3-20-2017

Improving Dementia Care through Online Training Programs: A Systematic Review and Evaluation

Michelle L. Pleasant
University of South Florida, mfc980@gmail.com

Scholar Commons Citation
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Improving Dementia Care through Online Training Programs: A Systematic Review and Evaluation

by

Michelle L. Pleasant

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Aging Studies
College of Behavioral and Community Sciences
University of South Florida

Major Professor: Victor Molinari, Ph.D., ABPP
Kathryn Hyer, Ph.D., MPP
Hongdao Meng, Ph.D., M.P.H.
Debra Dobbs, Ph.D.
Michelle Bourgeois, Ph.D., CCC-SLP

Date of Approval:
March 21, 2017

Keywords: Online interventions, PRISMA review, Caregivers

DEDICATION

To Alice & Tom, Mimi & Pappy, Irene & Jack, and everyone I meet in my time as Hospice volunteer. Thank you for the inspiration to become a Gerontologist.

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ABSTRACT

Over the next thirty years, Alzheimer’s disease rates will increase alongside global aging. To handle the anticipated increase in demand, knowledgeable and skilled dementia caregivers are in need throughout the long-term care spectrum. Online training programs have emerged as a viable and convenient platform to educate both formal and informal caregivers. The first and second study systematically reviewed online dementia training programs and evaluated the CARES® Dementia Basics Training Program among formal and informal caregivers.

The first study is a systematic review of online dementia-based training programs for both formal and informal caregivers conducted using the Preferred Reporting Items for Systematic Reviews (PRISMA) method. Methodological quality of the final sample (*N*=15) was assessed by the Cochrane Collaboration Back Review Group criteria. Results of the systematic review suggests that online interventions improve the condition and preparedness of caregivers, but future evaluations should consider study designs with multiple time points, control groups, and content that is personalized and interactive.

In the second study, an evaluation of the online CARES® Dementia Basics Program among formal and informal caregivers was performed. The sample (N=233) included respondents from the states of OR, WA, CA and IL over three time points. Results indicate baseline differences in education, race, and caregiver type and a modest improvement in knowledge among both formal and informal caregivers. Recommendations are provided for future development and evaluation of online interventions.

CHAPTER ONE:

INTRODUCTION

The predicted increase in Alzheimer’s disease rates is at the forefront of policy initiatives at local, state, national and worldwide levels. The U.S. and other nations anticipate care needs will rise as persons with dementia (PWD) are projected to grow to 13 million in the U.S. and 131.5 million world-wide over the next thirty years (Alzheimer's Association, 2014; Prince et al., 2015). To prepare for the inevitable progression of Alzheimer’s disease, recruitment of high-quality caregivers at home and within the long-term care (LTC) spectrum is essential. It is widely theorized that psychoeducational training programs improve dementia care. An emerging method to disseminate educational content to caregivers is via the internet, also referred to as online education. Interest in this modality coincides with the increase in online learning throughout all education levels as well as the increase in daily internet use among children and adults (AARP, 2016; Liang & Chen, 2012). As research progresses in this direction, it is important to examine intervention effectiveness among formal and informal caregivers and determine factors that potentially contribute to success. The goal of this dissertation is to analyze the current online dementia care literature and evaluate the CARES® Dementia Basics Program. The CARES® acronym serves as the guiding systematic philosophy of the training program —**C**onnect, **A**ssess, **R**espond, **E**valuate and **S**hare. This introduction outlines the subsequent chapters.

The goal to improve dementia care quality, both at home and across the LTC spectrum, has been a topic of concern for over thirty years (GAO, 2015; OBRA, 1987). In Chapter Two, a discussion of contributing factors and potential remedies to improve dementia care quality is presented. Challenges reported by dementia caregivers are often centered on the deterioration of communication and presentation of behavioral symptoms (Gitlin, Kales, & Lyketsos, 2012). Many theoretical models exist to help guide caregivers and health care professionals (e.g., Algase et al., 1996; Hall & Buckwalter, 1987; Kunik et al., 2003; Lawton & Nahemow, 1973), but few who provide care are trained to observe or interpret these behaviors (Harahan & Stone, 2007; IOM, 2008). Increased education and exposure to alternative nonpharmacological therapies play a large part in transitioning care culture away from inappropriate medication use and towards person-centered care (Bonner, 2013; Tjia, Gurwitz, & Briesacher, 2012). The profile of U.S. caregivers and summary of educational intervention outcomes in formal and informal settings is also described. Further, in Chapter Two, an outline of the online dementia training literature is presented to provide context for the systematic review in the first study (Chapter Four) and the intervention in the second study (Chapter Five). Online programs allow caregivers to decide the when, where and length of training sessions. Beyond convenience, online programs incorporate a wide range of perspectives and expertise that can be shared in communities where dementia care knowledge is lacking (IOM, 2008).

In Chapter Three, the guiding theoretical frameworks of the Empowerment Theory and the Quality Health Care Model are described in addition the main aims for the first and second study. The Empowerment Theory posits that through interventions such as education, caregivers become more confident in their ability to perform caregiving tasks. The Quality Health Care Model takes this a step further and outlines the multiple factors (e.g., system, client) that potentially influence interventions in health care environments. Together these models illustrate how to improve care quality through the mechanism of educational interventions.

Chapter Four contains the first dissertation study, a Preferred Reporting Items for Systematic Reviews (PRISMA) systematic review of online dementia educational training programs among all caregivers. No previously published systematic review has analyzed online dementia training programs among both formal and informal caregivers, providing insight into program components that are successful between groups. Inclusion criteria included a pre- to post-training evaluation, reported training effects from an online training program with at least one dementia component, and published between years 2000-2016. Internet-based interventions were largely not conducted or published prior to the year 2000. A systematic search of Web of Science, PsychInfo, and Pubmed resulted in a final sample of (N=15). Methodological quality was rated by the Cochrane Collaboration Back Group criteria.

In Chapter Five is the second dissertation study, an evaluation of the online CARES$^{®}$ Dementia Basics program among caregivers within the states of Oregon, Washington, California, and Illinois over three time points. The impact of the CARES$^{®}$ intervention and potential influence of demographic and caregiving characteristics on dementia knowledge, competency in caregiving, and identification of person-centered care were examined in the second study. The longitudinal study design and use of multi-level ordinal models uniquely contributes to the literature in this area. Further, this work tested an online intervention among both formal and informal caregivers, also not often seen in the literature. Future development of online interventions can be enhanced with more evidence of how diverse caregivers respond to the CARES$^{®}$ Dementia Basics Program. Future recommendations and general and policy implications reflecting on Studies 1 & 2 are provided in Chapter Six.

CHAPTER TWO:

DEMENTIA CAREGIVING AND ONLINE TRAINING BACKGROUND

To begin, the macro factors that influence dementia-care quality throughout the long-term spectrum are explored in Chapter Two. Systemic issues within the health care system contribute to inadequate caregiver training and inappropriate medication use (Stone & Harahan, 2010; Thomas & Applebaum, 2015; Tjia et al., 2012). Little evidence, however, addresses differences in training outcomes based on caregiver type, care setting, care recipient, past experience, licensure and demographic characteristics. Although the content between training programs targeted at formal and informal caregivers varies, behavioral symptoms of dementia are a universal concern among all caregivers (Alzheimer's Association, 2014; Camp, Cohen-Mansfield, & Capezuti, 2002; Cohen-Mansfield, 2001; Schultz & Martire, 2004). Behavioral symptoms improve with a better understanding of the disease trajectory, communication skills, and person-centered care techniques. In an effort to disseminate dementia-based educational training, online platforms are explored further in detail in this chapter.

Improving Dementia Care across the LTC Spectrum

Diseases that cause symptoms of dementia currently affect over 5 million Americans. Prevalence rates are predicted to rise to 13 million by 2050, paralleling the unprecedented growth in adults age 65+ (Alzheimers Association, 2014). Alzheimer’s disease, the dominant condition that contributes to symptoms of dementia, impairs cognitive processes such as memory, thinking, and decision-making. Together these symptoms challenge an individual’s ability to remain independent in their instrumental and everyday activities of daily living. Caring for PWD is complicated and extends beyond the daily care of an adult with other chronic conditions. Dementia caregivers benefit from knowledge in a variety of domains to address the progressive and debilitating changes in communication, behavior, personality and care preferences. Demand for formal caregivers across the long-term spectrum is expected to exceed the current workforce due to increased disease rates and unique barriers to recruitment (Stone & Harahan, 2010; Stone & Wiener, 2001), notably the combination of low pay and limited professional respect within a labor intensive and high stress environment. Reflecting a widespread role among many Americans, informal caregivers provided 17.7 billion hours of dementia care at an estimated cost of $220 billion in 2013 (Alzheimer Association, 2014). Opportunity exists to prepare caregivers to provide high quality, compassionate care and it begins with educational programs that focus on Alzheimer's disease progression, communication, and person-centered care.

Behavioral Symptoms in Dementia

Changes in communication and the presentation of behavioral symptoms in PWD are highly prevalent and are often cited as the most difficult aspects of caregiving (Lyketsos et al., 2011; Selbaek, Engedal, & Bergh, 2013). Behavioral symptoms of dementia, also referred to as neuropsychiatric symptoms, or disruptive or challenging behaviors, are widely viewed as a form of communication due to declining cognitive abilities in response to unmet environmental, psychological, or biological needs (Camp et al., 2002; Cohen-Mansfield, 2000b). Behavioral and psychological symptoms include agitation, irritability, wandering, restlessness, boredom, vocalizations, apathy, or restiveness to care (Findel, Costa e Silva, Cohen, Miller, & Sartorius, 1995). Behavioral symptoms can be indicative of physical, medical and psychological changes whose causes need investigation when an individual's behavior alters from its usual state. The reality, however, is that caregivers are not routinely trained to observe or interpret behavioral symptoms of dementia. Low rates of geriatric-trained health care professionals and inadequate mental health training within the LTC spectrum contributes to the pervasiveness of undertrained caregivers (Bartels, 2003; Bartels, Moak, & Dums, 2002; IOM, 2008).

