers. Technology-based delivery included dementia education delivered via the Internet, telephone, telehealth, videophone, computer, or digital video device (DVD). In the review, twenty-eight studies were identified with fourteen included in a meta-analysis, and these data revealed a medium effect of technologically based dementia education on reducing caregiver distress in response to observed behavioral problems. Although there was a significant small effect of dementia education on reducing caregiver depression observed, this effect was significant only for one measure (BDI-II), and the size of the effect was small for both measures included in the meta-analysis (CES-D, and BDI-II). No evidence was found for a significant effect of the educational intervention on caregiver burden or self-efficacy, which are known to be gendered aspects of caregiving. However, none of the studies included in the meta-analysis reported separate outcomes for male and female care providers, which has implications for gendered caregiving norms and aspects of care.

*Keywords:* dementia, education, technology-based, caregivers, Cochrane review

## Study 1 Introduction

Timely delivery of dementia diagnosis, care strategies, support, and management planning can greatly improve health outcomes for persons with dementia (Di Gregorio et al., 2015; Innes et al., 2014). Persons with dementia experience progressive worsening of cognition and independent functioning, resulting in assistance with activities of daily life (Bailes et al., 2016). Informal caregivers, typically family members or friends, are involved in aspects of long-term and complex care and thus privy to the progression of dementia symptoms, making their experience more intimate than healthcare professionals' (Jensen et al., 2015). Informal caregivers report challenges in daily care: lack of external/community supports (Bailes et al., 2016), difficulties associated with insufficient dementia knowledge and support (Bailes et al., 2016), and barriers to obtaining and sharing information (Jensen et al., 2015), resulting in isolation in caregiving responsibilities (Bailes et al., 2016). Informal caregivers also face auxiliary challenges such as frustration, anxiety, depression, and burnout (i.e., state of prolonged stress; (Bailes et al., 2016; Jensen et al., 2015).

Research has shown that a lack of knowledge in one or more aspects of dementia care not only affects the mental health of caregivers (Bailes et al., 2016; Jensen et al., 2015) but also, their caregiving abilities (Adler et al., 2015; Broughton et al., 2011; Brown, 2009; Gandesha et al., 2012a; Hallberg et al., 2016). Dementia care costs in Canada are estimated to be five and a half times higher for individuals diagnosed with dementia than those of individuals who were diagnosed with other chronic conditions (Alzheimer Society of Canada, 2016). The cost of care in Canada for Alzheimer's Disease and other dementias exceeds the cost of all other neurodegenerative conditions (Public Health Agency of Canada, 2019). The bulk of this cost falls on the shoulders of informal caregivers and is represented in lost wages and hours spent providing care at home (Hsu & Willis, 2013). Tasks of caregiving typically increase both in complexity and diversity, until eventually the informal caregiver assumes all household and financial aspects of care (Hsu & Willis, 2013; World Health Organization, 2015). Given the importance of informal care providers in provision of care, with consideration for both time and cost, these findings present an important case for more education on dementia for informal

caregivers. Dementia education is comprised of strategies for care of close individuals who are diagnosed with dementia, knowledge about dementia course and progression, and self-care strategies and prevention of care burnout (Bailes et al., 2016; Jensen et al., 2015). Dementia education has been also noted to enhance care management and social support seeking behavior by informal caregivers (e.g., seeking counselling, joining discussion forums, and informal support groups; (Jensen et al., 2015). Disparities in education among higher- and lower-educated caregivers can also impact the quality of care delivered (Black et al., 2013; Brown et al., 2013). However, dementia education can reduce knowledge disparities among higher- and lower-educated caregiver groups (Broughton et al., 2011). Other barriers to caregiving include insufficient information about behavioral symptoms of dementia and accurate understanding of the benefits of timely diagnosis (Peterson et al., 2016). Studies have shown benefits to caregiver's abilities when interventions include psychoeducation (Huis In Het Veld et al., 2015) and are targeted at increasing communication between the informal caregiver and caree (Haberstroh et al., 2011). Overall, dementia education for informal caregivers seems to have a positive influence on both the care and the health outcomes of persons with dementia (Boise et al., 1999; Broughton et al., 2011; Galvin et al., 2011; Gandesha et al., 2012a).

Benefits of dementia education are well supported (Gandesha et al., 2012a; Haberstroh et al., 2011; Huis In Het Veld et al., 2015; Jensen et al., 2015; Peterson et al., 2016), and informal caregivers indicate receptiveness to a variety of educational modes, including community-based and Internet-based resources (Peterson et al., 2016) and online portals (Hattink et al., 2015). Internet-based interventions have been shown to improve caregiver confidence (Boots et al., 2014; Kajiyama et al., 2013; Lewis et al., 2010; Mavandadi, Wright, et al., 2017), reduce perceived burden (Glueckauf et al., 2004), increase self-efficacy (Hattink et al., 2015), decrease anxiety (Hattink et al., 2015), decrease feelings of depression (Chiu et al., 2009; Glueckauf et al., 2004), and increase dementia knowledge (Pleasant et al., 2017). A recent systematic review examining benefits of digitally-delivered education for caregivers found that these interventions reduced caregiver burden (Frias et al., 2020). Some examples of technology-based interventions for caregivers include websites (Chiu et al., 2009), tailored web-based interventions with expert recommendations (Gaugler et al., 2016), hybrid interventions that include an online component and an interactive telephone component (e.g., dementia care consultation; (Glueckauf et al., 2004), and interventions with a telephone-only component (Goodman & Pynoos, 1990). Studies



comparing dementia education versus participation in a network of caregivers found that interventions containing both an educational component (Goodman, 1990; Hayden et al., 2012) and an interactive component had the greatest benefit and impact on skills (Mavandadi, Wright, et al., 2017), stress (Kajiyama et al., 2013), attitudes (Hattink et al., 2015), knowledge (Pleasant et al., 2017), self-efficacy (Lewis et al., 2010), and perceived caregiver burden (Glueckauf et al., 2004). Interactive components of interventions, featuring discussion boards (Chiu et al., 2009), email (Chiu et al., 2009; Gaugler et al., 2016), and multiple forms of informational presentation (e.g., video, case-based vignettes) (Arnautovska et al., 2016; Boots et al., 2014; Goodman, 1990), were the most highly rated (Arnautovska et al., 2016; Boots et al., 2014; Chiu et al., 2009; Gaugler et al., 2016; Goodman & Pynoos, 1990).

### ***Digital Educational Tools for Caregivers***

Digital modes of education, such as knowledge conveyed via electronic devices, media, Internet, closed-circuit computer networks, or web-based platforms, have an equivalent impact on learning as face-to-face modes (Cobbett et al., 2016). Additionally, such learning offers an advantage of remote or asynchronous delivery, where each participant progresses through educational material in a self-paced manner (Harvey et al., 2006; Waldorff et al., 2009). Asynchronous digitally-based learning holds additional benefits for individuals living in remote or rural areas, where long wait times for specialized services and a lack of information/local educational programs are common (Kosteniuk et al., 2016). Recent changes within health services and efforts to move services to virtual methods due to the COVID-19 pandemic have seen online-based learning gain a new importance (Saini, 2020; Son et al., 2020). Searching and summarizing existing research on current modes of digital education for informal care providers can serve as an important step toward implementing digital dementia education programs for caregivers and enhancing access to educational and support resources.

Past systematic reviews have examined Internet-based interventions for caregivers of persons with dementia (Guay et al., 2017), focusing on evaluation methods, including qualitative interviews, satisfaction-based interviews, and organizational feedback (Christie et al., 2018), as well as interventions delivered via telephone (Waller et al., 2017) and computer (Waller et al., 2017). The present review examined the effect of digital dementia education delivered via technology with remote delivery capabilities, including smart phone applications, telephone, video, and computer (online and network), and focused on studies with pre- and post- measures

in order to more accurately determine the impact of digital education. Motivation and accessibility were factors considered in the focus of this review. Increased availability and ownership of smart devices with access to the Internet have changed digital delivery of information within the past decade, as well as motivation to engage in education (Cadare et al., 2014; Jubien, 2013).

## **Study 1 Method**

### ***Study Objectives and Search Strategy***

The review used Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2009), and Cochrane guidelines for systematic reviews and meta-synthesis (Jørgensen et al., 2006; Moseley et al., 2009). Risk of bias was evaluated for each domain by two independent reviewers with assist from the Cochrane handbook. The overall risk of bias was decided taking into consideration all of the domains and estimating the least favourable assessment across those domains. The review addressed the questions: 1.) What learning technologies, devices, online resources, and digital education tools on dementia are available for caregivers? 2.) How have these educational technologies been evaluated? And 3.) What are the outcomes for informal caregivers? Databases were limited to the University databases, which included PsychINFO, MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Sociological Abstract, AgeLine, and Embase. These databases were selected in consultation with a research librarian (for the syntax used in the search strategy, see Appendix A). The review includes the initial literature search performed in 2018, and an update which was performed in 2020. Both of the reviews were performed by the same reviewers. This includes data screening, extraction, and analysis.

### ***Data Screening, Extraction and Analysis***

Two reviewers independently screened titles, abstracts, and full text of systematically obtained studies. Reasons for exclusion of studies were recorded in the PRISMA diagram shown in Figure 1, and included a focus on a different population, no educational intervention offered, or no outcome measures reported. When studies contained multiple intervention groups, only studies with the group of interest (caregivers of persons with dementia) were retained. In cases where studies reported caregivers as a subset of a larger population of interest, data on caregivers were reported separately. Disagreement on study inclusion was resolved verbally, with a third individual serving as an adjudicator during lack of consensus. Adapted and customized data

extraction forms that included study details such as author, publication year, country, reasons for inclusion or exclusion, design, methods, duration of intervention, participant characteristics, outcomes, and risk of bias (composed at individual and aggregate levels for studies included in the meta-analysis (Jørgensen et al., 2006; Moseley et al., 2009), were used to extract information from studies. Studies were managed, stored, and analyzed with Review Manager (*Review Manager (RevMan) [Computer program]. Version 5.3.*). Meta-synthesis was also performed with RevMan for the studies using identical outcomes and measures. This process was repeated in its entirety for the review update (Figure 2).

### ***Study Inclusion and Exclusion Criteria***

Studies were peer-reviewed, published within the past 10 years, available via the University library electronic database, and included at least one technology or digital tool (defined below) used to convey dementia education which was targeted to informal caregivers (e.g., partners, family friends, or adult children of persons living with dementia). The search criteria and databases were selected in consultation with a research librarian who specializes in social sciences. We decided to focus on studies published in the English language due to limitations in understanding of other languages by the two reviewers. Digital tools included e-learning and other electronic media, intranet, teleconferencing networks, and telephones. Digital delivery did not have to be online, for example internal resources available via computer networks within organizations were also considered. Lastly, selected studies contained interventions with pre- and post- outcome measures. Excluded studies were other systematic reviews, studies with only a face-to-face educational component, studies targeting participants other than caregivers of persons with dementia, studies where care recipients were diagnosed with conditions other than dementia, and studies where dementia education did not constitute a substantial portion of the intervention.

### ***Risk of Bias and Study Quality***

Risk of bias was evaluated with Cochrane Collaboration's Risk of Bias tool as low, medium, high or unknown (Moseley et al., 2009). Quality of the findings from studies included in the meta-analysis were evaluated using Grading of Recommendations, Assessment, Development and Evaluations (GRADE) (Welch et al., 2017). The quality of findings from studies not included in the meta-analysis was assessed by adapting the checklist from the Critical Appraisal Skills Programme (2014), where the range of possible quality scores for studies ranged

from 0 to 21 for studies using a randomized controlled trial design, and 0 to 18 for studies using a single group with a pre- and post-intervention measure (see Table 1 and Table 2).

## **2.4 Study 1 Results**

### ***Study Demographics***

A total of 28 studies were included in the review. Of these, 14 used the RCT design, equivalent scales, and outcomes and were included in a meta-analysis (see Table 3). The remaining 14 studies included a mixture of RCT ( $n = 6$ ) and pre- and post-intervention design ( $n = 8$ ) and were described qualitatively (see Table 4). The 6 RCT studies excluded from the meta-analysis did not use equivalent scales and outcomes. Studies were published between 1990 and 2020 and included a technology-based dementia education component (see Table 3 and Table 4). The number of participants in studies ranged from  $N = 8$  to  $N = 290$ , and the percentage of female caregivers ranged from 63% to 91%. Study duration ranged between 17 days to 1 year, and intervention follow-up ranged from immediate post-intervention up to 12 months post-intervention.

Of the total 28 studies, the studies were conducted in the United States ( $n = 22$ ), Netherlands ( $n = 3$ ), Poland/Spain/Denmark ( $n = 1$ ), France ( $n = 1$ ), and China ( $n = 1$ ) (see Table 5). In 82% of the studies, the authors did not report whether each study was conducted with rural or urban populations. A single study reported using a mixed sample (rural and urban), one study reported using a rural population, and three studies used urban populations. Most participants in the studies were reported either as a spouse, partner, a significant other ( $n = 15$ ), or an adult child ( $n = 11$ ).

Several studies ( $n = 8$ ) used a theoretical model to conceptualize their interventions. These models were Borkman's Model (Borkman, 1984) ( $n = 1$ ), emphasizing peer support among caregivers, Medical Model of Dementia (American Psychiatric Association & Task Force on DSM-IV, 2000) ( $n = 1$ ), International Classification of Functioning, Disability and Health Model ( $n = 1$ ) (Jette, 2006), Adaptation Coping Model (Droes et al., 2011) ( $n = 1$ ), Theory of Reasoned Action (Ajzen & Fishbein, 1980) ( $n = 1$ ), Transactional Model of Behavior Change (Prochaska & DiClemente, 1983) ( $n = 1$ ), Bandura's Self-Efficacy Model (Bandura, 2005) ( $n = 2$ ), Psychosocial Transition and Stress Coping Theory (Sörensen et al., 2002); (Tremont et al., 2008) ( $n = 1$ ), and the Stress Process Model ( $n = 5$ ) (Lazarus & Folkman, 1984). One study used

a model developed specifically for the delivered intervention, the *CARES for Families* model (Hobday et al., 2010) ( $n = 1$ ).

### ***Risk of Bias***

Risk of bias (ROB) was assessed at the study level (see method) and aggregated for studies included in the meta-analysis. Most studies had an unknown risk of bias due to a lack in reporting of randomized allocation ( $n = 15$ ). Many did not report concealment of allocated condition ( $n = 17$ ), blinding of participants to condition ( $n = 15$ ), and condition at outcome assessment levels ( $n = 21$ ), and thus received an unknown ROB rating. Due to the nature of treatment (participation in an educational intervention), it is likely that blinding was not possible in all cases. Some studies reported incomplete outcome data or only significant outcomes ( $n = 7$ ) and were thus rated as having a high ROB. Many reported complete outcome data and appeared free of selective reporting ( $n = 17$ ), and thus received a low ROB rating (see Table 6 and Table 7).

### ***Study Quality***

GRADE was used to assess quality of findings from studies included in the meta-analysis at the outcome level for measures of depression (measured by the Center for Epidemiological Studies Depression Scale [CES-D] or the Beck Depression Inventory [BDI-II]), behavioral problems, caregiving self-efficacy, caregiver burden, and positive caregiving experience (Table 8). Of the studies included in the meta-analysis, twelve studies included some measure of depression. Depression (measured by the BDI-II), caregiving self-efficacy, caregiver burden, and positive caregiving experience were rated at a low level, enhancing confidence that the true effect lies closely to estimate of the effect. These studies had smaller effect sizes with larger confidence intervals. Outcomes such as behavioral problems measured by the Revised Memory and Behavior Problem Checklist (RMBPC) and (BDI-II) were rated as very low, expressing limited confidence in the effect estimate, due to concerns about heterogeneity of results, and a high risk of publication bias (see Table 1.7 and Table 1.8).

The quality of the studies excluded from the meta-analysis was performed with CASP criteria, allowing for quality evaluation at each study level (see Table 1 and Table 2). RCT studies ( $n = 6$ ) were rated as high quality (score range between 13 and 18), and non-RCT studies ( $n = 8$ ) were all rated as medium quality (score range from 8 to 14), with the exception of two studies, which were rated as high (score range from 15 to 21). CASP quality ratings of medium

to high indicated that study authors measured the intended constructs in their intervention assessments.

### ***Characteristics of Learning Technologies***

Telephone-based dementia education was the most common intervention modality ( $n = 18$ ), followed by video-based learning ( $n = 18$ ), and online-based learning ( $n = 11$ ) (see Table 9). One study used a novel approach with virtual reality to simulate the experience of an individual diagnosed with dementia. Studies also used a variety of methods to deliver educational content including learning modules ( $n = 8$ ), a website platform ( $n = 1$ ), and a live online class featuring an instructor ( $n = 2$ ). A few telephone-based interventions used a telephone support group ( $n = 3$ ). One live version of a telephone-delivered lecture included a live instructor who delivered education ( $n = 1$ ), and two studies featured pre-taped lectures which were accessible via telephone. Mixed modes of telephone and visual content were delivered via devices such as a videophone ( $n = 1$ ), computer-telephone integration system ( $n = 1$ ), and Smartphone or tablet device ( $n = 1$ ). Video-based learning included supplementary visual resources featuring role playing and modeling via storytelling ( $n = 2$ ). Other supplementary resources were textual resources such as printed materials and workbooks, immediate feedback, exercises, knowledge tests, and references to other online resources (reported in 12% of studies).

### ***Evaluation of Digital Educational Tools***

All of the studies ( $n = 28$ ) used scales to assess the outcomes of dementia knowledge, caregiver burden/distress, competence in aspects of care, supports, management, health of the caregiver, and satisfaction with caregiving (see Table 3 and Table 4). Some of the more commonly used scales by the studies were the Revised Memory and Behavior Problems Checklist (RMBPC) for measure of observable behavioral problems in dementia patients (Johnson et al., 2001). The Beck Depression Inventory (BDI-II) (Beck et al., 1996) and the Center for Epidemiologic Studies Depression Scale (CES-D) (Lewinsohn et al., 1997), measured depression. Caregiver burden was measured by scales such as the Zarit Burden Inventory (ZBI) (Zarit et al., 1980), and the Revised Caregiving Self Efficacy Scale (CSES-R) (Steffen et al., 2002) was used to measure cognitive and behavioral approaches in managing care of persons with dementia. For the remaining scales, please refer to Tables 3 and 4.

### ***Focus of Educational Content***

The number of sessions varied from 3 to 24. The intervention was typically distributed between 17 days and 12 months, with an individual duration of 15 and 75 minutes, and involved various modes of delivery such as online, videophone, telephone, smartphone, virtual reality and DVDs. The focus of the content revolved around three main areas; enhancing dementia knowledge strategies, management of daily tasks, and self-management: support-seeking and self-care.

### ***Enhancing Dementia Knowledge***

Thirteen studies included a dementia knowledge component (Boots et al., 2018; Czaja et al., 2018; Finkel et al., 2007; Gallagher-Thompson et al., 2010; Gaugler et al., 2015; Glueckauf et al., 2007; Goodman, 1990; Griffiths et al., 2018; Kajiyama et al., 2013; Kwok et al., 2013; Martindale-Adams et al., 2013; Núñez-Naveira et al., 2016; Wijma et al., 2018). Areas of interest under strategies were problem-solving strategies, specifically related to aspects of care (Beauchamp et al., 2005; Czaja et al., 2013; Davis, 1998; Glueckauf et al., 2007; Martindale-Adams et al., 2013), and communication strategies with the care recipient (Czaja et al., 2013; Easom et al., 2013; Finkel et al., 2007; Gallagher-Thompson et al., 2010; Glueckauf et al., 2004; Kajiyama et al., 2013; Martindale-Adams et al., 2013; Mavandadi, Wright, et al., 2017; Steffen & Gant, 2016).

### ***Management of Daily Tasks***

Management of daily tasks included themes such as creating caregiving goals (Cristancho-Lacroix et al., 2015; Davis, 1998; Gallagher-Thompson et al., 2010; Glueckauf et al., 2007; Glueckauf et al., 2004; Goodman, 1990; Kwok et al., 2013; Mavandadi, Wray, et al., 2017; Núñez-Naveira et al., 2016), managing medical aspects of care (Goodman, 1990; Goodman & Pynoos, 1990), managing financial and legal aspects of care (Easom et al., 2013; Gallagher-Thompson et al., 2010; Goodman, 1990; Goodman & Pynoos, 1990; Martindale-Adams et al., 2013), managing home safety (Goodman, 1990; Martindale-Adams et al., 2013), and behavior management (Czaja et al., 2013; Finkel et al., 2007; Gant et al., 2007; Goodman, 1990; Kajiyama et al., 2018; Kwok et al., 2013; Mavandadi, Wray, et al., 2017; Núñez-Naveira et al., 2016; Steffen, 2000; Steffen & Gant, 2016).

### ***Self-Management***

The umbrella of self-management included categories of education targeted toward support seeking, which included sub-themes of social support seeking (Cristancho-Lacroix et al., 2015; Czaja et al., 2018; Finkel et al., 2007; Gallagher-Thompson et al., 2010; Glueckauf et al., 2007; Kwok et al., 2013; Wijma et al., 2018), family support seeking (Glueckauf et al., 2004), and seeking of respite through community resources (Czaja et al., 2018; Czaja et al., 2013; Easom et al., 2013; Goodman, 1990; Hicken et al., 2017). Under this same umbrella, a sub-category targeted toward self-care included themes of enhancing coping strategies (Beauchamp et al., 2005; Kajiyama et al., 2018; Mavandadi, Wright, et al., 2017), personal health management (Easom et al., 2013; Kwok et al., 2013; Martindale-Adams et al., 2013; Núñez-Naveira et al., 2016), personal mood management (Hicken et al., 2017), enhancing self-care (Finkel et al., 2007; Glueckauf et al., 2007; Hicken et al., 2017; Kajiyama et al., 2013), and increasing self-efficacy in care (Cristancho-Lacroix et al., 2015; Steffen & Gant, 2016). In summary, education was targeted toward many aspects of personal care. Information regarding care strategies was delivered with an even balance of strategies for care provision and external support attainment. It can be argued that educational content was comprehensive and addressed all aspects of personal and care provider wellbeing.

### ***Meta-Analysis***

Meta-analysis was performed using Review Manager Software, where the main outcomes were calculated as an overall effect size for each of the outcomes. Some of the outcomes were measured by different versions of the same scales (full versus shortened versions), thus standardized mean differences (SMD) with 95% confidence intervals (CI) were used to estimate pooled effect sizes for each outcome. Depression was measured separately and pooled by measures such as Center for Epidemiologic Studies Depression Scale (CES-D) and Beck Depression Inventory, Second Edition (BDI-II). Caregiver distress in response to observed behavioral problems was measured by the Revised Memory and Problem Behavior Checklist (RMBPC). Caregiving self-efficacy, or the ability to respond to disruptive behaviors and control upsetting thoughts was measured by the Caregiving Self-Efficacy Scale (CSES). Positive caregiving experience was measured by the Caregiver Appraisal Inventory (Prorok et al., 2015). Caregiver perception of burden was measured by the Zarit Burden Interview (ZBI). Results were obtained after pooling each outcome in the meta-analyses.



## ***Depression***

In seven studies measuring depression with the CES-D, there were no statistically significant differences in depression between treatment and control groups (SMD -0.11; 95% CI -0.25 to 0.02) (Fig 3), indicating no effect of dementia education on depression. However, in three additional studies measuring depression with the BDI-II, there was a statistically significant difference between the intervention and control groups (SMD -0.99; CI -1.39 to -0.58) (Fig 4), indicating a small effect of dementia education on depression. Provided that studies using both scales (CES-D and BDI-II) had small effect sizes, it is less likely that the observed significance on the BDI-II showed a meaningful effect of intervention on depression.

## ***Observable Behavioral Symptoms***

In eight studies measuring caregiver response to observed behavioral problems with the RMBPC, there was a significant difference (SMD -0.44; CI -0.61 to -0.27) (Fig 5), indicating a medium effect of dementia education on observable behavioral symptoms.

## ***Caregiving Self-Efficacy***

In the six studies measuring caregiving self-efficacy with the CSES, the control groups appeared slightly more favored than the intervention (SMD 0.21; CI -0.03 to 0.44) (Fig 6), indicating dementia education does not positively impact caregivers' ability to respond to behavioral symptoms or control upsetting thoughts.

## ***Caregiver Perceived Burden***

Six studies measuring caregiver burden with ZBI found no significant differences between the intervention and control groups (SMD 0.05; CI -0.20 to 0.30) (Fig 7), indicating no effect of dementia education on perceived burden.

## ***Positive Caregiving Experience***

Three studies measuring positive caregiving experience indicated no significant difference between intervention and control groups (SMD -0.04; CI -0.23 to 0.15) (Fig 8).

## ***Gender and Sex in Reporting of Study Outcomes***

A particularly interesting finding in this review is that none of the studies (both excluded and included in the meta-analysis) reported separate outcomes for male and female caregivers. A substantial body of literature indicates that male and female caregivers, particularly spousal care providers, report different levels of caregiver strain (Calasanti & King, 2007; Duxbury et al., 2011; Lee et al., 2013; Lee et al., 2015; Lee et al., 2001; Papastavrou et al., 2011), different

needs for attainment of emotional support (Boeije & Van Doorne-Huiskes, 2003; Brown et al., 2007; Pakenham, 2005; Schwartz et al., 2013; Stewart et al., 2016; Thomas, 2011; Zunzunegui et al., 2003), and different quality of life in relation to their gendered caregiving roles (Navaie-Waliser et al., 2002; Sanders & Power, 2009; Steck et al., 2000). Female care providers tend to report more symptoms of depression, as well as higher physical and emotional burden than male care providers (Lee et al., 2013). Female care providers also report feeling more obligated to fulfill a wider variety of roles including physical care and emotional support (Steck et al., 2000). Additionally, female care providers are typically viewed as natural and preferred caregivers due to cultural norms (Chadiha et al., 2003; Lee et al., 2015).

While women report higher emotional strain than men (Chesley & Poppie, 2009), women are also more likely to seek out social supports (Brown et al., 2007). And while women report greater emotional strain and symptoms of depression (Lee et al., 2001), men are more likely to process emotional and psychological effects of their role individually without sharing feelings with others (Boeije & Van Doorne-Huiskes, 2003; Brown et al., 2007). Therefore, men and women differ in the way they approach their caregiver role as well as in the ways they cope (Calasanti & King, 2007). This is particularly meaningful because a 10-year risk of Alzheimer's Disease was found to be greater for APOE  $\epsilon$ 44 genotype carriers (Rasmussen et al., 2018) which is more predictive of AD when associated with cerebrovascular disease, and for women, middle to late adulthood hypertension was associated with an increased risk of dementia (Gilsanz et al., 2017; Xie et al., 2008). Taking into consideration the female gendered roles in care provision and the likelihood that female spouses are at a higher risk of dementia, it would be important and relevant to target interventions and report separate outcomes for male and female care providers.

### **Study 1 Discussion**

Studies included in this review used a variety of methodological approaches, scales, and measured outcomes; and due to this variation, a meta-analysis was only possible for five outcomes. The findings from the meta-analysis showed a small effect of interventions on a reduction in depression, which was only observed with only one of the scales (BDI-II), and thus likely constitutes a negligible effect on self-reported symptoms of depression (Gitlin et al., 2003; Jensen et al., 2015; Pahlavanzadeh et al., 2010; Terayama et al., 2018). The meta-analysis also showed a medium effect of interventions on caregiver distress in response to behavioral symptoms, which is consistent with other literature showing a similar effect (Basu et al., 2015).

The meta-analysis did not demonstrate a significant effect of intervention on self-efficacy or positive aspects of caregiving. While caregiver burden and self-efficacy are broad constructs (Acton & Kang, 2001; Gossink et al., 2018), it is possible that they were not consistently captured across studies, which may explain an absence of a significant effect. It is also important to note that many of the studies did not adequately report randomization, nor blinding at the participant or outcome assessment levels. Due to these omissions, many studies received an unknown risk of bias rating. Also, many of the studies received a very low to low quality rating due to a lack of reporting and study design (namely due to study heterogeneity, imprecision, and publication bias). Other factors contributing to review limitations are a focus on studies published in the English language, lack of evidence regarding which digital technologies are superior to others, lack of reporting regarding the rurality or urbanity of caregivers, and a lack of reporting of results based on caregiver sex. These limitations not only limited data to studies published in the English language, but also made it difficult to ascertain the most effective or impactful mode of digital education delivery, impact of digital education on rural versus urban caregivers, as well as how the findings differ based on caregiver sex and gender.

Previous literature indicates mixed findings for the effects of dementia education on self-reported caregiver burden, with some authors noting positive effects on burden (Gitlin et al., 2003; Jensen et al., 2015; Pahlavanzadeh et al., 2010; Terayama et al., 2018), and some indicating no effect (Acton & Kang, 2001; Basu et al., 2015; Gossink et al., 2018), thus, supporting mixed findings to support for the effectiveness of educational, digitally-based interventions on self-reported caregiver burden and self-efficacy. Factors which may impact the effect of education on caregiver burden are the type of intervention, where gain-focused re-appraisal strategies may have a greater effect on burden than education alone for example, allowing to create concrete goals to alleviate specific burdens (Cheng et al., 2016). Interventions that are higher in intensity and duration may also exert a greater effect on burden (Gitlin et al., 2003). Other possible contributing factors may be the timing of follow-up, where significant effects diminish over time (Pahlavanzadeh et al., 2010), and point in progression of dementia, where the effect of an intervention on burden may be higher for caregivers of persons with dementia earlier in the progression of dementia, rather than later (Andren & Elmstahl, 2008). Caregiver burden findings are consistent with the noted variations in effects in previous literature, and likely due to similar alterations in structure and design of previous studies.

Meta-analysis also showed no effect of the educational intervention on caregiving self-efficacy. These results could be consistent with variation in caregiver reports in self-efficacy, where caregivers note a positive change after treatment, but not necessarily a statistically significant change from the control group (Gossink et al., 2018). The positive change may also vary by duration of follow-up, where longer time to follow-up leads to a reduction in effects (Pahlavanzadeh et al., 2010). Caregiver self-efficacy and burden are large, multidimensional constructs for a variety of aspects of dementia care. Self-efficacy encompasses the ability to obtain respite, respond to a range of behavioral symptoms and control upsetting thoughts, while burden encompasses depression, mental health, negative affect, social support, stress, and coping.

Another review completed by Frias and colleagues (2020) which also included technology-based educational interventions and in-person educational interventions found similar contradictory findings of intervention on intended outcomes. For example, this review found that technology-based and in-person group-based interventions differed in their impact levels on caregivers, where the technology-based interventions had a reduced impact on outcomes such as burden, mental health, and perceived self-efficacy. The findings of the Frias and colleagues (2020) review could be partially due to unintended effects such as formation of a group, support-like environment, where the benefit of relationship formation and support experienced among the members attending in-person interventions (attending as a part of a group), may have mitigated some of the isolation typically experienced when learning alone. Group-based educational interventions could be beneficial for caregivers whether these are delivered digitally or in-person, and digitally-based interventions allowing for group member interaction such as live discussion boards or videoconferencing could produce similar positive effects (O'Connell et al., 2014). Randomized controlled trials allowing comparisons among the digitally delivered and in-person educational interventions would be beneficial to discern variations in impact of learning technologies on caregivers, especially with regards to perceived burden and mental health.

For the studies included in the current review digitally-based learning occurred via a variety of methods, including online-learning, telephone-based learning, and video-based learning. Studies using mixed modes of educational delivery (e.g., video, case-based learning, role playing, discussion platforms, and periodic knowledge tests) were also used to deliver

education to caregivers. The qualitative analysis revealed digitally-based interventions, focused on enhancing dementia knowledge, care abilities, behavior management, caregiver distress, skills/goals, and coping strategies. Some interventions also focused on obtaining specific supports such as community resources, medical care, legal and financial advice, home safety, and social support. Finally, interventions also focused on enhancing aspects of caregiver health such as healthy lifestyle, mood management, self-care, relationships, and self-efficacy.

Future research examining specific benefits for caregivers, such as group-based education for dementia, is needed. This research could help illuminate the potential benefits of group-based activities on positive outcomes, as well as help in determining if there is a more effective digitally-based mode of delivery which could match in-person interactions. For example, we could speculate that videoconferencing could create similar group dynamics that provide more group cohesion and support than educational interventions delivered via telephone. This work is needed to better understand how digital education can be most effective in delivering positive outcomes.

While the review found some interesting findings regarding effect of digitally-delivered education on dementia, it also revealed some apparent gaps in the body of literature indicating that although there is a clear advantage for using digitally-based education for caregivers in rural areas, the majority of the studies (82%) did not specify the living demographics of their caregivers (e.g., rural versus urban living). Urban and rural populations significantly differ in their ability to access and secure external supports and services (Kosteniuk et al., 2016; Morgan et al., 2015), thus such a distinction would have been useful in determining the effect of the intervention when access to services is limited. Caregivers from rural areas face unique challenges in care due to a lack of access of community-based resources, respite programs, and specialist care (physiotherapy, occupational therapy, counseling etc.) (Kosteniuk et al., 2016; Kosteniuk et al., 2015). The ability to secure such supports could influence chosen outcomes, therefore it would be beneficial to determine service accessibility and barriers before employing certain measures. Future studies could address specific populations (e.g., rural), and design their based dementia education interventions for such populations. Studies aimed at digitally-based dementia education for rural caregivers would be important because the busy daily care workload could effectively reduce time to participate in any kind of dementia education (Somers et al., 2016).

Another notable gap in literature identified in the present review was a lack of attention to sex and gender. None of the studies reported separate outcomes for males and females nor adapted aspects of their interventions for male and female care provider needs respectively. This gap in the literature is perplexing given the evidence suggesting male and female caregivers differ in their caregiving roles, with a greater emphasis on gendered care roles (Brown et al., 2007; Calasanti & King, 2007; Chadiha et al., 2003), and in ways in which they cope, for example, women are more likely to seek external resources and respite (Boeije & Van Doorne-Huiskes, 2003; Navaie-Waliser et al., 2002). Previous literature indicates that male and female caregivers differ in the amount of reported emotional strain and burden (Arbel et al., 2019; Schwartz et al., 2013). For example, female caregivers typically report higher emotional strain, burden (Schwartz et al., 2013) and depression than male caregivers (Calasanti, 2007; Duxbury et al., 2011; Lee et al., 2015). Female caregivers are more likely to seek emotional supports than male caregivers (Calasanti, 2007; Duxbury et al., 2011; Lee et al., 2015). Also, male and female caregivers differ in their approach to caregiving, where female caregiver tend to engage in more emotionally focused approaches and males in more task-oriented approaches (Hong et al., 2016).

Differences in reported strain and support seeking among caregivers are important because women have a higher chance of cerebrovascular disease in later life (Gilsanz et al., 2017), as well as a higher chance of carrying an APOE 4 genotype (Rasmussen, 2018), which when combined with cerebrovascular disease is more predictive of Alzheimer's Disease (Gilsanz et al., 2017; Xie et al., 2008). These findings play an important role in the future of caregivers, where more males will likely engage in caregiving for their spouses (Papastavrou, 2011), which will in turn necessitate a greater shift toward supporting these groups in alleviating their respective burden and emotional strain. One way this can be addressed in future research is to design interventions for differing needs of male and female caregivers. For example, designing interventions to target self-efficacy (Calasanti, 2007; Duxbury et al., 2011; Lee et al., 2015), depression (Arbel, 2019; Pöysti et al., 2012; Xiong et al., 2020; Hong & Coogle, 2016), and strain (Schwartz, 2013; Arbel et al., 2019), for female caregivers, and interventions that would target social support seeking for male caregivers (Brazil, 2009). While these are some of the suggestions, it would be also extremely valuable to seek input from male and female caregivers and obtain information regarding specific gaps or barriers in their care tasks. Having a more

informed approach in designing any intervention could be as valuable as broadening knowledge on perceived educational gaps.

### **Study 1 Conclusion**

The systematic review findings and the meta-analysis indicate that digitally based dementia education can have a positive effect on caregiver ability to manage behavioral issues in caregiving. The focus of sessions in the included digitally-delivered interventions (in the present review) cover a wide area of topics including dementia knowledge, ability to provide care, behavior management, coping strategies, access to supports such as community resources, medical care, legal and financial advice, enhancing home safety, support seeking, and other aspects of caregiver health such as mood management, self-care, and sense of self-efficacy. The present time of pandemic and isolation necessitates more efforts to deliver education remotely, and while remote education has been demonstrated to have similar effects as face-to-face education (Boots et al., 2014; Kajiyama et al., 2013; Lewis et al., 2010; Mavandadi, Wright, et al., 2017), the urge to deliver interventions remotely has never been greater. The authors of the present study outline and stress the urge in accelerating efforts to deliver remote digitally-based dementia education to caregivers.

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Table 1.1 Adapted quality rating criteria for randomized controlled trial studies (studies not included in meta-analysis)

Quality criteria	Specific questions relating to rating considerations	Rating
1. Did the research question clearly address a focused issue?	<ul style="list-style-type: none"> <li>• Was the research question focused on the target population, and the intervention?</li> <li>• Were outcomes in research considered?</li> </ul>	0 = no; 1 = partially; 2 = yes
2. Was the assignment of participants randomized to the intervention or the control group?	<ul style="list-style-type: none"> <li>• How was randomization achieved?</li> <li>• Was randomization concealed from researcher or participants?</li> </ul>	0 = no; 1 = partially; 2 = yes
3. Were all of the participants properly accounted for at the conclusion of the intervention?	<ul style="list-style-type: none"> <li>• Were the participants analyzed in groups to which they were randomized?</li> </ul>	0 = no; 1 = partially; 2 = yes
4. Were participants, and care recipients blind to whether they were in the intervention or the control group?	<ul style="list-style-type: none"> <li>• Consider reporting of participant blinding to intervention/control, and blinding of researcher(s) to condition in assessment of outcomes.</li> </ul>	0 = no; 1 = partially; 2 = yes
5. Were the intervention and control groups similar at the start of the study?	<ul style="list-style-type: none"> <li>• Were the intervention and control groups similar in terms of their age, sex, social class...etc?</li> </ul>	0 = no; 1 = partially; 2 = yes
6. Aside from the intervention group, where the intervention and	<ul style="list-style-type: none"> <li>• Here also consider duration of intervention or placebo.</li> </ul>	0 = no; 1 = partially; 2 = yes

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control groups treated equally?		
7. How large was the treatment effect?	<ul style="list-style-type: none"> <li>• Was/were the primary outcome(s) clearly stated?</li> <li>• What were the results for each outcome?</li> </ul>	0 = no; 1 = partially; 2 = yes
8. How precise was the estimate of the treatment effect?	<ul style="list-style-type: none"> <li>• What were the confidence limits?</li> </ul>	0 = no; 1 = partially; 2 = yes
9. Can the results be applied to the local population?	<ul style="list-style-type: none"> <li>• How similar were the participants to the population to which the recommendations were applied?</li> </ul>	0 = no; 1 = partially; 2 = yes
10. Were all clinically important outcomes considered?	<ul style="list-style-type: none"> <li>• Was there other information about the outcomes that was missed?</li> </ul>	0 = no; 1 = partially; 2 = yes
11. Are benefits worth the harms and costs?	<ul style="list-style-type: none"> <li>• Here consider possibility of harm in the control condition, if education piece was missed.</li> </ul>	0 = no; 1 = partially; 2 = yes
		Range: 0-21

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*Note:* 1-7 = low range, 7-15 = medium range, 16-21 = high range



Table 1.2 Adapted quality rating criteria for non-randomized controlled trial studies (studies not included in meta-analysis)

Quality criteria	Specific questions relating to rating considerations	Rating
1. Are the research aims and questions/hypotheses clearly stated?	<ul style="list-style-type: none"> <li>Do(es) the author(s) clearly state what they plan to research?</li> </ul>	0 = no; 1 = partially; 2 = yes
2. Are ethical issues addressed?	<ul style="list-style-type: none"> <li>Do(es) the author(s) state that ethical approval was sought?</li> </ul>	0 = no; 1 = partially; 2 = yes
3. Are the methodology/study design appropriate to the research question and rationale for choice evident?	<ul style="list-style-type: none"> <li>Do(es) the author state what research methodology they have chosen?</li> <li>Is the chosen methodology appropriate to research question?</li> <li>Does the author(s) justify the research design used?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
4. Are the sample size, selection and description appropriate?	<ul style="list-style-type: none"> <li>Do(es) the author(s) clearly state how the study sample size was identified?</li> <li>Do(es) the sample size appear to be large enough?</li> <li>Do(es) the author adequately describe the sample (e.g., gender, age, relationship to care receiver) so that the reader can determine transferability of findings?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
5. Are the method(s) of data collection appropriate, reliable, and valid?	<ul style="list-style-type: none"> <li>Do(es) the author(s) justify that the measure is suitable for this population?</li> <li>Do(es) the author(s) use measures that measure the desired constructs?</li> <li>Do(es) the author(s) indicate that the measures have good psychometric properties?</li> <li>Do(es) the author(s) indicate that the measures used have demonstrated validity?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
6. Are the method(s) of data analysis reliable and valid?	<ul style="list-style-type: none"> <li>Do(es) the author(s) state which statistic tests were used?</li> <li>Do(es) the author(s) use statistical tests that appear to be appropriate to the nature of the data collected?</li> <li>Were statistical tests appropriate to research question?</li> <li>Do(es) the author(s) provide evidence of statistical findings or state levels of significance?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes

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7. Are the findings and discussion clearly stated and appropriate?	• Do(es) the author(s) present the statistical data in a clear manner, or clearly differentiate between significant or non-significant findings?	0 = no; 1 = partially; 2 = yes
8. Can the results be applied to the local population?	• How similar are the participants to the population to which the recommendations are applied?	0 = no; 1 = partially; 2 = yes
9. Were all clinically important outcomes considered?	• Was there other information about the outcomes which was missed?	0 = no; 1 = partially; 2 = yes
		Range: 0-18

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*Note:* 1-6 = low range, 7-12 = medium range, 13-18 = high range

Table 1.3 Review studies included in meta-analysis

Author, year	Theoretical model	Design, sample size, attrition, female (%)	Duration of type of intervention	Follow-up	Outcome scales
Beauchamp, 2005	Stress Process Theory (62), Theory of Reasoned Action (57), Transactional Model of Behavior Change (58).	RCT, $n = 150$ (treatment group), $n = 149$ (waitlist control), $n = 30$ , Female: 73%	30 days, 3 online modules focusing on problem-focused techniques and social support skills.	Baseline, 30 days	CSS (subscales), CSI, PAC, CES-D
Boots, 2018	The Stress Process Model (62) and Bandura's Self-Efficacy Model (59)	RCT, $n = 31$ (intervention), $n = 37$ (waitlist control) (130), $n = 13$ , Female: 78%	8 weeks, face-to-face intake session, tailored online thematic modules, focusing on psychoeducation, behavioral modeling, reflective assignments, change plans, and email feedback from the coach, face-to-face evaluation session	Baseline, post-intervention	CSES, CES-D, PMS, HADS-A, ICECAP-O, GDS
Czaja, 2013	No model	RCT, $n = 38$ (intervention), $n = 36$ (attention control), $n = 36$ (130), $n = 36$ (information only control) $n = 17$ ,	5 months, 6, 1-hour monthly sessions, 4 educational seminars, delivered via videophone, 5 videophone support	Baseline, 5 months	CES-D, RMBPC, Social support, PAC

		Female: 81%	sessions		
Gallagher-Thompson, 2010	No model	RCT, $n = 40$ (skills training intervention), $n = 36$ (education DVD control), $n = 24$ , Female: 87%	12 weeks, 2.5 hours, CBT skills training program delivered via DVD	Baseline, 6 weeks	CES-D, RMBPC
Glueckauf, 2007	No model	RCT, $n = 12$ (intervention group), $n = 8$ (routine education/support control), $n = 22$ , Female: 71%	12 weeks, 12 weekly telephone-delivered educational sessions	Baseline, 1-week post-treatment	CAI, CSES-R, CES-D, ISS, IFS, ICS
Kajiyama, 2013	No model	RCT, $n = 75$ (treatment group), $n = 75$ (education/information condition control), $n = 47$ , Female: 84%	3 months, 6 online modules	Baseline, post-intervention	PSS, RMBPC, CES-D, PQoL
Martindale-Adams, 2013	No model	RCT, $n = 75$ (treatment group), $n = 75$ (print materials control), $n = 15$ , Female: 83.75%	1 year, 12, 1-hour sessions on education, and skills-building, delivered via telephone	Baseline, 6 months, 12 months	ZBI, CES-D, GWBS, RMBPC
Núñez-Naveira, 2016	No model	RCT, $n = 31$ (usual lifestyle control), $n = 30$ (treatment group), $n = 16$ , Female: 63%	3 months, 5 online modules delivered via Smartphone or tablet, covering topics of care and management	Baseline, post-intervention	ZBI, GDS, CES-D, CCS, RCSS
Cristancho-	Stress Process Theory (62),	RCT, $n = 24$ (usual care	3 months, weekly	Baseline, 3	PSS, CSES-R,

Lacroix, 2015	Bandura's Self-Efficacy Model (59)	control), $n = 17$ (treatment group), $n = 7$ , Female: 78%	web-based psycho-educational sessions lasting 15 to 30 minutes	months, 6 months	RMBPC, ZBI, BDI-II), Self-Perceived Health
Finkel, 2007	No model	RCT, $n = 12$ (basic education control), $n = 13$ (treatment group), $n = 21$ , Female: 69%	6 months, 12 educational sessions, 8 hours in average duration, delivered via videophone	Baseline, 6 months	CES-D, RMBPC, CHHBS, SSS
Gant, 2007	No model	RCT, $n = 17$ (video/teleconference condition), $n = 15$ (education condition), $n = 4$ , Female: 0%	10 video sessions on caregiving strategies, weekly telephone calls from a coach	Baseline, post-intervention	CSES-R, PNAS, RMBPC,
Steffen, 2000	No model	RCT, $n = 10$ (video series), $n = 9$ (classroom viewing), $n = 9$ (waitlist/control condition), $n = 5$ , Female: 75.8%	8 weeks, once a week, psychoeducational session with a 30-minute video segment.	Baseline, post-intervention	CgAI, BDI-II, CSES-R
Steffen, 2016	No model	RCT, $n = 23$ (behavioral coaching), $n = 35$ (basic education), $n = 31$ , Female: 100%	14 weeks, 10, 30-minute video segments (DVD), 10 weekly telephone calls, 2 maintenance calls	Baseline, post-intervention, 6 months	BDI-II, RMBPC, NAS, MAACL-R (subscales)
Kwok, 2013	Psychosocial Transition and Stress Coping Theory (60, 61)	RCT, $n = 20$ (remote video group), $n = 18$	12 weeks, 12, 30-minute	Baseline, post-	ZBI, CSES-R

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(treatment group),  $n = 4$ , Female: 71%      psychoeducational intervention, 3 sessions delivered via telephone, DVD containing educational information

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RCT = randomized controlled trial, AD = Alzheimer's Disease, CSS = Coping Skills Scale, CSI = Caregiver Strain Instrument, PAC = Positive Aspects of Caregiving, CES-D = Center for Epidemiologic Studies Depression Scale, RMBPC = Revised Memory and Behavior Problems Checklist, CAI = Caregiver Appraisal Inventory, CSES = Caregiving Self-Efficacy Scale, CSES-R = Caregiving Self-Efficacy Scale-Revised, ISS = Issue Severity Scale, IFS = Issue Frequency Scale, ICS = Issue Change Scale, PSS = Perceived Stress Scale, PMS = Pearlin Mastery Scale, PQoL = Perceived Quality of Life, GWBS = General Well-Being Scale, GDS = Global Deterioration Scale, HADS = Hospital and Anxiety Depression Scale, ICECAP-O = the Investigating Choice Experiments for the Preferences of Older People Capability measure for Older People, CCS = Caregiver Competence Scale, RCSS = Revised Caregiving Satisfaction Scale, BDI-II = Beck Depression Inventory II, CHHBS = Caregiver Health and Health Behaviors Scale, SSS = Social Support Scale, PNAS = Positive and Negative Affect Scale, CgAI = Caregiver Anger Interview, NAS = Negative Affect Scale, MAACL-R = Multiple Affect Adjective Check List Revised.

Table 1.4 Review studies not included in meta-analysis

Author, year	Theoretical model	Design, sample size, attrition, female (%)	Duration of type of intervention	Follow-up	Outcome scales
Goodman, 1990	Borkman's Model (Borkman, 1984)	RCT, $n = 22$ (network lecture sequence), $n = 18$ (lecture network sequence), $n = 41$ , Female: 75%	3 months, 12 phone-delivered lectures where participants could call at any time	Baseline, 3 months, 6 months	MPBC, ZBI, MHI, knowledge of AD
Czaja, 2018	Stress Process Theory (Lazarus & Folkman, 1984)	Pre and post measures, $n = 146$ , Female: 76%	6 months, 12, 60-min individual (6 face-to-face and 6 telephone) skill building and educational sessions and 5 telephone support groups	Baseline, 6 months, 12 months	CES-D, BDI, SSS, CSES, SSQ, PACS, QLS
Wijma, 2018	No model	Pre and post measures, $n = 42$ , Female: 77%	3 weeks, virtual reality 360 degrees simulation video featuring three scenarios, 3, 20 minute e-lessons	Baseline, 3 weeks	ADQ, IRI, PIC, TOA, DRS
Goodman & Pynoos, 1990	No model	RCT, $n = 35$ (lecture component), $n = 31$ (network component), $n$	12 weeks, 12 telephone accessed taped lectures about	Baseline, 12 weeks	ZBI, Mental health, CERS, Social support measure, Networking

		= 15, Female: 77%	Alzheimer's disease over a 12-week period		measure, Information about AD
Hattink, 2015	Medical Model of Dementia (DSM-IV, 2004), International Classification of Functioning, Disability and Health Model (Jette, 2006), Adaptation Coping Model (Droes et al., 2011)	RCT, <i>n</i> = 27 (group began program right away), <i>n</i> = 32 (group began program after 4 months), <i>n</i> = 59, Female: 49%	4 months, 8 online modules relating to different topics on dementia and dementia care	Baseline, 4 months	ADKS, Attitudes regarding dementia-ADS
Hicken, 2017	No model	RCT, <i>n</i> = 77 (Internet group), <i>n</i> = 78 (telephone group), <i>n</i> = NA, Female: 90%	4-6 months, weekly delivery of educational information using the Internet or a home telehealth device	Baseline, post intervention	ZBI (short form), MARWIT (short form), PHQ, DIS
Mavandadi, Wray, et al., 2017	No model	RCT, <i>n</i> = 140 (enhanced caregiver services), <i>n</i> = 290 (clinical assessment and referral), Female: 73%	3 months, module calls delivered 2 to 3 times a month, each 45 to 60 minutes in duration.	Baseline, 3 months, 6 months	ZBI (short form), NPI, RMBPC
Mavandadi, Wright, et al. 2017	No model	RCT, <i>n</i> = 31 (dementia care management), <i>n</i> = 25 (usual care), <i>n</i> = 32, Female: 97.3%	3 months, 7 online modules	baseline, 3 months, 6 months	ZBI, NPI, RMBPC, Management of Meaning, LCAS
Davis, 1998	No model	Pre and post measures, <i>n</i> = 17, <i>n</i> = 5, Female:	12 weeks, 2-hour in home training session, 12, 45-60	Baseline, 12 weeks	RMBPC, RPSI, USS, CLS



		75%	minute structured phone calls		
Gaugler, 2015	CARES for Families (Hobday et al., 2010).	Pre and post measures, $n = 41$ , $n = NA$ , Female: 90%	17.05 days, online, 1 hour informational modules.	Baseline, post intervention	Dementia Care Knowledge
Easom, 2013	No model	Pre and post measures, $n = 85$ , $n = 76$ , Female: 78%	6 months, telephone support group sessions on topics concerning communication and caregiving	Baseline, 6 months	RAA, ZBI, CES-D, RMBPC, CSES-R, DIS
Glueckauf, 2004	No model	Pre and post measure, $n = 20$ , $n = 9$ , Female: 90%	4 months, series of six 45-minute live online, interactive classes	Baseline, 4 months	CSES, SRGS, CAI
Griffiths, 2018	Stress Process Theory (Lazarus & Folkman, 1984)	Pre and post measure, $n = 57$ , $n = 7$ , Female: 91%	6 weeks, 75 minute teleconferences led by instructors, 5- 15 videos with educational messages	Baseline, 6 weeks to 1 months after completion	ZBI, CES-D, PCMS, RMBPC
Kajiyama, 2018	No model	Pre and post measure, $n = 19$ , $n = 6$ , Female: 76%	4 weeks, 18 Webnovella episodes, 15–20 minutes in duration	Baseline, 4 weeks	PSS, CES-D, Knowledge Survey

*Note:* RCT = randomized controlled trial, NA = not available, AD = Alzheimer’s Disease, MPBC = Memory and Problem Behavior Checklist, BDI = Overall Burden Interview, ZBI = Zarit Burden Interview, MHI = Mental Health Index, CERS = Caregiver Elder

Relationship Scale, ADQ = Approach to Dementia Questionnaire, IRI = Interpersonal Reactivity Index, PIC = Pressure from Informal Care, TOA = Trust in Own Abilities, DRS = Dyadic Relationship Scale, ADKS = Alzheimer's Disease Knowledge Scale, ADS = Approaches to Dementia Scale, MARWIT = Marwit-Meuser Caregiver Grief Inventory, SSS = Social Support Scale, QLS = Quality of Life Scale, SSQ = Social Support Questionnaire, PHQ = Patient Health Questionnaire, DIS = Desire to Institutionalize Scale, NPI = Neuropsychiatric Inventory Questionnaire, PACS = Positive Aspects of Caregiving Scale, RMBPC = Revised Memory and Behavior Problems Checklist, LCAS = Lawton Caregiving Appraisal Scale, RPSI = Rational Problem Solving Inventory, USS = Use of Social Support, CLS = Caregiver Life Satisfaction, RAA = Risk Appraisal Assessment, CES-D = Center for Epidemiologic Studies Depression Scale, CSES-R = Caregiving Self-Efficacy Scale-Revised, CSES = Caregiving Self-Efficacy Scale, SRGS = Stress-Related Growth Scale, CAI = Caregiver Appraisal Inventory, PCMS = Pearlin Caregiver Mastery Scale, PSS = Perceived Stress Scale,

Table 1.5 Characteristics of included studies

Description	<i>N</i> (%)
<b>Country of study</b>	
United States	22 (78)
Netherlands	3 (10)
Poland/Spain/Denmark	1 (4)
France	1 (4)
China	1 (4)
<b>Caregivers</b>	
Spouse/Partner/Significant Other	15 (29)
Adult Child	11 (23)
Caregiver of Veteran	2 (4)
Sibling	2 (4)
Other relative	14 (27)
Volunteer	1 (2)
Professional Caregiver	1 (2)
Caregiver (relationship unknown)	5 (9)
<b>Location</b>	
Urban	3 (10)
Rural	1 (4)
Mixed	1 (4)
Unknown	23 (82)
<b>CASP Study Quality NIMA-RCT</b>	
High	6 (100)
Medium	0 (Hodges et al.)

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Low	0 (Hodges et al.)
CASP Study Quality NIMA-non-RCT	
High	2 (25)
Medium	6 (75)
Low	0 (Hodges et al.)

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*Note:* CASP = Critical Appraisal Skills Programme, NIMA = Not included in meta-analysis – CASP Study Quality was performed only for studies not included in the meta-analysis; number of health professionals is greater, since some of the studies used multiple types of health professionals in their interventions.

Table 1.6 Risk of bias assessment for RCT studies not included in meta-analysis

Author, Year	Random sequence generation	Allocation concealment	Blinding of participants	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Czaja, 2018	?	?	?	?	+	?
Goodman, 1990	?	?	+	?	+	-
Goodman & Pynoos, 1990	?	?	?	?	-	-
Hattink, 2015	?	?	?	?	-	-
Hicken, 2017	?	?	?	?	?	?
Mavandadi, Wray, et al., 2017	+	?	+	?	+	-
Mavandadi, Wright, et al., 2017	-	-	?	?	-	+
Wijma, 2018	?	?	?	?	-	+

*Note:* RCT = Randomized Controlled Trial, ? = unknown risk of bias, - = low risk bias, + = high risk bias

Table 1.7 Risk of bias assessment for RCT studies included in meta-analysis

Author, Year	Random sequence generation	Allocation concealment	Blinding of participants	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Beauchamp, 2005	?	-	?	?	-	-
Czaja, 2013	?	?	-	?	-	-
Gallagher-Thompson, 2010	-	-	+	?	+	-
Glueckauf, 2007	?	?	?	?	+	-
Kajiyama, 2013	?	?	?	?	-	-
Martindale-Adams, 2013	?	?	?	?	-	-
Núñez-Naveira, 2016	-	?	?	?	-	-
Cristancho-LaCroix, 2015	-	?	?	?	-	-
Finkel, 2007	?	?	-	-	+	+
Gant, 2007	?	?	?	?	-	-
Steffen, 2000	?	?	?	?	-	-
Steffen, 2016	-	-	-	?	-	-
Kwok, 2013	-	?	?	?	+	-
Boots, 2018	+	+	-	?	+	-

*Note:* RCT = Randomized Controlled Trial, ? = unknown risk bias, - = low risk bias, + = high risk bias

Table 1.8 Quality of studies included in meta-analysis conveyed with Grading of Recommendations, Assessment, Development and Evaluations (Pourahmadi et al.)

Outcomes	No. of participants (studies)	Certainty of the evidence (Pourahmadi et al.)
Depression assessed with: Center for Epidemiological Studies Depression Scale (CES-D)	1300 (8 RCTs)	⊕⊕○○ LOW
Observable Behavioral Problems assessed with: Revised Memory and Behavior Problem Checklist (RMBPC)	592 (8 RCTs)	⊕○○○ VERY LOW
Caregiving Self-Efficacy assessed with: Caregiving Self-Efficacy Scale (CSES)	305 (7 RCTs)	⊕⊕○○ LOW
Caregiver Burden assessed with: Zarit Burden Interview (ZBI)	241 (3 RCTs)	⊕⊕○○ LOW
Depression assessed with: Beck Depression Inventory (BDI-II)	134 (3 RCTs)	⊕○○○ VERY LOW
Positive Caregiving Experience assessed with: Positive Aspects of Caregiving (PAC)	444 (3 RCTs)	⊕⊕○○ LOW

Table 1.9 Teaching and learning approaches

Teaching/learning approaches	<i>N</i> (%)
<b>Online-based learning</b>	
Information/educational modules	8 (12)
Website platform	1 (2)
Live interactive classes with instructor	2 (3)
<b>Telephone-based learning</b>	
Telephone support group	3 (4)
Telephone educational sessions	8 (12)
Teleconferences with instructor	1 (2)
Home telehealth device	1 (2)
Telephone-accessed taped lectures	2 (3)
Videophone support group sessions	1 (2)
Computer-telephone integration system	1 (2)
Mobile device/Smartphone/tablet	1 (2)
<b>Video-based learning</b>	
Video-instructional/visual resources	13 (21)
DVD- role playing and narration	2 (3)
Video-role playing	1 (2)
Educational Webnovella videos	1 (2)
Virtual Reality Simulation	1 (2)
<b>Other resources</b>	
Textual resources	8 (12)
Interactive feedback	2 (3)
Interactive exercises	1 (2)



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Knowledge tests	2 (3)
References to other resource websites	3 (4)

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*Note:* Number of studies is greater, since some of the studies used multiple approaches to teaching or learning.

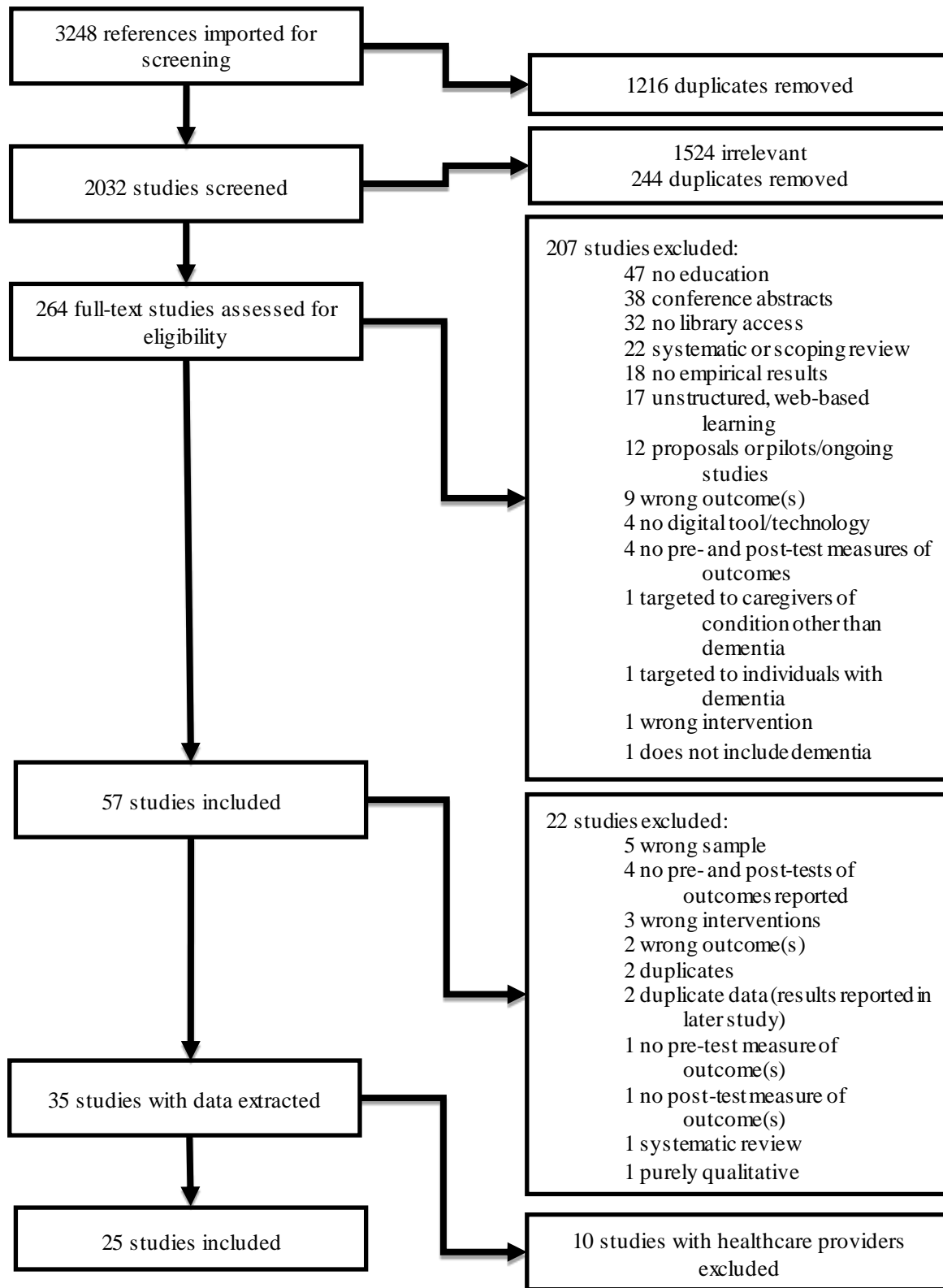
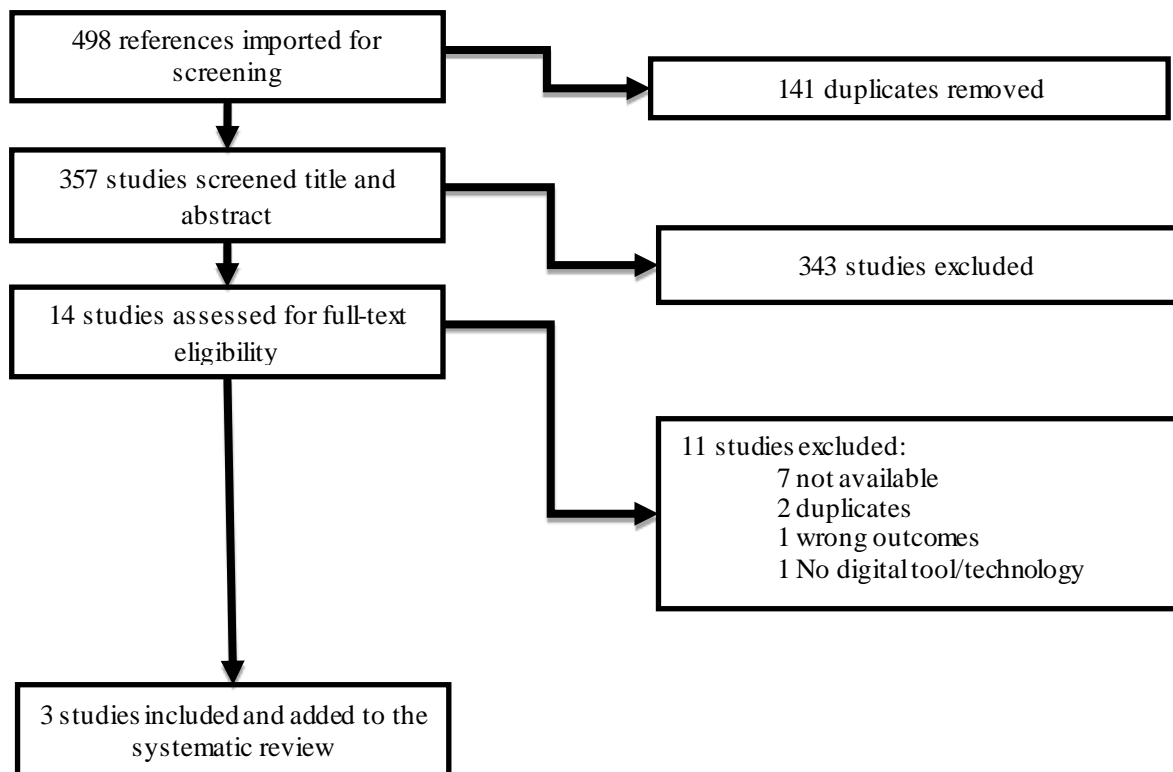


Figure 1.1 Preferred reporting Items for Systematic Reviews and Meta-Analysis (Moher et al.2009)



*Figure 1.2* Preferred reporting Items for Systematic Reviews and Meta-Analysis (Moher et al., 2009) Update

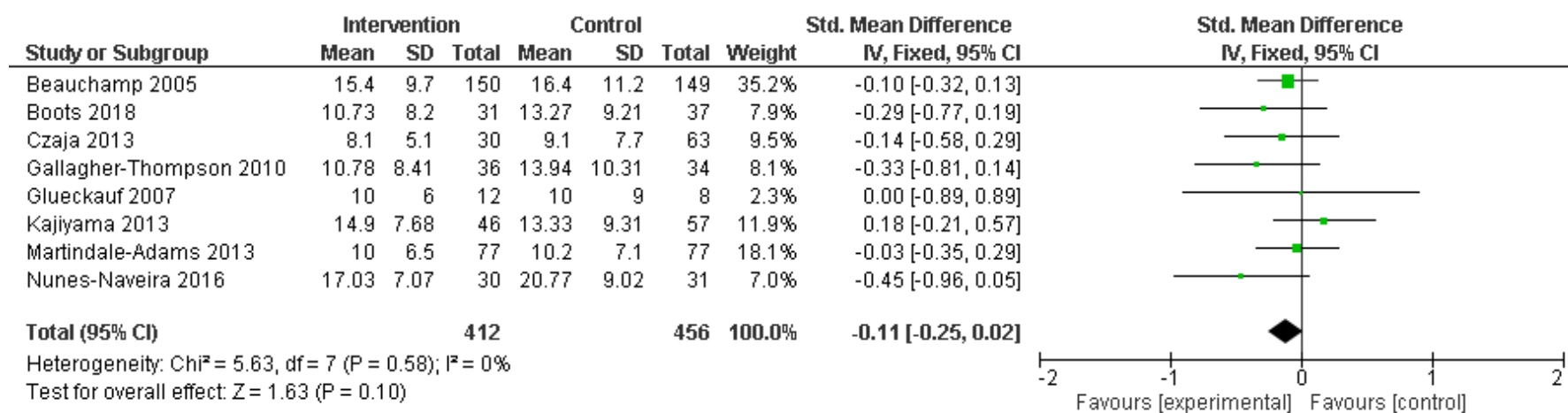


Figure 1.3 Depression assessed with: Center for Epidemiological Studies Depression Scale (CES-D)

Note: In the above figure, Mean is the mean score on the CES-D, SD is the standard deviation for each group (intervention group and control group). Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity ( $I^2$ ) = 0%,  $p$  value indicates level of statistical significance.

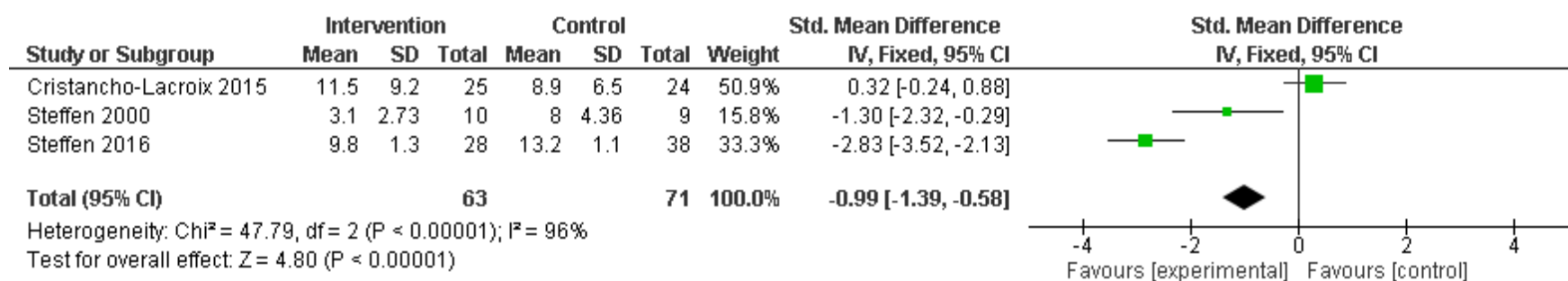


Figure 1.4 Depression assessed with: Beck Depression Inventory (BDI-II)

Note: In the above figure, Mean is the study mean on the BDI-II for each group, intervention group and control group, and SD is the standard deviation for each group. Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity (I<sup>2</sup>) = 96%, p value indicates level of statistical significance.