Viewing behavioral symptoms through a theoretical model allows for caregivers, clinicians, and researchers to systematically treat behaviors associated with mid- to late-stage dementia. Expressions of behavior are associated with the natural course of the disease process, suggesting that a range of intervention models can be utilized to intervene with an individual in their present state (Jost & Grossberg, 1996). Models of disruptive behavior that have been used to analyze dementia-specific interventions include person-environment fit (Lawton & Nahemow, 1973), progressively lowered stress threshold model (Hall & Buckwalter, 1987), mutable and fixed factors for behavioral symptoms (Kunik et al., 2003), the need-driven dementia-compromised behavioral model (Algase et al., 1996), and the A-B-C (i.e., Antecedent-Behavioral-Consequence) approach (Karlin, Visnic, McGee, & Teri, 2014). In a meta-analysis of caregiver interventions in the community, caregivers who employed nonpharmacological interventions (e.g., skill training, tailored activities, environmental design) were effective in reducing behavioral symptoms with a medium effect size comparable to common pharmacological interventions (Brodaty & Arasaratnam, 2012). Although the dominant form of therapy for behavioral symptoms of dementia has been pharmacological, evidence-based nonpharmacological therapies are effective, minimally invasive, and come without high drug side-effect burden (Cohen-Mansfield, 2000a; Gitlin et al., 2008; Karlin et al., 2014; van der Ploeg et al., 2013).

Inappropriate Medication among Persons with Dementia

The consequence of undertrained caregivers within a growing population of PWDs has been high rates of inappropriate psychoactive medications, and in particular, inappropriate antipsychotic medication in LTC (Bonner et al., 2015; Kamble, Chen, Sherer, & Aparasu, 2009) and community settings (GAO, 2015). The use of antipsychotic medication comes with increased risk of cardiovascular death, falls and injury (Carson, McDonagh, & Peterson, 2006; Gill et al., 2007; Huybrechts et al., 2012; Schneider, Dagerman, & Insel, 2005). Varied classes of anti-psychotic medications have been classified with a black box warning by the Food and Drug Administration in 2005 and 2008 (FDA, 2005; FDA, 2008). To help prevent unnecessary and inappropriate medication use, nonpharmacological therapies must be adopted as first line treatments, tailored to the individual, and reinforced at an institutional level. Behavioral symptoms are a form of communication, and a system of care that seeks to better understand behavioral symptoms will reduce caregiver stress and enhance care recipient well-being.

A major challenge of adapting nonpharmacological therapies into the LTC spectrum lies in the attempt to gain administrative “buy-in” and support. Nonpharmacological therapies can only be as effective as the environment in which they are introduced. Increased presence of mental health experts within the LTC spectrum would enhance the range of therapies available and promote person-centered care. Examples of nonpharmacological therapies that could be utilized are caregiver education, support groups, and interventions customized to the visible behavior (Gitlin et al., 2012). Identification and modification of a behavior’s antecedent and consequence can be embedded within every-day care routines to provide a common language between caregivers and clinical professionals (Kales, Gitlin, & Lyketsos, 2014).

Caregivers

Caregivers will be referred to as either formal or informal in the dissertation. Formal caregivers are largely paraprofessional paid caregiving staff, such as certified nurse assistants, certified medication assistants, home health aides, and direct care workers caring for persons with Alzheimer's disease or related dementias. Informal caregivers are individuals providing care in the community without compensation for someone with Alzheimer's disease or a related dementia.

Formal Caregivers

In the LTC spectrum (nursing homes, assisted living facilities, adult day care, hospice), the majority of hands-on patient care is performed by formal caregivers, a population that is largely paraprofessional (Noelker, 2001; Sengupta, Ejaz, & Harris-Kojetin, 2012; Squillace et al., 2009). Traditionally dementia care was provided in nursing homes, but with the development of assisted living facilities, care shifted to the least restrictive and more affordable option, although care quality is more loosely regulated within assisted living facilities at both the state and federal level compared to nursing homes (Smith, Buckwalter, Kang, Ellingrod, & Schultz, 2008). The LTC workforce is largely female and ethnically/racially diverse with the average educational level of a high school diploma (Katz & Frank, 2011; Squillace et al., 2009). Home health aides share a similar profile as nursing homes aides as they are predominately female, represent a range of ethnicities, and over half of this population hold a high school diploma (Fishman, 2004). Formal caregivers are the foundation of the LTC industry, yet their worth is not reflected in their pay or workload.

Educational training remains inadequate for the demands of the job. Federal law states that nursing home facilities funded by either Medicare or Medicaid require 75 hours of initial training and 12 hours of general continuing education (Stone & Bryant, 2012), but guidelines for assisted living facilities are not established on a federal level, though various states do require additional training and certification (IOM, 2008). Out of the four states where assisted living facility participants were recruited in the second study (IL, CA, OR, WA) of this dissertation, Illinois and California have annual, specific requirements for dementia training while Washington and Oregon have vague dementia training requirements. In Illinois, assisted living employees with direct care contact must complete 12 hours of in-service training annually covering Alzheimer's disease (Illinois Administrative Code, 2012). In California, caregivers in assisted living facilities caring for PWD must complete an annual eight hour in-service training specific to dementia care (California Administrative Code, 2010). In Oregon, there is a 12-hour annual requirement in ALFs, but it does not specifically state the required topics of this training (Oregon Administrative Code, 2007). In Washington, dementia caregivers must have specialty training with a competency test, but there is no content or time frames specified (Washington Administrative Code, 2011). The state-by-state variations in training requirements is particularly concerning when reports of residents in assisted living facilities have demonstrated high rates of dementia and psychiatric conditions (Rosenblatt et al., 2004), a population traditionally seen within nursing homes (Smith et al., 2008).

The states of Illinois, Oregon, Washington and California do not have additional dementia-specific training requirements in nursing homes outside of the Federal educational requirement. The Institute of Medicine recognized this imbalance and recommended that the training requirement be increased to 120 hours for all formal caregivers, with geriatric caregiving competencies formally demonstrated before entering the workforce (IOM, 2008; Rowe, Fulmer, & Fried, 2016). When asked, 40% of direct care workers from nursing homes, home health agencies and assisted living facilities responded that additional training beyond their initial job training and continuing education would be helpful in their job (Menne, Ejaz, Noelker, & Jones, 2007). Direct care workers indicated that caring for residents with dementia, communicating with residents, caring for residents with mental illness, resident care skills, and CPR would be useful topics for training (Menne et al., 2007).

Informal Caregivers

Defined as providing care for someone outside of the typical bounds of a family or friend relationship (Schultz & Martire, 2004), informal caregiving for someone with dementia can be both a rewarding and exhaustive experience. Compared to a formal or professional caregiver, informal caregivers enter their caregiving role through necessity and not by career choice. The degree of involvement and intensity of daily care routines is associated with higher physical, emotional and psychological burden as compared to caregiving for other health conditions (Alzheimer's Association, 2014; Bouldin & Andresen, 2014). Informal caregivers also encounter the hurdle of learning as they go, having entered a caregiving trajectory with little to no background or training for diseases that impair cognitive function, personality, communication and behavior. However, it is not accurate to say that caregiving only comes with negative emotions and hardships. Caregivers report positive benefits in this role, and recent literature suggests researchers should take a multidimensional view of informal caregiving (Roth, Freedman, & Haley, 2015) in terms of health and satisfaction.

Informal caregivers are two-thirds women and are likely to be caring for a parent or spouse (Bouldin & Andresen, 2014). Data from a sample of informal caregivers across eight states indicate that 57% of caregivers provide up to 8 hours of care a week, while 15% of caregivers provide 40 hours of a care a week. Informal caregivers were likely to be Non-

Hispanic white (82.6%), have some college (49.7%) or a high school degree (24%), are currently working (59%) and married (69.9%) (Bouldin & Andresen, 2014).

Educational Interventions

Formal Settings

A growing literature base supports the association between educational interventions and care quality. Certainly, a relationship exists between minimal dementia-based education and care quality in LTC. Limited dementia education in nursing homes contributes to poor quality care (IOM, 2002, 2008), staff turnover (Castle, Engberg, Anderson, & Men, 2007), job dissatisfaction (Ejaz, Noelker, Menne, & Bagaka, 2008), and difficulty in caring for persons with complicated needs (Beeber, Zimmerman, Fletcher, Mitchell, & Gould, 2010). On the other hand, education interventions have been shown to improve staff retention (Castle et al., 2007), job satisfaction (Coogle, Head, & Parham, 2006), positive communication (Burgio, Allen-Burge, et al., 2001), and behavioral symptoms among care recipients (Karlin et al., 2014; McCallion, Toseland, Lacey, & Banks, 1999). Staff educational interventions, however, do not always lead to change in behavioral symptoms in care recipients (Visser et al., 2008) and outcomes assessing care recipient status are not often evaluated.

The issues of time and resources may influence the implementation of new caregiving techniques in formal settings. Protocols with extensive time and resources may reduce the likelihood that a facility could maintain caregiving techniques long-term beyond the study period. Positive changes for caregiver self-efficacy (Davison et al., 2007) and burnout (Mackenzie & Peragine, 2003) have resulted from educational interventions, but changes were not maintained due to the above mentioned factors adversely affecting sustained outcomes.

Schnelle, Cruise, Rahman and Ouslander (1998) proposed that the potential to incorporate education into regular practice should be first evaluated in organizations before continuing education is implemented. Beck et al. (1999) also recommended that facilities should be analyzed to determine if their organizational culture affects their ability to carry out quality dementia care. Without organizational support to incorporate new behaviors into daily practice, it is nearly impossible to maintain the positive effects of educational training programs. Noted barriers attributed to organization culture include an unsupportive atmosphere, lack of reinforcement, inadequate staff support to test new skills, and peer pressure to resist new care models (Broad, 1997; Kaasalanien, 2002; Stolee et al., 2005).