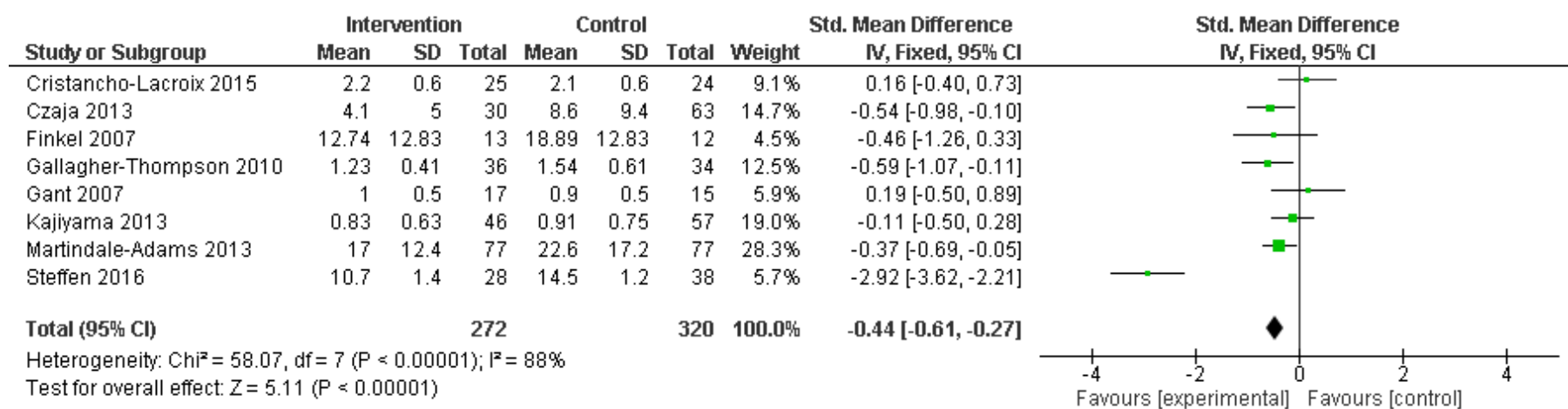


Figure 1.5 Behavioral problems assessed with: Revised Memory and Behavior Problem Checklist (RMBPC)

Note: In the above figure, Mean is the study mean on the RMBPD for each group, intervention and control, and SD is the standard deviation for each group, Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity (I<sup>2</sup>) = 88%, p value indicates level of statistical significance.

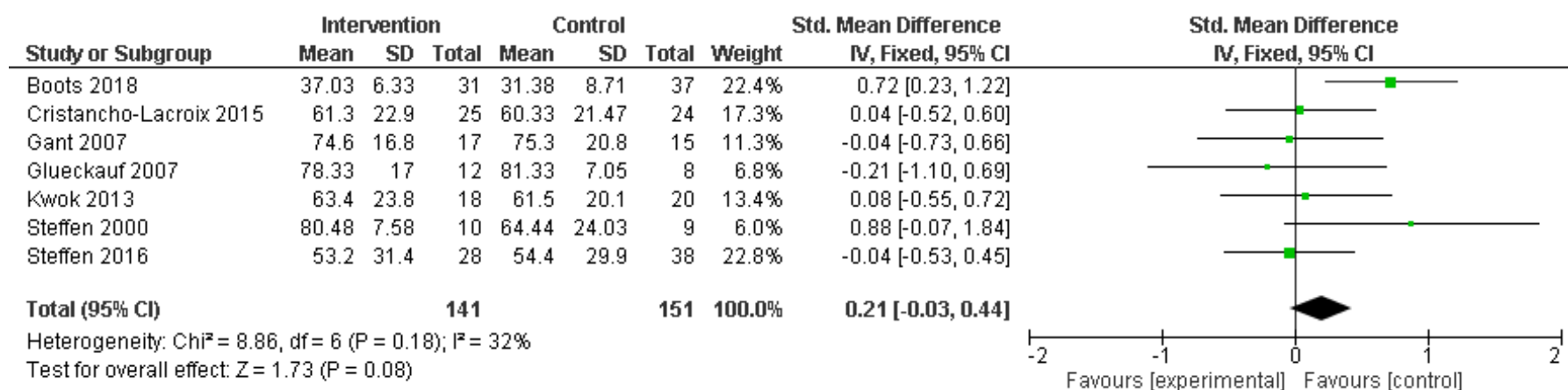


Figure 1.6 Caregiving Self-Efficacy assessed with: Caregiving Self-Efficacy Scale (CSES)

Note: In the above figure, Mean is the study mean on the CSES for each group, intervention and control, SD is the standard deviation for each group, Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity ( $I^2$ ) = 32%, p value indicates level of statistical significance.

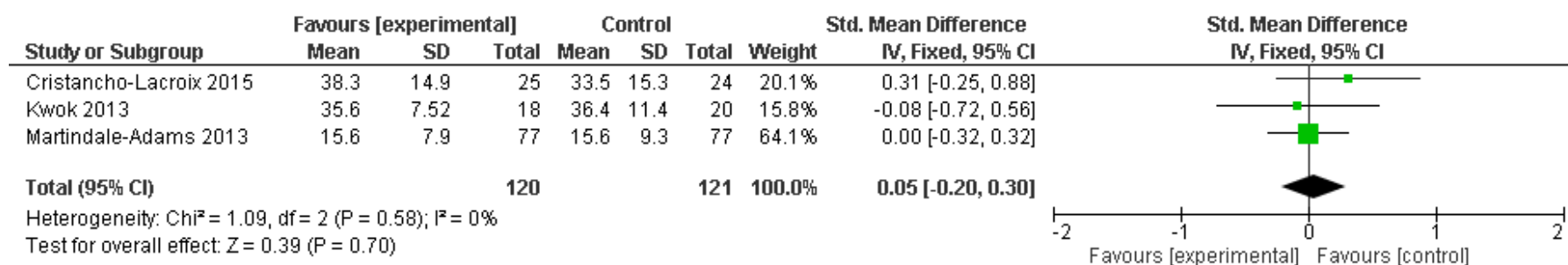


Figure 1.7 Caregiver Burden assessed with: Zarit Burden Interview (ZBI)

Note: In the above figure, Mean is the study mean on the ZBI for the intervention and control groups, and SD is the standard deviation for each group, Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity ( $I^2$ ) = 0%, p value indicates level of statistical significance.



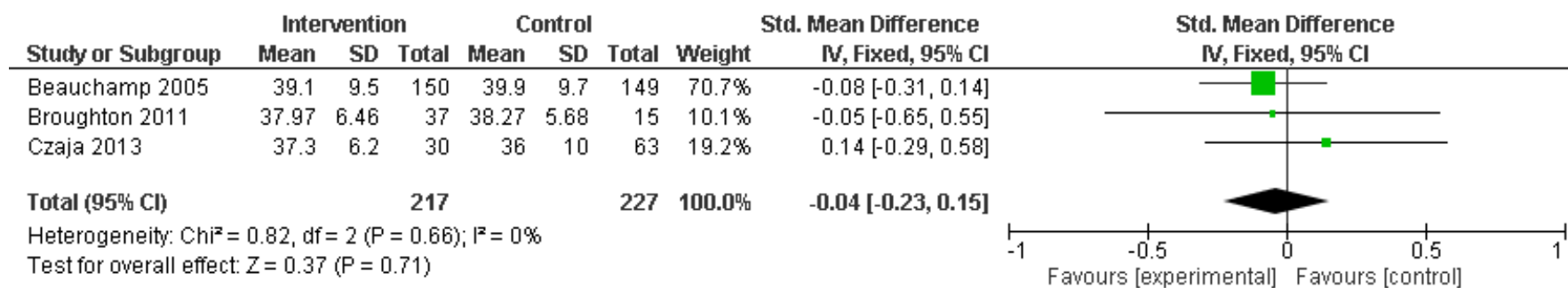


Figure 1.8 Positive Caregiving Experience assessed with: Positive Aspects of Caregiving (PAC)

Note: In the above figure, Mean is the study mean of the PAC for the intervention and control groups, and SD is the standard deviation for each group, Total is the total number (N) in each group, Weight is the influence of studies on overall meta-analysis, Std. Mean Difference is the overall effect, Heterogeneity (I<sup>2</sup>) = 0%, p value indicates level of statistical significance.

### **Link From Study 1 to Study 2**

The first systematic review revealed that digitally-based dementia education programs for caregivers of individuals diagnosed with dementia have been effective in reducing dementia knowledge gaps, increasing the self-reported efficacy of caregivers to provide daily care, improved the ability of caregivers to communicate with their carees, alleviated caregiver stresses and burdens regarding daily care, successfully addressed presenting and future anticipated care needs, as well as improved overall caregiver wellbeing and mental health. The first systematic review revealed so many studies reporting use of digitally-based dementia education for caregivers, that we were able to perform a meta-analysis and reveal common findings among studies such as a reduction in self-reported distress in response to perceived behavioral issues. The findings here indicated a plenitude of available education and resources. The remaining unknown are the healthcare providers, who face unique challenges with regards to practice in rural and remote areas, and who also report a lack of knowledge regarding dementia diagnosis. The following systematic review was performed to inform on content and availability of digitally-based dementia education programs for rural healthcare providers.

## Study 2 Abstract

Continuing education on dementia for healthcare providers has been shown to have positive effects on diagnostic confidence, knowledge, and care management. Technological approaches to educational delivery have been found to have comparable effects in terms of quality and efficacy. The purpose of the systematic review was to synthesize and present an evidence base for technology-delivered dementia education for healthcare providers. The review used PRISMA guidelines and Cochrane methods focusing on studies with a pre- and post-intervention evaluation. Technology-based delivery of dementia education was broadly defined as any technology-based medium delivered in real time or asynchronously. Ten studies were identified and analyzed using content analysis. The review revealed positive outcomes post-intervention, for dementia knowledge, readiness to change, receptiveness to training, communication skills, and self-efficacy. Studies were rated as medium to high quality on a scale for measurement of published data in research, and there was generally an unknown risk of bias due to a lack of a control group in most studies ( $N = 7$ ). The findings revealed benefits of digitally-based, asynchronous continuing education for healthcare providers, which allow schedule flexibility and the ability to deliver remotely. Findings also revealed benefits of presentations using a variety of interactive educational materials via videos, voice recordings, textual media and online discussion groups. Suggestions for intervention improvements include tailoring training for the specific needs and knowledge levels of healthcare practitioners and using validated scales to measure outcomes. This study has been published.

Scerbe, A., O'Connell, M. E., Astell, A., Morgan, D., Kosteniuk, J. & DesRoches, A. (2019). Digital tools for delivery of dementia education for health-care providers: a systematic review. *Educational Gerontology*, 45(11), 681-699. doi.org/10.1080/03601277.2019.1687149

## Study 2 Introduction

Dementia exigency is not only a world (World Health Organization, 2015) and a Canadian predicament (Alzheimer Society of Canada, 2010), but also a provincial one in predominantly rural provinces such as Saskatchewan (Canadian Academy of Health Sciences, 2019). Delivery of care strategies and supports for individuals with dementia is contingent on timely diagnosis (Di Gregorio et al., 2015; Innes et al., 2014), but inadequate dementia knowledge increases the potential for missed diagnoses (Coogle et al., 2004). Once diagnosed, healthcare providers require knowledge of psychosocial and physical aspects of care (Coogle et al., 2004).

Among healthcare providers who encounter individuals with dementia, there is a general lack of dementia training and education, and this applies across healthcare groups including physicians (Adler et al., 2015; Barrett et al., 1997; Gandesha et al., 2012a; Hallberg et al., 2016), registered nurses, licensed practical nurses, psychiatric nurses, occupational therapists, physiotherapists, and social workers (Adler et al., 2015; Brown, 2009; Bryans et al., 2003; Gandesha et al., 2012a; Manthorpe et al., 2003). Lack of dementia education impacts on the quality of services (Broughton et al., 2011), with healthcare professionals noting that deficits in their dementia knowledge directly hinders their care abilities (Adler et al., 2015; Broughton et al., 2011; Brown, 2009; Gandesha et al., 2012a; Hallberg et al., 2016).

Dementia education for healthcare providers can improve both knowledge (Boise et al., 1999; Broughton et al., 2011; Gandesha et al., 2012a) and clinical practice (Brody & Galvin, 2013; Eggenberger et al., 2013; Elliott et al., 2012; Fossey et al., 2014; Galvin et al., 2011; Spector et al., 2013). For example, dementia education (Arnautovska et al., 2016; Gandesha et al., 2012a; Harvey et al., 2006) has been shown to help overcome many knowledge barriers reported by healthcare providers (Cody et al., 2002; Mitchell et al., 2011; Spector et al., 2016), increase confidence and skill level (Boise et al., 1999; Broughton et al., 2011; Gandesha et al., 2012a), encourage better, coordinated care (Buhler et al., 2011), increase adherence to best practice guidelines (Galvin et al., 2011), improve attitudes (Manthorpe et al., 2003; Sizemore et al., 1998), and reduce diagnostic uncertainty (Broughton et al., 2011; Harvey et al., 2006; Rokstad et al., 2017). Dementia education can take a variety of forms, and technology-based modes of delivery have become more available in recent years.

## **Digital Tools for Healthcare Providers**

Digital education refers to transmission of knowledge through electronic media, computer networks, or other virtual media such as web-based or software interventions. While digital methods are noted to positively impact learning outcomes (Cobbett et al., 2016), they have an added advantage of remote, asynchronous delivery (Harvey et al., 2006; Waldorff et al., 2009). This offers benefits for rural and remote healthcare providers facing additional challenges such as vast distances to visit patients (e.g., long travel time and isolation), and a lack of access to specialized dementia services and continuing education (Kosteniuk et al., 2016).

Digital tools for healthcare providers offer benefits of remote information delivery (Broughton et al., 2011; Ruiz et al., 2006), skills/knowledge building (Broughton et al., 2011; Cobbett et al., 2016; Jones & Moyle, 2016; Ruiz et al., 2006), and attitude change (Jones & Moyle, 2016), and have garnered positive reception from healthcare providers (Broughton et al., 2011; Irvine et al., 2003). The scope of digital tools used in interventions is broad, and may include any digital, web-based, online, e-learning (elearning), applications delivered via a cell phone, distance education, online learning/training/instruction, and computer-assisted software.

Modes of delivery such as DVD-based training (Broughton et al., 2011) and CD-ROM-based training (Irvine et al., 2003) have delivered improvements in knowledge and support strategies (Broughton et al., 2011), improved reported self-efficacy (Irvine et al., 2003), and increased the use of correct care strategies (Irvine et al., 2003). Healthcare providers report being generally receptive toward technology-based information delivery (Galvin et al., 2011), including delivery via mobile apps (Pitts et al., 2015). There is a strong preference among healthcare providers for interactive components of educational materials, including continuous participation and contemplation on previous experience (Degryse et al., 2009; MacDonald et al., 2004), as well as opportunities to apply learned information in the program, and the ability to debrief and share experiences with colleagues (MacDonald et al., 2004). Healthcare professionals also desire content on diagnosis and medication, culturally competent education (Fahey- McCarthy et al., 2009), and a recognition of involvement (e.g., completion certificate; Eggenberger et al., 2013).

Comprehension of healthcare provider's specific needs and diverse disciplinary backgrounds is important in the development of educational tools (Degryse et al., 2009). Degryse and colleagues (2009) found that successfully translating a technology-based education tool required the use of a culturally targeted approach (Scott et al., 2015), with an emphasis on the

unique needs of diverse professional communities (Degryse et al., 2009). In other words, interventions targeted toward the needs of specific healthcare groups were more likely to have a positive effect on knowledge acquisition and behavior change in that group. Conversely, it was found that interventions that do not align with healthcare professional needs were less effective (Degryse et al., 2009; Scott et al., 2015).

### **Present Review**

Although not the first review on this topic, the present review differs from earlier ones (Alushi et al., 2015; Beeber et al., 2010; Boots et al., 2014; Brody & Galvin, 2013; Eggenberger et al., 2013; Elliott et al., 2012; Fossey et al., 2014; Kuske et al., 2007; Raymond & Iliffe, 2013; Spector et al., 2013; Surr et al., 2017), in two important ways: 1) It focuses on a broad range of settings, healthcare professions, and types of digitally-based dementia education interventions; and 2) It focuses on studies with quantitative measures corresponding to anticipated outcomes. Studies in this review include a pre-intervention (baseline measure) and a post-intervention measure of change on outcomes. The current review also serves to establish a summary of existing digitally-based modes of dementia education, which can be used to design future digitally-delivered, asynchronous modes of dementia education for healthcare providers.

## **Study 2 Method**

### **Objectives and Search Strategy**

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations (Moher et al., 2009), and Cochrane guidelines for systematic reviews and meta-synthesis (Jørgensen et al., 2006; Moseley et al., 2009) were employed. The review addressed the following questions: 1) What learning technologies, online resources, and digital education tools on dementia are available? 2) At whom are the tools aimed (e.g., relevant characteristics of targeted healthcare providers)? 3) How many of the tools are for learning about dementia (e.g., causes, types, and symptoms) versus dementia management or other purposes? 4) How are the digital education tools evaluated? 5) What are the measured, intended, or unintended outcomes?

Studies were identified by searching electronic databases and reviewing the citations of articles selected for inclusion in the review (Figure 2.1). Review of citations was performed using Covidence, an online systematic review management software (*Covidence [Computer program]*). The search strategy process followed the Cochrane guidelines (Moseley et al., 2009), and the list

of databases included PsychINFO, MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Sociological Abstract, AgeLine, and Embase. These databases were selected in consultation with a research librarian, specializing in the social sciences. The selection of databases was based on the relevance to the topic of investigation (e.g., technologically based dementia education in the healthcare professions). The search syntax was adjusted for each database to enhance the search results (for a sample syntax for PsychINFO, see Appendix A).

### **Data Screening, Extraction, and Analysis**

Two reviewers independently screened titles and abstracts of procured references. Studies were coded as *obtain* (eligible or potentially eligible/unclear) or *do not obtain* (ineligible). Full texts of obtained studies were individually reviewed by the same two reviewers for inclusion. The reasons for exclusion were recorded in a PRISMA diagram (see Table 1). Disagreement regarding inclusion was resolved via verbal deliberation. A third individual was available to arbitrate when disagreements could not be resolved. All irrelevant titles were excluded, and full text papers were obtained where the titles were deemed relevant, or where the eligibility was unclear. Data extraction was performed in duplicate by the same two reviewers, with an adapted and customized data extraction form adapted from the Cochrane Collaboration (Higgins & Green, 2011). This form included details such as publication dates reasons for inclusion or exclusion, study design, methods, duration, participant characteristics, sample size, attrition, demographic information, intervention details, outcomes, and risk of bias (Figure 2.1).

A meta-analysis was not possible due to the heterogeneity in outcomes and lack of a control group in many of the studies. The results of the studies were qualitatively examined using content analysis to formulate categories or over-arching themes and to derive answers to the five research questions listed above. The goal of the analysis was to synthesize the available information into a summary of digital dementia learning interventions for healthcare professionals.

### **Inclusion Criteria**

Studies included in the review were available through the University of Saskatchewan electronic library database, were published in English, and included at least one technology or digital tool that was used to convey dementia education targeted to healthcare professionals such as physicians, nurses, care workers, care aides, or personal support workers. The digital tools included e-learning and other electronic media via computer networks, teleconferencing

networks, or telephones. Digital delivery did not have to occur online; for example, internal resources such as DVDs developed within organizations which were not available to the public were considered. The included interventions had a measure of pre- and post-outcome findings and offered structured education delivered in a homogenous manner for each participant. We defined structured education as the delivery of predetermined dementia information, with a clear underlying philosophy on which the intervention is based. Case studies, pilot studies, randomized, and non-randomized studies were also considered in the review.

### **Exclusion Criteria**

Excluded studies were other systematic reviews, studies lacking an evaluative component, studies that used a satisfaction measure as the sole measure of the intervention effect, studies lacking structured education, studies lacking technology, studies targeting types of recipients other than healthcare professionals, studies lacking an educational dementia component, and studies where the educational component contained dementia in addition to other medical education, but where findings included a compounded analysis (e.g., the effect of the intervention on dementia knowledge could not be separated from the overall effects).

### **Risk of Bias and Study Quality**

The risk of bias was assessed in duplicate by two reviewers using a set of criteria adapted from Cochrane methods for risk of bias evaluations (Higgins & Green, 2011). The risk of bias was rated independently by each reviewer for each study as *low*, *medium*, or *high* risk, and later deliberated to achieve 100% agreement. Due to the heterogeneity of study outcomes, risk of bias was performed only on an individual study basis. The included studies were also subject to a quality review, which was performed by adapting checklists from the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2014). Two types of quality criteria checklists were adapted. One set of criteria was developed for evaluating studies of randomized controlled trials, and one set was developed for studies with a single group evaluated pre- and post-intervention (see Tables 1 and 2).

The range of possible quality CASP scores for studies using non-randomized controlled trials (non-RCT studies) ranged from 0 to 18, where low quality studies ranged from 1 to 6, medium quality studies ranged from 7 to 12, and high-quality studies ranged from 13 to 18. The range of possible quality CASP scores for randomized controlled studies (RCT studies), utilizing a single group who received the intervention, ranged from 0 to 21, where low quality studies



ranged from 1 to 7, medium quality studies ranged from 7 to 15, and high-quality studies ranged from 16 to 21. The quality criteria were not used to determine study exclusion, but rather to provide a description of study quality. Studies which were deemed ‘high quality’ met most of the quality criteria. Studies which were deemed in the ‘medium quality’ range met an acceptable level of quality, and studies which were deemed in the ‘low quality’ range did not meet enough quality criteria. The evaluation of study quality was performed independently by two reviewers. Disagreements were resolved verbally, and a third individual was available to arbitrate.

## **Study 2 Results**

In total, ten studies meeting the search criteria standards were included in the review (see Table 2.3). The studies were published between 2002 and 2017. Most of these studies were completed with a single intervention group with pre- and post-intervention measures (6 studies; (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Pleasant et al., 2017; Ruiz et al., 2006)). Three studies included a randomized controlled trial (RCT; (Broughton et al., 2011; Downs et al., 2006; Rosen et al., 2002)), and one study included a case-controlled study (CCS; (Luconi, 2008)). Of these ten studies, five included an education program derived from a theoretical model (Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017), while the other five (Banks et al., 2014; Broughton et al., 2011; Downs et al., 2006; Rosen et al., 2002; Ruiz et al., 2006) did not utilize a theoretical model. Theoretical models included learning models such as the Adult Learning Theory (Knowles, 1984), the Four-Stage Theory of Physicians’ Learning (Slotnick, 2001), and the Clinical Reasoning Model (Barrows & Feltovich, 1987). Other models were derived from larger theories in psychology, such as the Social Cognitive Learning Theory (Bandura, 1977) and the Expanded Theory of Reasoned Action (Fishbein & Ajzen, 1975). The remaining studies employed concepts derived from the *CARES<sup>TM</sup>* Dementia-Friendly Hospital Learning Principles (Merkt et al., 2011) and *CARES<sup>TM</sup>* Dementia Basics Program principles (Hobday et al., 2010). From a total number of participants ( $N = 760$ ), sample sizes ranged from  $n = 8$  to  $n = 113$ , of which 38% to 100% were female. Study attrition ranged from 1 to 11 participants, but many studies (4 studies; (Banks et al., 2014; Hobday et al., 2017; Luconi, 2008; Ruiz et al., 2006)) did not report their attrition rates. The intervention duration ranged from a single 2-hour long session to a 12-month period with asynchronous completion of computer modules. Half of the studies were conducted in the United States (5 studies; see Table 2.4; (Hobday et al., 2017; Irvine et al., 2013; Pleasant et al., 2017;

Rosen et al., 2002; Ruiz et al., 2006)). The setting of interventions included long-term care/nursing homes (4 studies; (Broughton et al., 2011; Chao et al., 2016; Irvine et al., 2013; Rosen et al., 2002)), secondary education or professional settings (2 studies; (Luconi, 2008; Ruiz et al., 2006)), general practices/hospitals (4 studies; (Banks et al., 2014; Downs et al., 2006; Hobday et al., 2017; Pleasant et al., 2017); see Table 2.4). The geographic location of studies was largely unreported and unknown (in 9 studies), with only one study reporting a rural location (Luconi, 2008).

### **Risk of Bias**

Risk of bias ratings for most studies was unknown due to the study design (see Table 2.5, Figure 2.2, Figure 2.3; e.g., single treatment group without controls or random allocation). For RCT studies (3 studies; (Broughton et al., 2011; Downs et al., 2006; Rosen et al., 2002)), true random allocation was presumed, but not always clearly reported. Only one RCT study reported how the random allocation was performed (Downs et al., 2006). Given the methods used by the majority of the included studies (either absence or presence of dementia education: 7 studies; (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Ruiz et al., 2006)), concealment of allocation, blinding of participants, and blinding of assessment outcomes procedures were not always possible. That is, most participants knew that they received an educational intervention, and most researchers knew the outcomes which they were measuring. In terms of data reporting, five studies reported only significant outcomes (Banks et al., 2014; Chao et al., 2016; Downs et al., 2006; Pleasant et al., 2017; Ruiz et al., 2006), and half of the studies reported all outcomes (Broughton et al., 2011; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002).

### **Study Quality**

The RCT studies (3 studies; (Broughton et al., 2011; Downs et al., 2006; Rosen et al., 2002)), were evaluated using the CASP quality criteria for RCTs, and the single treatment group studies (non-RCTs; 7 studies; (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Ruiz et al., 2006) Table 2.1 and 2.2) were evaluated using CASP quality criteria for non-RCT studies. The RCT studies had high quality ratings overall, and demonstrated meticulousness in reporting, including descriptions of the population of interest, and unbiased approaches to reporting of findings. However, one RCT study did not report on the blinding of participants (Broughton et al., 2011). The quality of non-

RCT studies ranged from medium (in 1 study; (Banks et al., 2014)) to high range (in the remaining 5 studies). One aspect affecting most of the non-RCT studies, thus lowering their overall quality from high to medium range, was a lack of standardized scales to measure outcomes (in 5 of the non-RCT studies; (Banks et al., 2014; Hobday et al., 2017; Irvine et al., 2013; Pleasant et al., 2017; Ruiz et al., 2006) ) and a tendency to use non-validated scales (in 6 studies; (Banks et al., 2014; Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Ruiz et al., 2006)). The breakdown of the average quality ratings for individual quality criteria for RCT and non-RCT studies can be found in Figures 2 and 3, respectively.

### **Types of Healthcare Professionals Included in Interventions**

Nurses were the most common type of healthcare professionals and were included in half of the interventions (5 studies; (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Hobday et al., 2017; Rosen et al., 2002; Ruiz et al., 2006)). Registered nurses (RNs) received most of their training remotely (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Rosen et al., 2002), and licensed practical nurses (LPNs) received their training via a computer in a classroom setting (Ruiz et al., 2006). Other healthcare professionals were managers and directors of a long-term care facility (Irvine et al., 2012). Two studies included family physicians (Banks et al., 2014; Luconi, 2008). One study focused solely on physician education (Luconi, 2008), and one study included a physician in an intervention targeted to diverse health professionals (Banks et al., 2014). The remaining professions represented included recreational activity officers (Banks et al., 2014; Broughton et al., 2011), dietitians, occupational therapists, physiotherapists, speech and language pathologists, managers (Banks et al., 2014), non-direct care staff in long-term care (Irvine et al., 2013), and other formal carers of individuals with dementia, such as volunteers with some training in care provision and who were in regular contact with patients (Pleasant et al., 2017). Recruitment of participants occurred in nursing home settings (Broughton et al., 2011), long-term care settings (Irvine et al., 2013), educational settings (Rosen et al., 2002; Ruiz et al., 2006), and mixed settings, which included a combination of health centers and hospitals (Chao et al., 2016; Downs et al., 2006). Recruitment occurred using public message announcements (Chao et al., 2016), existing organization-networks, and online recruitment strategies (Banks et al., 2014; Luconi, 2008; Pleasant et al., 2017).

## **Learning Methods and Types of Educational Tools**

The digital modes of learning frequently featured more than one medium to convey knowledge, including video, audio-narration, asynchronous computer-based modules with educational content, graphics, and some interactive content (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002); see Table 2.6). Many studies included multi-feature components of learning, including videos. For example, Banks et al. (2014) used educational video resources; Hobday and colleagues (2017) used unscripted video resources that featured scenarios with real patients and interviews with experts; Irvine and colleagues (2013) used video-modeling vignettes to emphasize case scenarios and interviews with experts; and Rosen and colleagues (2002) used interactive video modules, specially designed in a news-documentary format with exercises and questions relating to the visual content.

Many of the studies also supplemented their online learning content with other mediums such as audio narration (Hobday et al., 2017; Irvine et al., 2013), online group discussion forums (Banks et al., 2014; Luconi, 2008), and quizzes with automatic feedback (Luconi, 2008). A study by Pleasant and colleagues (2017), relied mostly on presenting textual information (Pleasant et al., 2017). Additional learning features were assigned readings (Banks et al., 2014), interactive text entry, graphics, case studies (Hobday et al., 2017), and email reminders (Luconi, 2008). Two studies used designated platforms to deliver educational content; for example, one study used online education available via a work-site home page (Irvine et al., 2013), another study (Ruiz et al., 2006) used computer-based learning modules, accessible only via a computer-testing laboratory of an educational institution, and another study used modules available via an online platform licensed to the institution (Luconi, 2008).

Two studies did not convey their education online; for example, Downs and colleagues (2006) used an electronic tutorial with an indexing system embedded in existing medical records software, which produced prompts and provided real-time learning about diagnosis and management of dementia. Lastly, two studies featured a required in-person attendance component. Banks and colleagues (2014) featured blended learning where participants accessed, read, and watched e-learning resources, and communicated in an online forum prior to attending five half-day lectures. In their study, Chao and colleagues (2016) included a portion of learning

delivered in a classroom and a portion of learning delivered via structured Internet-based learning.

### **Focus of Educational Content**

The broad topics of education included categories such as dementia screening and assessment (Pleasant et al., 2017), clinical decision making (Downs et al., 2006), individualized care (Hobday et al., 2017; Pleasant et al., 2017; Ruiz et al., 2006), care management (Luconi, 2008; Rosen et al., 2002), enhancing skill and confidence (Irvine et al., 2013; Luconi, 2008), enhancing communication abilities (Irvine et al., 2013; Rosen et al., 2002), coping (Rosen et al., 2002), attitudes toward dementia care (Ruiz et al., 2006), vulnerability and ethical issues (Pleasant et al., 2017; Rosen et al., 2002), and end of life care and discharge (Pleasant et al., 2017). Interventions also targeted larger groups of healthcare professions with a varying skill level and focused on developing materials with 6<sup>th</sup> to 8<sup>th</sup> grade reading levels (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002).

The learning materials included content about memory profiles in dementia (Banks et al., 2014; Broughton et al., 2011; Rosen et al., 2002; Ruiz et al., 2006), clinical reasoning (Downs et al., 2006), dementia diagnosis (Luconi, 2008; Pleasant et al., 2017), patient care strategies (Broughton et al., 2011; Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006), managing behavioral and psychological aspects of dementia (Chao et al., 2016), changing attitudes toward dementia care (Ruiz et al., 2006), working with vulnerable populations (Pleasant et al., 2017; Rosen et al., 2002), and communication strategies (Broughton et al., 2011; Chao et al., 2016; Irvine et al., 2013; Rosen et al., 2002).

### **Evaluation of Digital Educational Tools**

The studies generally focused on evaluating dementia knowledge (Banks et al., 2014; Hobday et al., 2017; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006) and included scales developed by study authors, some of which were validated (Hobday et al., 2017; Ruiz et al., 2006). For example, Hobday and colleagues (2017), Rosen and colleagues (2002), and Ruiz and colleagues (2006) did not include scale validation, and measures used by Banks and colleagues ((2014); Approaches to Dementia Scale: ADS) and Pleasant et al. ((2017); Dementia Knowledge Questionnaire: DKQ) included scale validation (see Table 2.7). Studies also focused on satisfaction with caregiving. For example, Broughton and colleagues (2011) used two types of

scales (Positive Aspects of Caregiving Questionnaire: PAC, and Caregiver Satisfaction; both validated scales with high convergent validity and internal consistency reliability), plus patient communication skills via self-reported surveys. Chao and colleagues (2016) used four validated scales (Communication Knowledge Scale: CKS-C, Communication Skills Attitudes Scale: CSAS-C, Patients' Receptive and Expressive Ability: PREAS, and Revised memory and Behavior Problems Checklist: CSDD-C; all scales were Chinese versions), all with evidence of high reliability and validity.

Studies also measured self-efficacy and competence in care but varied in the quality of their measurement. Banks and colleagues (2014) and Ruiz and colleagues (2006) used non-validated scales developed for the purpose of assessing their respective program materials. Similarly, Irvine and colleagues (2013) used a measure of situational self-efficacy in response to a video-situation test which was specially developed and validated for intervention purposes. Pleasant and colleagues (2017) used a validated scale (Sense of Competence in Dementia Scale: SCIDS) to assess participant competency, and Irvine and colleagues (2013) used the video situation test with validated measures to assess attitudes toward dementia care and behavioral intentions with regards to behavior change. The study by Luconi (2008) measured only reaction to training with the Barometer scale (non-validated scale, developed to measure readiness to learn), as well as confirmation of new learned knowledge with existing knowledge using the Participant Reaction Questionnaire (PRQ-I, also not validated). Lastly, a study by Downs and colleagues (2006) measured dementia detection rates and concordance with guidelines by directly extracting tracked information from patient health records and using coded checklists for diagnosis concordance and management concordance.

## **Outcomes**

Study outcomes corresponded to the measures developed or chosen for specific hypothesized effects. Seven studies used a single group pre- and post-test design, and three were RCTs: see Table 2.3 and 7). These scales were subsumed in this review under themes of dementia knowledge, readiness to change practice, reaction to training program/intervention, dementia care strategies, knowledge of specific aspects of dementia care, communication skills with staff, patients and patient families, self-efficacy and competence in practice, and attitudes and beliefs regarding dementia care.

Of the 10 selected studies, four studies (Downs et al., 2006; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006) evaluated dementia knowledge, and all four found significant improvement on measures of dementia knowledge (see Table 2.7). Other aspects of dementia knowledge that were measured included dementia care, dementia care management knowledge, and change in practice (Downs et al., 2006; Hobday et al., 2017). Hobday and colleagues (Hobday et al., 2017) found a significant difference in dementia care knowledge, while Downs and colleagues ((2006); using a checklist reflecting dementia practice) did not find a significant change in practice which is consistent with other research indicating general impedance to adoption of guidelines in practice (Berner et al., 2003; Sivananthan et al., 2013). While all of the studies used different measures to assess change, each study reported a meaningful change in dementia care and management by students/trainees from baseline to post-intervention, in their practice.

Some studies employed unique ways to measure the effects of their interventions. For example, Irvine and colleagues (2013) integrated a video situation test followed by content-based questions, which included self-reported intentions to change practice (Irvine et al., 2013). Another study (Luconi, 2008) examined reaction to training using two types of questionnaires. The first questionnaire (Participant Reaction Questionnaire: PRQ-I) indicated a response to the intervention, and a secondary questionnaire (Barometer) was specifically developed to measure readiness to learn and engage in the intervention. Both measures revealed significant self-reported positive reception toward learning and training.

Two studies (Banks et al., 2014; Broughton et al., 2011) addressed knowledge of care strategies in their outcomes. These studies used measures such as the Approaches to Dementia Scale, Positive Aspects of Caregiving, and caregiver satisfaction to measure knowledge of care, all of which indicated a significant positive change in knowledge relating to dementia care strategies. A study by Chao and colleagues (2016) examined communication skills with validated, adapted, and translated scales (adapted for Chinese speakers), all of which indicated significant findings, with the exception of a scale indicating a lack of change in communication-related attitudes (Communication Skills Attitudes Scale-Chinese Version: CSAS-C).

Four studies (Banks et al., 2014; Irvine et al., 2013; Pleasant et al., 2017; Ruiz et al., 2006), measured a change in reported self-efficacy and found significant changes. Lastly, a study by Irvine and colleagues (2013) measured change in attitudes toward dementia care and found

significant results, indicating that the intervention was effective in enhancing more positive attitudes toward dementia care.

## **Study 2 Discussion**

The systematic review was designed to address questions surrounding the available learning technologies for dementia for healthcare providers. The review also answered questions pertaining to what the relevant characteristics of healthcare professionals are using these technologies. Ten studies describing technology-based dementia education to healthcare professionals with pre- and post-education comparisons were identified. The review revealed that dementia education was delivered frequently with more than one medium which included video, online learning content, audio narration, textual presentation, and blended formats including online learning combined with face-to-face lectures (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002). Also, the technologies were primarily targeted to nursing staff (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Hobday et al., 2017; Rosen et al., 2002; Ruiz et al., 2006), family physicians (Banks et al., 2014; Luconi, 2008), and other healthcare professionals, including dietitians, occupational therapists, recreation therapists, physiotherapists, speech and language pathologists, long-term care home managers, and other affiliated long-term care staff (Banks et al., 2014; Broughton et al., 2011; Luconi, 2008; Irvine et al., 2012; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006).

Another aim of the review was to determine how many of the tools were for learning about dementia (e.g., causes, types, and symptoms) versus dementia management or other purposes. The focus of the educational content revolved primarily around dementia screening and assessment (Pleasant et al., 2017), clinical decision making (Downs et al., 2006), care management (Hobday et al., 2017; Luconi, 2008; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006), communication with patients and families (Irvine et al., 2013; Rosen et al., 2002), ethical and vulnerability issues (Pleasant et al., 2017; Rosen et al., 2002), and enhancing personal coping and confidence (Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002). When the material was targeted toward more varied groups of healthcare providers, with varying skill and education levels, the material was designed at the grade 6 to 8 reading levels to ensure better information uptake (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002).



An important outcome of this review was to determine how the digital education tools were evaluated? The educational tools primarily evaluated dementia knowledge (Banks et al., 2014; Downs et al., 2006; Hobday et al., 2017; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006), satisfaction with caregiving (Broughton et al., 2011), communication (Chao et al., 2016), self-efficacy in care giving (Banks et al., 2014; Ruiz et al., 2006; Pleasant et al., 2017), and intentions with regards to behavior change (Luconi, 2008). The studies used validated (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Pleasant et al., 2017), and unvalidated scales (Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi 2008; Rosen et al., 2002; Ruiz et al., 2006) to measure outcomes. The primary measured outcomes were dementia knowledge (Downs et al., 2006; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006), and dementia care management (Banks et al., 2014; Broughton et al., 2011; Downs et al., 2006; Hobday et al., 2017). Other studies measured communication skills (Chao et al., 2016), self-efficacy (Banks et al., 2014; Irvine et al., 2013; Pleasant et al., 2017; Ruiz et al., 2006) and attitudes toward dementia care (Irvine et al, 2013). Studies evaluating these aspects generally found positive effect of interventions on outcomes. Studies measuring change in practice (Downs et al., 2006; Luconi, 2008), did not find a significant change which is consistent with other literature indicating that general adoption of new guidelines for healthcare providers is a laborious and uncertain process, where attitudes are not the best predictors of behaviour change (Berner et al., 2003; Sivananthan et al., 2013).

While previous systematic reviews focused on satisfaction-based evaluations of educational interventions (Surr et al., 2017), specific work settings (Beeber et al., 2010; Kuske et al., 2007), healthcare populations (Alushi et al., 2015), communication (Eggenberger et al., 2013), approaches (Fossey et al., 2014), organizational outcomes (Elliott et al., 2012), or defined aspects/outcomes of dementia training, such as management (Brody & Galvin, 2013), the present review focused only on digital modes of dementia education for healthcare professions which included pre- and post-intervention measures. A note-worthy observation was that each study found some positive changes in the outcomes, including improved dementia knowledge, readiness to change practice, receptiveness to training, communication skills, self-efficacy, and competence. Although incomplete, these data help to address the final aim of the current review and explore the measured, intended, or unintended outcomes of dementia related education.

Most of the interventions used varying types of media to convey knowledge, where combinations featuring interactive components have been shown to have positive effects on interest and continued participation (Broughton et al., 2011; Degryse et al., 2009; MacDonald et al., 2004). Asynchronous learning was deemed convenient as it allowed more flexibility for participants to choose to progress through the materials at their own pace, with a particular value for professionals practicing in rural and remote areas (Harvey et al., 2006; Kosteniuk et al., 2016; Waldorff et al., 2009). There were no differences in the effects on outcomes in terms of the three approaches (asynchronous online, combined face-to-face and online, online with an applied component), where each approach found a positive post-intervention change on dementia management and knowledge.

While research shows that there is a differential risk for dementia based on sex (Ferretti et al., 2018; Little, 2013; Podcasy & Epperson, 2016) and gender, each impacting risk disparately (Mielke et al., 2014), it was largely unknown in the studies, whether the educational content included such information (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006). It would be beneficial to include such knowledge in future interventions. Lastly, interventions that included a variety of health professionals (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002) developed materials for 6<sup>th</sup> to 8<sup>th</sup> grade reading levels to capture a variety in skill levels. These studies recommend that it is important to tailor educational materials for a wider scope of skill levels when designing materials for professions with a range of education and training.

Despite a variability in educational mediums and educational delivery, and although recent research indicates that interactive components have better effects on learning receptiveness (Surr et al., 2017), all of the studies demonstrated positive changes in outcomes, although it is important to note that mild publication bias has been noted in both fields of psychology and medicine (van Aert et al., 2019). Additionally, the studies featured an array of professionals, working in a wide variety of work environments, using adaptable and flexible technologically delivered modes of education. Future technology-based dementia educational interventions for healthcare providers would greatly benefit from the inclusion of a control group, such as in an RCT design and the inclusion of validated scales. Such additions could improve the quality and generalizability of study findings.

While the risk of bias assessment could not be completed due to a lack of a control condition in most studies, the CASP quality rating of literature indicated that the authors were measuring the intended constructs in their interventions. A meta-analysis of the findings was also not possible due to the heterogeneity in measurement tools and outcomes. Nevertheless, all studies found at least some positive impact of the interventions on outcomes, regardless of the mode of intervention, materials used in the intervention, or validation of scales, indicating that technology-based dementia education did have a positive impact on learning for healthcare providers.

### **Limitations/Strengths/Recommendations**

A limitation of this review is that it focused only on studies available in English. Due to a wide variety of measures/outcomes, a meta-analysis also was not possible, and due to the same heterogeneity, most studies had an unknown risk of bias. Studies with this type of intervention, targeting healthcare providers that feature a control group or an RCT design could improve the ability to perform bias ratings, and thus provide a better evaluation of study quality. Additional benefits of an RCT design are a greater confidence in the results and an assurance that a meaningful change occurred.

Due to the heterogeneous nature of interventions and desired outcomes, it was difficult to distinguish which types of approaches were more efficacious than others. However, it is noteworthy that all of the interventions, regardless of their design, duration, type of digital tool, or content of materials, noted a positive change in outcomes. Videos featuring modeling, case-based scenarios, and interviews with experts were deemed beneficial. Other features deemed useful by participants were email reminders to complete modules, a calendar function, and available technical support (Luconi, 2008). Future interventions should focus on including a variety of interactive, textual, and graphic materials. Interventions designed to retain attention and keep participants stimulated are also likely to ensure continued engagement. Periodic testing of the learned materials may also be useful for rehearsing and encoding learned information, and can favorably affect not only the intended outcomes, but also long-term knowledge retention (Karpicke & Smith, 2012).

When developing an intervention for a specific healthcare population, it may be advantageous for researchers to consider the level of knowledge, skill, or previous training of such populations. By building on existing knowledge, skills, and needs of healthcare

practitioners, one can ensure that an intervention will ameliorate knowledge gaps and increase receptiveness. Additionally, the choice of content delivery may depend on intended outcomes. For example, if a successful outcome is improving the knowledge of a memory profile in dementia, then the materials in the intervention should focus on conveying and assessing such knowledge. Another useful feature of a technology-based, asynchronous dementia education is content development based on healthcare provider input, need, or skill-level as indicated by performance on a pre-intervention measure. As noted in previous research by Degryse and colleagues (2009) and Scott and colleagues (2015), interventions that are suited to the unique needs of specific healthcare practitioner groups are more likely to have a positive effect on knowledge acquisition and behavior change.

All of the studies in the review used scales to measure outcomes; however, some of the studies used newly developed scales (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002), and not all of the scales were validated (Hobday et al., 2017; Rosen et al., 2002; Ruiz et al., 2006). Researchers recommend using validated scales to help ensure that any obtained differences are not present due to measurement bias (Arribas-Marín et al., 2017; Wood et al., 2002). Nevertheless, many studies did not employ this approach. Therefore, increased confidence in the intervention outcomes could be obtained with the use of validated scales. Last but not least, future researchers may consider administering education based on a learning model or a theory. While this approach does not guarantee significant or observable changes, a theory will help to determine the delivery of information and potential outcomes and can assist in determining appropriate measures.

### **Study 2 Conclusion**

The review uncovered compelling confirmation of effectiveness of various digitally conveyed dementia education modes for healthcare providers. The review also revealed a variety of interventions, including computer-based and video-based learning, targeting a large array of health professionals, featuring materials developed to suit a broad range of skill levels and knowledge. The most common type of intervention occurred via computer and through the completion of learning modules. The content of interventions focused on a variety of topics including dementia diagnosis (Downs et al., 2006; Pleasant et al., 2017), issues related to care (Hobday et al., 2017; Pleasant et al., 2017; Ruiz et al., 2006), and issues related to management (Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002).

While there was little consistency in use of validated measures to assess intended outcomes, and while in some cases development of new measures was imperative, validation prior to measurement would have assisted in ensuring that the intended construct(s) were being measured. The duration of an intervention did not appear to affect outcomes as long as the intended information was conveyed (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006). Lastly, regardless of the intervention duration, all of the studies found a significant positive change in their outcomes, with an exception of two outcomes: change in participants' practice (Downs et al., 2006), and attitudes toward communication skills (Chao et al., 2016). Past research shows that changing practice is difficult (Berner et al., 2003; Sivananthan et al., 2013), and change in attitudes may require additional time or ongoing support and consultation to achieve (Hayes, 2003). Taking all of the evidence in consideration, the variety of educational material presentation, together with interactive nature of materials, was generally advantageous for learning and continued participation of healthcare professionals.

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Table 2.1

Adapted quality rating criteria for non-randomized controlled trial studies

Quality criteria	Specific questions relating to rating considerations	Rating
• Are the research aims and questions/hypotheses clearly stated?	• Do(es) the author(s) clearly state what they plan to research?	0 = no; 1 = partially; 2 = yes
• Are ethical issues addressed?	• Do(es) the author(s) state that ethical approval was sought?	0 = no; 1 = partially; 2 = yes
• Are the methodology/study design appropriate to the research question and rationale for choice evident?	<ul style="list-style-type: none"> <li>• Do(es) the author state what research methodology they have chosen?</li> <li>• Is the chosen methodology appropriate to research question?</li> <li>• Do(es) the author(s) justify the research design used?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
• Are the sample size, selection and description appropriate?	<ul style="list-style-type: none"> <li>• Do(es) the author(s) clearly state how the study sample size was identified?</li> <li>• Do(es) the sample size appear to be large enough?</li> <li>• Do(es) the author adequately describe the sample (e.g., gender, age, relationship to care receiver) so that the reader can determine transferability of findings?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
• Is/Are the method(s) of data collection appropriate, reliable, and valid?	<ul style="list-style-type: none"> <li>• Do(es) the author(s) justify that the measure is suitable for this population?</li> <li>• Do(es) the author(s) use measures that measure the desired constructs?</li> <li>• Do(es) the author(s) indicate that the measures have good psychometric properties?</li> <li>• Do(es) the author(s) indicate that the measures used have demonstrated validity?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes
• Are the method(s) of data analysis reliable and valid?	<ul style="list-style-type: none"> <li>• Do(es) the author(s) state which statistical tests were used?</li> <li>• Do(es) the author(s) use statistical tests that appear to be appropriate to the nature of the data collected?</li> <li>• Were statistical tests appropriate to research the question?</li> </ul>	0 = no; 1 = partially but with weaknesses/missing info; 2 = yes

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<ul style="list-style-type: none"> <li>• Are the findings and discussion clearly stated and appropriate?</li> <li>• Can the results be applied to the local population?</li> <li>• Were all clinically important outcomes considered?</li> </ul>	<ul style="list-style-type: none"> <li>• Do(es) the author(s) provide evidence of statistical findings or state levels of significance?</li> <li>• Do(es) the author(s) present the statistical data in a clear manner, or clearly differentiate between significant or non-significant findings?</li> <li>• How similar are the participants to the population to which the recommendations are applied?</li> <li>• Was there other information about the outcomes which was missed?</li> </ul>	<p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>Range: 0-18</p>
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*Note:* 1-6 = low range, 7-12 = medium range, 13-18 = high range

Table 2.2

Adapted quality rating criteria for randomized controlled trial studies

Quality criteria	Specific questions relating to rating considerations	Rating
12. Did the research question clearly address a focused issue?	<ul style="list-style-type: none"> <li>• Was the research question focused on the target population, and the intervention?</li> <li>• Were outcomes in research considered?</li> </ul>	0 = no; 1 = partially; 2 = yes
13. Was the assignment of participants randomized to the intervention or the control group?	<ul style="list-style-type: none"> <li>• How was randomization achieved?</li> <li>• Was randomization concealed from researchers or participants?</li> </ul>	0 = no; 1 = partially; 2 = yes
14. Were all of the participants properly accounted for at the conclusion of the intervention?	<ul style="list-style-type: none"> <li>• Were the participants analyzed in groups to which they were randomized?</li> </ul>	0 = no; 1 = partially; 2 = yes
15. Were participants and care recipients blind to whether they were in the intervention or the control group?	<ul style="list-style-type: none"> <li>• Consider reporting of participant blinding to intervention/control and blinding of researcher(s) to condition in assessment of outcomes.</li> </ul>	0 = no; 1 = partially; 2 = yes
16. Were the intervention and control groups similar at the start of the study?	<ul style="list-style-type: none"> <li>• Were the intervention and control groups similar in terms of their age, sex, social class...etc?</li> </ul>	0 = no; 1 = partially; 2 = yes
17. Aside from the intervention group, were the	<ul style="list-style-type: none"> <li>• Here also consider duration of intervention or placebo.</li> </ul>	0 = no; 1 = partially; 2 = yes

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<p>intervention and control groups treated equally?</p> <p>18. How large was the treatment effect?</p> <p>19. How precise was the estimate of the treatment effect?</p> <p>20. Can the results be applied to the local population?</p> <p>21. Were all clinically important outcomes considered?</p> <p>22. Are benefits worth the harms and costs?</p>	<ul style="list-style-type: none"> <li>• Was/were the primary outcome(s) clearly stated?</li> <li>• What were the results for each outcome?</li>   <li>• What were the confidence limits?</li>   <li>• How similar were the participants to the population to which the recommendations were applied?</li>   <li>• Was there other information about the outcomes that was missed?</li>   <li>• Here, considers the possibility of harm in the control condition if the education piece was missed.</li> </ul>	<p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>0 = no; 1 = partially; 2 = yes</p> <p>Range: 0-21</p>
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*Note:* 1-7 = low range, 7-15 = medium range, 16-21 = high range

Table 2.3

Studies included in the review ( $N = 10$ )

Author, year	Theoretical model	Design, sample size, attrition, female (%)	Duration of type of intervention	Follow-up	Outcome scales
Chao, 2016	Adult Learning Theory	QEWPP, $n = 105$ , $n = 2$ , Female: 100%	16 weeks; 4 learning modules: modules 1 and 2, 4-hour classroom lectures and workshop, modules 3 and 4 online modules	Week 4, week 16	CKS-C, CSAS-C, PREAS
Hobday, 2017	The CARES™ Dementia-Friendly Hospital Program Learning Principles	WSPP, $n = 25$ , $n = NA$ , Female: 96%	7 to 10 days; 4 online learning modules, 15-20 minutes in duration	Baseline, 10 days	Dementia Knowledge Scale
Irvine, 2012	Social Cognitive Theory, Expanded Theory of Reasoned Action	WSPP, $n = 57$ , $n = 11$ , Female: 85.9%	2 hours total, self-paced; 5 modules available via work website	Baseline, 14 days, 30 days	Video Situation Test: attitudes, self-efficacy, behavioral intentions
Ruiz, 2006	No model	WSPP, $n = 38$ , $n = NA$ , Female: 89%	2 days, 7 modules, each 20-30 minutes, administered via CD-ROM in computer lab	Baseline, post intervention	Dementia knowledge, Self-perceived efficacy
Banks, 2014	No model	PP, $n = 113$ , $n = NA$ , Female: NA	5 months, online learning modules completed prior to study/community	Baseline, post intervention	ADS, Self-efficacy

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			setting days		
Pleasant, 2017	CARES™ Dementia Basics Program Principles	PP, $n = 51$ , $n = 11$ , Female: 88%	2 weeks, 4 online learning modules, 40 minutes in duration	Baseline, post intervention, 30 days	DKQ, SCIDS
Luconi, 2008	Cognitive Constructivism Theory, Socio-Constructivism, Four-Stage Theory of Physician's Learning, Clinical Reasoning Model	CS, $n = 8$ , $n = NA$ , Female: 38%	14 hours, over 9 months, 7 online modules, each 3 hours in duration	Baseline, 6 months	PRQ, Barometer
Broughton, 2011	No model	RCT, $n = 34$ (training group), $n = 15$ (control group), $n = 3$ , Female: 86.5%	Training DVD, 50 minutes	Baseline, post intervention, 3 months	PAC, Caregiver Satisfaction Questionnaire
Downs, 2006	No model	RCT, $n = 9$ (practice-based workshop), $n = 8$ (electronic tutorial), $n = 8$ (decision-based software), $n = 10$ (control), $n = 1$ , Female: 79.4%	12 months, electronic tutorial available on a CD-ROM, integrated in electronic patient files	Baseline, post intervention	Dementia diagnosis concordance, dementia management concordance
Rosen, 2002	No model	RCT, $n = 103$ (Lecture site, attrition = 15%), $n = 70$ (Computer-based training, attrition =	6 months, 12 computer-based interactive video	Baseline, post intervention	Dementia knowledge

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26%),  $n = 106$  (control, training modules  
attrition = 26%),  
Female: NA

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*Note:* RCT = randomized controlled trial, QEWPP = quasi-experimental with pre- and post- measures, WSPP = within subjects with pre- and post- measures, PP = pre- and post- measures, CS = controlled case study, NA = not available, CKS-C = Communication Knowledge Scale – Chinese version, CSAS-C = Skills and Attitudes Scale- Chinese version, PREAS = Patient’s Receptive and Expressive Ability Scale, ADS = Approaches to Dementia Scale, CCS = Communication Competency Scale, CPS = Communication Performance Scale, DKQ = Dementia Knowledge Questionnaire, SCIDCS = Sense of Competence in Dementia Care- Staff Scale, PRQ-I = Participant Reaction Questionnaire, PAC = Positive Aspects of Caregiving.



## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 2.4

Characteristics of included studies ( $N = 10$ )

Description	N (%)
<b>Country of study</b>	
United States	5 (50)
United Kingdom	1 (10)
Canada	1 (10)
Australia	1 (10)
Scotland	1 (10)
Taiwan	1 (10)
<b>Health professionals<sup>a</sup></b>	
Nurses	5 (50)
Licensed practical nurses	1 (10)
Certified nursing assistants	2 (20)
Non-direct care staff	1 (10)
Family physicians	2 (20)
Recreational activity officers	2 (20)
Dieticians	1 (10)
Occupational therapists	1 (10)
Physiotherapists	1 (10)
Speech and Language Pathologists	1 (10)
Managers	1 (10)
Volunteers	1 (10)
Allied health professionals	1 (10)
<b>Setting</b>	

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Long-term care	2 (20)
Nursing home	1 (10)
General practice	2 (20)
Secondary education/professional development	2 (20)
Primary care	1 (10)
Acute care	1 (10)
Hospital	1 (10)
Location	
Urban	0 (0)
Rural	1(10)
Unknown	9 (90)
Study Quality	
High	8 (80)
Medium	2 (20)
Low	0 (0)

<sup>a</sup>Number of health professionals is greater, since some of the studies used multiple types of health professionals in their interventions.

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 2.5

Risk of bias assessment ( $N = 10$ )

Author, year	Type of study	Random sequence generation	Allocation concealment	Blinding of participants	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Chao, 2016	Pre/Post	?	?	?	?	-	-
Hobday, 2017	Pre/Post	?	?	?	?	+	-
Irvine, 2012	Pre/Post	?	?	?	?	+	-
Ruiz, 2006	Pre/Post	?	?	?	?	-	-
Banks, 2014	Pre/Post	?	?	?	?	-	-
Pleasant, 2017	Pre/Post	?	?	?	?	-	-
Luconi, 2008	Pre/Post	?	?	?	?	+	-
Broughton, 2011	RCT	?	-	-	?	+	-
Downs, 2006	RCT	-	-	-	?	-	-

DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

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Rosen, 2002	RCT	?	?	?	?	+	-
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*Note:* Pre/Post = study with a single group, utilizing a measure of effect, pre and post intervention, RCT = study utilizing randomized controlled trial in design, ? = unknown risk bias, - = low risk bias, + = high risk bias

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 2.6

Teaching and learning approaches ( $N = 10$ )

Teaching/learning approaches	$N$ (%)
Computer-based learning	100 (100)
Learning via alternate mediums	
CD-ROM	2 (20)
DVD	1 (10)
Learning with an online component	7 (70)
Learning with an online and a face-to-face component	2 (20)
Access via a moderated platform	2 (20)
Video-based learning	
Video scenarios	2 (20)
Video modeling vignettes	4 (40)
Videos featuring unscripted interactions (patients, staff, caregivers)	1 (10)
Videos featuring expert commentary	2 (20)
Case studies	2 (20)
Interviews with staff members	1 (10)
Audio-narration	2 (20)
Interactive text entry	1 (10)
Discussion board	2 (20)
Moderated discussion board	1 (10)
Quizzes with automatic feedback	1 (10)
Course email/calendar	1 (10)
Technical assistance help function	1 (10)

DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 2.7

Classification of statistically significant outcomes by scales

Outcome, scales	Dementia education available online				Dementia education available via alternate mode(s)			Dementia education with an applied component or requiring in-person presence		
	Rosen, 2002	Luconi, 2008	Pleasant, 2017	Hobday, 2017	Downs, 2006	Broughton, 2011	Irvine, 2012	Banks, 2014	Ruiz, 2006	Chao, 2016
<b>Dementia general</b>										
<b>knowledge</b>										
Dementia diagnostic knowledge	+ <sup>b</sup>								+ <sup>b</sup>	
DKQ			+							
Diagnosis concordance					+ <sup>b</sup>					
<b>Dementia care/management knowledge</b>										
Management concordance					0 <sup>b</sup>					
Dementia Care Knowledge Scale				+ <sup>b</sup>						
<b>Readiness to change</b>										
Video Situation Test- Behavioral							+ <sup>b</sup>			

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Intentions			
<b>Reaction to training</b>			
PRQ-I	+ <sup>b</sup>		
Barometer- Readiness to Learn	+ <sup>b</sup>		
<b>Care strategies</b>			
ADS			+
PAC		+	
Caregiver Satisfaction		+	
<b>Communication skills</b>			
CKS-C			+
CSAS-C			0
PREAS			+
CSDD-C			+
<b>Self-efficacy and competence</b>			
Video Situation Test-Self-efficacy			+
Self-efficacy			+ <sup>b</sup>

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

SCIDS	+	
Self-Perceived Efficacy		+ <sup>b</sup>
<b>Attitudes</b>		
Video Situation Test- Attitudes	+	

*Note:* Participant Reaction Questionnaire = PRQ-I; Dementia Knowledge Questionnaire = DKQ; Approaches to Dementia Scale = ADS; Positive Aspects of Caregiving Questionnaire = PAC; Communication Knowledge Scale-Chinese Version = CKS-C; Communication Skills Attitudes Scale-Chinese Version = CSAS-C; Patient's Receptive and Expressive Ability = PREAS; Revised Memory and Behavior Problems Checklist-Chinese Version = CSDD-C; Sense of Competence in Dementia Care Stall Scale = SCIDS; +: statistically significant effect of the intervention on measured outcome, 0: not statistically significant effect, <sup>b</sup>: validation process of the measure was not reported.



## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

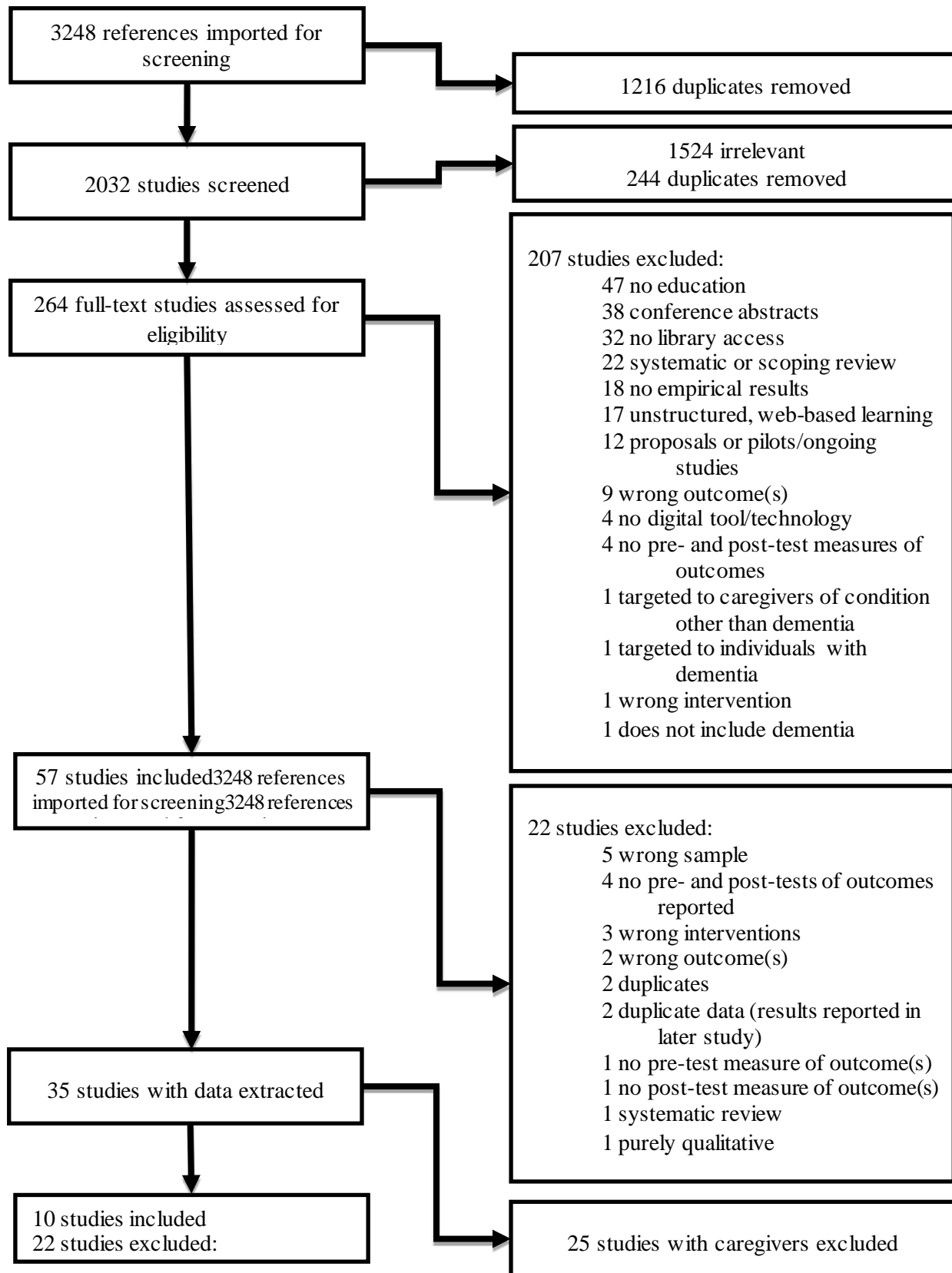


Figure 2.1 Preferred reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)

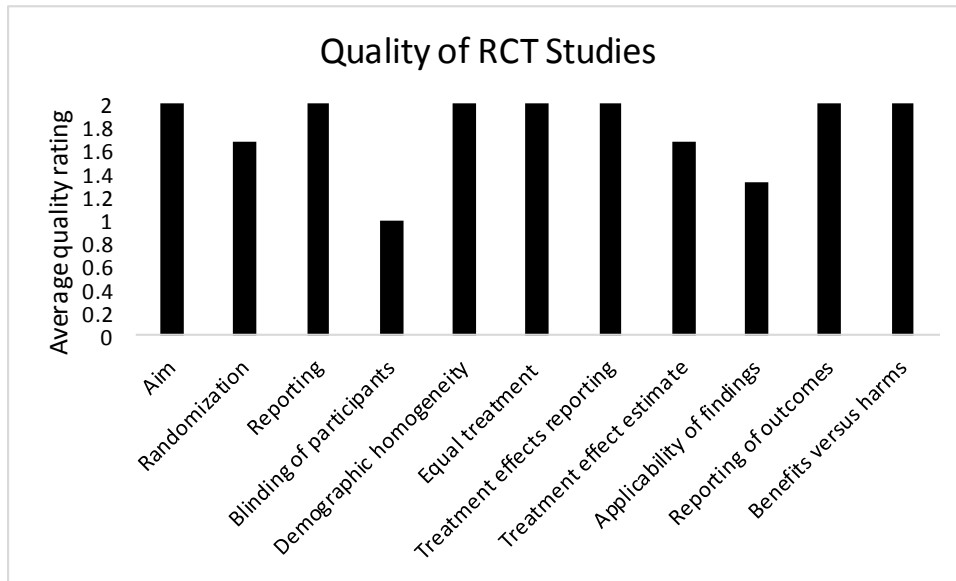


Figure 2.2 Average quality rating represents an average rating of all studies under each quality category

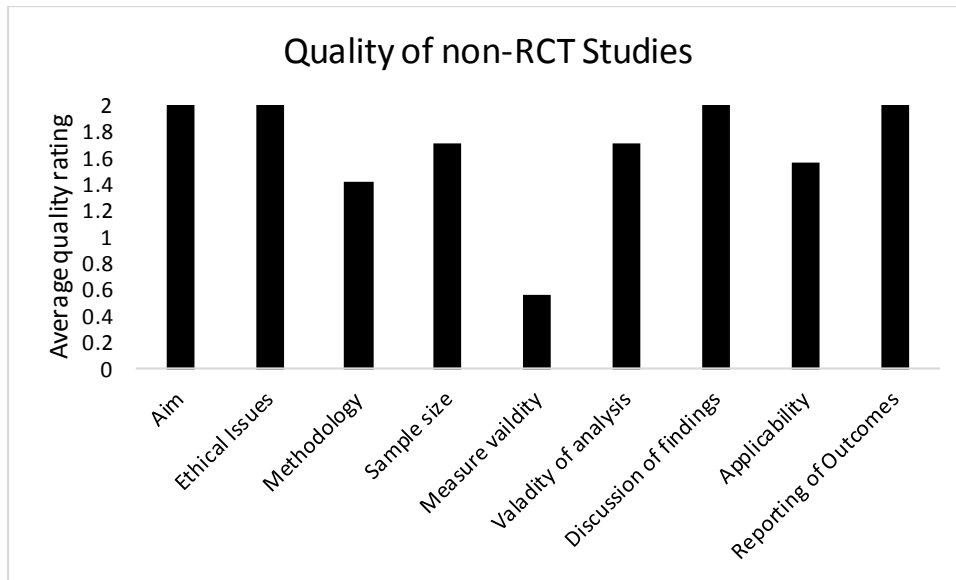


Figure 2.3 Average quality rating represents an average rating of all studies under each quality category

### **Link From Study 1 and Study 2 to Study 3**

The present thesis involved a research-informed approach to planning and evaluating a pilot which would introduce asynchronous, digitally-based remote dementia education to two populations of interest, namely caregivers and healthcare providers. The systematic reviews (Study 1 and Study 2) were used to identify important themes and findings which were used to plan and carry out the feasibility of an educational intervention pilot study. The first systematic review on digitally-based dementia education for caregivers revealed an overwhelming number of studies indicating a plenitude of educational interventions for caregivers. We identified so many studies with shared outcomes, that we were able to perform a meta-analysis. Based on this finding, we decided to re-focus our attention on the educational gaps in dementia knowledge of rural healthcare providers, as this was a population with evident knowledge gaps, and less available digitally-based dementia education interventions. The second systematic review also revealed that most of the studies on asynchronous digitally-delivered dementia education did not distinguish the rurality or urbanity of healthcare providers, with only one exception (a study by Luconi et al., 2008). Rural healthcare providers are notably a unique population, facing long travel distances, less access to specialists, and relative work isolation; however, we did not find many digitally-based education programs or interventions that addressed these barriers (Kosteniuk, et al., 2016; Harvey, et al., 2006; Waldorff et al., 2009). Due to these findings the need for a pilot study geared toward unique needs and barriers of rural healthcare providers appeared even more important. Findings from the two systematic reviews were used to inform study 3 (development of a feasibility study for asynchronous digital dementia education for rural healthcare providers). Feasibility studies are particularly useful when the population of interest has some unique aspect which has not been adequately studied e.g., rural healthcare providers. We postulated that this approach to formulation and conception of a pilot, would enhance flexibility and accessibility, and be more likely to meet the targeted population needs.

### **Study 3 Abstract**

This feasibility study uses acceptability, demand, and implementation from Bowen's Framework to examine potential reception of asynchronous digitally-based dementia education for rural primary healthcare. Lessons were gleaned about digitally-delivered dementia education for primary healthcare providers from a systematic review and used to organize the initial phase of the study. In phase I of the study, we engaged in a collaborative interview with a rural primary healthcare provider to determine aspects of intervention which would have the greatest chance of positive reception and success among a rural primary healthcare team, such as preferred mode of delivery, and useful strategies to increase knowledge retention and participation (e.g., spaced education, appointment-based dynamic, and gamification). This phase indicated overall a high level of enthusiasm and receptiveness to intervention and determined the best mode of educational delivery (case-based scenarios and whiteboard animation). The interview also identified a third potential mode of delivery, podcast. In phase II of the study, we applied the lessons learned from the interview to determine acceptability, demand, and implementation among a sample of rural healthcare providers. This phase also included the podcast mode of delivery. The findings indicated high acceptability, demand, and high likelihood of successful implementation, particularly for case-based scenarios and the podcast.