Informal Settings

In a recent review of systematic reviews that evaluated intervention effectiveness among informal caregivers, psychoeducational interventions yielded convincing evidence of caregiver benefit, while respite and supportive interventions had mixed results (Gaugler & Burgio, 2016). Psychotherapy was also effective, but sessions were typically longer and more intensive. Interventions targeting informal caregivers have shown that high caregiver self-efficacy for managing symptoms of dementia was associated with lower rates of caregiver depressive symptoms and physical health burden (Fortinsky, Kercher, & Burant, 2002). The Tailored Activity Program by Gitlin et al (2008) demonstrated that a caregiver training intervention led by occupational therapists decreased behavioral symptoms by utilizing tailored activity plans. Within this intervention, PWD declined in agitation, shadowing, and repetitive vocalizations, while informal caregivers improved in self-efficacy and reported spending fewer hours being “on duty” (Gitlin et al., 2008; Gitlin et al., 2009) while being cost effective for families (Gitlin, Hodgson, & Jukowitz, 2010). A randomized control trial by Gitlin and colleagues is currently underway to assess the impact of tailored activities on neuropsychiatric symptoms within a racially diverse sample of dementia caregiving dyads (Gitlin et al., 2016).

An interesting aspect of targeting informal caregivers is gaining access to this population. A relationship has been reported between high caregiver burden and information seeking behavior (Chiao, Wu, & Hsiao, 2015). Caregivers with such characteristics as poor health, inadequate coping mechanisms, anxiety, depressive symptoms, and the inability to manage behavioral symptoms were more likely to experience caregiver burden (Chiao et al., 2015). When the likelihood of help seeking internet behavior among informal caregivers was examined, those with greater caregiving challenges were more likely to search the internet for help, but this relationship was influenced by caregiving and socioeconomic factors. Caregivers were less likely to search the internet for help if they were over 60 years old or if they were the primary caregiver, but more likely to search if they went to college, had income over $50,000, were experiencing caregiving strain, or if their health had improved recently (Li, 2015). When asked what type of help or support was needed, informal caregivers enrolled in a qualitative study identified respite, emotional reactions, caregiving essentials and self-care (Mastel-Smith & Stanley-Hermanns, 2012).

Randomized trials of educational and skills training concluded that to connect with informal caregivers, material must be individualized and tailored to the needs of each participant (Schultz et al., 2003). Results from the multi-site randomized control trail, Resources for Enhancing Alzheimer’s Caregiver Health (REACH), concluded dynamic caregiving challenges cannot be ameliorated by one “single, easily implemented, and consistently effective intervention” (Schultz, 2003). Positive effects from caregiver trainings modeled in this manner echo the importance of systematic, yet customizable training (Gitlin et al., 2008; Karlin et al.,

2014) that covers a wide range of caregiving topics that speak to the needs of informal caregivers.

As outlined, many related issues influence the quality of dementia care in LTC and community settings. An increase in demand for dementia caregiving is anticipated due to the projected number of older adults living longer with cognitive impairment, memory issues, and Alzheimer’s disease. This increase will impact both formal and informal caregivers. Current caregivers report one of the most difficult aspects of caregiving is handling behavioral symptoms of dementia, of which there is little training. Therapies and interventions targeting reduction of behavioral symptoms have been shown to be empirically effective. Widespread training for all healthcare professionals framed in person-centered care philosophy with emphasis on behavioral strategies can help alleviate miscommunication and foster better care practices across the health care spectrum. An emerging method to offer educational content to caregivers is through online training. Online learning is both convenient and easy to disseminate.

Online Dementia Educational Training Programs

Online dementia educational training programs come with many advantages. For caregivers, the flexibility of this modality adds both ease and control to the process. Online learning has become more attractive in the last decade with the increase in personal computer use and the adoption of online learning in school systems from primary to post-secondary education (Cavanaugh, Barbour, & Clark, 2009; Liang & Chen, 2012). Older adults have also embraced online technology. A 2016 AARP nationally representative survey of caregivers showed that 97% of caregivers aged 50+ and 96% of 65+ were comfortable using a personal computer (AARP, 2016). Online training programs are useful for non-traditional students, shift workers, and caregivers who balance other professions and commitments. Furthermore, training program compliance could potentially improve with online formats (Beeber et al., 2010; Rosen, Mulsant, Kastango, Mazumdar, & Fox, 2002).

In addition to the user-friendly benefits, an online format has the possibility for greater dissemination among caregivers. As summarized by the Institute of Medicine's 2008 report on preparing a health care workforce, online training allows educational materials to extend to rural or underpopulated areas where geriatric specialists are not likely available. Additionally, it may provide multiple interdisciplinary perspectives in geographic areas where such resources are not accessible (IOM, 2008). Online training permits continuous training of new staff in institutional settings and can easily incorporate booster sessions. Staff attendance has been a challenge within traditional dementia educational programs (Beeber et al., 2010) and online training may reduce conflict with training sessions during work hours. Demand for online trainings mirrors advances in the telehealth community between consumers and health care providers.

Evidence for Learning in Online Interventions

The online dementia-based educational program research to date can be characterized as limited but steady growth. What is evident from the existing literature is a wide range of topics, sample size, study design, analyses, and follow-up. One of the few systematic reviews of online dementia-based interventions specifically examining informal caregivers described the literature as methodologically underdeveloped (Boots, de Vugt, Knippenberg, Kempen, & Verhey, 2014) and unclear regarding training program compliance.

In review of caregiver trainings, there is no consensus on a standard length of training that is most beneficial for caregivers. A 2005 study by Beauchamp and colleagues found exposure to an online intervention for 32 minutes resulted in improvements of depressive symptoms, anxiety, strain and increased perception of caregiver gains after a 6-month follow-up.

Other training programs have reported improvements in psychosocial metrics after two (Irvine, Beaty, Seeley, & Bourgeois, 2012) or twelve sessions (Rosen et al., 2002) that spanned a minimum of two to six hours. Studies have also cited time as self-paced and contained varied follow-ups ranging from pre-post only, fourteen days, to six months (Hayden, Glynn, Hahn, Randall, & Randolph, 2012; Irvine, Bourgeois, Billow, & Seeley, 2007; Kajiyama et al., 2013; Lewis, Hobday, & Hepburn, 2010). However, when student engagement (defined as length of time a student spent on a video), was examined in a sample of college courses, engagement was highest in sessions that were no longer than 6 minutes, and the most successful videos changed from lecture, to power point, to interactive demonstrations throughout (Guo, Kim, & Rubin, 2014).

Goals of Training Programs between Caregiver Groups

Preliminary research suggests that formal caregiver interventions mostly focus on dementia-knowledge, caregiving competency, and skill change. Formal caregivers participate in trainings that build skills to successfully interact and care for PWD and to assess/defuse aggressive or disruptive behaviors, with the goal of educating and empowering formal caregivers. Significant, positive changes in attitudes, knowledge, self-efficacy, or competency (Devor & Renvall, 2008; Featherstone, James, Powell, Miller, & Maddison, 2004; Kuske et al., 2009; Mackenzie & Peragine, 2003; Peterson, Berg-Weger, McGillick, & Schwartz, 2002) have been reported from educational training interventions (both online and in-person) targeting formal caregivers. Formal caregiving programs touch on issues of emotional or psychosocial issues, but often as a smaller component, likely because caregiving duties are shared among all formal staff members within the LTC spectrum.

In comparison with educational interventions for formal caregivers, informal caregiving trainings focus on alleviating stress, promoting coping skills and enhancing the wellbeing of the caregiver. Evaluations of informal caregiving programs are more likely to include outcomes on emotional distress (e.g., depressive symptoms) and caregiver burden in addition to dementia-knowledge and competency. The findings on informal caregiver training has been linked to emotional well-being for caregivers (Kajiyama et al., 2013), reduced stress and anxiety (Beauchamp, Irvine, Seeley, & Johnson, 2005) and increased feelings of competency (Devor & Renvall, 2008). Evaluations of online dementia educational training programs that included both formal and informal caregivers are rare (Hattink et al., 2015; Pleasant et al., 2016). The observations discussed here regarding training content and caregiver types will be examined further in the first study (Chapter Five).

Next Steps for the Evaluation of Dementia Training Programs

It is clear that the need for effective, convenient educational opportunities will grow as the demand for caregivers increase in the coming years. Online educational training programs can be disseminated to a wide audience of caregivers and be enhanced with interdisciplinary and expert content, an advantage for caregivers in geographic areas where these resources are not available (IOM, 2008). Online programs are also gaining widespread popularity among caregivers with multiple responsibilities. A next step is to investigate caregiver performance over time and to establish factors that may enhance or hinder learning. Study Two (Chapter Six) examined the CARES® Dementia Basics program and investigated caregiving and demographic factors associated with longitudinal performance.

The CARES® Dementia Basics Program contains content that is appealing and useful to both informal and formal caregivers. CARES® Dementia Basics begins with an activity describing person-centered care through the use of a scrap book. The first lesson emphasizes the value of building relationships and understanding a care recipient's life history, specifically "knowing each person outside of their room number, diagnosis and impairments". Person-centered care translates into understanding behavior as a form of communication, a symptom of dementia that is challenging for both formal and informal caregivers.

Similar to the DICE (Describe, Investigate, Create, Evaluate) protocol developed by Kales, Gitlin, and Lyketsos (2014) to improve communication between informal caregivers and health care practitioners, CARES® also presents a systematic framework. Using the acronym CARES® (**C**onnect, **A**ssess, **R**espond, **E**valuate, **S**hare), this program assists caregivers in communicating with family members, other staff, or health care professionals about changes in the state of the care recipient. Both approaches instruct caregivers to describe and assess the presenting behavioral symptom, which encourages caregivers to disentangle the behavioral symptom from their own emotional reaction. Informal caregivers are more likely to have deep personal, emotional attachments with their care recipient and therefore it is necessary to provide a framework of care that encourages systematic monitoring and non-biased reporting. In this way, caregivers begin to view behavioral changes as a symptom of the disease, environment, health status or emotional need.

Training programs have shown improvements in Alzheimer's disease knowledge from pre- to post-training (Hobday, Savik, & Gaugler, 2010; Kuske et al., 2009; Peterson et al., 2002; Pleasant et al., 2016; Rosen et al., 2002). To prepare caregivers for the trajectory of Alzheimer's disease, it is necessary to outline the cognitive and functional changes, and establish how these symptoms differ from normal aging.