*Keywords:* dementia, education, technology-based, healthcare providers, educational delivery

### **Study 3 Introduction**

Dementia diagnoses are frequently made later in the progression of the disease (Bamford et al., 2004; Boise & Connell, 2005; Bond et al., 2005; Boustani et al., 2003; Connell et al., 2004; Iliffe et al., 2009; Koch et al., 2010; Schoenmakers et al., 2009; Waldemar et al., 2007; Wilkinson & Milne, 2003). Some of the barriers to timely diagnosis are a failed recognition of earlier symptoms (Bond et al., 2005; Delrieu et al., 2009; Iliffe et al., 2012), lower confidence in diagnosis (Pimlott et al., 2009), atypical presentation (Cahill et al., 2006; Iliffe et al., 2012), and inadequate dementia training (Bond et al., 2005; Delrieu et al., 2009; Iliffe et al., 2012). Health professionals note that they perceive dementia as more complex than other chronic conditions because it encapsulates multiple aspects of wellbeing such as psychology and biology (Harris et al., 2009; Pimlott et al., 2009). Rural healthcare professionals face added challenges due to remoteness and lack of access to specialized healthcare services (Kosteniuk et al., 2016). For these reasons, healthcare professionals (particularly rural healthcare providers) may choose to refer a patient to a specialist for a diagnosis. Dementia education may reduce some of these challenges (Scerbe et al., 2019). The present study investigates the feasibility of a digitally-delivered education intervention on dementia aimed at rural primary healthcare.

One aspect considered in the education intervention was spaced education, which is often incorporated with educational delivery for healthcare providers (Kerfoot, 2010; Kerfoot & Baker, 2012a; Kerfoot et al., 2009). Spaced education is derived from spacing and repetition effects, where learning is facilitated by spaced presentation of educational materials (e.g., the material is repeated until answered correctly) (Middleton et al., 2016; Robinson et al., 2017). Spaced education is noted to boost knowledge retention of new information and improve overall knowledge of specific topics in healthcare (Daruwalla et al., 2016; Gandhi et al., 2016; Gyorki et al., 2013; Kerfoot & Baker, 2012a; Kerfoot et al., 2010; Kerfoot et al., 2009; Matos et al., 2017; Minter, 2013; Nkenke et al., 2012; Pernar et al., 2013; Robinson et al., 2017; Sampson et al., 2015; Shaw et al., 2011; Tshibwabwa et al., 2017). Spaced education is typically delivered using technology-based mediums (Daruwalla et al., 2016; Kerfoot, 2010; Minter, 2013; Pernar et al., 2013), such as e-mail (Gyorki et al., 2013; Kerfoot, 2010; Kerfoot & Baker, 2012a; Kerfoot et al., 2009; Long et al., 2010; Nkenke et al., 2012) or smart phone applications (Gandhi et al., 2016;

Robinson et al., 2017), and has been noted to have similar effects as face-to-face education (Gandhi et al., 2016; Long et al., 2010; Nkenke et al., 2012; Robinson et al., 2017; Sampson et al., 2015). Healthcare professional characteristics such as education, expertise, occupation, and skills are identified as important factors in organization of learning materials in spaced education (Urh et al., 2015), as well as specific elements of the presented materials, such as perceived value of information and perceived enjoyment of the materials (Hamari & Koivisto, 2015).

Several spaced education interventions targeted to healthcare professionals have successfully incorporated gamification and appointment-based dynamic (Kerfoot & Baker, 2012a, 2012b). The appointment-based dynamic refers to permanent loss of a point allotted for the question (or an automatic grade of 0) for questions which are not answered within a prescribed time frame. It is argued that healthcare professionals are typically aware of this dynamic particularly because it constitutes a portion of daily practice (e.g., patients who do not show up for appointments lose their place on the appointment waiting list and have to wait for another appointment further in the future) (Kerfoot & Baker, 2012a). Gamification has also been typically introduced with spaced education and refers to introduction of a competitive aspect to stimulate increased participation by demonstration of achievements (Kerfoot & Baker, 2012b). This alteration has been noted to have a positive effect on participation as it creates a more fun and competitive edge (Kerfoot et al., 2012). Overall, both strategies have been demonstrated as useful in enhancing participation in educational interventions (Kerfoot & Baker, 2012a, 2012b).

### **Lessons Learned About Digitally-Delivered Dementia Education for Healthcare Providers from a Preliminary Systematic Review**

A systematic review of digitally-delivered dementia education for healthcare providers (Scerbe et al., 2019) revealed a variety of digitally-delivered interventions for primary healthcare providers, indicating effectiveness and usefulness; however, the review uncovered a lack of emphasis on healthcare provider location, where only one study indicated targeting their intervention to rural healthcare providers (Luconi, 2008). Rural healthcare providers are a unique population and face unique challenges, characterized by physical distance and a lack of readily accessible learning (Harvey et al., 2006; Kosteniuk et al., 2016; Waldorff et al., 2009). The unique characteristics of rural healthcare practice emphasize the importance of gaining insight

from rural healthcare providers in development of education targeted toward unique rural healthcare needs. The following is a summarized list of lessons from the systematic review which were considered in the present study (Scerbe et al., 2019):

**1.** The review revealed that the modes of remote learning varied in terms of presentation styles (audio-narration, graphics, interactive content), and in terms of scales used to measure outcomes (e.g., some studies used non-validated scales) (Banks et al., 2014; Hobday et al., 2017; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006). Despite heterogeneity in presentation of educational materials and assessment, the outcomes tended to be invariably positive and significant (Chao et al., 2016; Downs et al., 2006) in that they improved dementia knowledge, and management (Downs et al., 2006; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006; Surr et al., 2017). In summation, most digitally-delivered interventions have an impact on knowledge attainment and retention, regardless of mode or outcome measures, which means that any mode of delivery is better than no delivery/no intervention.

**2.** Most educational interventions in the review used more than one mode to convey education (Banks et al., 2014; Chao et al., 2016; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Rosen et al., 2002), which was deemed desirable and interesting by the healthcare professionals (Banks et al., 2014; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008); thus, mixed modes of presentation may be more attractive and captivating for healthcare professionals in gaining greater user buy-in.

**3.** Asynchronous delivery was deemed convenient as it allowed a more flexible approach to learning (Harvey et al., 2006; Waldorff et al., 2009); thus, asynchronous interventions may be perceived as more desirable as they allow users to progress through the content at their own pace.

**4.** Learning materials targeted to a broader range of healthcare providers were written in a more accessible way to allow better retention and comprehension of information by individuals from varying healthcare professions and of varied training backgrounds (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002); thus, materials presented in educational interventions should be suited to the audience in terms of language/accessibility.

**5.** Study duration did not seem to affect the significance of outcomes, indicating that benefits of learning remained regardless of length of intervention (Banks et al., 2014; Broughton



et al., 2011; Chao et al., 2016; Downs et al., 2006; Hobday et al., 2017; Irvine et al., 2013; Luconi, 2008; Pleasant et al., 2017; Rosen et al., 2002; Ruiz et al., 2006); thus, pointing to the effectiveness of an educational intervention of any duration.

### **Feasibility**

Feasibility studies are frequently used to determine the appropriateness of an intervention with a specific population and in a unique setting (e.g., rural setting) (Bowen et al., 2009; Donald, 2018; Hjelmfors et al., 2018; MacAndrew et al., 2019; Tickle-Degnen, 2013). Feasibility studies are also appropriate in situations where researchers are looking to pave the way for a full-scale research or evaluation of an intervention prior to financial and time investment (Bowen et al., 2009; Hjelmfors et al., 2018; Morgan et al., 2018; Morris & Rosenbloom, 2017a). Another purpose is to ensure that pilot study implementation is practical and that threats to validity of study outcomes have been minimized (Tickle-Degnen, 2013). A feasibility study also examines the extent to which an intervention is perceived as suitable by the recipients - its perceived appropriateness, fit, positive or negative effect on practice, actual use, and expressed interest (Bowen et al., 2009).

Inclusion of recipients in a feasibility study may garner greater adherence to needs and wants of the targeted population (Khanlou & Peter, 2005), better participation and buy-in (Morris & Rosenbloom, 2017b), and elimination of redundancies in planning (Lathren et al., 2013; Ziliak & McCloskey, 2008). Other benefits are reduction of researcher bias (Ziliak & McCloskey, 2008) and a more impartial and enriched approach to methodology (Lathren et al., 2013; Latour, 2005; Law, 2004; Mantoura & Potvin, 2013; Stengers, 2000). Through a combination of researcher knowledge and recipient knowledge, collaboration may also serve as a buffer against single-sided conceptualization of an intervention (Viswanathan et al., 2004). Involving the intervention recipients and acknowledging their expertise allows for co-learning to occur whereby the researcher and the intended recipients become co-learners in capacity building and disparity reduction (Israel et al., 2003; Khanlou & Peter, 2005).

Bowen and colleagues (2009) identified eight areas of focus which could be addressed in feasibility studies. These are acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited-efficacy testing (Bowen et al., 2009). In development and

application of gamified educational interventions, it would be helpful to consider user characteristics and content of presented materials, as well as confer with potential audience/users before implementation. Considering the limited evidence of digitally-based education for rural healthcare professionals (found in only one study in the systematic review; (Luconi, 2008)), and the unique attributes of the rural healthcare professional environment (Kosteniuk et al., 2016; Harvey et al., 2006; 2016; Waldorff et al., 2009), a feasibility study was carried out to determine whether the attributes such as digitally-based spaced education, gamification, and appointment-based dynamic are appropriate for use with healthcare providers in a rural healthcare setting. In consideration of a potential pilot that would deliver digitally-based dementia education for healthcare providers, we were interested in questions concerning reception by the intended participants (e.g., what is the interest level of participants, and would they receive the intervention favourably?), the demand for the intervention (e.g., is there a demand for such education among the intended participants?), and how easy would it be to implement such an intervention with the intended population without inducing additional burden. These questions were subsumed under three areas of focus of Bowen's Feasibility Framework typically addressed in feasibility studies, thus we decided to use the three areas, namely acceptability, demand, and implementation to assess feasibility. We wanted to examine whether there is a potential for positive reception and potential demand. The remaining five categories of the Bowen's Framework were not used in the present study. The latter categories including practicality, adaptation, integration, expansion, and efficacy testing could be captured in a future follow-up feasibility study.

Phase I of the study was a co-design process, where certain elements of feasibility were examined with the help of a rural healthcare provider collaborator. We used lessons learned from the systematic review, namely inclusion of mixed modes of educational delivery (to examine which mode would be most attractive/preferred), asynchronous education, delivery of materials in a language that is accessible to the prospective recipients, and determining the most acceptable duration of such an intervention (Scerbe et al., 2019). Bowen's framework was used to develop questions around three areas of focus; a.) acceptability (determining to what extent an intervention is judged as suitable to prospective recipients), b.) demand (estimated future use by

intervention recipients), and c.) implementation (examining the potential way an intervention can be implemented) (Bowen et al., 2009). The objective of the first phase was to determine the potential delivery and format of intervention, as well as to identify the prospective recipients. In phase II of the study, we examined the same three areas of Bowen's framework with a small diverse sample of healthcare professionals and prospective intervention recipients.

### **Study 3 Phase I Collaborator Interview**

Bowen's framework also helped to guide development of questions around three areas of interest (Bowen et al., 2009). The questions subsumed under the acceptability category examined perceived appropriateness of the intervention, the fit with the existing culture and framework, and potential positive or negative effects on the organization. The questions subsumed under the demand category were designed to address the perceived demand among healthcare providers for such an intervention, as well as potential interest and likelihood of use. The questions under the implementation category were designed to address factors potentially affecting the implementation of the intervention, which would enhance ease of use or potentially produce difficulty. For the complete list of questions used in the interview, please refer to Table 1.

### **Collaborator**

The collaborator was selected based on convenience and availability, as well as her enthusiasm and approbation for continuing education and professional development. Additionally, the collaborator was a guide in translating the typical language and social expectations among colleagues used in healthcare workplace. The collaborator worked as a nurse for 33 years and a nurse practitioner for 13 years. During this time, she worked in two small rural communities where she often had to travel to see patients. Presently she works in a primary health clinic team with many older adult patients with chronic diseases. The collaborator is also an active member of a research project in a rural Saskatchewan area, working to adapt Canadian dementia guidelines for primary care in rural settings and has been a key stakeholder in advocating and inspiring a similar project in her community aimed at promotion of senior health.

### **Educational Content**

Educational content used in the present intervention was developed from a referral algorithm that leverages aspects of the Primary Care Dementia Assessment and Treatment

Algorithm Project (PC-DATA) being used by the rural primary healthcare team (Morgan, Kosteniuk, O'Connell, et al., 2019; Morgan, Kosteniuk, Seitz, et al., 2019). For the referral algorithm, see Figure 1. The referral algorithm was re-developed into educational content, case-based scenarios, and whiteboard animation, with multiple choice questions. The educational content developed from the referral algorithm content, encompassed a variety of topics such as age of onset, evidence of cognitive decline, functional decline, amnesic presentation, presence of hallucinations, concentration, sleep patterns, typical versus atypical presentation of symptoms, visuospatial abilities, expressive and receptive language presentation, changes in personality, cardiovascular factors, collateral information, and most importantly, precedents for referral to a specialist.

### **Digital Platform for Presentation of Content**

The educational materials were programmed in a smart phone application called Ethica. This smart phone application was developed for healthcare research use in partnership between the University of Toronto and University of Saskatchewan computer science departments. It allows for presentation of materials in various forms, real time collection of data, and participant enrollment. This application was also chosen for safety of data storage reasons, as the data was stored in an on-campus server and only available to researchers.

### **Design and Setting**

Ethics approval was sought for the collaborator interview portion of the study. As the interview was subsumed under quality improvement studies, this portion of the study received an ethics exemption. The presentation, demonstration of learning modes, and interview occurred in a private meeting room on campus. This portion of the study included a brief twenty-minute presentation on the educational content, including the theoretical and research-based suggestions for digitally-delivered dementia education, followed by a semi-structured interview. The collaborator received a presentation on spaced education, gamification, and purpose of digitally-delivered dementia education for healthcare providers, followed by a demonstration of questions as they would appear to participants on the Ethica smart phone application, whiteboard vignettes, and case-based scenarios. The presentation and demonstration were followed by a set of questions related to content (see Table 1), followed by additional time to allow for questions and

suggestions by the collaborator. Lastly, an electronic copy of the materials was emailed to the participant after the interview, for a closer in-depth look, to allow sufficient reflection time for provision of any additional feedback.

In the collaborator presentation, principles of gamification, and appointment-based dynamic were explained, including how the dynamic could be integrated in the context of primary healthcare teams. Suggestions made in literature regarding measurement of outcomes, such as percent of questions answered correctly on first presentation versus second presentation, as well as a possibility of presentation of same questions two months following completion of the program to examine long-term retention of information were presented to the collaborator (Cepeda et al., 2009; Gyorki et al., 2013; Hamari & Koivisto, 2015). It was also explained that participants may be interested in acknowledgment of completion, or the possibility of adding a completion certificate or credits to their professional portfolios. Research found that such signifiers of accomplishment have been useful in stimulating buy-in and motivation to participate in continuing medical education (Cabral et al., 2017; Chappell, 2017). The collaborator was allowed to take this information in during the presentation and formulate her own reactions and responses.

Presentation of materials included three types of modes: case-based scenarios, white board vignettes, and traditional fill-in-the blank questions (see Table 2). The collaborator was informed about the presentation format and timing of presentations. According to spaced education theory, the questions that received correct answers should be repeated two weeks after initial exposure, and questions that received incorrect answers should be repeated one week after exposure. The lag in spacing, one week to two weeks, corresponds to theory, which notes that a gap in exposure to knowledge is hypothesized to enhance consolidation and retention in memory; therefore, both scenarios (for correct and incorrect response) involve time gaps (Raaijmakers, 2003; Thios & D'Agostino, 1976; Wahlheim et al., 2014). The suggested time duration for educational vignettes from a research study by Fishman (2016) was one to two minutes. Research found that optimal duration of educational videos and vignettes also referred to as micro learning rests at two minutes; the participant's attention is at its peak until two minutes, after which there

is a sharp decrease in attention (Fishman, 2016). The collaborator received all of this information in the presentation before the interview was conducted.

### **Data Collection and Analysis**

The interview began with background questions regarding the collaborator's experiences in practicing in rural areas. The main categories of questions were determined *a priori* to address Bowen's criteria of acceptability, demand, and implementation (Bowen et al., 2009). The interview session was recorded and transcribed verbatim. The transcript was analyzed with NVivo electronic analysis software for qualitative data (*NVivo Qualitative Data Analysis Software [computer software]*, 2018). Qualitative data generated from the respondent interview was analysed using thematic content analysis. Content analysis was chosen as it served three main purposes: to condense data into a summary, to establish links among research findings, and to compose a framework for processes which are evident in the data (Dotevall et al., 2018) using a primarily inductive approach to increase understanding of the participant's thoughts and impressions (Dotevall et al., 2018; Graneheim & Lundman, 2004).

### **Situating Self in Interviewer Role**

The approach of situating self in the interview process was imperative for attainment of good rapport with the interviewee (Fontana & Prokol, 2007; Josselson, 2013). The researcher began by asking more general questions and then gradually progressed to more specific questions. The goal of engaging with the collaborator in this manner was to avoid aloofness and engage in real conversation from perspective of a healthcare practitioner, and with empathetic understanding. Another goal was to engage in co-creation of the interviewing process which necessitated paying attention to both content and process of the interview (Josselson, 2013). To achieve this, the use of language was particularly important. While medical language is typically difficult to understand with nonmedical staff, some medical jargon was used particularly to help engage the collaborator. In this approach, focus was used on medical language, and academic language was transformed into more accessible and discussible topics. Nonverbal communication was also used to convey topics, which focused on use of interpersonal space for example, sitting down to converse, use of relaxed body language to convey a more informal conversational interaction, and variation in quality of voice to incite a questioning tone (Fontana & Prokol,

2007). The researcher first positioned herself as an academic or someone who is interested in potential intervention outcomes, and then noted her years of experience working in public health, and other healthcare settings. While it was important to convey her background, it was also important to acknowledge the goal of improving patient care (Josselson, 2013). All the noted aspects were important in establishing trust and rapport.

### **Study 3 Phase I Results**

#### ***Acceptability***

The collaborator indicated enthusiasm for the digital format of educational delivery, particularly the mobile application versus use of email. She noted that email-based delivery would be too tedious in the age of smart phone applications. She also pointed out that new healthcare professionals are younger and likely more tech savvy; thus, it is likely that they would take an interest in the smartphone application idea more readily. The collaborator suggested that nurses and other healthcare professionals and physicians could be incentivised by different types of acknowledgments for completion. For example, she indicated that physicians would be most incentivised to participate by dispensation of continuing medical education credits. Acknowledgment of participation for nurses and other allied healthcare staff was suggested as a certificate of completion. She indicated this was especially valuable to nursing staff in the context of inclusion in yearly professional development portfolios.

The collaborator indicated that notifications of new available questions or content in the application should resemble those of well-known streaming and media applications such as Netflix. For example, when new questions arrive (weekly or bi-weekly), a red dot would indicate newly available educational content which would show up on the application icon (on the smartphone). This notification system would be represented visually and may also include a notification sound. Visual representation of new materials or one accompanied by a sound could be decided by the recipient. She also noted that it would be acceptable and relevant if some of the educational content was drawn from frequently accessed sources of dementia education by healthcare providers. She suggested that this may make it easier for healthcare professionals to have more trust in the information they are receiving. Additionally, she noted that including

information or links to websites and resources could assist with satiating a need for any additional knowledge based on personal preferences.

Stimulating buy-in from healthcare teams was deemed to be best in person, where a single representative would travel to the healthcare sites and present the educational application during staff meetings. This method of stimulating buy-in was also preferred over correspondence via email or telehealth, as it demonstrated greater investment in the outcome of the intervention. Another element with potential to stimulate further buy-in was identifying team leaders who would be tasked with hosting team meetings, and who would keep track of team progress toward completion. These team leaders could also foster a group/team environment, where individuals could talk about their experiences with the educational application.

### ***Demand***

The collaborator indicated enthusiasm regarding the whiteboard vignette presentation of content. She indicated while both are attractive, in a setting which allows only verbal delivery of information, for example while driving, sound would be preferable. Varied presentation of educational materials, for example, the whiteboard vignette, the case-based scenario, or fill-in-the-blank format were all favorably received. She noted that it would be interesting to see how each format would be received by the healthcare providers, and whether there is a difference in information retention or completion of the educational intervention. Case study format was indicated as a particularly attractive mode of delivery due to its close nature to real, encountered problems in the field. She noted that this format of delivery would likely increase demand, as it fits real life work situations and makes it easier to apply learned knowledge. Conversely, receiving educational content via email was described as a possible deterrent, where issues of potential shortage of cellular data to receive and send emails, and the time it took to check one's email were identified as obstacles.

The collaborator was particularly interested in delivery of podcast type education. She described her favorite medical podcast which she regularly listened to on her way to work or home. She noted that being able to listen while driving could be beneficial not only for rural healthcare professionals who must travel longer distances, but also healthcare professionals who commute in the city. Otherwise, she noted that the content and the instructions were easy to



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understand, and the presented content was readily applicable to what she typically encountered in her field. She noted that the brief and spaced presentation of educational materials over several weeks meant that the healthcare providers would likely not perceive the intervention as burdensome.

### *Implementation*

The collaborator generally found the module application easy to use. In terms of physician involvement, she indicated that this may vary. Some of the factors she noted could be previous experiences with dementia, propensity for team-based healthcare, personal preferences regarding digital education, and comfort with English as an additional language. In terms of other team members' general engagement, she noted that she could foresee the rest of her primary healthcare team readily engaging in the intervention. In terms of quantity of content, she indicated that physicians would likely respond well to limited content, for example receiving two questions each week, whereas other healthcare providers (her included) may be open to more questions or educational content. She acknowledged that she may be an exception in seeking more questions/content and indicated that two questions delivered at a time is adequate.

The collaborator noted that the appointment-based dynamic would likely be well received by the healthcare professionals as it fits with the existing healthcare practice. Inclusion of gamification such as a leader board or appointment-based dynamic was also received favorably. The collaborator indicated that there is an inherent element of competitiveness in the healthcare profession, with nurses strongly endorsing the competitive elements. She noted that such spaced education format of questions and answers would likely be advantageous in that it would not be too burdensome. She also indicated that it would be a great idea to re-test the newly acquired knowledge months down the line and find out if healthcare providers are benefiting from educational content through long-term retention. Lastly, she noted that healthcare providers in northern communities could particularly benefit from digital-based dementia education, due to the ability to receive education remotely. The interview concluded with a discussion on importance of continuing education for primary healthcare providers. The collaborator noted that the dementia education is crucial in filling in existing training gaps for healthcare professionals. She also noted that since becoming involved with research efforts designed to address rural

senior needs, she has become more aware of the effect of dementia on families and communities, which made such an intervention even more relevant. For a more comprehensive summary of identified themes, see Table 3.

### **Study 3 Phase I Summary**

The collaborator showed general excitement and enthusiasm regarding the mobile app format of educational delivery. The interface and notifications of new content was recommended to resemble popular existing app notifications such as the new content section added to Netflix. In a setting that allows for visual and auditory presentation of information, both were preferred; however, in a setting where only auditory presentation was possible, for example while driving, podcast style of presentation was suggested. Additionally, the collaborator indicated dislike for use of email to deliver content, citing difficulties with obtaining sufficient data to access emails. It was also noted that it would be interesting to compare differing presentation formats to determine which presentation fostered better knowledge retention. The collaborator showed the most enthusiasm for case-based scenarios, noting that this is how healthcare professionals tend to think and conceptualize newly acquired information, thus she thought that such a format may be the most relevant and interesting. She also indicated it may be useful to re-test some of the acquired knowledge to determine long-term retention and provide immediate feedback to receive confirmation if an answer was correct or incorrect.

Repetition of content was preferred, as it would foster better retention of new educational materials. Delivery of two questions at a time was deemed appropriate; however, it was suggested that adding other information or extra resources would be useful for healthcare professionals who want more content/information. Acknowledgment of completion was, according to the collaborator, best if separated by profession, where continuing medical education credits were preferable for physicians and completion certificates for other allied healthcare professionals such as nurses. Gamification of materials was strongly favored as it would perceivably encourage participation through positive (competitive aspects, or team-based dynamics) and negative reinforcement (appointment-based dynamic and permanent loss of questions). Stimulating buy-in was suggested to be made via in-person presentation of the educational tool. It was noted that physical presence and engagement would likely stimulate

better participation from healthcare providers. Another suggestion was identification of a team leader or a champion, an individual whose task would be to guide and keep the team on track through periodic check-ins regarding progress through educational materials.

Moving forward with information gathered from the interview, the next steps of this study included a follow-up study to seek feedback from other healthcare professionals and gain a variety of views on acceptability, demand, and implementation of digitally-based dementia education, particularly the format of delivery (case-based scenario, whiteboard animation, or podcast). We decided to change several things about the content based on the feedback from our collaborator. Namely, we excluded the fill-in-the blank format of question, as this format was identified as least desirable by the collaborator and replaced it with a podcast (deemed most desirable). We also decided to shift toward delivering material in a case-based scenario as it was suggested by the collaborator that this was the most appealing format for healthcare providers due to its suitability for typical situations encountered at work (relevance and applicability). The content of the case-based scenarios was not changed; however, the content of the whiteboard animation was slightly changed to include more information from the referral algorithm about typically presenting dementia and referral to a specialist, and the content of the podcast was designed to include indications and contra-indications of medication used for Alzheimer's Disease. The content in the podcast was changed to emulate and better suit the content typically delivered in other medical podcasts and remain true to the format.

### **Study 3 Phase II**

#### **Study 3 Phase II Survey**

Participants in the follow-up study included primary healthcare providers who attended the Twelfth Annual Summit of the Knowledge Network in Rural and Remote Dementia Care, hosted by the Rural Dementia Action Research Program and the Alzheimer Society Saskatchewan. A total of four participants responded to the online questionnaire.

#### **Educational Content**

Educational content on dementia included three modes of presentation; a podcast, a whiteboard animation, and textual case-based presentation (see Table 2). These educational modes were developed by experts and delivered via digital tablets. The podcast included

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indications and contraindications of medication prescribed for individuals who were diagnosed with dementia. This podcast was delivered by a neurologist who is a geriatric specialist. The podcast was two minutes in duration, in keeping with the recommendations of micro learning (Fishman, 2016). The whiteboard animation included visual graphics, textual information, and over-voice provided by a clinical neuropsychologist who also specializes in geriatrics. The whiteboard animation included information regarding more salient aspects of typically presenting cases of dementia and aspects which warrant a referral to a specialist. The third mode of digital education included a textual presentation of a case-based scenario discussing an atypical presentation of dementia, followed by a multiple-choice question designed to elicit recognition of typical versus atypical symptoms. The case-based scenario focused on conveying information regarding typically presenting versus atypical symptoms of dementia which warrant a referral to a specialist. This scenario was developed with collaboration and expertise of a post doctorate neuropsychologist, a geriatric neuropsychologist, and a graduate student in psychology.

### **Digital Platform for Presentation of Content**

The digital platform for presentation of the podcast included a recording which was played for the participants via a touch screen tablet and using earphones. The whiteboard animation was composed using an online software program specifically designed for composition of educational materials, featuring visual stimuli and over-voice to convey information. The whiteboard animation was also presented to participants on a tablet with use of earphones to facilitate better sound. The case-based scenario was presented using PowerPoint, which included textual presentation of a case and multiple-choice answers that were linked to additional information, based on the correctness of the answer. The participants could read the scenario and provide their answer by clicking among the available multiple choices on the tablet. The choices were linked to additional information (based on correctness). The participants were immediately notified if their choices were correct or incorrect and re-routed to additional information that would help clarify characteristics of atypical dementia symptoms, warranting a specialist referral.

### **Setting and Materials**

The setting was the Twelfth Annual Summit of the Knowledge Network in Rural and Remote Dementia Care. Participant impressions about the educational materials were gathered

during a research poster session. The three modes of educational content were presented at a table near the poster outlining the study with study goals and long-term plan of commencing a pilot. The participants could preview materials, engage with the presenting researchers, and ask any follow-up questions once they viewed the educational materials. Participants' contact information was gathered upon registration for the conference. This information was subsequently used to contact participants following the conference and offer a chance to provide feedback on the educational materials. The stipulation for provision of feedback was that these participants were healthcare providers and had reviewed the available educational materials. Participant feedback was acquired digitally, via a secure survey platform (*SurveyMonkey*, 2020). The participants received a link via email invitation, which when accessed immediately linked the respondents to the survey. The survey did not collect personal information such as respondent email addresses or IP addresses. Only anonymous responses were gathered, aggregated, and used in the analysis.

### **Design**

Ethics approval was sought and received for the survey portion of the study. The study design included collection of answers via a digital survey platform (*SurveyMonkey*, 2020). The survey included demographic questions (e.g., age, sex, type of profession, number of years of work in respective field, area of practice: urban or rural, and types of patients typically encountered at work). The question format included open-ended questions regarding general impressions of the materials and visual analog ratings of impressions regarding the three digital educational formats, participant's enthusiasm regarding the digitally-based dementia education, and general impressions or thoughts regarding digital education. The open-ended questions were used to more freely gauge impressions of the material presentation and content. Visual analog scales were used to determine acceptability of the three educational formats, ease of conveyance of education, confidence that the material will improve healthcare practitioner knowledge of dementia, enthusiasm regarding the educational content, rank order preference of the three formats, and general ideas surrounding presentation of educational materials on dementia via a digital platform. The scale included a sliding button without other visual aids, which allowed the respondents to move the button along a continuum from 0 to 100 and gauge their response. Visual analog scales were chosen to help overcome some of the limitations associated with

ordinal measures such as the Likert-type scales, which include categorical and interval measurement which elicit responding styles (selection of neutral or middle response categories) (Albaum, 1997) or extreme responses (Greenleaf, 1992). The visual analog scales do not require interval data (Allen & Seaman, 2007) or ordinal data (Bollen & Barb, 1981), which can be difficult to interpret and may lead to underestimating factor loadings (Babakus et al., 1987). A continuous scale, such as the visual analog scale can be argued to be more reliable and valid (Sung & Wu, 2018), and thus comprised the scaled portion of the survey.

### **Study 3 Phase II Results**

#### ***Participant Demographics***

The participants in the phase II were a nurse practitioner, a health services manager, a registered nurse, and a social worker. Three participants were female, and one was male. One participant was between the ages of 35 and 44, and three participants were between the ages of 45 and 54. One participant indicated practicing in an urban area, two participants reported practice in a rural area, and one participant indicated working in both urban and a rural area. One participant indicated working in their profession for one year or less, one participant indicated working one to two years, one participant indicated working five to six years, and one participant indicated working fifteen years or more. Types of patients typically seen by these healthcare providers included geriatric patients, patients residing in long-term care, and geriatric patients diagnosed with dementia and other chronic diseases. Three participants reported practicing both alone and as a part of a professional healthcare team, while one participant reported solely practicing alone.

#### ***Acceptability, Implementation, and Demand for the Three Educational Formats***

General impressions of digital education tools were measured with visual analogue scales (VAS) and corresponded to the three areas of Bowen's framework, acceptability, demand, and implementation. Average rating indicating acceptability of educational materials for the podcast was 87, for whiteboard animation was 84, and for case-based scenario 86 (see Figure 3.2). Confidence that implementation of education using various formats will improve healthcare practitioner understanding of dementia was also measured via VAS for each format. Average rating for podcast was 83, for whiteboard animation 81, and for case-based scenario 86. Participants were asked to rate their enthusiasm (subsumed under demand) regarding three

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educational formats, using VAS. Average rating for podcast was 83, for whiteboard animation 73, and case-based scenario 95. General impressions regarding digital education tools were also organized within the three categories of Bowen's framework (see Table 4) and indicated generally high VAS ratings for all three areas (acceptability, demand, and implementation).

### **Rank Order Preference of Format**

Participants were asked to rank their favorite presentation format by indicating their first, second, and third choice. Case-based scenario was ranked as first, podcast was ranked second, and whiteboard animation was ranked third.

### **Qualitative Questions**

Participants were asked to indicate any aspects they would like to see improved or changed about each educational format. Only one participant provided answers. This individual noted that it would be preferable for each format to be supplemented with a face-to-face interaction, much like in a classroom. This individual also noted that the length of the presentation of each format may have affected their ability to remain focused, indicating that the initial decision to keep materials at a short duration (1.5 to 2 minutes) to facilitate micro learning may still have been too long.

### **Study 3 Phase II Summary**

The application was generally regarded as easy to use and interface was deemed appropriate. Individual involvement of physicians was deemed to likely vary based on personal experience, language barriers, and preference for team-based care. In conclusion, the educational content was identified as important for primary healthcare, and likely to not incur burden. The collaborator indicated that northern communities with larger Indigenous populations may especially benefit from similar interventions for healthcare providers due to their remoteness from major city centers and a lack of access to specialized healthcare services. Overall, she noted that delivery of digital dementia education can serve as a potential benefit to rural primary care and generate more enthusiasm and care for aging clients.

The four participants from the survey portion of the study indicated practicing in rural and rural/urban mixed areas and working with geriatric populations. Three also reported practicing as a member of a professional healthcare team. Acceptability of three educational formats was on

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average rated as quite high (84-87), as was confidence that the three formats could improve understanding of dementia once implemented (81-86), and demand and enthusiasm for the three formats (73-95) (see Figure 2). The most preferred choice of format was case-based scenario, followed by podcast, and finally by whiteboard animation. The feedback regarding improvements to three formats included suggestion to combine each format with live interactive learning and reduction in duration of presentation of materials. Generally, participants indicated that education on dementia can improve patient outcomes, enhance team-based approach to care, and enhance best practice. Participants also indicated that they could see themselves becoming leaders of digital education on dementia and indicated that they perceived the intervention as beneficial and likely to make their work easier. Participants also indicated that they understood the positive potential and purpose of such materials, have had positive experiences with similar learning technologies in the past, and saw the potential of such technologies to improve performance of healthcare providers. Lastly, the participants indicated some trepidation with respect to ability to implement such technology during work shifts, place of work, and the ability to capably perform job tasks, while engaging and learning through such a technology. These answers may indicate some hesitation with regards to implementation of continued learning and concern that it may incur burden on daily work tasks.