Preliminary evidence of a significant, positive change in knowledge and mastery of caregiving was demonstrated among formal caregivers after completing the CARES® Dementia Basics program (Hobday, Savik, Smith, & Gaugler, 2010; Hobday, Savik, & Gaugler, 2010; Pleasant et al., 2016). One study's sample also included informal caregivers and reported significant, but modest gains in knowledge and competency (Pleasant et al., 2016). However, it is important to note that separate analyses of informal caregivers within this study were not performed. It is hypothesized that informal caregivers will react positively to the content of CARES® Dementia Basics due to the relevant content regarding communication, person-centered care and expected changes with Alzheimer's Disease. The CARES® Dementia Basics program evaluation in the second study of this dissertation is unique because of the inclusive caregiving sample, longitudinal data and analysis of demographic and caregiving characteristics. Recommendations will be provided based on the results of each study.

CHAPTER THREE:

THEORETICAL FRAMEWORKS AND RESEARCH AIMS

In Chapter Four, the aims of this dissertation within the framework of the Empowerment Theory and the Quality Health Care Model are presented. The Empowerment Theory evaluates the potential for behavioral change at the individual and organization level, while the Quality Health Care Model provides context for educational interventions within the LTC system spectrum. Both frameworks are used as justification to promote educational interventions for caregivers in order to improve the knowledge base of dementia caregivers, which can result in behavior changes in the care of PWD.

Theoretical Models

Empowerment Theory

The Empowerment theory as it applies to caregiving for PWD began within the person-centered care movement in LTC. Empowerment, a multifaceted concept, can be thought of as consisting of four major constructs: meaning (e.g, the value of a goal or work), competence (e.g., belief in capabilities to perform skill), self-determination (e.g., perceiving the control to implement new skill) and impact (e.g., outcome of new skill or action) (Spreitzer, 1995; Thomas & Velthouse, 1990). Empowerment at the individual level consists of “situational-specific control” and is the process by which individuals gain greater control in their lives and environment (Perkins & Zimmerman, 1995). At an organizational level, empowerment theory suggests employees will work towards organizational goals when support, information, and resources permit the employee to contribute and to be acknowledged within the organization

(Kanter, 1979). Increased education empowers formal caregivers and leads to improvements in staff retention (Castle et al., 2007; McCallion et al., 1999) and job satisfaction (Coogle et al., 2006), which contributes to a person-centered care culture. Increased caregivers' empowerment is the first step towards skill change.

When the subscales of the empowerment construct were examined, support was the largest contributing factor for providing individualized care (Caspar & O'Rourke, 2008). Further analyses reveal formal caregivers feel both a lack of recognition for their work and a lack of educational opportunities, negatively influencing their ability to provide individualized care (Caspar & O'Rourke, 2008). Increased feelings of empowerment can be achieved among caregivers by training rooted in the concepts of person-centered care and behavioral modification. Within Study Two, through the mechanism of educational training, the four constructs of empowerment-- meaning, competence, self-efficacy and impact are proposed to lead to improved dementia care knowledge, sense of competency, and mastery of person-centered care techniques.

Quality Health Care Model

This dissertation is additionally grounded by the Quality Health Care Model (QHCM) (Mitchell, Ferketich, & Jennings, 1998; Mitchell & Lang, 2004). Measurement of health care quality is heavily influenced by Donabedian's Structure-Process-Outcome (SPO) theory, first introduced in 1966 (Donabedian, 1966). SPO posited that the structure (e.g., facility-level characteristics) and process (e.g., delivery of care) of an institution influences patient-level outcomes (e.g., health, satisfaction). As a result, improvements within structure and process lead to positive changes in patient health outcomes. SPO has been expanded by the QHCM, first discussed by Mitchell, Ferketich, and Jennings (1998). The pathway between interventions and outcomes is multi-directional as both the intervention and outcome can be influenced by system and client characteristics (Figure 1) (Mitchell et al., 1998). The QHCM therefore reflects the environment where educational interventions are introduced within the LTC spectrum. The QHCM framework distinctively allows the constructs of system and client to be conceptualized at both the individual and population levels (Mitchell & Lang, 2004) to reflect individual interactions within the system-wide goals of care (Mitchell et al., 1998). This framework is mostly closely linked to effectiveness research, or the evaluation of an intervention in a real-world scenario.

In viewing Figure 1, the two potentially moderating factors, client and system, can be viewed at multiple levels of individual, family or community (Mitchells 2004). Within the second study, the system factors of individual, organization, and group components include diverse caregivers' characteristics within either formal or informal settings. The other moderating factor, client, can also be viewed at multiple levels, either the individual (e.g., care recipient), family and community (e.g., supports). Without consideration of individual characteristics of both the individual and organization, the resulting intervention can only target the typical caregiver in the typical setting, without taking into consideration the variation in experience and history of the caregiver and care recipient (Bourgeois, Schultz, & Burgio, 1996). QHCM reflects the range of factors that may interact and influence the outcome of an educational training program. The absence of environmental factors in previous educational interventions is a noted criticism of the field (Stolee et al., 2005).

For educational training programs to be successful, the content must be tailored to the caregiver, and the intervention strategies tailored to the preferences of the care recipient. A criticism of past studies that utilized the QHCM framework was the focus on negative care outcomes rather than positive achievements and improvements (Mitchell & Lang, 2004). The outcomes in the second study measured improvements in caregiver knowledge, competency, and person-centered care identification.

Study Aims

The first and second study aims inform the present state of online dementia training programs. In the first study, a systematic review of online training programs among both formal and informal caregivers was conducted. Specifically, the author evaluated the current evidence of online dementia-based caregiving trainings published between 2000 and 2016 for both formal and informal caregivers. In the second study, an evaluation of the CARES® Dementia Basics Program among formal and informal caregivers was conducted. In this study, the aim was to determine if improvements from the intervention are universal. The aims was to investigate whether types of caregiving or demographic variables were associated with online education performance.

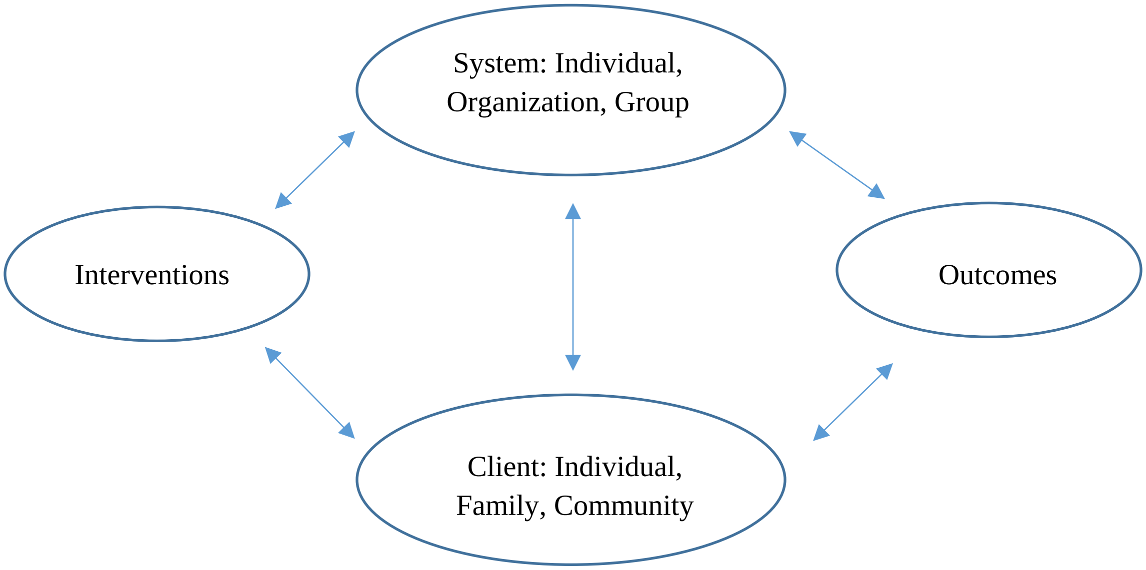

Figure 1. The Quality Health Care Model

CHAPTER FOUR:

SYSTEMATIC REVIEW OF ONLINE DEMENTIA TRAINING PROGRAMS

Few diseases impact an individual’s life in the same way as Alzheimer’s disease. Although high quality of life can be maintained throughout the disease process (Orsulic-Jeras, Judge, & Camp, 2000; van der Ploeg et al., 2013; Volicer, Simard, Pupa, Medrek, & Riordan, 2006), a time comes when it is not possible for someone with progressive cognitive impairment to continue life independently. This cause and effect requires another person to become involved in daily care of PWD in the form of either family or formal long-term care settings. The state of caregiving for PWD deserves much discussion, evaluation, and planning as the global rates of Alzheimer’s disease are anticipated to swell to 131.5 million by 2050 as adults continue to age with increased longevity (Alzheimer's Association, 2014; Prince et al., 2015).

In the pursuit to improve the caregiving experience, what is known about caregiving has been split into two defined groups: formal-- those who provide care for payment or profession and informal-- those who provide care without compensation, typically for close family members or friends. Caregivers of dementia, however, have more in common between groups than they have differences. Both groups are caregiving for the same disease process that comes with changes in behaviors, communication, and self-care abilities. Both groups require skill and strategy to connect a person’s history and personal interests with meaningful activities to reduce loneliness, boredom and depressive symptoms. Both groups are challenged to meet the care recipient where they are in the disease process and support them as best possible.

Differences between formal and informal caregiving, as described in the current literature can be viewed under the umbrella of social support. Both groups experience stress and burnout (Brodaty & Donkin, 2009; Stone & Wiener, 2001) but for formal caregivers, their employer and organizational culture have great influence on rates of turnover and satisfaction (Wiener, Squillace, Anderson, & Khatutsky, 2009). Early work in formal dementia trainings emphasize the importance of organizational culture in determining the likelihood of intervention success (Beck, Ortigara, Mercer, & Shue, 1999). For informal caregivers, self-perceived psychological health and support is critical to health outcomes while caregiving (Chiao et al., 2015). Unique components seen in programs targeting informal caregivers consist of adjusting one’s appraisal and reaction to a stressful event and promoting health-seeking behavior. For both types of caregivers, dementia training programs are recommended to both delay institutionalization and reduce LTC turnover because of evidence that empowered and educated caregivers can handle daily caregiving challenges (Caspar & O'Rourke, 2008).

Online educational interventions are an innovative medium deserving of further study. No previous systematic review has examined online training programs among both formal and informal caregivers. The goal of this systematic review is to analyze the current evidence to assist in the design and dissemination of future educational interventions.

Method

The present systematic review examined the evidence from online dementia-based caregiving training programs published between 2000 and 2016 among formal and informal caregivers. Prior to the year 2000, the majority of remote interventions were delivered through teleconferencing or CD-Rom. This systematic review of dementia-based online learning identifies gaps in the literature and presents recommendations for future program development and evaluation.

Study Design

A systematic review of online dementia care trainings with attention to assessment of learning was performed in accordance to the Preferred Reporting Items for Systematic Reviews (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & group, 2009). PRISMA guidelines provide a standardized approach for conducting systematic reviews and this method is widely respected and utilized in intervention research. No comprehensive review of online dementia-based educational programs among all caregiver types currently exists and therefore no preregistered protocol was utilized.

Inclusion criteria consisted of a pre- post evaluation, effects of training reported, and an online format (with at least a dementia component or module) published from years 2000-2016. The PICOS (i.e., P for population of interest, I for intervention, C for comparator group, O for outcome and S for study Design) framework (Table 1) operationalized the eligibility criteria to facilitate the search process (Liberati et al., 2009; Moher et al., 2009). The PICOS framework was also used in a recent synthesis of systematic reviews of family caregiver interventions (Gaugler & Burgio, 2016). Guidelines established by the Cochrane Collaboration Back Group were utilized to rate the methodological quality of the systematic review, specifically the statistical, descriptive and internal validity of the studies (van Tulder, Assendelft, Koes, Bouter, & Group, 1997). The Cochrane Collaboration Back Group criteria has been used in an educational systematic review previously (Boots et al., 2014). Meta-analysis was not performed as part of the present systematic review.

Search Methods

The literature search consisted of three electronic databases (Pubmed, PsychINFO, Web of Science), articles known to the research team, and references found within the manuscript sample from years January 2000- June 2016. Articles identified within the systematic literature search were in English and peer reviewed.

Keywords for the search were: dementia, Alzheimer's disease, mental health, training, caregiver, online, web, internet, psychosocial, intervention, evaluation, formal caregiver, informal caregiver, LTC and community. The search strategy for Web of Science is listed as an example: "Dementia" OR "Alzheimer's Disease" OR "Mental Health" AND "Training" OR "Education" OR "Intervention" OR "Evaluation" AND "Dementia caregiver*" OR "caregiver*" OR "Informal caregivers" OR "Formal caregivers" AND "online" OR "internet" OR "web" AND "psychosocial" OR "long-term care" OR "community".

Reiterative Process

Upon searching the electronic databases, some interventions included a live personal component, such as a therapist, coach, or facilitator in combination with the online educational content. Articles were considered if the participant received the live component remotely. The PICOS framework was updated to reflect the criteria change. Interventions with both an online and in-person training component were not included.

Analysis

Description of Article Selection

Figure 2 presents the search process in a flowchart. The database search described above ended with (*n*=189) articles identified. Three additional articles known to the primary reviewer and included. The initial sample (*n*=192) was examined for duplicates and (*n*=87) were removed.

The remaining records' (*n*=105) abstracts were screened for eligibility criteria, a process that excluded (*n*=62) records. The remaining (*n*=43) articles were assessed for eligibility by full-text review, a process that excluded (*n*=28) articles for reasons listed in Figure 2.

The remaining 15 full-text articles' reference lists were examined for additional sources and (*n*=51) potential articles were examined for inclusion. Upon inspection, the sources identified in the reference review were either already included in the collected sample (*n*=34) or did not meet the inclusion criteria for the systematic review (*n*=17). Therefore, no additional articles were included in the systematic review after inspection of the references. The final sample consisted of (*N*=15) peer-reviewed articles.

Data Collection and Data Items

A single reviewer (MP) collected the data from the final sample (*N*=15) with no formal interrater process; however, consultation from the second reviewer (VM) was obtained as needed. Data was collected from peer-reviewed, published literature and one publication author was contacted in the review process to clarify whether the study met the inclusion criteria. Systematic data was collected on the following components: study characteristics (study design, caregiver type targeted in training, setting of training, recruitment, eligibility criteria); participant characteristics (demographics); intervention characteristics (intervention type, duration/dose, engagement, control group, individualized component, content covered); methodological characteristics (measures); and outcomes (findings reported, satisfaction). See Table 2 for the data collected from the final sample.

Methodological Quality

Assessment of methodological quality (i.e., descriptive, statistical and internal validity) was reviewed with the Cochrane Collaboration Back Group guidelines (van Tulder et al., 1997) in Table 4. Table 5 further describes the guideline’s criteria. Total score of internal validity ranged from 0-9, with a point awarded for each criteria met (i.e., b, e, f, g, h, i, k, n, p). Total score was not negatively impacted by a rating of no (N), don’t know (DK), or not applicable (NA).

Results

The final sample consisted of N=15 peer-reviewed publications with a total of N=16 unique studies of online caregiver dementia training programs. The Irvine et al., (2012) article included two separate trials with distinct study design and methodology.

Study Design

Of the records examined, 50% (n=8/16) were randomized control trials (RCTs) (Beauchamp et al., 2005; Blom, Zarit, Groot Zwaaftink, Cuijpers, & Pot, 2015; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Irvine, Billow, Bourgeois, & Seeley, 2012; Irvine et al., 2007; Kajiyama et al., 2013; Rosen et al., 2002) and 50% (n=8/16) were pre-post cohort design. Of those eight, one had a control group (van der Roest, Meiland, Jonker, & Droes, 2010) and seven did not have a control groups (Ducharme, Dube, Levesque, Saulnier, & Giroux, 2011; Gaugler, Hobday, Robbins, & Barclay, 2015; Griffiths, Whitney, Kovaleva, & Hepburn, 2016; Hobday, Savik, Smith, et al., 2010; Hobday, Savik, & Gaugler, 2010; Irvine, Billow, et al., 2012; Irvine et al., 2013). Please see Table 2 for additional details on study design.

Description of interventions

The online interventions examined were largely interactive, multimedia platforms with video and audio lessons (Table 2). Even though the educational interventions were implemented remotely, many interactive exercises were employed within the training units. Some examples included learning module quiz/activities (Hattink et al., 2015; Irvine et al., 2007), workbooks/exercises (Ducharme et al., 2011; Griffiths et al., 2016; Irvine, Billow, et al., 2012;

Irvine et al., 2013; Kajiyama et al., 2013; Rosen et al., 2002), online forums (Cristancho-Lacroix et al., 2015; Hattink et al., 2015) and homework assignments (Blom et al., 2015). Videos embedded within the interventions depicted real or scripted caregiving scenarios to demonstrate care techniques. The number of training modules were reported in 12 studies with a range of three to 36 modules, an average of nine modules and median of seven modules. Two studies did not report specific modules, but rather employed a multi-media platform for participants explore the educational content as desired (Irvine et al., 2007; van der Roest et al., 2010). Time and dose of material varied widely between programs and is discussed in a subsequent section.

Program content contained a variety of dementia-based programs (Table 2). Interventions with Diapason, Tel-Savy, and iCare Stress Management Programs were adapted from previously validated in-person trainings (Cristancho-Lacroix et al., 2015; Griffiths et al., 2016; Kajiyama et al., 2013). Two program types appeared in more than one study: the CARES® program (although the specific content varied between studies) (Gaugler et al., 2015; Hobday, Savik, Smith, et al., 2010; Hobday, Savik, & Gaugler, 2010) and the Caring Skills: Working with Mental Illness Series (Irvine, Billow, et al., 2012; Irvine et al., 2013). Even though program content appears more than once, the participant samples differed between studies and therefore justified their inclusion within the final sample.

Level of Engagement and Personalization

Out of the sixteen studies included in the review, six contained a component that allowed for content personalization or individual feedback. Three of the six studies (Blom et al., 2015; Ducharme et al., 2011; Griffiths et al., 2016) included a live coach or facilitator to provide feedback on homework exercises, lead sessions, or was available for individual consultation and questions. Of the three studies that included a facilitator or coach to the curriculum, Ducharme et al. (2011) described training of coaches while Griffiths et al (2016) provided a manual to guide trainers. Blom et al. (2015) did not provide explicit details of the training of the coach, but stated he/she was a psychologist with experience in Alzheimer’s disease.

The other three studies included a component with personalization capabilities without the presence of a live person. Beauchamp et al. (2005) included an algorithm that provided situational-specific content in relation to a questionnaire that participants complete at the start of training. Hattink et al. (2015) included software that guided participants on a certain path based on their experience. The Hattink et al. (2015) study, however, was unique in that participants only needed to complete four of the available eight modules. With this design, more experienced caregivers could skip the introductory and basics of the disease process. Lastly, the van der Roest et al. (2010) study described both general and individually tailored information available based on participant interactions with the web-based platform. It appears the individualized component from the van der Roest et al., (2012) study was specific to dementia information and available community services.

Results of these six studies were favorable; quantitative and qualitative feedback highlighted the impact of the personalization and interactive component among the subsample of studies. For instance, caregivers reported the most conducive aspect of learning in the intervention was the personalized coaching component (Ducharme et al., 2011) and that the coach added a positive reinforcement to a virtual environment. Another study that employed a live teleconference weekly along with internet modules saw significant, positive results in both caregiver and care recipient measures (Griffiths et al., 2016). Support from other caregivers was also noted as a valuable interactive component; however, support through social media rather than teleconferences or messaging applications was utilized at a lower rate. Interestingly, the guided learning path was utilized at a more frequent rate by more experienced caregivers

(Hattink et al., 2015), suggesting that newer caregivers were interested in all aspects of the training, but more experienced caregivers customized the training based on specific needs. Caregivers noted the ability to connect with the material in a meaningful way, both through choice in material or through feedback/coaching that was available to them.