### **Study 3 General Discussion**

While the phase I of the Study 2 indicated general enthusiasm on learning about dementia via a digital platform, the phase II study with a more diverse sample of healthcare professionals found similar levels of acceptability, demand, and enthusiasm regarding implementation. Phase II included a presentation mode via a podcast, as suggested by the collaborator in the initial study, which was generally well-received. As suspected the most highly ranked/preferred format of educational delivery was via a case-based scenario. The collaborator indicated that this type of learning most closely emulated the work environment, therefore healthcare professionals would be more likely to perceive it as helpful. Perception of the podcast type presentation was rated as second highest. Once again, this indicates that the collaborator's sentiment regarding podcast type education was also reflected by other healthcare providers in the follow-up study. This finding is a possible confound, based on differences in educational content and presenter for the



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animation vs podcast. Random assignment of presenter and context to other educational interventions is required to properly conclude the preferred method for educational intervention. Nevertheless, general perceptions of digital education on dementia were favorable, indicating positive attitudes toward digital education, and high enthusiasm, indicating demand, which was contradicted by lower ratings of implementation ability or potential integration of such materials in every-day practice. This could reflect an already perceived high workload or a perceived imposition, requiring an adjustment. The interview and the follow-up study revealed an overall positive reaction toward and reception of digitally-based spaced education. Some suggested changes include enhancing the mobile application interface to include immediate feedback after a response, and a notification system like that of popular applications such as Netflix. Another suggestion in the follow-up study included enmeshment of digital dementia education in an interactive classroom-based learning experience. There was also a strong support for podcast style presentation of educational content by the collaborator, which was supported when tested with a more diverse group of healthcare providers. The convenience of such a podcast type educational tool for example, while multi-tasking or driving was cited as a strong incentive. The term podcast is derived from two words, namely pod from Apple's iPod and cast from broadcasting. Podcasts can take form as audio or audio and visual presentation (O'Bannon et al., 2011). Podcasts are quickly gaining popularity in conveying education and have been noted to have positive effects on learning (Brittain et al., 2006; Campbell, 2005; Cebeci & Tekdal, 2006; Dale, 2007; Richardson, 2008; Solomon & Schrum, 2007); thus, podcasts may offer another valuable educational mode for healthcare providers.

The interview also revealed a preference for informational videos. One version of podcasts includes a video/animation with over-voice conveying information, akin to the video/information snippet presented to the collaborator. Educational videos like the one shown are typically found on websites such as YouTube. While audio only information conveyed via podcasts have served as an educational tool and impacted positive effects on learning (Campbell, 2005; Cebeci & Tekdal, 2006; Dale, 2007; Richardson, 2008), so have educational videos on YouTube (Harrison et al., 2016). YouTube videos are frequently accessed by individuals seeking health information and have been found to have a broad influence in dissemination of knowledge

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(McMullan, 2006; Nanji, 2015). In past studies, YouTube educational videos have been effective in conveying information for first aid for burn treatment (Butler et al., 2013) and pediatric needle pain treatment (Farkas et al., 2015), and thus, seem to present a valuable digital education dissemination format.

Voice only podcasts are typically listened to without the need for attention to visual information. This format of information communication can be listened to via a smart phone application or satellite radio (at home or in car, while travelling). Audio only podcasts in a sample of university students have been shown to have similar effects on learning as live lectures (O'Bannon et al., 2011). Additionally, students found the podcasts easy to use and interesting. The only issues or barriers that were identified among the population of students in the O'Bannon and colleagues (2011) study were technical problems such as gaining access or downloading. Other noted benefits of audio podcasts include convenience and ease of use, interest and support in self-directed learning (Berlanger, 2005; Evans, 2008), simplicity, convenience, flexibility of use (Berlanger, 2005; Evans, 2008; Fernandez et al., 2009; Vogt et al., 2010) (for example, they can be accessed at any time, paused, and continued), and perceived control over one's learning (Kay, 2012). Additionally, there are noted benefits for individuals who have English as an additional language, where podcasts have facilitated comprehension of complex concepts and yielded increased understanding (Berlanger, 2005). When delivered via smart phone application, podcasts have also been shown to have positive effects in supplementing medical education (Kho et al., 2006; Tews et al., 2011). It would seem reasonable to continue to investigate benefits of educational podcasts and consider that podcasts are also a valued and relevant conveyance of medical knowledge for primary healthcare practitioners. As indicated in the follow-up phase II study, podcasts were rated as the second most preferred mode of educational delivery; therefore, podcasts may prove to be a valuable delivery mode.

The interview revealed a preference for content which included case-based scenarios. The preference for case-based scenarios was confirmed in the follow-up study, where case-based scenarios were ranked as the most preferred mode of digital dementia education delivery. Case-based scenarios typically feature scripted or real-life conceptualizations of patient issues and have been noted to have educational benefits for healthcare providers, where learners feel that their

queries are better addressed with ‘real’ examples (Bhardwaj et al., 2015; Nasir et al., 2017; Vora & Shah, 2015). Learning from examples has been noted to be effective in other fields (Atkinson et al., 2000) and can be used to actively problem solve (VanLehn, 1999). When coupled with corrective feedback, case-based examples can induce less of a cognitive load for learners and help improve knowledge retention (Stark et al., 2011); thus, case-based scenarios when used in medical education can provide a valuable and relevant learning experience.

While both initial and follow-up studies revealed general enthusiasm and receptiveness of digitally-based dementia education, this was contrasted with lower scoring of perceived ability to integrate such technologies in everyday practice. This may be reflective of general healthcare practitioner attitudes toward perceived burden of continuing education, rather than digital conveyance of such education (Kosteniuk et al., 2016). It is also easy to speculate that after provision of digitally-based continuing dementia education via a mobile application, if favoured without induction of added burden, it would be advantageous to sporadically re-introduce the same information via the same medium (e.g., the digital education application). In this way, continuing medical education and assessment of acquired information will be a routine part of enhancing daily practice which will improve patient outcomes, rather than be perceived as an intimidation or a burden (Bashook & Parboosingh, 1998; Kerfoot, 2010; Kerfoot & Baker, 2012b; Long et al., 2010). Moving forward with information gathered from the interview and the follow-up study with primary healthcare providers, the next steps in design of a pilot include developing a strategy for gaining participant buy-in, which may include presentations by team researchers, implementation of a team champion, and plans for intermittent check-ins with healthcare providers.

### **Limitations and Strengths**

A potential limitation of the present interview was use of a single collaborator. However, the collaborator has been employed in the healthcare field for over 33 years and has gathered significant experience working in a team-based setting in a rural area. She also stated that her team was reportedly “closely knit,” which indicates that she often communicated with team members of various professions and is aware of the nature of their work and their educational needs and preferences. In this case, it can be argued that the limitation was also a strength

whereby the collaborator due to her enthusiasm for team-based activities was also attuned to her colleagues, how they practice, and their preferences.

### **Study 3 General Conclusion**

The feasibility study has revealed that rural healthcare providers are receptive to implementation of a digitally-based dementia education. There is a demand, and a likelihood of a successful implementation. However, some considerations in moving forward are to keep the educational delivery short. One preference which has been noted several times was to have the education delivered in small, “bite-sized” pieces over a longer span of time (e.g., via spaced-education). Elements of appointment-based dynamic and gamification were deemed attractive as they emulated existing healthcare appointment-based structure and included some friendly competition. Modes of delivery which were most preferred were case-based scenarios and podcasts. This indicates that rural healthcare professionals would be best served if their information was not perceived as overwhelming, had a fun factor (emulated existing practices), was readily applicable to their everyday work tasks, and was delivered in such a manner which does not require textual reading. The feasibility study has demonstrated that any intervention with the highest likelihood of success with the intended recipients should conform to the unique needs of that population e.g., rural healthcare providers. Moving forward with a pilot, it would be important to keep this in mind, especially when questions about seamless implementation with daily work tasks emerge. Some healthcare professionals expressed a concern with implementation with daily work tasks, as well as the ability to successfully perform daily work tasks while engaging in the intervention (as indicated in lower VAS ratings). An intervention should easily fit into the daily routine, without addition of burden. When corresponding with a rural site and introducing the intervention, this must be carefully communicated to each healthcare professional team to help assuage doubts and concerns, as well as to garner buy-in.

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## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 3.1

### Interview Questions

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#### Acceptability

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- Do you think that the intervention can be adequately integrated in the existing healthcare infrastructure, or do you think it will add burden on the recipients?
  - How should we acknowledge participation and completion of the intervention? Should we include different types of participation acknowledgment for different healthcare professionals?
  - Do you think that the intervention would easily fit into the existing healthcare framework? What are some of the benefits and anticipated challenges?
  - Do you think there is another way to gain more buy-in participation from intervention recipients?
- 

#### Demand

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- Which of the proposed three types of delivery modes are likely to be perceived as most desirable/attractive?
  - Is there another mode which we have not considered which would likely be perceived as even more desirable/interesting?
  - Do you think that healthcare professionals would find this information relevant and useful in their practice?
- 

#### Implementation

---

- Who are the targeted prospective recipients of the intervention?
  - What are the most desirable outcomes for the intervention? Are we interested in percent of knowledge retention?
  - What is the appropriate number of questions allotted to each presentation of information?
  - Should we include the appointment-based dynamic to stimulate greater involvement?
  - Should we include gamification to make participation more appealing/interesting to potential recipients?
  - Should we include spaced education to stimulate greater retention of new information?
  - How do we want to measure knowledge retention? Should we include a measure to capture long-term retention?
-

Table 3.2

Modes of Educational Delivery Phase I and Phase II

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**Case-Based Scenarios Phase I and II**

- A textual presentation of a potential scenario which would require a particular piece of information/knowledge, followed by multiple choice question, and an education piece which would be presented after the recipient provides their answer.

**White Board Vignettes (Phase I and II)**

- A visual presentation of materials which would expose the recipient to relevant information/knowledge, followed by multiple choice question, and an education piece which would be presented after the recipient provides their answer.

**Fill-In-the Blank Question (Phase I)**

- Textual presentation of materials which would expose the recipient to relevant information/knowledge, followed by multiple choice question, and an education piece which would be presented after the recipient provides their answer.

**Podcast Presentation (Phase II)**

- Auditory presentation of materials which would expose the recipient to relevant information/knowledge, followed by multiple choice question, and an education piece which would be presented after the recipient provides their answer
-

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 3.3

Qualitative Themes From the Collaborator Interview Organized Around Bowen's Framework

<b>Acceptability</b>	<b>Demand</b>	<b>Implementation</b>
Positive perceived relevance of information, ease, applicability of information.	Enthusiasm regarding visual and auditory content.	Notification of new content should resemble popular movie streaming services.
Support for inclusion of acknowledgment for completion.	Enthusiasm regarding inclusion of case studies.	Support for repetition of educational content.
Belief that intervention will not incur burden on primary healthcare.	Endorsement for inclusion of varied presentation formats.	Suggestion to keep number of questions presented at a time to two and provide immediate feedback.
Enthusiasm regarding mobile application format.	Favorable reception and involvement of physicians.	Suggestion for researchers to present in person to stimulate initial user buy-in.
Importance of continuing dementia education for primary healthcare.	Endorsement for podcast type education.	Enthusiasm regarding information appeal to authority. Endorsement for testing long-term knowledge. Endorsement of gamification-stimulation of healthy competition. Dislike for emailing of educational content.

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Table 3.4

Average Visual Analog Scale Ratings for Acceptability, Demand, and Implementation of Digital Education Tools for Healthcare Providers

<b>Acceptability</b>	
<i>Average VAS Rating</i>	
95	Perceived ability of digital education to educate healthcare providers on dementia and improve patient care.
93	Perceived potential of digital education on dementia to improve patient outcomes.
85	Perceived potential of digital education on dementia to enhance team-based approach to care.
95	Perceived potential of technology to enhance best practice.
<b>Demand</b>	
<i>Average VAS Rating</i>	
85	Perceived possibility of becoming a champion of leader for digital dementia education within their respective healthcare teams.
97	Perceived personal benefit of the digital dementia education.
86	Perceived possibility that digital dementia education could make their job easier.
88	Perceived ability to understand the purpose of digital dementia education after viewing the materials.
80	History of past successful experiences with similar digital educational applications.
<b>Implementation</b>	
<i>Average VAS Rating</i>	
62	Perceived potential of digital education on dementia to enhance activities completed during work shifts.
97	Perceived ability of ability of the digital educational on dementia to improve performance of healthcare providers.
70	Perceived ability to implement such a digital education on dementia in the place of work.
72	Perceived capability to successfully perform one's job while engaging in and learning about dementia through such a digital application.

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*Dementia: Yes or No Algorithm*

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Gathering information from collateral informants, such as family members, is highly recommended to obtain a clinical history for diagnosing dementia.

- If it is young onset (atypical) – prior to age 65 – always refer (cite guidelines for YOD)
- If you have completed all of the physical exam and blood work (PC-DATA dementia visit flowsheet section 4, 5, and 6) and cognitive testing referred to in PC-DATA dementia visit flowsheet information (MMSE, MOCA), and the patient appears cognitively healthy but the clinical history and collateral information suggests there are difficulties – refer
- If you have judged there to be sufficient evidence of cognitive decline from the PC-DATA dementia visit flowsheet information. Sufficient evidence of cognitive decline is defined by a decision that the screening information and clinical history suggests a decline in two more more areas of cognition (Cognitive symptoms in PC-DATA dementia visit flowsheet), this cognitive decline is sufficient to be considered impaired, and the clinical history and functional assessment (Functional assessment section in PC-DATA dementia visit flowsheet) suggest that the cognitive impairment impacts daily functioning – next
- If you have sufficient evidence of cognitive decline from following the PC-DATA dementia visit flowsheet information. If clinical history shows that the onset is sudden and occurs over hours or days – perform more medical investigations to rule out delirium – if results are inconclusive – refer as per 4th Canadian Conference on the Diagnosis and Treatment of Dementia.
- If you gather sufficient evidence of cognitive decline, but these are not sufficient to cause functional impairments as assessed with the FAQ, KATZ, and the functional abilities assessment (functional assessment section in PC-DATA dementia visit flowsheet)– yes – diagnose MCI – if uncertain – refer
- If CT is available – order head CT if it is indicated - a computed tomography scan or magnetic resonance imaging is indicated in the assessment of a person with cognitive impairment if the presence of unsuspected cerebrovascular disease would change clinical management - next
- If your patient has cognitive and functional decline – suspect dementia - next
- Is this a typically presenting case of suspected dementia (next flow sheet) – if no – refer
- if yes – next

---

*Figure 3.1 Dementia Referral Algorithm*

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*Typically Presenting: Yes or No Algorithm ...Continued*

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Typically presenting case of suspected dementia (post age 65 indicated in prior flow sheet)

Is this an amnestic presentation –

- Memory changes on formal exam (problems with encoding and consolidation – cues do not appreciably help) are part of an amnestic presentation
- Impaired ability to acquire and remember new information is part of an amnestic presentation
- Repetitive questions or conversations within the span of minutes or up to 1-2 hours are part of an amnestic presentation
- Misplacing personal belongings is part of an amnestic presentation
- Forgetting events or appointments are part of an amnestic presentation
- Getting lost on a familiar route (wayfinding problems) is part of an amnestic presentation

If this is an amnestic presentation consider dementia due to Alzheimer disease (AD) - link to 2011 McKahn article

- Are there other cognitive impairments present?
- Impaired reasoning and handling of complex tasks are symptoms of cognitive impairment
- Poor judgment is a symptom of cognitive impairment (symptoms include: poor understanding of safety risks, inability to manage finances, poor decision-making ability, inability to plan complex or sequential activities)

If other cognitive impairments occur in the presence of an amnestic presentation - consider dementia due to Alzheimer disease (AD)

If other cognitive impairments (examples) are the predominant symptom - consider atypical presentation or other dementia – refer

- Are impairments of visuospatial abilities present? (symptoms include: inability to recognize faces or common objects or to find objects in direct view despite good acuity, inability to operate simple implements, or orient clothing to the body)

If impaired visuospatial abilities occur in the presence of an amnestic presentation - consider dementia due to Alzheimer disease (AD)

If impaired visuospatial abilities is the predominant symptom - consider atypical presentation or other dementia (see below) or refer

Impaired language functions can include problems speaking, reading, writing; symptoms include: difficulty thinking of common words while speaking, long latencies during word finding; speech, spelling, and writing errors

If impaired language functions occur in the presence of an amnestic presentation - consider dementia due to Alzheimer disease (AD)

If impaired language functions are the predominant symptom - consider atypical presentation or other dementia – refer

Changes in personality, behavior, or comportsment can include uncharacteristic mood fluctuations such as agitation, loss of empathy, compulsive or obsessive behaviors, socially unacceptable behaviors

Changes in personality, behavior, or comportsment can include impaired motivation, impaired initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities

Personality change appears to be marked and more widespread – refer

Collateral informant response to query of personality change describes lack of interest in activities or giving up activities – consider apathy as a supporting symptom

---

*Figure 3.1 Dementia Referral Algorithm*

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### *Typically Presenting: Yes or No Algorithm ... Continued*

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Collateral informant response to query of personality change describes symptoms of separation anxiety from primary caregiver - consider anxiety as a supporting symptom

Supporting symptoms provide more support for dementia due to AD, but are not specific to dementia due to AD

Was the onset difficult to pinpoint (insidious onset) this is a typical presentation of dementia due to AD

If evidence for memory impairments, additional cognitive impairments, functional impairments, and insidious onset is unambiguous consider dementia due AD - link to 2011 McKahn article

– dx in PHC

- If unclear – refer

Cardiovascular risk factors and CT head supportive of white matter disease is suggestive of consider mixed vascular dementia due to AD

Mixed vascular dementia and dementia due to AD is an indication for the use of cholinesterase inhibitors

Diagnosed mixed vascular and dementia due to AD in PHC and manage cardiovascular risk factors

Is the presentation of cognitive impairment characterized by impairments in visuoconstruction/visual perception, attention, and/or executive function

- if yes - consider dementia due to Lewy body disease
- If, in addition to these cognitive impairments, is there also an amnesic presentation

Did the amnesic presentation occur later in the illness - still consider dementia due to Lewy body disease.

If amnesic presentation was early in course - consider dementia due to AD

Also consider following core criteria for DLB because many persons with attention/executive function impairments complain about memory impairments in daily life, but the nature of their neuropsychological profile is actually different - this can be challenging to rely solely on self/collateral reports - if unsure - refer

Do they have hallucinations? Do these hallucinations occur exclusively while going to sleep or waking up – if yes – these are benign and not a core feature of a dementia

- If true hallucinations exist – consider dementia due to Lewy body disease

Are these hallucinations recurrent complex visual hallucinations (i.e., people etc. well-formed and detailed) – if yes – more support for dementia due to Lewy body disease - core clinical feature of DLB (link to 2017 paper).

Hallucinations can occur later in disease presentation of other dementias too.

Tactile and auditory hallucinations are possible, but are more of an atypical presentation, so refer

Is there evidence of fluctuating cognition early in the course of the presentation of dementia

Is the fluctuating cognition occurring on a repeating basis and is not due to change in medication, problems with management of medication (i.e., double dosing), or glucose management problems

Spontaneously impaired alertness and concentration (i.e., appears drowsy but awake, looks dazed, is not aware of what's going on) is suggestive of fluctuating cognition

Confusion that tends to vary recently from day to day or week to week - for example, becoming worse, then perhaps improving for a while (i.e., up and down) is suggestive of fluctuating cognition

- If yes fluctuating cognition - consider dementia due to Lewy body disease -core clinical feature of DLB (link to 2017 paper)

Excessive daytime sleepiness is more support for dementia due to Lewy body disease (supportive feature)

---



*Figure 3.1 Dementia Referral Algorithm*

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***Typically Presenting: Yes or No Algorithm ...Continued***

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Evidence of parkinsonism – tremor/bradykinesia/rigidity on physical exam is consistent with dementia due to Lewy body disease - core feature of Lewy body disease (link to 2017 paper)

- Do the parkinsonism signs “falls short of what is seen in Parkinson’s disease” of Lewy body disease (link to 2017 paper p. 2)

A clinical history of REM behavior movement disorder (note: an actual diagnosis of REM behavior movement disorder requires polysomnographic recording unless an established synucleinopathy diagnosis exists) is

- acting out dreams is evidence of REM behavior movement disorder and this may precede any other symptoms
- REM behavior movement disorder is consistent with dementia due to Lewy body disease - core clinical feature of DLB (link to 2017 paper)

Cognitive changes coincide or precede physical changes – Lewy Body Disease

if yes evidence of REM behaviour movement disorder consider dementia due to Lewy body disease - core clinical feature of Lewy Body Disease (link to 2017 paper)

- If unsure – refer

Severe antipsychotic sensitivity is more support for dementia due to Lewy body disease

Frequent falls are more support for dementia due to Lewy body disease

Postural instability is more support for dementia due to Lewy body disease

Orthostatic hypotension is more support for dementia due to Lewy body disease

Reduced ability to smell is more support for dementia due to Lewy body disease

Urinary incontinence is more support for dementia due to Lewy body disease

Problems with constipation is more support for dementia due to Lewy body disease

Psychiatric symptoms of delusions, apathy, anxiety, and/or depression - consistent with but not specific to DLB

- If evidence for hallucinations/fluctuating cognition/parkinsonism is clear consider dementia due to Lewy body disease – dx in PHC
- If unclear – refer

Is there a history of stroke and significant cardiovascular risk factors? If yes, consider head CT evidence as per neuroimaging guidelines.

Is the CT evidence positive and does the history demonstrate clear stepwise decline in cognition and function – yes – vascular dementia dx in PHC

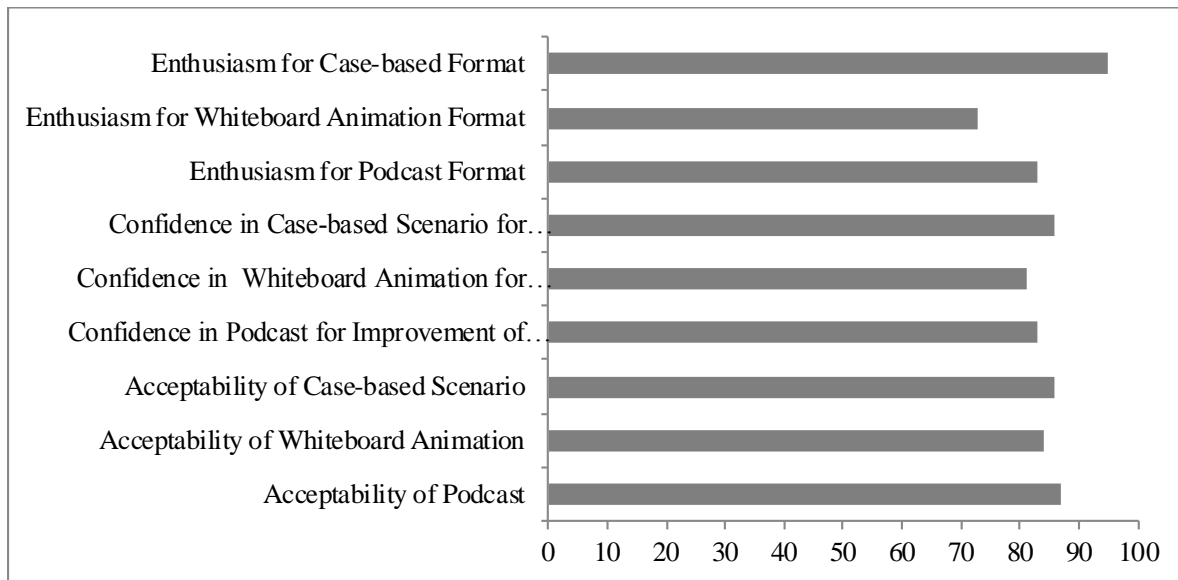
Does the CT evidence suggest marked white matter changes – if yes – consider vascular dementia dx in PHC

- If behavioral and or personality changes are predominant – e.g., changes in judgement and difficulties in problem solving, or changes in social behavior – refer.
- If language disturbance is marked in expressive or receptive language (word finding problems are common in dementia due to AD so consider the context) – refer
- If motor issues are beyond bradykinesia/rigidity - refer
- If you see motor signs in an amnesic presentation – refer

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*Figure 3.1 Dementia Referral Algorithm*

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION



*Figure 3.2 Average Visual Analog Scale Ratings for Each Format of Digital Dementia Education*

## General discussion

### Study Findings

This dissertation contributed to knowledge on digitally-based dementia education for caregivers and healthcare providers of individuals with dementia. The purpose of the research was to address questions regarding what kinds of learning technologies are available and how the application of knowledge gathered from these learning technologies could inform a future pilot study. While there are many interventions that can deliver learning technologies on dementia for caregivers and healthcare providers (Abdallah et al., 2014; Acton & Kang, 2001b; Basu et al., 2015), we were interested in how many of these interventions included dementia education, how many of these interventions were well received by the intended recipients, and whether the interventions met their intended outcomes. We discussed the implications of our findings for rural caregivers and healthcare providers, who face added challenges associated with life and work in remote areas, including limited access to services and specialists (Harvey et al., 2006; Kosteniuk et al., 2016; Waldorff et al., 2009).

Existing literature on educational interventions on dementia for caregivers and healthcare providers indicates positive effects of dementia education (Abdallah et al., 2014; Acton & Kang, 2001b; Basu et al., 2015); however, it was not clear whether these interventions were always effective in their outcomes (e.g., alleviating reported burden, enhancing dementia knowledge or diagnostic skills) (Acton & Kang, 2001b; Lathren et al., 2013; Nasir et al., 2017). It was also not clear whether interventions were targeted to unique populations, such as rural caregiver populations (Beauchamp et al., 2005; Boots et al., 2018). To explore these questions further, we completed two systematic reviews focussed on education on dementia for caregivers of persons with dementia and healthcare providers. We did not include education targeted to persons with dementia because research has indicated that individuals with dementia, their caregivers, and their healthcare providers express different learning needs (Hancock et al., 2003; Orrell et al., 2008). For example, persons with dementia reported more needs regarding support with psychological distress, whereas caregivers and healthcare providers had similar needs that commonly focused on dementia education and support with caregiving demands (Hancock et al., 2003; Miranda-Castillo et al., 2013; Orrell et al., 2008; Van der Roest et al., 2009).

In Study 1, we completed a systematic review of digitally-based dementia education for informal caregivers of persons with dementia. This review identified 28 studies meeting our criteria, of which 14 used common measures. The meta-analysis demonstrated positive effects on outcomes, such as a reduction in self-reported symptoms of depression and lower distress in response to perceived behavioral issues in persons diagnosed with dementia. Some of the studies used a theoretical model to contextualize their interventions ( $n = 8$ ) and deliver education with a goal of not only enhancing caregiver knowledge (Boots et al., 2018; Czaja et al., 2018; Finkel et al., 2007; Gallagher-Thompson et al., 2010; Gaugler et al., 2015; Glueckauf et al., 2007; Goodman, 1990; Griffiths et al., 2018; Kajiyama et al., 2013; Kwok et al., 2013; Martindale-Adams et al., 2013; Núñez-Naveira et al., 2016; Wijma et al., 2018) but also, in facilitating management of daily care tasks (Cristancho-Lacroix et al., 2015; Davis, 1998; Gallagher-Thompson et al., 2010; Glueckauf et al., 2007; Goodman, 1990; Kwok et al., 2013; Mavandadi, Wray, et al., 2017; Núñez-Naveira et al., 2016), and management of self-care/self (Cristancho-Lacroix et al., 2015; Czaja et al., 2018; Finkel et al., 2007; Gallagher-Thompson et al., 2010; Glueckauf et al., 2007; Kwok et al., 2013; Wijma et al., 2018). The most common mode of delivery was telephone-based education and online learning but regardless of mode of delivery, one commonality was that all the studies in the systematic review reported some significant positive change on one or more outcomes. We concluded that there were fewer gaps to address with caregivers as studies for this population were numerous (more than expected), used the same measures, and focused on similar outcomes. Thus, we shifted our focus from caregivers toward education on dementia targeted at healthcare providers (Bellaver et al., 1999; Di Gregorio et al., 2015; Innes et al., 2014; Kosteniuk et al., 2016).

Next, we completed a systematic review on digitally-based dementia education for healthcare providers. All the interventions showed positive effects on their intended outcomes; however, the interventions lacked the uniformity of measurement needed to statistically compare the effectiveness of interventions across studies. This lack of consistency in measurement did not allow us to carry out a meta-analysis. Nevertheless, the findings allowed us to glean several lessons which were used toward the feasibility study. We found that although digitally-delivered education modes varied in styles of presentation, as well as in scales used to measure outcomes,

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

all of the studies had some positive effects on dementia knowledge. This allowed us to deduce that any digitally-based dementia education is better than no education. We also discovered that healthcare providers deemed asynchronous delivery to be more flexible, and that materials that had been developed and written in a more accessible manner for healthcare professionals from a variety of disciplines were regarded as desirable. Many interventions used more than one mode to deliver dementia education, and this multimodality was perceived as interesting and attractive by healthcare providers.

While the systematic review on healthcare providers showed positive outcomes for intervention recipients and for gains in dementia knowledge (Scerbe et al., 2019), only one of the studies reported outcomes separately for rural and urban healthcare providers (Luconi, 2008). Rural healthcare providers are a unique population, in that they face barriers to continuing education, for example, heavy workloads, or inability to reserve paid time off to participate in education, or to secure coverage while away from work (Curran et al., 2006; Dal Bello-Haas et al., 2014). Rural healthcare providers also tend to be understaffed, dealing with larger than reasonable workloads, and typically encountering a wider variety of healthcare concerns in the patient population (Kelley et al., 2003; Rohatinsky et al., 2018). We concluded that this was an omission in present literature, and, for the final study (feasibility study), we directed our attention toward rural healthcare providers.

A feasibility study was conducted to examine receptiveness of rural healthcare providers to an intervention that would deliver asynchronous digitally-based dementia education via a smartphone application. Based on the lessons learned from the systematic review, there were positive impacts of remote dementia education on outcomes regardless of mode of delivery (e.g., computer-based, or telephone-based) or length of intervention. The reviews also revealed a preference for mixed mode of presentation and asynchronous delivery, as well as demonstrating the necessity of appropriate wording of materials for a wider variety of healthcare professionals (corresponding to educational attainment and training). We developed a plan for a pilot study based on existing research on spaced-education (delivering small, bite-sized pieces of information over a longer period of time); medical education delivery via a Smartphone application (ability to engage in portable education during busy work shifts on one's

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Smartphone), asynchronous delivery (not adhering to set times for lectures/lessons thus increasing flexibility), making participation more interesting through appointment-based dynamic and leader boards (fostering healthy competition among healthcare providers), and finding different formats of presentation to see which one would be deemed more attractive (case-based scenario, whiteboard animation, or multiple-choice question). Once we designed a presentation containing this information (for education delivered in the above-described manner), we sought input regarding dementia education delivery from a collaborator who reviewed this information and provided feedback in a follow-up interview and sought input regarding educational format and potential acceptability of dementia education from a sample of rural healthcare providers. The purpose of this interview was to gain insight regarding feasibility of delivery of digitally-based dementia education in a rural area.

The results from Study 3 resulted in some changes in planned educational delivery. We changed delivery from multiple choice format to podcast (featuring an interview with a neurologist on indications and contraindications of Alzheimer's Disease medication), we included a whiteboard animation (with a voice-over of a neuropsychologist differentiating between simple and complex dementia presentations), and a written case-based scenario (with non-complex dementia presentation). Study 3 results suggested a preference for case-based mode of delivery and suggested inclusion of a podcast educational mode. This information was used to adjust the learning modes and then test them with a sample of healthcare providers. The rural healthcare providers in their ratings of the three educational formats indicated high acceptability, demand, and receptiveness toward dementia education. They rated the case-based delivery as the most desirable mode of delivery. However, they indicated some trepidation regarding the possibility of a perceived burden of including education with tasks of daily work, which may reflect their high daily workloads and a perceived lack of support (Harvey et al., 2006; Kosteniuk et al., 2016; Waldorff et al., 2009). Overall, the findings from the feasibility study indicate high receptiveness of healthcare providers toward asynchronous dementia education. These findings may be used to lay the groundwork for a pilot study in the future, which is outside of the scope of the present dissertation and may be explored in follow-up studies.

### **Study Implications**

The systematic reviews found positive effects of dementia education for healthcare providers and caregivers of individuals diagnosed with dementia. The positive effect of digitally-based medical education for healthcare providers was also supported by other systematic reviews, which noted that it is comparable to face-to-face learning (Militello et al., 2014; Nurash et al., 2020). Other systematic reviews on digitally-delivered education for caregivers also indicated positive effects on care (Christie et al., 2018; Hopwood et al., 2018; Waller et al., 2017), problem solving strategies (Guay et al., 2017; Klimova et al., 2019), and self-reported symptoms of depression (Jensen et al., 2015). While spaced-education has been shown to be effective for healthcare providers (Kerfoot & Baker, 2012; Kerfoot et al., 2010), introducing asynchronous dementia education targeted to rural population needs of caregivers may carry similar benefits to those of the healthcare providers, including high perceived acceptability, demand, and receptiveness.

For example, introducing spaced education in 15-minute intervals in much the same way for healthcare providers could also be suited to caregivers. Rural caregivers, much like rural healthcare providers have barriers to access to specialized services (Greenway-Crombie et al., 2012), support agencies in the community (Dal Bello-Haas et al., 2014), and reduced ability to attend training sessions due to travel limitations (Bellaver et al., 1999; Dal Bello-Haas et al., 2014; Greenway-Crombie et al., 2012; Jennings et al., 2015); therefore, the same model of remote education could help alleviate similar access barriers. It is also important to acknowledge that interventions are better received when content is conveyed in the educational and reading level of recipients (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002); thus, rural caregivers could benefit from interventions with content and language level tailored to caregivers' level or understanding to ensure that conveyed information is more accessible.

Caregivers of individuals with dementia carry heavy workloads associated with their caregiving roles (cleaning, cooking, physical care, etc.; Biegel & Schulz, 1999; Braithwaite, 1992; Brodaty & Donkin, 2009; Mioshi et al., 2013; Pearlin et al., 1990; Riedijk et al., 2006). Caregiver roles also change and evolve over time as dementia progresses, and require more physical and emotional involvement which can increase perceived burden (Braithwaite, 1992;

Pearlin et al., 1990). Furthermore, the type of dementia diagnosis may also affect burden, where caregivers of individuals diagnosed with frontotemporal dementia report greater burden than caregivers of individuals diagnosed with other types of dementia (Mioshi et al., 2013). One theory posits that this is likely due to greater behavioral and personality changes in the care recipient (Mioshi et al., 2013). Higher levels of burden are also associated with higher levels of depression and anxiety reported by caregivers and have a direct impact on mental health (Brodaty & Donkin, 2009). A meta-analysis of educational interventions for caregivers of individuals diagnosed with dementia found that interventions would benefit caregivers more if focused on meeting needs at different stages of dementia (Hopwood et al., 2018). Therefore, education targeted for increasing expected levels of care and or type of dementia could prepare caregivers for increasing demand of care tasks and could help mitigate some of the mental health struggles and burnout.

Case-based learning was identified as one of the most attractive modes of educational delivery in the feasibility study for healthcare providers. This preference for case-based learning was also supported in another research (Malau-Aduli et al., 2013; Pan et al., 2020; Peacock et al., 2013). A study by Malau-Anuli and colleagues (2013) examined the use of case-based learning in an undergraduate medical curriculum and found that case-based learning was not only well received but also very successful in enhancing knowledge retention among students. Another study by Peacock and colleagues (2013) examined two types of case-based learning where cases were supplemented with alternative scenario outcomes and found that the presentation of content influenced learning whereby clearer, less complex cases enhanced knowledge retention. The findings on case-based learning, particularly presenting the information in a direct, less complex manner, is supported in our study, as well as another research (Malau-Aduli et al., 2013; Pan et al., 2020; Peacock et al., 2013).