Duration of Training

Articles reported the duration of the training in differing ways. Some reported the length of the study period (*n*=6), a few reported the anticipated time to complete modules (*n*=6), and others reported the actual time spent by users in a program or website (*n*=6). Some studies did not report time of the study or intervention (*n*=4). Duration of training programs reported ranged from 6 weeks to 6 months (Beauchamp et al., 2005; Blom et al., 2015; Griffiths et al., 2016; Hattink et al., 2015; Kajiyama et al., 2013) with the majority ranging from 2 to 3 months.

Anticipated time for completion ranged from one-time exposures to daily and weekly sessions. Two studies estimated 3-hours to complete the one-time training (Gaugler et al., 2015; Hobday, Savik, & Gaugler, 2010). Other studies estimated the time per module as 6-13 minutes daily for 36 days (Griffiths et al., 2016), 15-30 minutes for each module (12) (Cristancho-Lacroix et al., 2015), 35-45 minutes for each module (12) (Rosen et al., 2002), and 60-90 minutes for each module (7) (Ducharme et al., 2011).

Actual time spent in the training or website was tracked by six studies. Beauchamp et al. (2005) reported the average time spent across the modules was *M*=32:2 (*SD*=43:5) minutes, with 59% of the sample visiting once and 41% more than once. Cristancho-Lacroix et al. (2015) reported users visited *M*=19.7 (*SD*=12.9) times for a total of *M*=262:2 (*SD*=270:7) minutes. Hattink et al. (2015) reported that 82% of participants used the learning program software to customize their path through the training. Kajiyama et al. (2013) reported participants visited the website *M*=6.42 times monthly. Irvine et al., (2013) detailed that 83% of participants accessed the modules for *M*=84:7 (*SD*=28:2) minutes. Lastly, van der Roest (2010) showed participants engaged with *M*=5.14 (*SD*=3.32) sessions for *M*=14:36 (*SD*=10:46) minutes.

Comparison of Formal and Informal Content

Of the 16 trainings, eight were targeted for informal caregivers, seven were targeted for formal caregivers and one targeted both informal and formal. Interestingly, patterns emerged in the outcomes targeted between caregiver populations. Informal caregiver trainings programs measured psychological symptomology (i.e., stress, anxiety), burden, quality of life, appraisal of stressors, daily life skills, support, health behaviors, and met/unmet needs. Formal caregiver trainings evaluated the outcomes of knowledge, competency in dementia care, attitudes, behavioral intentions, compliance, program adherence and satisfaction. One study blended outcomes and measured knowledge, attitudes, empathy, quality of life, burden and sense of competency among a sample of both formal and informal caregivers (Hattink et al., 2015).

Methodological Quality

Internal validity, descriptive quality and statistical quality were scored in Table 4 according to the Cochrane Collaboration Back Group guidelines. Please see below for further explication. Total score was not impacted by a rating of no (N), don’t know (DK), or not applicable (NA).

Internal Validity

Internal validity was made up of 9 items (Table 4) established by the Cochrane Collaboration Back Group Guidelines. Interval validity for the entire sample ranged in scores of 2-7, *M*=4.12 (*SD*=1.32) and median of 4. No study earned all 9 total points. Two criteria, ‘outcome assessor blinded to the intervention’ and ‘co-interventions avoided or comparable’ was not met by any of the studies. Studies with a total internal validity score of 4 or higher (*n*=9) were likely to be RCTs (*M*=5.13 (*SD*=1.13) with range of 4 to 7) and studies with a score of 3 or less (*n*=7) were more likely to have a pre-post cohort study design (*M*=3 (*SD*=.53) with range of 2 to 4).

Two of the strongest methodologies were Cristancho-Lacrox et al., (2015) and Blom et al., (2015) with scores of 6 and 7, respectively. The highest score concealed treatment allocation to participants (Blom et al., 2015) while both performed intent-to-treat analysis (Blom et al., 2015; Cristancho-Lacroix et al., 2015). All RCTs assessed outcomes for both groups in comparable time periods. The entire sample of studies scored 'Yes' for the relevance of outcome measures and acceptability of intervention compliance. Withdrawal and dropout rate was adequately described in 94% of the total sample.

Descriptive Quality

Descriptive quality was made up of 6 items ranging from eligibility criteria to baseline differences to length of follow-up period (Table 4). Eighty-eight percent of the studies described eligibility criteria and 100% of the sample described the intervention and or control groups. Half of sample demonstrated that the control and intervention group were similar at baseline or described how differences were controlled for in analysis. In addition, the entire sample performed a short-term follow-up. Only one study performed a long-term follow-up. No adverse events were reported.

Statistical Quality

Statistical quality consisted of 2 items: descriptions of the sample group and primary outcome measures (Table 4). All studies met the two criteria for statistical quality. The item 'sample size for each group described' was scored 'Yes' if the study accurately described a one-group study design.

Outcomes

The nine outcomes of interest for the present review (Table 1) were knowledge, competency, self-efficacy, caregiver burden, caregiver stress, depression, anxiety, care recipient status, and satisfaction. Primary outcomes were significant for most of the studies (Beauchamp et al., 2005; Blom et al., 2015; Gaugler et al., 2015; Griffiths et al., 2016; Hobday, Savik, Smith, et al., 2010; Hobday, Savik, & Gaugler, 2010; Irvine et al., 2013; Irvine et al., 2007; Kajiyama et al., 2013; Rosen et al., 2002). Four studies had a mix of significant and non-significant findings (Ducharme et al., 2011; Hattink et al., 2015; Irvine, Billow, et al., 2012; van der Roest et al., 2010). One study did not have significant main outcomes (Cristancho-Lacroix et al., 2015). Small to medium effect sizes were reported in 62% of studies (Beauchamp et al., 2005; Blom et al., 2015; Cristancho-Lacroix et al., 2015; Griffiths et al., 2016; Hattink et al., 2015; Irvine, Billow, et al., 2012; Irvine et al., 2013; Irvine et al., 2007; van der Roest et al., 2010). Sample sizes for all studies ranged from 16 to 299, with a median of 56, *M*=99 (*SD*=96). When grouped by study design, RCTs included larger samples with a median of 117, *M*=155 (*SD*=105) compared to the pre-post cohort studies with a median of 31, *M*=43 (*SD*=38).

The most widely used outcome was knowledge, evaluated in 63% (10/16) of trainings, and improved in 90% of studies post-training (Cristancho-Lacroix et al., 2015; Gaugler et al., 2015; Hobday, Savik, Smith, et al., 2010; Hobday, Savik, & Gaugler, 2010; Irvine, Billow, et al., 2012; Irvine et al., 2013; Irvine et al., 2007; Rosen et al., 2002). Self-efficacy was evaluated in 44% (7/16) of studies, with positive gains reported in 86% of caregivers post-training (6/7) (Beauchamp et al., 2005; Ducharme et al., 2011; Irvine, Billow, et al., 2012; Irvine et al., 2013; Irvine et al., 2007; van der Roest et al., 2010).

Caregiver psychological symptomology was an outcome assessed in 31% (5/16) of total studies for depression and in 19% (3/16) for anxiety. Improvements were seen across the board in anxiety (Beauchamp et al., 2005; Blom et al., 2015; Griffiths et al., 2016), but only in three of the five studies that examined depressive symptoms (Beauchamp et al., 2005; Blom et al., 2015; Griffiths et al., 2016).

Caregiver stress and burden were included as outcomes in 31% (5/16) and 19% (3/16) of training programs, respectively. Two studies decreased caregiver stress (Beauchamp et al., 2005; Kajiyama et al., 2013) and two had mixed results (Cristancho-Lacroix et al., 2015; Ducharme et al., 2011). Caregiver burden was alleviated in two out of three studies (Griffiths et al., 2016; Hattink et al., 2015). Caregiver competency was evaluated in three studies, with improvement reported in one study (van der Roest et al., 2010).

Evaluation of care recipient status was included as an outcome in four studies (Cristancho-Lacroix et al., 2015; Griffiths et al., 2016; Kajiyama et al., 2013; van der Roest et al., 2010) as frequencies of behavioral and memory problems associated with dementia. Two studies (Griffiths et al., 2016; van der Roest et al., 2010) reported improvement in behavioral and psychological symptoms of dementia as rated by the caregiver.

Almost the entire sample included an assessment of satisfaction or user opinion of the training with 94% (15/16) of the studies performing a quantitative or qualitative evaluation of user experience. The majority of ratings were favorable from users-- when asked generally about program acceptance/usefulness as well as when rating specific components (such as manual, coaches, or video content). Constructive feedback ranged from more interaction with other participants, autonomy in the program, worksheets/guidelines to complement material, and specific detail on caregiving skills (such as personal care tasks and toileting

Discussion

The aim of this systematic review was to describe the current literature on dementia-based online learning, identify gaps, and to present recommendations to create training programs that are satisfactory and beneficial to caregivers. While dementia-based training programs continue to evolve to meet the needs of caregivers, it is valuable to understand the training components and content that have been successful at improving the caregiving experience. To our knowledge, the present systematic review is the first to examine online learning among dementia caregivers, both formal and informal. Guided by the PRISMA standard in collection and evaluation of peer-reviewed literature, this review additionally used the Cochrane Review Group recommendations to rank the internal validity, statistical and descriptive quality of intervention studies.

The final sample included 16 studies reflecting caregivers in the U.S. and international settings. Impressively, just over half of the included studies were RCTs. RCTs are the gold-standard intervention design to assess efficacy of an intervention (D'Agostino & D'Agostino, 2007) and it is encouraging that the results of this systematic review reflected a trend towards a greater utilization of RCTs in evaluations of online dementia-based training programs.

Intervention outcomes were largely positive. Growth or improvement were reported in at least half if not more in outcomes of knowledge, self-efficacy, anxiety, depression, caregiver burden and satisfaction. Improvements in stress, competency and care recipient status had less consistent results. Most studies achieved a significant change in their main outcomes as result of the online intervention. The studies, however, that reported a mix of findings suggested factors such as small sample size, low power, measure selection, and engagement of sample could have possibly contributed to null results (Cristancho-Lacroix et al., 2015; Ducharme et al., 2011; Hattink et al., 2015; Kajiyama et al., 2013).

Internal validity assessed experimental design and prevention of confounding variables. The Cochrane Review Group guidelines have been used previously in a review of educational interventions that utilized a variety of study designs to evaluate statistical, descriptive and internal validity (Boots et al., 2014). RCTs had the highest total score compared to studies that employed pre-post study design. RCTs had opportunities to achieve high scores because of criteria specific to the utilization of a control group (i.e., randomization, intention to treat analysis). Although it is common in educational interventions to measure change against an individual's baseline (using participants as their own control), future studies could enhance validity by use of a control group, randomization, and concealment of treatment allocation. It not always possible, however, to conduct a RCT, given the level of resources and time that is required. Pre-post cohort designs are appealing because they require less investment in time/resources and are useful when piloting or conducting feasibility assessments of interventions, as reflected in some of the present sample. It is important to note that the RCTs in this sample were more likely to be targeted at informal caregiving populations as compared with formal caregivers who were more likely to be included as part of a pilot study.

The present sample met the two listed statistical quality criteria and the majority of the descriptive quality criteria outside of the use of long-term follow-up. The overwhelming presentation of short-term analysis, however, limits the generalizability of findings. Defined as more than 3 months after training, long-term follow up was included in only one of the sixteen studies. Without extended evaluation of training effects, it is impossible to state with confidence that online dementia training programs lead to change in meaningful ways beyond the study period. The field needs to extend evaluation from efficacy of training content to effectiveness of training content in real-world scenarios beyond a two-time point study period.

The interactive and personalization capabilities of the sample was notable. Three studies utilized an interactive component with a live coach or facilitator to guide caregivers, while three others personalized content based on caregiver type or location. These components minimize a disadvantage of online training programs—the perception of being isolated or learning content not appropriate for a specific situation. While a live person with expertise in dementia care is an ideal scenario, it may not be realistic in program design or widespread dissemination without continuous resources and personnel. Personalization or customizing content through algorithm or questionnaires to meet caregivers' needs (i.e., type of caregiver and experience) perhaps may be a more plausible goal for upcoming program design and future research. In this model, an online training program can consist of core modules that are included commonly in both informal and formal training programs and then allow a caregiver to receive additional information based on their profile, experience, and cognitive status of their care recipient. Personalized learning paths, as seen in Hattink and colleagues (2015), cater to the needs of caregivers with various levels of experience. More experienced caregivers were able to skip over the introductory modules and begin with lessons on behavioral issues, with favorable feedback. Caregiver qualitative feedback suggests online programs that are personal, allow for social interaction, and adjustable are desirable (e.g., Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Hobday, Savik, Smith, et al., 2010).

Distinctive themes emerged from the examination of intervention content of the sample studies. When analyzed by type of caregiver, four main areas emerged for formal and informal caregivers--- knowledge of dementia, behavioral management, caregiving skills, and systematic approaches. Programs for informal caregivers also contained content regarding self-care, support, and communication. A 2012 study by Mastel-Smith and Stanley-Hermanns presented qualitative feedback that informal caregivers wanted information on caregiving essentials, self-care, emotional reactions and respite. By contrast, programs targeted to formal caregivers had additional content regarding safety. Given the emphasis within the long-term care system for publicly reported quality measures it is not surprising that formal caregivers have more content regarding safety procedures. However, the dominant focus on knowledge, self-efficacy, and safety in formal caregiving trainings may be excluding the possibility of emotional burden or caregiver burden from the literature. To enrich the future of the formal training programs, additional psychosocial outcome measures could provide more context for the notable challenges of the long-term care industry, specifically high turnover and in extreme cases, caregiver abuse.

The study sample did not consistently report the length of time commitment to the online intervention, making a comparison of appropriate or recommended doses of training difficult. The current sample was divided in the documentation of study period between length of the total study period including intervention and measurement period, anticipated time to complete the online intervention, or actual time spent completing the online program. An advantage of online interventions is the ability to track time spent in the intervention, so it is feasible to report actual time spent as well as anticipated completion time as outcomes in future studies. Given the range of international studies, the outcomes measures were diverse among the study sample. Uniform reporting would enhance the comparison of studies and future growth in the field.

Generally, the results from this systematic review are favorable and encouraging for online dementia training and educational programs. The majority of studies found significant changes in participant outcomes from pre- to post-testing, with small to medium effect sizes.

There is adequate evidence to suggest online training programs are a valid modality to guide dementia caregivers and deserving of future investigation. Limitations, however, are noted. A challenge with online training programs is the question of active engagement and if other information was sought elsewhere during the study period. Study design could also be improved in future evaluations. Inconsistent results in stress and competency seen in this systematic review could be partly attributed to the range of different measures used to assess stress and competency as well as the need for booster sessions and extended follow-up. Introducing information on the progressive decline of Alzheimer's disease to caregivers without proper ongoing support may elicit feelings of stress with the long-term caregiving tasks ahead. Perhaps future studies could examine the impact of longer evaluation periods (3 to 6 months or 1 years post-training) along with intermediate booster sessions or some system of ongoing mentorship.

In conclusion, the present systematic review informed the status of online dementia training programs in multiple ways. Results are encouraging that the training programs included in this systematic review improved caregiver knowledge, self-efficacy, anxiety, depression, caregiver burden and satisfaction. Results, however, were less consistent when evaluating competency, stress, and care recipient status. Possible ways to improve the research quality in this field would be to increase the use of multiple-time point study designs, booster sessions, and control groups when possible. As this systematic review details, many distinct dementia programs and content were effective in improving outcomes. When examined for content, programs commonly focused on knowledge of dementia, behavioral management, caregiving skills, and systematic approaches. Informal caregivers additionally learned self-care techniques and emotional responses while formal caregivers received additional safety and regulatory policy. Future intervention development should consider utilizing 'core' material and customizing additional topics based on experience and preference of the caregiver. Personalization within the intervention or presence of a live coach or mentor would furthermore support caregivers, with long-term mentorship desirable. Lastly, evaluations that observe the quality of life, behavioral symptoms and needs of the care recipient in addition to the main caregiver would best inform the effectiveness and usefulness of online training programs.

Table 1

PICOS Framework for Systematic Review

Category	Criteria
Population of Interest	Informal or formal dementia caregivers of any age.
Intervention of Interest	Entirely online educational or training intervention with at least a dementia component. Programs that included a moderator, therapist, or researcher component were included if conducted remotely.
Comparator	Any comparator (any control group such as placebo, usual care, active control) or no comparator were permitted.
Outcome of Interest	Outcomes assessed were knowledge, competency, self-efficacy, caregiver burden, caregiver stress, psychological symptomology, caregiver recipient evaluation, satisfaction with training, user engagement in training.
Timing	No restrictions were placed on post-test or follow-up test timing. Publication period was from Jan 1, 2000- July 1, 2016.
Setting	No restrictions were placed on the setting of training and caregivers can be from anywhere along the LTC spectrum.