Supplementing one mode of delivery such as case-based learning with another mode may also hold certain benefits for learning (Pan et al., 2020). A study by Pan and colleagues (2020) found that a case-based learning model designed for pediatrician education was more successful in enhancing knowledge retention when combined with another mode (micro-film). They noted that using a combined approach resulted in more interest, competency, and higher coping skills



(Pan et al., 2020). This finding is complementary to the finding in a systematic review of digitally-based education for healthcare providers, where content delivered in a straight-forward manner (preferably written and targeted to the educational attainment of targeted healthcare professionals – bachelor’s level or higher) (Kostenius et al., 2018) and via varying modes of presentation was regarded as more interesting and attracting attention (Scerbe et al., 2019). Thus, combining different educational modes and conveying information in a more accessible manner targeted to healthcare professional’s educational attainment could in the same way increase acceptability and learning in digitally-delivered education.

Podcast learning was suggested as the second most desirable mode by our sample of healthcare professionals in the feasibility study. This preference is also supported in other research on medical education for healthcare professionals (Alam et al., 2016; Back et al., 2017; Malecki et al., 2019; Prakash et al., 2017). Prakash and colleagues (2017) found that podcasts were helpful in improving medical students’ knowledge in biochemistry. This study also noted that differing lengths of podcasts had different effects where a shorter duration (five minutes or less) was received positively by the student sample. The duration seems to be the key whereby education delivered in short bursts akin to spaced education (Scales et al., 2016) had a positive reception. Alam and colleagues (2016) found that medical knowledge received by podcast had a better effect on reported learning, when supplemented with modeling of clinical skills (similar to case-based learning), which once again hints at the perceived value of case-based learning by healthcare providers (feasibility study finding), and supports previous findings that mixed modes of delivery are typically found to be more attractive (Kostenius et al., 2018). Back and colleagues (2017), examining the effect of an educational podcast on physician’s knowledge, not only found a positive effect on knowledge retention, but also found that this manner of presentation was regarded as a form of entertainment by physicians in their study. These findings indicate that podcasts are not only effective in delivery of medical information but that a shorter duration may increase receptiveness and a perception that learning via podcasts is entertaining (Back et al., 2017; Malecki et al., 2019). Also, podcasts used as a supplement to other modes of learning (e.g., case-based learning) (Alam et al., 2016) may be easier to integrate into a busy schedule as they

require less undivided attention (e.g., an individual can focus on other routine tasks while listening to a podcast) (Back et al., 2017).

While the study implications show that digitally-delivered education holds a host of benefits for both caregivers and healthcare providers, the feasibility study helped to identify certain models of delivery as well as educational formats which would be accepted, with a high level of perceived utility and feasibility. Although the studies are optimistic in their applications and benefits and are supported in other literature acknowledging the same benefits, there are a number of limitations which would need to be addressed and thoroughly acknowledged to provide a more balanced and well-rounded view of the findings.

### **Study Limitations**

The meta-analysis in the review on educational interventions for caregivers found some very promising results indicating effectiveness of intervention on self-reported symptoms of depression and distress in response to perceived behavioral issues; however, it did not reveal a significant effect of intervention on burden or self-efficacy. Self-efficacy has an important role in facilitating the caregiver to care for oneself (Romero-Moreno et al., 2012) and their caree (Zhang et al., 2014). Research shows that self-efficacy is also a mediating factor for caregiver burden (Yang et al., 2019) and can predict caregiver depression over time (Romero-Moreno et al., 2012; Zhang et al., 2014). Thus, it seems that self-efficacy and burden are correlated where a change in one (e.g., self-efficacy) will likely influence perceptions of burden (Romero-Moreno et al., 2012; Yang et al., 2019; Zhang et al., 2014).

Burden has also been conceptualized as an umbrella term, encompassing a wider array of definitions subsumed under different categories such as objective burden and subjective burden (Braithwaite, 1992; Brodaty & Donkin, 2009). Provided the complexity in definition of burden, burden has been difficult to conceptualize or measure in a consistent manner across studies as it requires other correlated factors such as self-efficacy (Romero-Moreno et al., 2012), changing needs of the caree, relationship with the caree (Kramer, 1993), acceptance of the situation (Lloyd et al., 2014), and cultural influences (van Wezel et al., 2016; Yu et al., 2016), to remain constant (Romero-Moreno et al., 2012; Zhang et al., 2014). While it is argued that burden is difficult to measure (Lloyd et al., 2014; Romero-Moreno et al., 2012; van Wezel et al., 2016; Yu et al., 2016;

Zhang et al., 2014), some of the studies included in the meta-synthesis showed a small effect on burden (Kwok et al., 2013; Martindale-Adams et al., 2013), and one study showed no effect (Cristancho-Lacroix et al., 2015). These findings are also consistent with other literature, where some studies indicate a significant positive effect of intervention on burden (Gitlin et al., 2003; Jensen et al., 2015; Pahlavanzadeh et al., 2010; Terayama et al., 2018), others indicate no effect, and again others have suggested this literature is plagued by measurement difficulties for the amorphous and multifaceted construct of burden (Acton & Kang, 2001a; Basu et al., 2015; Gossink et al., 2018).

The content of intervention may also impact perceived burden (Cheng et al., 2016; Gitlin et al., 2003). For example, if the intervention was designed to specifically focus on and alleviate factors directly affecting burden (e.g., strategies for overcoming difficulties in care), such an intervention would have more effect on burden than interventions focusing solely on education (Cheng et al., 2016). Also, interventions that are more intense in their delivery, for example delivered over a shorter period, have been shown to have a greater effect on alleviating burden (Gitlin et al., 2003). The studies in the meta-synthesis were delivered over different time durations, with one study delivering the intervention over a few weeks (Kwok et al., 2013), one over several months (Cristancho-Lacroix et al., 2015), and one over a year (Martindale-Adams et al., 2013). According to a study by Gitlin and colleagues (2003), interventions delivered over several weeks would have more of an effect on burden. This postulation was supported by the findings of one study in the meta-synthesis that was delivered over several weeks had a small effect on burden (Kwok et al., 2013), and another study that demonstrated a small effect after the intervention was delivered over a much longer time (over a year long period) (Martindale-Adams et al., 2013). These findings suggest that duration and intensity of intervention may not be the only factors affecting burden (Acton & Kang, 2001a; Basu et al., 2015; Gossink et al., 2018); instead, other factors such as caregiving duties and psychological coping are likely responsible for most variance in burden. Other factors potentially affecting burden are ability to obtain respite, knowing how to respond to behavioral symptoms, ability to control one's negative thoughts, and ability to obtain social supports (Gossink et al., 2018), once again indicating multiple correlated or mediating factors. These findings led us once again to conclude that burden

is best conceptualized as an umbrella term rather than a single measurement variable (Braithwaite, 1992; Brodaty & Donkin, 2009). Finally, as with any intervention, the positive effects tend to recede over time; thus, burden may return at a later point in time and be rated as higher (Pahlavanzadeh et al., 2010). Considering that the studies measured burden at different points in time (e.g., between several weeks to several months after intervention), the time to measure outcomes (not accounted for in the meta-analysis) may be another factor impacting burden.

Studies also show that male and female caregivers report different levels of burden (Calasanti & King, 2007; Duxbury et al., 2011; Lee et al., 2013; Pöysti et al., 2012; Xiong et al., 2020) and support seeking behavior (Arbel et al., 2019; Brazil et al., 2009). Interestingly, none of the studies included in the review reported separate outcomes for male and female caregivers related to sex (biological) and gender (social/environmental context) factors. This was an important finding for two reasons: female caregivers, particularly spouses of individuals with dementia, report higher levels of burden (Calasanti & King, 2007; Duxbury et al., 2011; Lee et al., 2013), and female caregivers are more likely to seek emotional support than male caregivers (Brown et al., 2007). Females also have a higher chance of being an APOE 4 genotype carrier which, when combined with cerebrovascular disease (also higher among women in later age) (Rasmussen et al., 2018), is predictive of higher likelihood of Alzheimer's disease (AD) diagnosis (Gilsanz et al., 2017; Xie et al., 2008), which alludes to the future possibility of more males entering the caregiving role. Male and female caregivers also differ in their approach to caregiving tasks; they approach caregiving from different coping strategies (e.g., emotionally-focused feminine orientations versus masculine task-oriented approaches) which has implications for greater emotional strain reported by female caregivers (Hong & Coogle, 2016). Understanding how these findings impact caregivers of individuals with dementia is important as it points to potential service gaps where males will be more engaged in caregiving roles (Gilsanz et al., 2017; Xie et al., 2008), which in turn may necessitate greater effort to orient male caregivers toward resources on support seeking (Papastavrou et al., 2011), and greater effort to orient female caregivers toward supports to alleviate emotional strain (Hong & Coogle, 2016).

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While the educational content was changed in the second portion of our feasibility study (with healthcare providers), there is a possibility that healthcare providers were reacting differently based on content and not based on mode of delivery. In the initial phase of the feasibility study, the materials were presented in three modes (whiteboard, multiple-choice, case-based scenario), and they included the same information (examples of complex versus uncomplicated dementia presentation and when to refer to a specialist). The second portion of the feasibility study (presented to healthcare providers) included different informational contents (e.g., medication contraindications delivered via a podcast, typically presenting dementia presentations delivered via whiteboard animation, and when to refer to a specialist, presented via a case-based scenario). However, prescribing and pharmaceutical knowledge were deemed as an important skill by healthcare providers in other studies, such as Ross and Maxwell (2012), and was considered a skill to be acquired in the field; thus, we thought it would be useful to include this type of information in education. Delivery of content in the feasibility study also included delivery by two types of healthcare professionals, a neurologist and a neuropsychologist. A study on cross-discipline communication of information by Abdallah and colleagues (2014) found that healthcare students appreciated content delivery from different healthcare professionals (perceived experts in their fields), which is why we chose to include experts from different professions in our delivery (Abdallah et al., 2014). Despite the differences in educational materials and potential for impact on perceptions, there was still a strong support for preference of case-based scenarios among healthcare providers, where case-based learning has been historically highly rated, and well received as it emulates real life situations typically encountered during work (Malau-Aduli et al., 2013; Pan et al., 2020; Peacock et al., 2013).

Another finding in the feasibility study indicated that healthcare providers although receptive toward remote dementia education, showed some trepidation toward implementing such an intervention into their busy workdays. The trepidation (as indicated on the VAS scale), may be a reflection of unique work demands of busy rural healthcare providers (Brailon, 2020). Rural areas are qualitatively different than urban areas. For example, rural areas have fewer specialized doctors and more generalists than urban areas (Rosenblatt, 2004). Additionally, rural hospitals have fewer beds and fewer stays with average shorter durations (Rosenblatt, 2004). Also, rural

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areas are less likely to attract medical school graduates (Curran et al., 2006; Rosenblatt, 2004). More importantly, there are differences in caseloads among rural and urban healthcare providers, with rural healthcare providers serving a more diverse population with heavier caseloads (Brems et al., 2007), which may help to explain some of our respondents' trepidation. Although there seems to be high receptiveness toward digitally-based dementia education, there are also important workload and compensation obstacles that would need to be addressed, including coverage and cost of training.

Other challenges for rural healthcare providers and caregivers not addressed in the feasibility study are differing levels of previous utilization and knowledge of technology (such as smartphone application) and varying levels of access to Internet in rural areas. Lack of training on use of technologies may particularly impact caregivers, where digitally-delivered education, although promising, would likely benefit caregiver knowledge and outcomes with more technology use training (e.g., how to use the smartphone app) (Klimova et al., 2019). Also, it is noteworthy that the studies included in the systematic review on caregivers did not specify how the caregivers were informed on use of technology to access the digitally-based intervention. Training on use of intervention for healthcare providers could be a potential barrier. As a manner of gaining buy-in, and demonstrating the intervention, implementing a presentation on technology for healthcare providers that would be delivered by the researcher, or an affiliated research member, could be a solution.

Another potential challenge for rural caregivers could be securing access to Internet due to limited or inaccessible Internet in remote areas (no wireless Internet coverage). The same lack of access to the Internet signal (e.g., "dead zones") could apply to the smartphone application. Rural areas experience lack of access to Internet not only due to a lack of connectivity and spotty network coverage, but also to considerations related to affordability (Boase, 2010; Furuholt & Sæbø, 2018; Wahabi et al., 2019). Internet usage costs could also apply to the use of an application, where longer use of the application could translate to a costlier phone bill (especially in areas where roaming occurs, and thus, roaming charges accumulate). Smart phone coverage, use, and costs are potential limitations, which could hinder access to digital education, which would have to be addressed prior to intervention design and or delivery.

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A lack of physician participation was also a limitation: none of the healthcare professionals who evaluated the educational content in the feasibility study were physicians. Gaining physician input would be important for gaining a deeper understanding regarding how the proposed intervention would be received by physicians, or what the potential barriers are to participating. A systematic review completed by Wahabi and colleagues (2019) on obstacles of physicians to participation in digitally-delivered medical education found that the effect of continuing education on knowledge and skills was uncertain, citing inconclusive findings, and noting that most studies in their review struggled with physician recruitment and retention, and could therefore not confidently identify all potential obstacles. One possibility to alleviate this lack of physician participation could be to include incentives for participation in the form of continuing education credits. Other suggestions include increasing accessibility (offering asynchronous education to enhance flexibility), securing paid time off, and providing coverage while physicians are engaging in continued education.

Although both reviews showed some benefits of digitally-based dementia education on outcomes, a recently published review by Frias and colleagues (2020) on technology-based dementia education interventions for caregivers of people with dementia indicated different benefits for caregivers. For example, the review found that while technology-based interventions significantly impacted burden, group-based in-person interventions affected anxiety, mood, insomnia, burden, perceived quality of life, and self-efficacy (Frias et al., 2020). This review indicates that remotely delivered education does not have identical effects on learning as face-to-face education (Cobbett et al., 2016). It is important to acknowledge that although digital interventions possess the capacity to deliver information remotely at a reduced cost, in-person interventions may offer other benefits such as immediate access to educators or other healthcare professions which can answer specific care queries. Attending in-person may also allow for development of relationships and supports with other attendees, which can be an unintended effect, and can directly contribute to the positive outcomes noted in Frias et al., (2020). Similar benefits of group-based education for caregivers may also extend to healthcare providers where development of supportive relationships among colleagues may encourage higher perceived support (Ashida et al., 2018; Ibarrola et al., 2020). Also, it should be noted that both reviews in

this dissertation demonstrated a large variability in modes of educational delivery (e.g., telephone, computer, video conferencing), varied educational content (e.g., dementia knowledge, behavior management, distress tolerance, etc.), varied durations (e.g., several weeks to a year), and varied measures for measuring outcomes, as well as interventions containing a group-based component with access to other participants, and solitary interventions without the group component. If access to group support facilitates learning and better outcomes, one possibility would be to address this in future interventions by including online access to group-based learning, or through inclusion of group forums and video chat for establishment of connections and supports. While some possibility remains that in-person educational interventions are more impactful on outcomes than remotely delivered interventions (Frias et al., 2020), in person interventions are not always feasible for rural caregivers.

Caregivers typically indicate a need for more ways to address their knowledge gaps regarding caregiving tasks (Bonner et al., 2015), management of own emotional needs (Ali & Bokharey, 2016), and information regarding progression of dementia (Lee et al., 2013). The bulk of dementia education is commonly shared via healthcare professionals in print form, including access to community resources, and Internet resources (James & Paulson, 2019b; Jensen et al., 2015; Lee et al., 2015; Peterson et al., 2016). However, simple information sharing has been deemed largely insufficient by caregivers (James & Paulson, 2019b; Jensen et al., 2015; Lee et al., 2015; Peterson et al., 2016), where education targeting knowledge gaps has been shown to ameliorate these perceived informational concerns (Ali & Bokharey, 2016; Elmståhl et al., 2012; James & Paulson, 2019a; Lee et al., 2015; Peterson et al., 2016). Accessibility to education, particularly for rural caregivers, has been a major barrier due to longer travel and lack of access to resources (Dal Bello-Haas et al., 2014; Jennings et al., 2015). A study by O'Connell et al., (2014) found that rural caregivers who had longer distances to travel to telehealth sites (which still were much closer than travelling to the next urban centre) had more absenteeism. This finding indicates that even in instances where travel is shortened by making education more accessible and offering it in rural sites, even shorter travel distances may serve as a barrier to some.



### **Suggestions for Future Research**

The studies in the systematic review on caregivers were not always clear as to whether they were measuring objective burden (related to tasks of caring) or subjective burden (the extent to which caregivers minded performing those tasks), which is an important distinction as these two types of burden are qualitatively different (Braithwaite, 1992; Brodaty & Donkin, 2009). Self-efficacy is also not a standalone variable but can also be a mediating factor in care burden (Romero-Moreno et al., 2012). Accounting for other mediating variables in addition to self-efficacy, such as anxiety and depression (Zhang et al., 2014), cultural influences (van Wezel et al., 2016), quality of relationship with caree (Kramer, 1993), acceptance of situation (Lloyd et al., 2014), and available supports (ability to obtain respite or access to social supports) (Gossink et al., 2018), could ensure that other factors are adequately accounted for. Added clarity in measurement of caregiver burden and self-efficacy in future research could ensure that each outcome is defined in a consistent manner (e.g., adjust educational content to specifically target defined outcomes, and make sure that the outcomes are measured consistently; Cheng et al., 2016; Gitlin et al., 2003).

Male and female caregivers report different levels of burden (Calasanti & King, 2007; Duxbury et al., 2011; Lee et al., 2013; Pöysti et al., 2012; Xiong et al., 2020) and support seeking behavior (Arbel et al., 2019; Brazil et al., 2009), which emphasizes the importance of reporting outcomes separately. In the systematic review, the outcomes for male and female caregivers were not reported separately. In future research, it would be important for studies to consider gender and socio-cultural factors impacting male and female caregivers (e.g., higher burden reported in female caregivers; Arbel et al., 2019) and socialized approaches to care such as emotionally-focused (feminine) versus task-oriented (masculine) (Hong & Coogle, 2016). It would be especially valuable to consider healthcare data and trends resulting in more males engaging in caregiving roles in the future (Gilsanz et al., 2017; Xie et al., 2008), adjust educational content to target gendered caregiver needs, and ensure to report outcomes for male and female caregivers separately.

In the feasibility study, there was a strong preference by healthcare providers for case-based learning (Malau-Aduli et al., 2013; Pan et al., 2020; Peacock et al., 2013). It would be important

to acknowledge this preference (Malau-Aduli et al., 2013; Pan et al., 2020; Peacock et al., 2013) when designing educational content and seeking buy-in from healthcare providers. Also, we found that inclusion of different modalities (e.g., educational modules with discussion boards) may be perceived as more desirable (Alam et al., 2016; Back et al., 2017; Malecki et al., 2019), which may become another consideration in the design of future interventions. While remote-education seems like a valuable cost- and time-effective way of informational delivery for both healthcare providers and caregivers, it is important to acknowledge different training needs. For example, there may be different levels of comfort with technology among health care providers and caregivers (Klimova et al., 2019). Thus, addressing training needs and dedicating time to train intervention recipients in the use of technology may not only assist in the use of the intervention but may also facilitate buy-in.

While gaining buy-in from healthcare providers in participation in continued education may be challenging, gaining buy-in from physicians may be even more difficult. Past literature on adherence to changing existing practice according to dementia best practice guidelines demonstrated at best a lack of fealty (Alzheimer Society of Canada, 2016; Mason et al., 2018; Moore et al., 2014; Sivananthan et al., 2013). Our feasibility study indicated a similar concern that was reflected in our failed attempts to obtain input from physicians in the evaluation of our educational materials in the feasibility study. However, a review by Sivananthan and colleagues (2013) found that the physician's lack of adherence to guidelines may be more reflective of a resistance to a push towards change in practice. These studies indicated that finding ways to engage physicians into identifying barriers to education and educational needs regarding dementia, without an over-emphasis on practice change, is valuable and important. In this regard, an offer of incentives such as continuing medical education credits could be another path to encouraging participation. Inclusion of a component that would connect learners to each other and allow sharing of inquiries/questions could also mediate the formation of a supportive group dynamic and encourage participation among healthcare professionals, including physicians (Abdallah et al., 2014; Ducharme et al., 2011; James & Paulson, 2019b). Allowing healthcare practitioners to communicate and share information via remote methods such as teleconferencing may also have a positive effect on establishing better networking, better supports, and

information sharing among various healthcare professionals (De Witt Jansen et al., 2018). This, in turn, may enhance collaboration and engagement across healthcare disciplines (De Witt Jansen et al., 2018). Additionally, cross education among healthcare professionals including sharing of first-hand or expert knowledge may be received favorably and have a positive effect on learning (Abdallah et al., 2014).

Finding ways to connect healthcare providers with caregivers may also have benefits for caregivers in increasing dementia knowledge and reducing sense of isolation. Caregivers receive the majority of their dementia knowledge from their healthcare providers (Abdallah et al., 2014; Ducharme et al., 2011; James & Paulson, 2019a). Creating more opportunities for healthcare providers to engage with caregivers in dementia information sharing could have educational benefits for caregivers (Blom et al., 2015; Lee et al., 2015). A systematic review completed by Frias and colleagues (2020) examined available psychoeducational interventions for caregivers of people with dementia. The review revealed a number of available technology-based and group-based interventions, which were either delivered digitally or face-to-face. While all types of interventions showed positive effects for caregivers, the technology-based interventions included in the review lacked opportunities for caregivers to submit queries. The authors argued that digitally-based dementia education programs allowing for real-time chats, advice giving, information sharing, and social supports could be more beneficial for caregivers (Chiu et al., 2009; Frias et al., 2020). It is important for future research to acknowledge the benefits of learning programs which incorporate interaction with program educators, and which allow for reciprocal support among users.

While dementia learning opportunities promote benefits among caregivers (Chiu et al., 2009; Frias et al., 2020), rural populations may be limited in accessing educational interventions due to unique challenges associated with rural living (Brems et al., 2007; Kosteniuk et al., 2016; Rosenblatt, 2004; Scerbe et al., 2019). Some of the challenges associated with rural living for caregivers are a lack of specialists in rural areas (Rosenblatt, 2004), fewer hospital beds and shorter hospitalizations (Rosenblatt, 2004), strained healthcare providers (Brems et al., 2007), longer travel times to training/education or specialists (Kosteniuk et al., 2016), and a lack of affordable or reliable access to Internet in rural areas (Boase, 2010; Furuholt & Sæbø, 2018).

These barriers need to be acknowledged and examined in the development of digitally-delivered dementia interventions. Another form of educational delivery out of the scope of the present dissertation which warrant further examination, and which may also carry positive effects on knowledge acquisition particularly in the delivery of health education is virtual reality (technology that allows one to engage in augmented reality) (Zhu et al., 2014).

### **Conclusion**

Overall, the three studies found that digitally-based dementia education targeted to caregivers and healthcare providers could serve as a valuable delivery mode for learning and supplementing knowledge gaps in dementia care. For caregivers, the digitally-based dementia education was useful in providing a model of care and adaptation, as well as a glimpse into future care needs with progression of disease (Ali & Bokharey, 2016; James & Paulson, 2019; Lee et al., 2015). For healthcare providers, digitally-based dementia education could be particularly useful for populations of healthcare providers who did not receive adequate dementia education during training (Bond et al., 2005; Delrieu et al., 2009; Iliffe et al., 2009). Rural healthcare providers who struggle with access to specialists and with inability to secure time away to attend continuing education training could particularly benefit from digitally-based dementia education (Curran et al., 2006; Pinzon et al., 2020; Rosenblatt, 2004). Overall, digitally-based education that is asynchronous and delivered in a manner which does not add burden to the already busy workloads could be promising. Furthermore, with asynchronous delivery and short-spaced delivery of information over longer period of time (15-minute intervals), it would be possible to integrate professional education within daily work tasks.

The present dissertation findings commend a benefit in delivery of digitally-based education to rural healthcare providers (Morgan et al., 2019) and rural caregivers (Brems et al., 2007; Rosenblatt, 2004). With the changing rural demographic landscape of healthcare professionals and increased number of aging individuals in rural areas (Curran et al., 2006; Dal Bello-Haas et al., 2014), finding ways to deliver education is important (Innes et al., 2011). While we know that digitally-based dementia education is beneficial, finding a way to deliver this in a way to overcome barriers of rural practice and living, such as work context and access barriers, could be

even more valuable (Innes et al., 2011; Kosteniuk et al., 2016; O'Connell et al., 2014; Morgan et al., 2019).

In our studies conducted for this dissertation, we also found several limitations. For example, a lack of physician involvement in the feasibility study made it difficult to gain physician impressions and input regarding the mode of educational delivery. Also, the studies included in the meta-analysis did not clearly define burden (objective versus subjective burden) (Braithwaite, 1992; Brodaty & Donkin, 2009), or other factors important for burden, one of which may have been self-efficacy (Romero-Moreno et al., 2012; Yang et al., 2019; Zhang et al., 2014), or duration of intervention (Martindale-Adams et al., 2013; Pahlavanzadeh et al., 2010). The studies did not report outcomes for male and female caregivers separately, which made it difficult to understand any potential gender-based differences in reporting of burden (Calasanti & King, 2007; Duxbury et al., 2011; Lee et al., 2013). The studies also failed to report sex-based differences (for example, females carrying a higher chance of being an APOE 4 genotype carrier, and having a higher chance of cerebrovascular disease, thus having a higher chance of being diagnosed with Alzheimer's Disease in later life and causing a potential future shift in higher number of male caregivers) (Gilsanz et al., 2017; Xie et al., 2008). Last but not least, the studies did not report how many participants were from rural or urban areas, which was a large omission given that rural counterparts face added burdens to obtaining and provision of care due to factors such as remoteness (Innes et al., 2011; Kosteniuk et al., 2016), and a lack of access to learning (Morgan et al., 2019) and specialists or specialized services (Kosteniuk et al., 2016).

### **Future of Dementia Care and Research in Rural Areas**

Rural healthcare providers see a variety of medical case presentations (Curran et al., 2006; Pinzon et al., 2020; Rosenblatt, 2004), and they face challenges with access to specialists and continuing education (Curran et al., 2006; Pinzon et al., 2020; Rosenblatt, 2004). They are also more likely to refer patients for further evaluation without clearly identifying a diagnosis, especially if they are uncertain or are unable to consult (Pinzon et al., 2020). While some international guidelines indicate a variability in preference for a specialist referral, especially in terms of complex dementia presentations (Aminzadeh et al., 2012; Mason et al., 2018), The Canadian Consensus Conference on the Diagnosis and Treatment of Dementia indicates that

diagnosis for typical dementia presentations of dementia should be made by primary care physicians (Ismail et al., 2020; Moore et al., 2014). This emphasizes the importance of dementia education for primary healthcare, especially in helping to alleviate diagnostic uncertainty (Pinzon et al., 2020; Rosenblatt, 2004). Other ways to alleviate diagnostic uncertainty may lie in the formation of dementia care networks among rural healthcare providers and caregivers (Ibarrola et al., 2020). Establishing collaborative networks among healthcare providers may not only be beneficial for healthcare providers, but also for caregivers, whereby caregivers could benefit from healthcare provider support in receiving more information and continuing support (Ashida et al., 2018; Ibarrola et al., 2020). Creating more opportunities for readily accessible education and collaboration among healthcare providers may also close some of the economic gaps among economically disadvantaged caregivers whereby healthcare providers who are better educated on dementia can make the diagnosis locally, which could positively impact caregivers by reducing travel burden and its financial consequences on the caregivers (Dal Bello-Haas et al., 2014; Innes et al., 2014; Jennings et al., 2015). Obtaining a timelier diagnosis may also allow for earlier discussions with healthcare providers regarding advanced care and treatment options which can impact informed decision-making surrounding plans for long-term care (Chuakhamfoo et al., 2020) or plans to remain in the preferred care situation (e.g., remain in their homes for as long as possible) (Elliot et al., 2021).

Obtaining rural caregiver experiences of care provision is also important in identifying and addressing unique barriers of rural living (Dal Bello-Haas et al., 2014; Greenway-Crombie et al., 2012; Innes et al., 2005; Jennings et al., 2015). Innes and colleagues (2005) interviewed rural caregivers of individuals with dementia. The study identified transport as a major obstacle, where a lack in transportation services (for example, cuts to bus services) resulted in reluctance to access specialized services. Other obstacles identified were poor quality roads, poor weather conditions, and expenses associated with cost of fuel. The caregivers also reported that, due to a lack of care homes in rural areas, they preferred to take care of their carees at home because moving the carees to formal care would likely require moving to another community. The caregivers also identified positive aspects of rural healthcare which included healthcare providers' genuine show of compassion for their patients and provision of care which went

beyond the expected care duties (Innes et al., 2005). Interventions that are sensitive to the unique aspects of caregiving in rural areas could be more effective, for example, taking into consideration the consultative and collaborative relationship with healthcare providers, and eliminating distance-based and access-based barriers (Dal Bello-Haas et al., 2014; Greenway-Crombie et al., 2012; Innes et al., 2005; Jennings et al., 2015). Furthermore, understanding the importance of the collaborative nature of relationships between caregivers and healthcare providers and educating the healthcare providers on how to disseminate information on dementia to caregivers could improve caregiver coping behaviors, increase wellbeing, and caregiving satisfaction (Carbonneau et al., 2011; Elmståhl et al., 2012).

For healthcare providers, enhancing job satisfaction has been noted to have a positive effect on the intention to remain working in the rural setting (Aloisio et al., 2018), and a rise in training and knowledge of dementia was noted to have positive effects on increasing skill level (Bryans et al., 2003; Lathren et al., 2013) and diagnostic confidence (Harvey et al., 2006). Conversely, some of the factors affecting job satisfaction negatively have been noted as burnout, lack of psychological empowerment, lack of self-determination, organizational slack time, and orientation/training (Aloisio et al., 2018). Finding ways to increase consultation and knowledge sharing among healthcare providers (Abdallah et al., 2014; De Witt Jansen et al., 2018), increasing opportunity for professional training (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002), and allowing more flexibility in caseloads and schedules could have a positive effect on job satisfaction, and help minimize some of the negative effects on job satisfaction (Aloisio et al., 2018). Future interventions could examine ways in which to incorporate elements of training to increase confidence in the ability to provide care and find ways to retain healthcare providers in rural areas. Other ways to enhance job satisfaction could include collaborating with employers to find ways to incorporate paid leave, work coverage, and paid travel expenses (Curran et al., 2006). Alternatively, some aspects of continuing education could also be offered locally to encourage attendance and buy-in (Kosteniuk et al., 2016). Other suggestions for increasing buy-in could include more flexible caseloads and access to specialists for consultation (Kelley et al., 2003).

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The future of rural dementia care rests on the ability of leaders in healthcare and policy to find ways to fill in the gaps in knowledge and supports for busy rural healthcare providers (Aloisio et al., 2018; Curran et al., 2006). Putting in the necessary supports, for example, providing dementia education earlier on in careers of healthcare providers, may help circumvent some of the expected pitfalls in dementia care, which include diagnostic delay (Bamford et al., 2004; Boise et al., 2004; Bond et al., 2005; Boustani et al., 2003; Bradford et al., 2009; Connell et al., 2004; Iliffe et al., 2009; Koch et al., 2010; Schoenmakers et al., 2009; Waldemar et al., 2007; Wilkinson & Milne, 2003) and delay in care planning (Chuakhamfoo et al., 2020; Curran et al., 2006; Elliot et al., 2021; Innes et al., 2014). Also, considering that healthcare providers typically share information with caregivers (Carbonneau et al., 2011; Elmståhl et al., 2012), education for healthcare providers could have a positive effect on caregivers in terms of support, timelier diagnosis, information sharing, and a resultant opportunity for advanced care planning (Ashida et al., 2018; Ibarrola et al., 2020). Furthermore, planning for the formation of care networks among healthcare providers may allow for information sharing and support among healthcare providers (Ashida et al., 2018; Ibarrola et al., 2020). Dementia education will become even more critical once Canadian laws such as Medical Assistance in Dying (MAID) for dementia patients come into effect (Bravo & Arcand, 2020; Bravo et al., 2018), which will necessitate more opportunities to relay information to healthcare providers and caregivers.

Recent changes in the world due to the COVID-19 pandemic necessitated some healthcare providers to shift their services online (Saini, 2020; Son et al., 2020). With ongoing challenges anticipated as new COVID-19 variants continue to require intermittent quarantine and distancing measures, it is likely that some healthcare services will maintain some aspects of online service delivery (Saini, 2020; Son et al., 2020). These measures will also continue to influence efforts to provide some education remotely. As previous research indicated, remote education has been shown to have similar effects on knowledge and information retention as face-to-face format (Boots et al., 2014; Kajiyama et al., 2013; Lewis et al., 2010; Mavandadi, Wright, et al., 2017). With these efforts and ongoing challenges as the healthcare professions navigate the quickly changing landscape of healthcare in the times of the pandemic, the need to provide online education will likely remain relevant.



While the present thesis outlined the importance of remote dementia education targeting the unique needs of rural healthcare providers and caregivers, as well as the importance of tailoring educational resources to gendered care approaches, it did not address cultural sensitivity of educational materials and needs or barriers of specific cultural rural groups. Saskatchewan is a province with a large Indigenous Peoples population (Cameron et al., 2014; Lafond et al., 2017) primarily residing in rural and remote areas, for example, Northern Saskatchewan where access to healthcare services is limited (Browne et al., 2011; Lafond et al., 2017). Evidence suggests that Indigenous Peoples in Canada face vast health disparities and a lower health status compared to non-Indigenous people (Adelson, 2005; Browne et al., 2011; Cameron et al., 2014; Dyck et al., 2010; Health Canada, 2014 [cited 2015 November 17]; Jacklin et al., 2016; Lafond et al., 2017; National Collaborating Centre for Aboriginal Health, 2011; Reading, 2009), much of which is a result of a history of social, political, and economic injustice (Reading, 2009). Many Indigenous Peoples residing in rural and remote areas face barriers to accessing healthcare services, particularly culturally appropriate services (Browne et al., 2011; National Collaborating Centre for Aboriginal Health, 2011). Furthermore, symptoms of dementia and Alzheimer disease are relatively new in Indigenous communities. The ways in which dementia diagnoses are communicated typically exclude Indigenous peoples' cultural beliefs regarding the natural life cycle (Jacklin et al., 2016). Additionally, many healthcare professionals lack training in Canadian colonial history, Indigenous Peoples' explanatory models of dementia, and ways to approach clinical care in a culturally sensitive manner (Jacklin et al., 2016). Future interventions addressing culturally specific barriers to healthcare and dementia education, as well as interventions incorporating a culturally-sensitive knowledge translation regarding dementia could be carried out to better prepare healthcare providers to care for Indigenous people residing in rural areas. Also, interventions incorporating knowledge regarding how Indigenous Peoples understand and respond to dementia could help healthcare providers in translating dementia knowledge in a culturally safe manner (Browne et al., 2011; National Collaborating Centre for Aboriginal Health, 2011).

Rural healthcare providers and caregivers have barriers to professional training/health education due to longer travel distance (Kosteniuk et al., 2016; Morgan et al., 2011) and less

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access to specialized support services (Dal Bello-Haas et al., 2014; Jennings et al., 2015), which may impact provision of care and services for dementia (Kosteniuk et al., 2016; Jennings et al., 2015) and indirectly affect support for caregivers (Boise et al., 1999; Broughton et al., 2011; Gandesha et al., 2012). The systematic reviews have shown that digitally-delivered dementia education can improve dementia knowledge for both healthcare providers and caregivers and can help to overcome some of the barriers of rural practice and living (Banks et al., 2014; Broughton et al., 2011; Chao et al., 2016; Gandesha et al., 2012; Hobday et al., 2017; Irvine et al., 2013; Boise et al., 1999; Pleasant et al., 2017; Ruiz et al., 2006). However, the systematic reviews have shown that separate reporting of numbers of rural and urban healthcare providers and caregivers was rarely made. In cases where these numbers were reported, the outcome data were not reported separately for urban and rural counterparts. Therefore, this is an area which requires some consideration in future research. The systematic review on caregivers also indicated a lack of attentiveness to caregiver sex differences (female sex; higher chance of being an APOE genotype carrier and associated later life cardiovascular health risk factors, which when combined are associated with a higher likelihood of Alzheimer's disease diagnosis) (Gilsanz et al., 2017; Xie et al., 2008) and gender differences in caregiving (Calasanti & King, 2007; Duxbury et al., 2011; Hong & Coogle, 2016). In consideration of these findings, future dementia education pilots for caregivers could benefit from attention to these important differences. Another area which should be given consideration in the development of digitally-based education is provision of education in an accessible manner (written in accessible language) and suitable to varying educational levels (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002). It was noted that education that is accessible to intended recipients is likely to have better reception and uptake of information (Hobday et al., 2017; Irvine et al., 2013; Rosen et al., 2002). Other areas beyond the scope of the present dissertation which could be explored in other research are inclusion of ways for healthcare providers and caregivers to connect while learning on digitally-based learning platforms. While positive effects of interactions with other participants in learning have been noted for caregivers (Frias et al., 2020), there could be benefits to connecting healthcare providers in their continued learning as well. The feasibility study with our collaborator revealed an already existing rural healthcare team where members routinely

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communicated with each other. Establishing networks for communication and knowledge translation among healthcare providers could serve as another venue for potentially reducing work isolation for rural healthcare providers. Furthermore, fostering a collaborative interdisciplinary environment as well as facilitating knowledge sharing among healthcare providers could benefit informal caregivers, whereby the information is shared from healthcare providers to caregivers. Finding ways to introduce digitally-delivered dementia education for rural healthcare providers and caregivers is a worthy task. Working on ways to improve access to dementia education by introducing digitally-based dementia education could help address some of the barriers encountered by rural practice and rural living and could help improve practice and support of rural healthcare providers and caregivers.

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<https://doi.org/10.7717/peerj.469>



DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

Appendix A

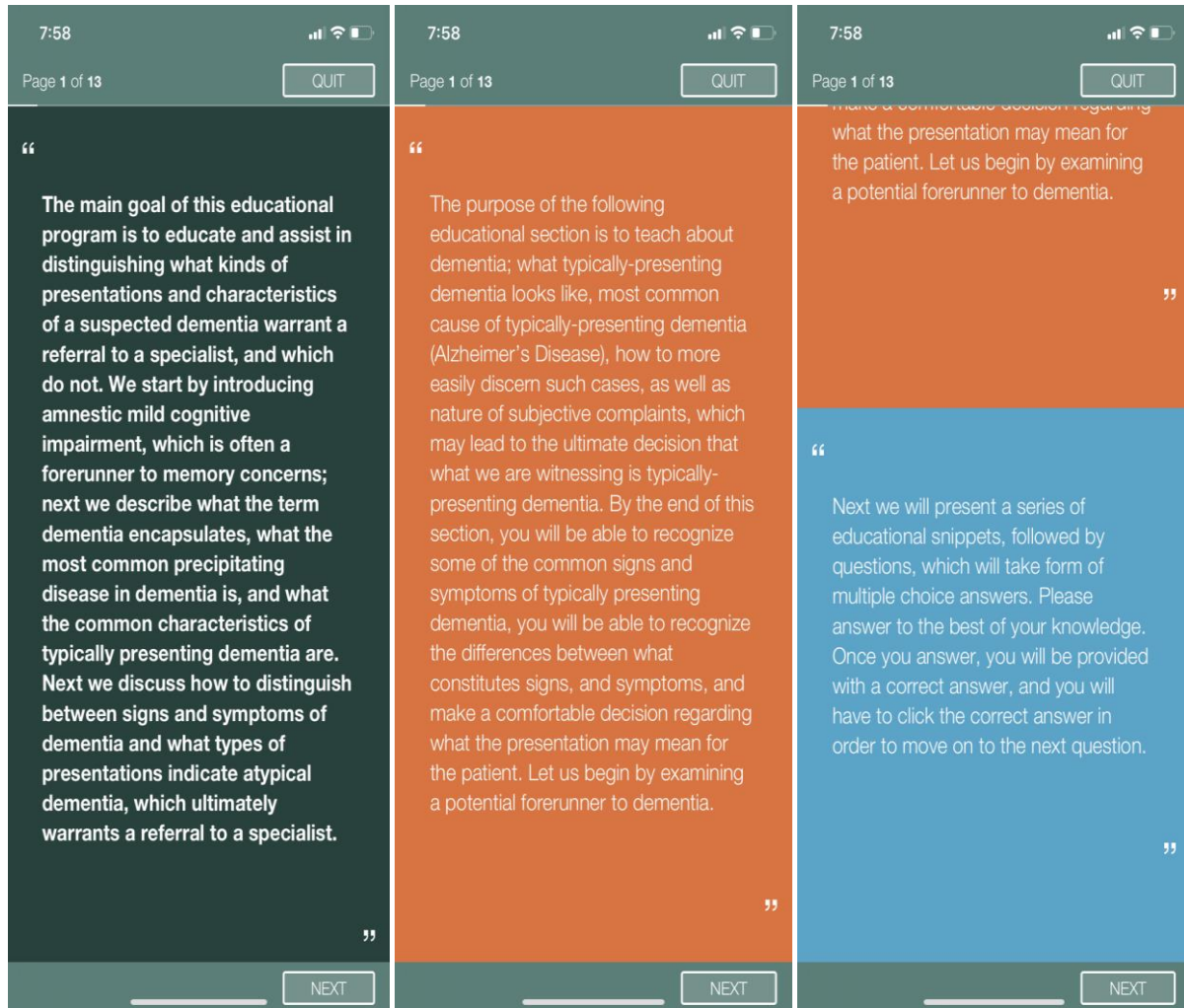
PsycINFO MeSH Terms and Keywords Logic Grid

<p>caregivers OR (care provid\$3 OR care partner OR family care\$6 OR family care partner OR family care provider OR familial care OR family carer OR informal carer OR primary caregiv\$2 OR child caregiv\$ OR spouse caregiv\$ OR informal caregiver OR informal caregiv\$).mp</p>	<p>dementia OR Alzheimer's disease OR Parkinson's disease OR vascular dementia OR dementia with Lewy bodies OR semantic dementia OR neurodegenerative diseases OR cognitive impairment OR neurodegeneration OR (frontotemporal dementia OR early onset dementia OR young onset dementia OR late onset dementia OR mild cognitive impairment OR late elderly dementia).mp</p>	<p>online education OR computer assisted instruction OR distance education OR Internet OR computer applications OR computer searching OR computer training OR technology OR machine learning OR virtual classrooms OR multimedia OR websites OR electronic learning OR mobile devices OR telemedicine OR teleconferencing OR videotape instruction OR telecommunications media OR telephone systems OR (online learning OR online training OR online program OR online tool OR online resources OR computer-based OR computerized OR asynchronous OR portal OR learning application OR videoconferencing OR telephone-based OR telephone-delivered).mp</p>
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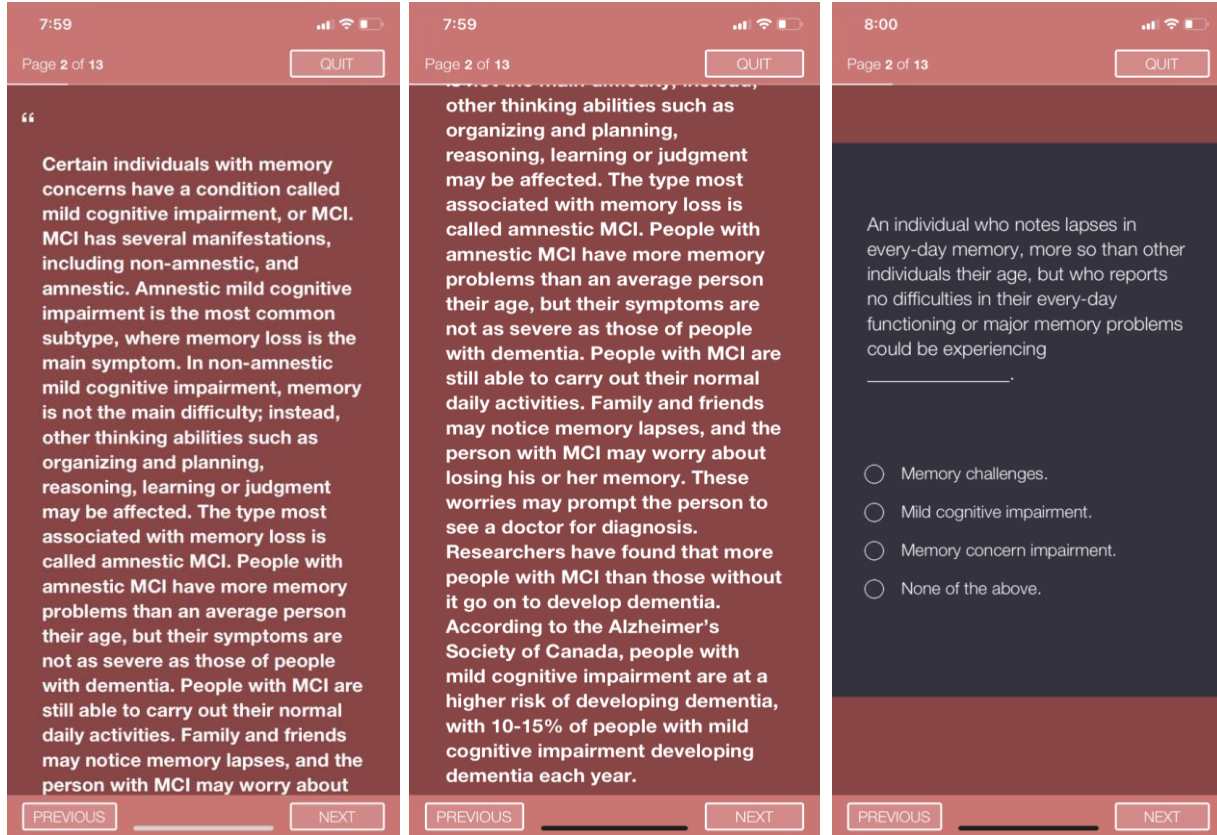
Appendix B

Introduction, Questions, and Whiteboard Animation

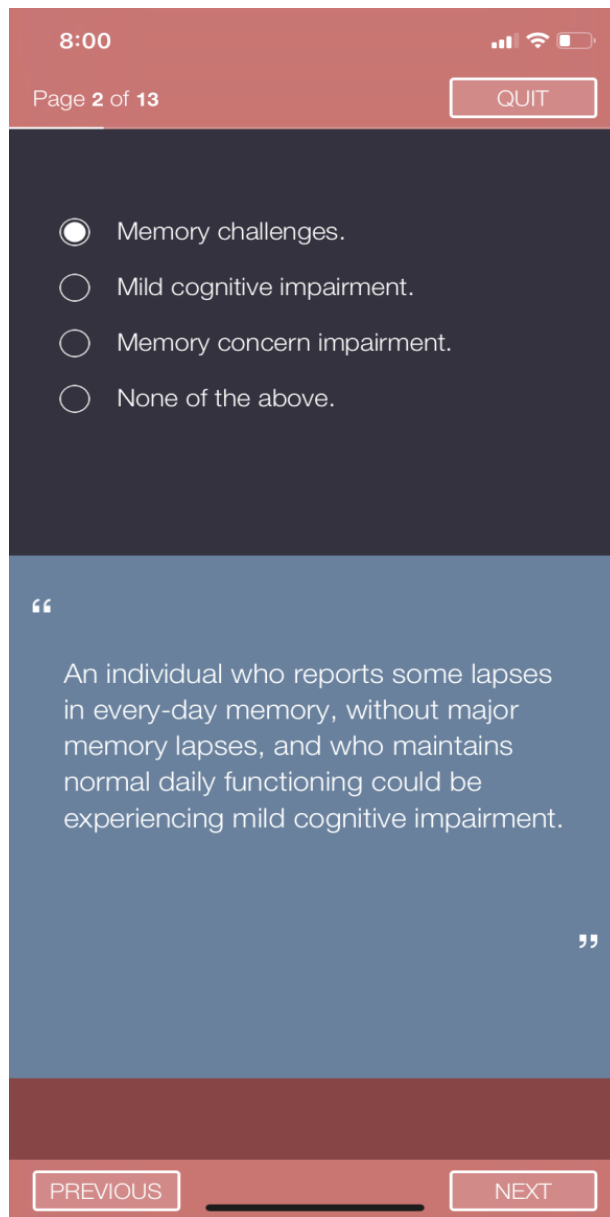
Introduction, Application View



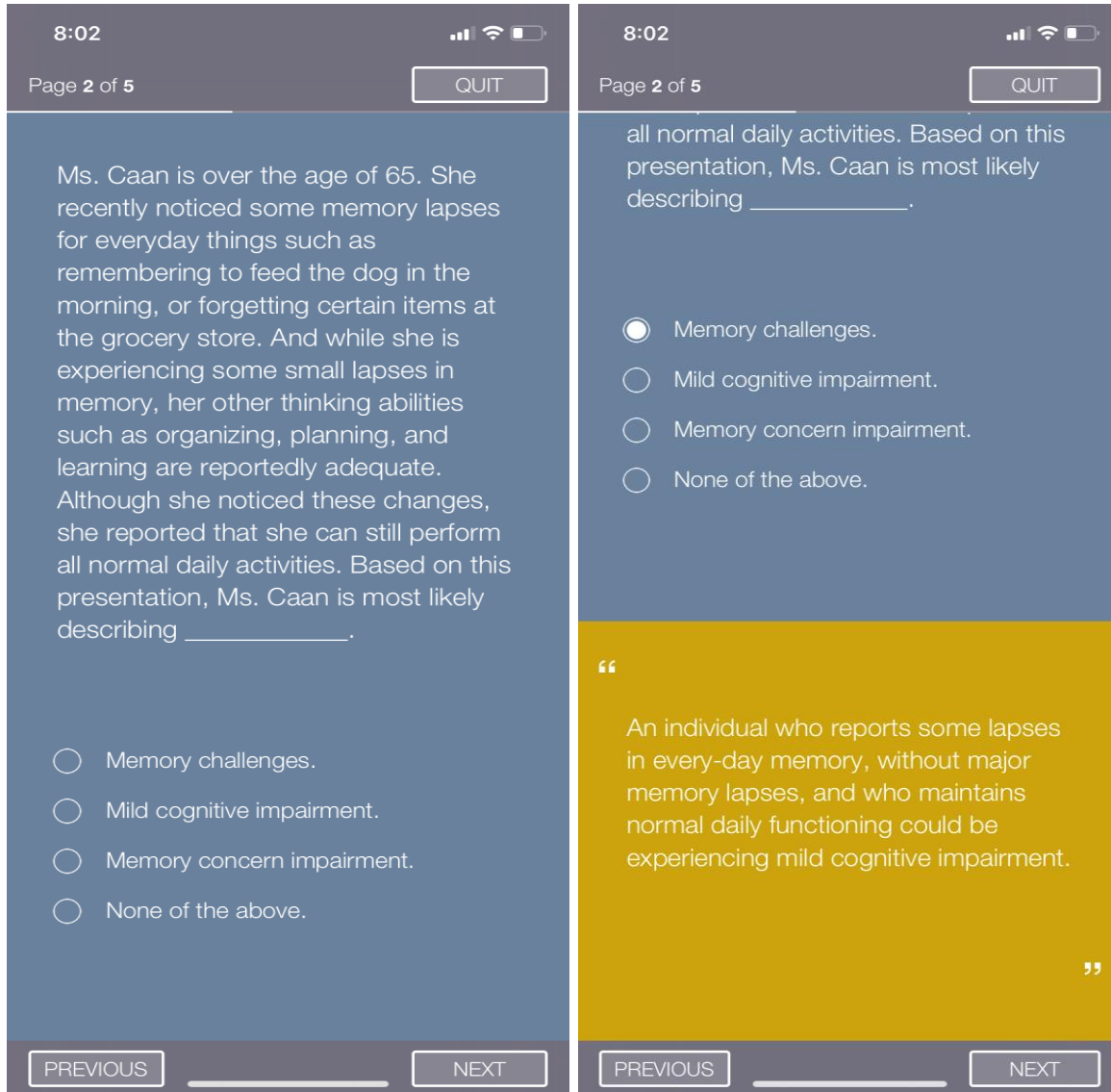
Educational Piece and Answer, Application View



Correct Answer, Application View



Case-Based Scenario, Application View



# DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

## White Board Animation



Appendix C

**Case-based Scenario**

Ms. Caan is a 75-year-old retired widow. She recently started noticing some memory lapses for everyday things such as remembering to feed the dog in the morning, leaving purchases behind at the grocery store, and at times forgetting to take her medication as prescribed. In addition to memory issues, she also noticed troubles with thinking, such as finding it difficult to stay on top of the plot twists in her favorite daytime soap series. In an interview with her daughter, it was revealed that these changes may have been present for about two years, and the interviewing health professional also discovered that more recently there were times when Ms. Caan appeared lethargic and confused about day and place. Furthermore, her daughter noted that during these times, Ms. Caan also required full direction with certain everyday tasks such as brushing her hair in the morning and making sure her shirt was not inside out. Conversely, her daughter noted that at other times Ms. Caan seemed fine, had no trouble with her daily hygiene, and seemed well, alert, and oriented. Through further interviews with Ms. Caan, it also came to light that she has reported seeing people who are not there, which on one occasion resulted in her preparing extra meals and asking how many people to cook for. Ms. Caan has had issues with her balance going back 4 years (which resulted in two major falls within the past 4 months), and her family members noted experiencing occasional but severe mood swings.

Please select the correct answer which would indicate the correct assumption about Ms. Caan's diagnosis.

- (a) Ms. Caan is experiencing problems with memory and thinking, which are indicative of Alzheimer's disease.
- (b) Although Ms. Caan reports issues with memory and thinking, the testing shows fluctuations in cognition, and interview indicates presence of hallucinations, and presence of falls (motor dysfunction) which are indicative of Lewy Body Dementia and should be referred to a specialist.
- (c) At this point in time, the evidence from interview and testing is inconclusive, and requires further examination/testing before a conclusion is drawn.
- (d) Ms. Caan is experiencing effects of normal aging, including memory lapses, problems with thinking, and increased risk of falls due to frailty. Her hallucinations may be occurring in the context of a psychiatric disorder and not dementia.

**Explanation of Correct Answer:** Lewy Body Dementia is a complex disease. Besides the cognitive symptoms common to most dementia, including Alzheimer's disease, such as changes

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in memory and thinking, there are other symptoms which are often missed such as fluctuating cognition, motor dysfunction (Parkinsonism), and vivid visual hallucinations. In addition to core symptoms, other supporting symptoms may also be present such as repeated fainting, hallucinations of sound, touch, smell, or taste, and unexplained periods of unresponsiveness.

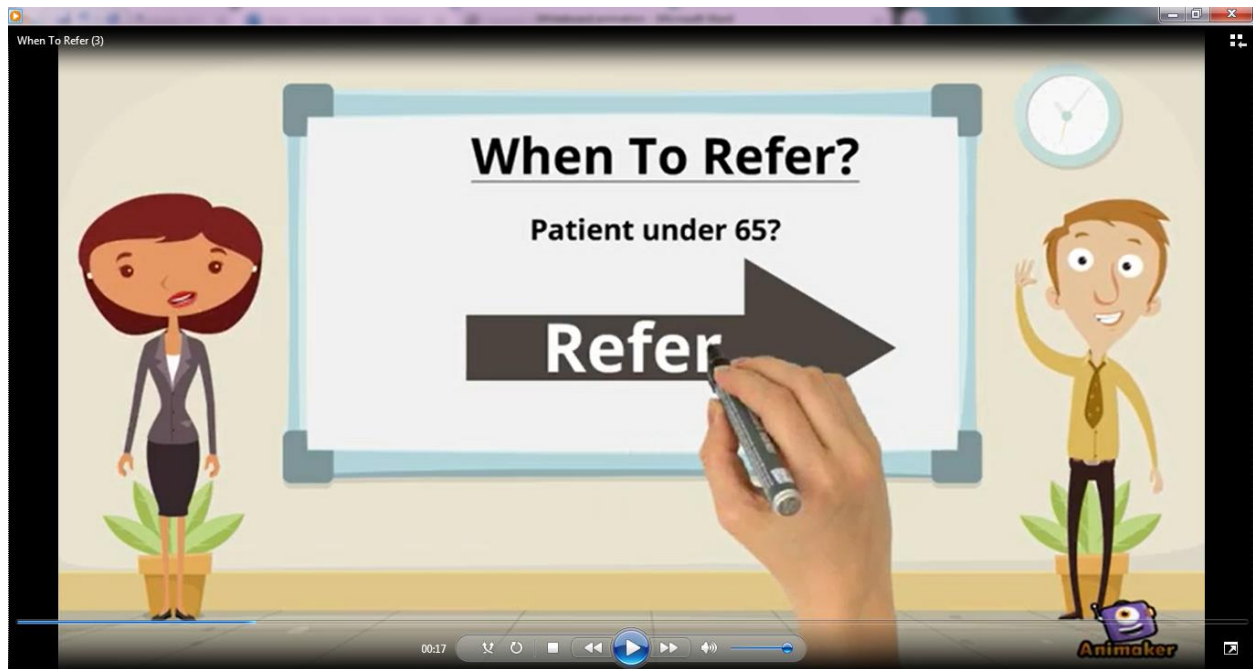
**Explanation of Incorrect Answer:** While Ms. Caan reports symptoms such as difficulties with memory and thinking, which are indicative of Alzheimer's disease, or may be associated with aging, there are other symptoms which are supportive of an often-missed sub-type of dementia, namely Lewy Body dementia. The supporting symptoms are fluctuating performance in memory and thinking on cognitive tests, presence of hallucinations, issues with balance/Parkinsonism features (presence of falls), and severe mood swings.

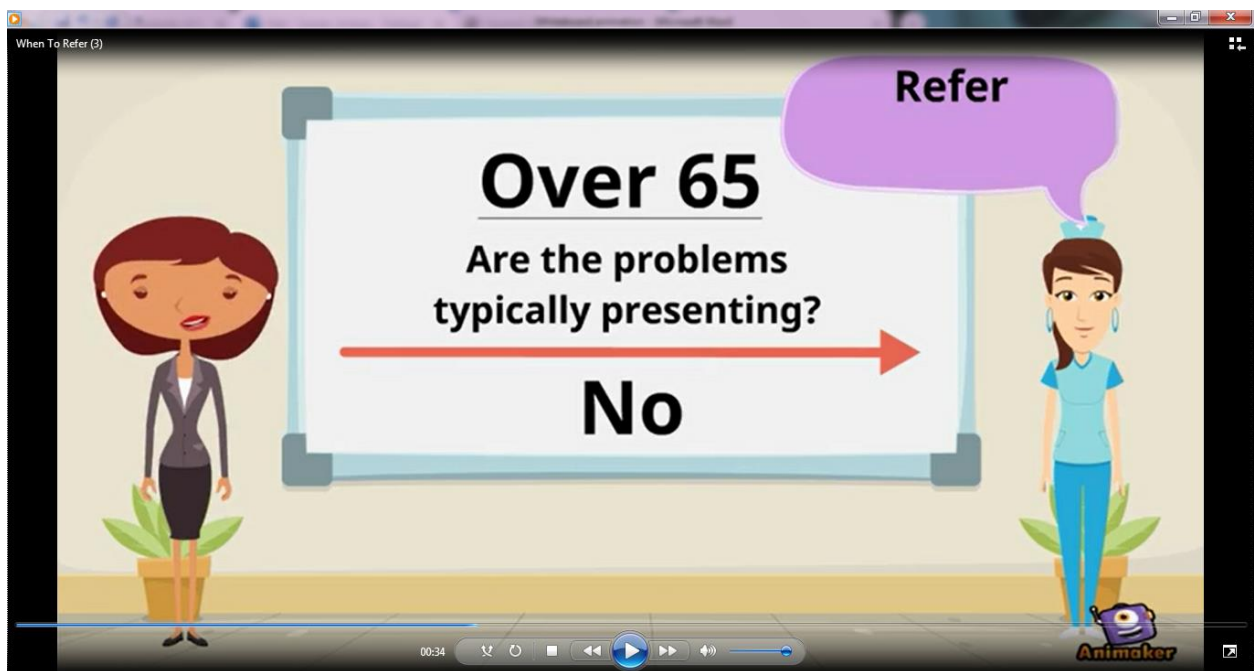
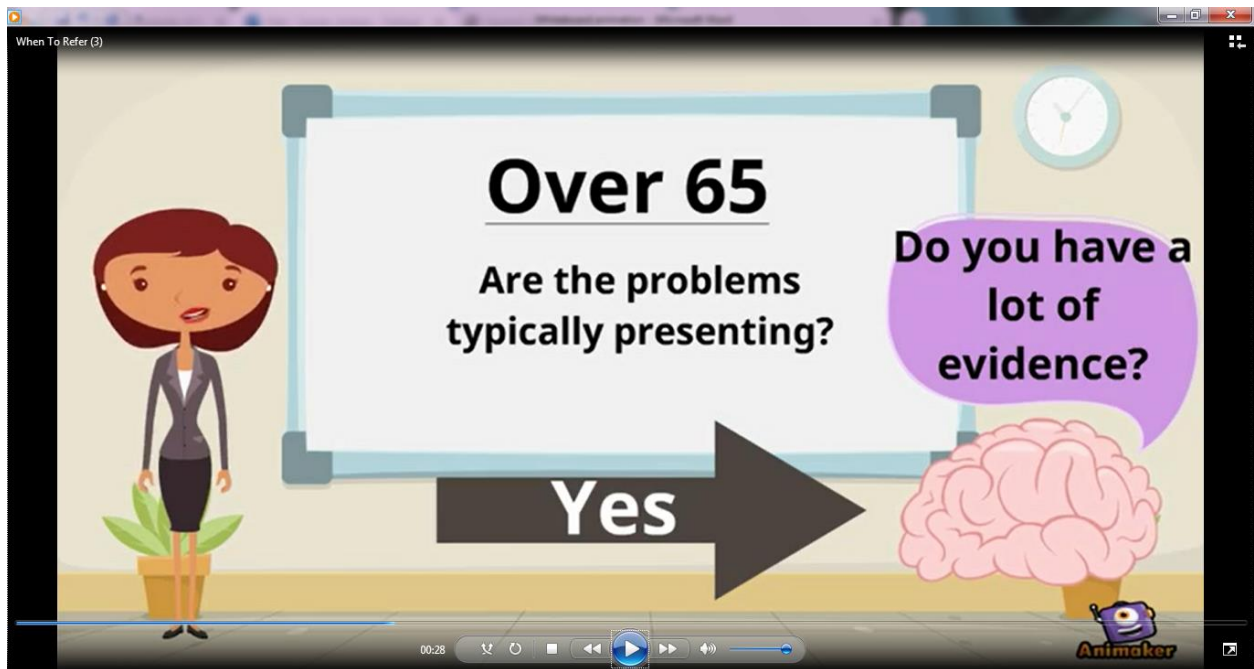
**Take Home Message:** Lewy Body dementia is complex and can be easily mistaken for Alzheimer disease, and if other supporting symptoms/signs are ignored, it can be easily missed or misdiagnosed.



Appendix D

**Whiteboard Animation**





Appendix E

**E-mail Invitation**

Hello,

If you are a **Health Care Provider** and you attended either the Summit poster session or full Summit meeting day on November 5<sup>th</sup> and/or 6<sup>th</sup> please take a moment to review this invitation:

**Digital Dementia Education Survey for Healthcare Providers:**

Thank you for attending and participating in the Twelfth Annual Summit of the Knowledge Network in Rural and Remote Dementia Care. We are reaching out to you to gather your impressions on different educational formats which were demonstrated during the poster sessions. Your responses are important in helping us to determine the best format of dementia educational delivery for primary healthcare providers.

If you are a healthcare provider and you have seen the demonstrated educational formats, and would like to provide your impressions, please respond to this email and we will send a link which will take you to the anonymous survey.

If you have any questions about this survey, please direct your inquiries to the researchers:  
Megan O'Connell at [megan.oconnell@usask.ca](mailto:megan.oconnell@usask.ca) or Andrea Scerbe at [andrea.scerbe@usask.ca](mailto:andrea.scerbe@usask.ca)

Many thanks

Appendix F  
Participant Survey



Digital Dementia Education Survey for Healthcare Providers

We would like to know how you feel about learning modes of digital education on dementia for primary healthcare providers. You may remember viewing three educational modes during the Twelfth Annual Summit of the Knowledge Network in Rural and Remote Dementia Care. The purpose of this questionnaire is to determine how you felt about the varying educational formats, their purpose, ease of use, and to determine if there are any potential barriers to successfully implementing these educational formats. You will be asked about your opinion of each educational mode, including any positive and negative aspects of implementation of such modes in real practice. You may choose to provide as much or as little information as you wish. This research is funded by CIHR Canadian Consortium in Neurodegeneration in Aging (CCNA) with Team 20 Rural projects funded by SHRF through a partnership with CIHR.

There are no known or anticipated risks to you by participating in this research. There is no immediate compensation for participating. Your personal information will not be gathered. Once your responses are submitted, they will no longer be linkable to you. Other personal information, including email addresses, and IP addresses will also not be stored or linkable to you. Dr. O'Connell will store all data for 5 years post publication. When data is no longer required after this date, it will be destroyed beyond recovery. Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort. You may choose to withdraw your answers, until the anonymous survey has been submitted, and identification of responses as yours is no longer possible. The information you share will be kept confidential and data you provide will not be shared beyond the research team. This survey is hosted by Survey Monkey. Your data will be stored in facilities hosted in Canada. Please see the following for more information on Survey Monkey's Privacy Policy.

This research project has been approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office: [ethics.office@usask.ca](mailto:ethics.office@usask.ca); (306) 966-2975; out of town participants may call toll free (888) 966-2975.

Researcher(s): Dr. Megan O'Connell, Ph.D., R.D. Psych, Associate Professor, Department of Psychology, University of Saskatchewan; 306-966-2496; [megan.oconnell@usask.ca](mailto:megan.oconnell@usask.ca).

Andrea Scerbe, Researcher, Graduate Student in Clinical Psychology, Department of Psychology, University of Saskatchewan; [andrea.scerbe@usask.ca](mailto:andrea.scerbe@usask.ca).

To obtain results from the study, please email Andrea Scerbe at: [andrea.scerbe@usask.ca](mailto:andrea.scerbe@usask.ca).

Your answers will help us guide and implement dementia education for primary healthcare in the near future. Your decision to proceed with the survey and submission of answers indicates that you have read and understand the description provided. By completing and submitting this questionnaire, your

# DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

**free and informed consent is implied and indicates that you understand the above conditions of participation in this study.**

1. To begin survey and click NEXT



2. What is your age? Please check one.

- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65 years and older
- Prefer not to disclose

3. What is your sex? Please choose one.

- Female
- Male
- Prefer not to disclose

4. What kind of a healthcare professional are you? Please indicate.

5. Do you practice in an urban or a rural area, please choose one or both.

- Urban area
- Rural area
- Both urban and rural

# DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

6. Please indicate city or location where you practice.

7. How long (years) have you been practicing in your current position?

8. What kinds of patients do you typically see? Please indicate.

9. Do you practice alone or as a part of a professional healthcare team?

- Practice alone
- Practice as part of a professional healthcare team
- Practice both alone and as part of a professional healthcare team



**Please indicate your agreement or disagreement with the following statements, by moving your cursor on the line to indicate how strongly you are leaning toward one position (completely disagree) or the other position (completely agree).**

10. Educational presentation using PODCAST format is an acceptable, and easy to facilitate manner of educating healthcare professionals about dementia

0 completely disagree 100 completely agree

11. Educational presentation using WHITEBOARD ANIMATION format is an acceptable, and easy to facilitate manner of educating healthcare professionals about dementia.

0 completely disagree 100 completely agree

12. Educational presentation using CASE-BASED SCENARIO format is an acceptable, and easy to facilitate manner of educating healthcare professionals about dementia.

0 completely disagree 100 completely agree

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

13. I feel confident that educational presentation using PODCAST format will improve healthcare practitioner understanding of dementia.

0 completely disagree 100 completely agree

14. I feel confident that educational presentation using WHITEBOARD ANIMATION format will improve healthcare practitioner understanding of dementia.

0 completely disagree 100 completely agree

15. I feel confident that educational presentation using CASE-BASED SCENARIO format will improve healthcare practitioner understanding of dementia.

0 completely disagree 100 completely agree



**Try to get used to rating your enthusiasm or a lack of enthusiasm. Imagine you have an 'enthusiasm thermometer' to measure your feelings according to the following scale. Notice how your level of enthusiasm changes after you have sampled three educational presentation formats and rate by moving your cursor on the line to indicate how strongly you are leaning toward one position or the other.**

16. How enthusiastic do you feel toward the PODCAST educational format?

0 have no enthusiasm 100 highest level of enthusiasm

17. How enthusiastic do you feel toward the WHITEBOARD ANIMATION educational format?

0 have no enthusiasm 100 highest level of enthusiasm

## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

18. How enthusiastic do you feel toward the CASE-BASED SCENARIO educational format?

0 have no enthusiasm

|

100 highest level of  
enthusiasm

19. IF YOU WERE TO RANK your favorite presentation format by listing 1 as your top choice, followed by 2 and 3 for your second and least favorite choices how would you rank the PODCAST?



Podcast



Whiteboard animation



Case-based scenario



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SASKATCHEWAN

20. Are there any things you would improve or change about the PODCAST presentation?

21. Are there any things you would improve or change about the WHITEBOARD ANIMATION presentation?

22. Are there any things you would improve or change about the CASE-BASED presentation?



# DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

23. Do you have any other thoughts about the presentation of these educational modes?



The following questions pertain to the general digital dementia education of healthcare professionals. When answering these questions think about all of the three digital educational formats you just sampled, and think of these in context of your work environment, and your practice.

Please indicate your agreement or disagreement with the following statements, by moving your cursor on the line to indicate how strongly you are leaning toward one position (completely disagree) or the other position (completely agree).

24. This educational technology on dementia can improve patient outcomes.

0 completely disagree 100 completely agree

25. This educational technology on dementia can enhance a team approach to care.

0 completely disagree 100 completely agree

26. This educational technology on dementia can enhance best practice.

0 completely disagree 100 completely agree

27. This educational technology on dementia can enhance the work activities I complete during my shift.

0 completely disagree 100 completely agree

28. I see myself as a champion/leader for this educational technology on dementia within my healthcare team.

0 completely disagree 100 completely agree



## DIGITAL TOOLS FOR DELIVERY OF DEMENTIA EDUCATION

37. I would be capable of successfully performing my job, while engaging in learning about dementia through this technology.

0 completely disagree 100 completely agree