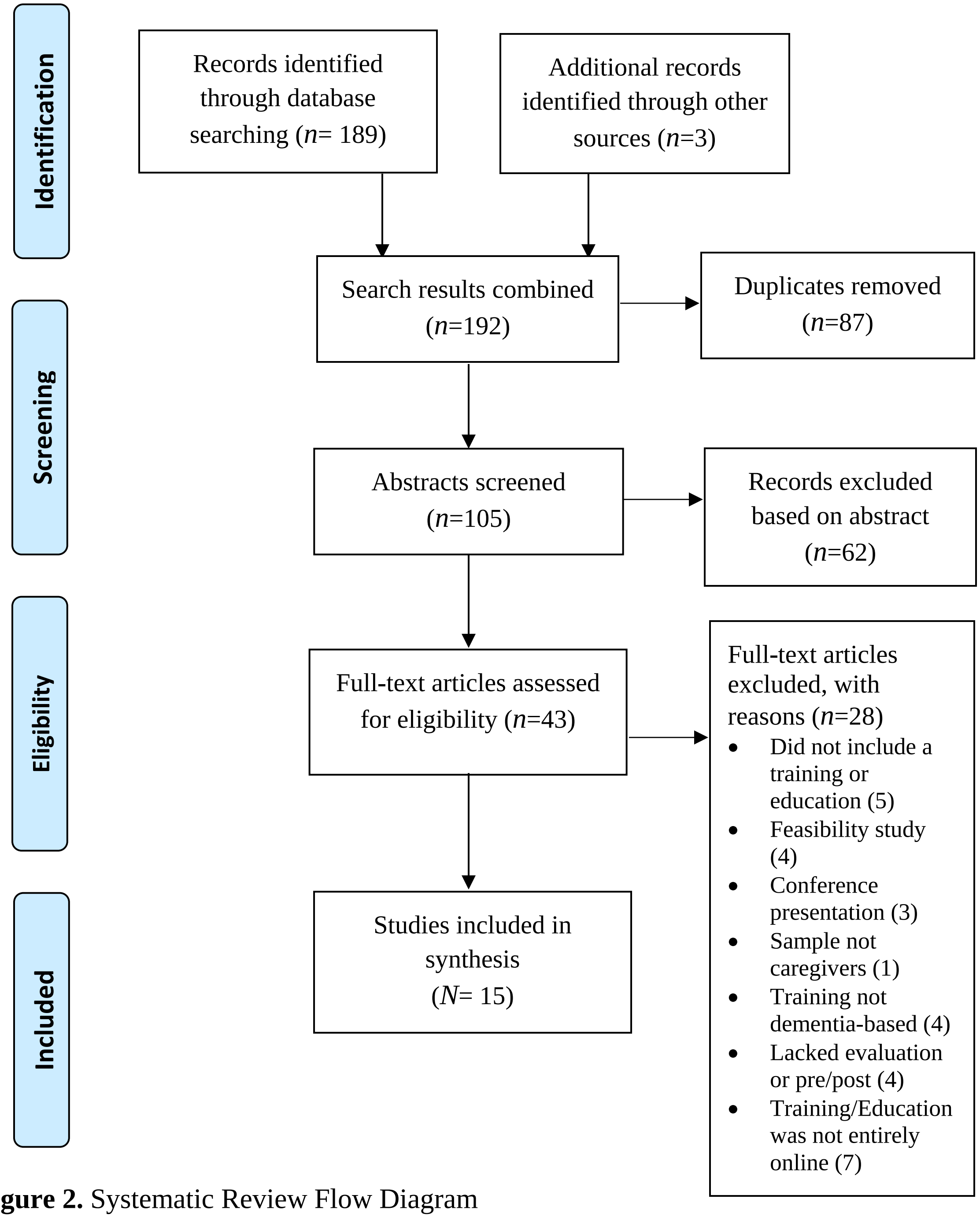

Figure 2. Systematic Review Flow Diagram

Table 2

Descriptions of Studies: Characteristics, Participants and Intervention

Study Characteristics				Participants		Intervention				
Author, year, location	Study Design	Type of caregiver and setting	Recruitment	Eligibility criteria	Demographics of Entire Sample	Intervention	Duration of training	User engagement	Control group	Customized
Beauchamp et al., 2005; USA	RCT with measures at baseline and 30-day follow up	Informal; workplace of caregivers	Recruitment from web sites, list-serves, newsletters, promotional flyers	At least part-time employment; 4 visits monthly with care recipient; report caregiver-related stress	*N*=299; age=46.9; female (73%); spouses (7%); children (67%); Caucasian (88%); some college (90%)	Online multimedia program with (3) modules	2 months	59% visited once, 41% more than once with *M*=32.2(*SD*=43.5) minutes spent across all visits	CG (*n*=149) usual care waitlist control	Yes, program guided algorithms to present situational-specific information
Blom et al., 2015; the Netherlands	RCT with measures at baseline and end of training	Informal; Participants completed on their own time	Recruited via the "Mastery over Dementia" website; newsletters; leaflets from the Alzheimer's Association; memory clinics	CES-D score of >4; score of >3 on the HADS-A or a minimum score of 6 on a burden scale	*N*= 245; age=61.2; female (69.4%); spouses (58.4%); children (39.6%); race/ethnicity (95% Dutch); education (47.3% BA or higher); live with care recipient (60.4%)	Online lessons (8) with written materials, videos, exercises; homework; and with a booster session	6 months	Not specified	CG (*n*=96) received dementia care ebullitions	Yes, given feedback on exercises
Cristancho-Lacroix et al., 2015; France	RCT with measures at baseline, 3- and 6-months post-training	Informal; Participants completed on their own time	Ads at hospital	French speaking; community-dwelling with 4+ hours weekly with care recipient; 18+; internet user; 12+ on the PSS-14	*N*=49; age= 61.6; female (65.5%); children (59%); live with care recipient (44.5%); high school education (75.5%)	Weekly 15-30 minute online sessions (12), an online forum, and educational documents	3 months	Visited website *M*=19.7 (*SD*=12.9) times for *M*=262.2 (*SD*=270.7) minutes over the study period	CG (*n*=24) usual care	No

Table 2 Continued: Descriptions of Studies: Characteristics, Participants and Intervention

Author, year, location	Study Design	Type of caregiver and setting	Recruitment	Eligibility criteria	Demographics of Entire Sample	Intervention	Duration of training	User engagement	Control group	Customized
Ducharme et al., 2011; Canada	Pre-post cohort with measures at baseline and one week post-training	Informal; Intervention took place in participant homes	From the website aidant.ca	Caregiver; at risk for caregiving-related health problems; French-speaking; No other therapies; Can use home computer with internet	*N*= 26; age=61.3; female (88%); spouses (19%); children (62%); live with care recipient (35%); edu not reported	Online sessions (7) with exercises reviewed by health care coaches	Each weekly session lasted 60-90 minutes	No specified	No	Yes, health care coach supervises online sessions and provides feedback
Gaugler et al., 2015; USA	Pre-post cohort with measures at baseline and post-training	Informal; Participants completed on their own time	Alzheimer's Association trial match service; regional offices; existing networks	Family member of someone with ADRD living at home or in an ALF; access to the internet	*N*=41; age=58; female (90.2%); Caucasian (90.2%); Bachelor's degree (72%)	Online modules (3) with care video vignettes and interviews with experts	3 hours	No	No	No
Griffiths et al., 2016; USA	Pre-post cohort with measures at baseline and post-training	Informal; on iPads in caregivers' homes	Atlanta VA Medical Center; the Geriatrics Research Education Committee; and other health care providers	Veteran caregiver or care recipient	N=22; Age=66, female (96%), spouses (73%); adult children (24%); African American (60%); education (82% HS or more)	Online daily video modules, weekly homework assignments, and one group videoconference monitored by a facilitator	6 days a week over 6 weeks; 6-13 mins daily and weekly hour video conference	No	No	Yes, weekly sessions were held by facilitator to discuss homework or questions

Table 2 Continued: Descriptions of Studies: Characteristics, Participants and Intervention

Author, year, location	Study Design	Type of caregiver and setting	Recruitment	Eligibility criteria	Demographics of Entire Sample	Intervention	Duration of training	User engagement	Control group	Customized
Hattink et al., 2015; the Netherlands and the UK	RCT with measures at baseline and post-training	Both formal and informal caregivers; Participants completed on their own time	the Netherlands: Alzheimer's org, websites; the UK: caregivers' cafes, caregiver groups, dementia organization	Computer literate; currently caregiving or volunteering with PWD	*N*=83; age=50.65; female (80.8%); spouses (30.5%); children (23%); edu not reported	Multilingual e-learning tool (8) modules; a learning path advisor; peer support with social media; learning assignments	2 to 4 months	Yes, 82% used learning advisor software	CG (*n*=46) wait list control	Learning advisor software was provided to customize learning paths based on experience
Hobday et al., 2010a; USA	Pre-post cohort	Formal; Participant completed on own time	Nursing home facilities were contacted to participate through professional colleagues by email	Direct care worker in sample nursing homes	*N*= 34; age=42.7; female (85.3%); race/ethnicity minority (67.5%); attended college or technical school (88.2%)	Online training program (3 modules)	3 hours	Users took 2.2 hours to complete three modules	No	No
Hobday et al., 2010b; USA	Pre-post cohort	Formal nurse aides	CNAs were recruited from four nursing homes and one ALF in four states	Current CNA	*N*=40; age=48.5; female (87.5%); racial/ethnic minority (64.7%); edu not reported	Online courses (4 modules)	Not specified	No	No	No

Table 2 Continued: Descriptions of Studies: Characteristics, Participants and Intervention

Author, year, location	Study Design	Type of caregiver and setting	Recruitment	Eligibility criteria	Demographics of Entire Sample	Intervention	Duration of training	User engagement	Control group	Customized
Irvine et al., 2007; USA	RCT with measures at pre- and post-training	Formal nurse aides; Participants completed on their own time	Recruited through email, website advertising, newsletter and newspaper ads	1) worked with residents with dementia; 2) somewhat confident about aggressive situations; valid email and computer	*N*= 62; (66%) between ages 26-45; Caucasian (79%); some college (40.3%)	An interactive multimedia (IMM) training; video; testimonial; narration; quizzes	Not specified	Not specified	CG (*n*=28)	No
Irvine et al., 2012; USA	Trial 1: RCT with measures at pre-post / Trial 2: Quasi-experimental pre-post design	Trial 1: Formal; Nurse Aides / Trial 2: Formal: Licensed health professionals	Recruited through email, website, newsletter, newspaper, ads	Trials 1 and 2: 1) worked with residents with dementia; 2) no more than somewhat confident about handling aggressive situations or training; valid email address and computer.	Trial 1: *N*=70; 80% between ages 21-45; female (92.9%); Caucasian (61.4%); some college (44.3%) / Trial 2: *N*=16; 50% between ages 21-45; female (93.7%); Caucasian (100%); college (75%)	Trials 1 and 2: Internet courses (5 modules) including video modeling, testimonials narration, quizzes	Not specified	Not specified	Trial 1: CG (*n*=34)/ Trail 2: No CG	No
Irvine et al., 2013; USA	Pre-post cohort	Formal; training on computers during working shifts at long-term care sites	LTCs were recruited for research by the corporate owner	Nurse aides currently employed at the LTC site; participants were paid by employer to complete	N=133; ages 21-45 (65%); female (89.5%); race/ethnic minority (56%); high school diploma (45.9%)	Internet modules (4) with video, narration, quizzes, testimonials	1.5 hours	83% completed all courses; average time on the site M=84.7 (SD=28.2)	No	No

Table 2 Continued: Descriptions of Studies: Characteristics, Participants and Intervention

Author, year, location	Study Design	Type of caregiver and setting	Recruitment	Eligibility criteria	Demographics of Entire Sample	Intervention	Duration of training	User engagement	Control group	Customized
Kajiyama et al., 2013; USA	RCT with measures at baseline and 3-months post-training	Informal; Setting not specified	Ads in family service agencies and other referral resources	over 21; caregiving for a PWD; internet; CES-D score <30 and caregiving for more than 8 hours weekly	*N*=150; age= 56.15; female (82.5%); spouses (49.5%); children (38.5%); Caucasian (91%); some college (44.5%)	Online session (8); videos of caregiving skills; workbook activities	3 months	Participants visited the website *M*=6.42 times per month	CG (*n*=75) received educational material	No
Rosen et al., 2002; USA	RCT with measures at baseline and post-training	Formal; Participants completed the program at their workplace	Three nursing homes were randomized	Core staff (RNs, LPNs, CNAs)	N=279; edu not reported	Online modules (12); module questions; interactive exercises	35-45 minutes per module over six months	Compliance was measured	Yes, CG (*n*= 106) and a lecture site (*n*=103)	No
van der Roest et al., 2010; the Netherlands	Pre-post with a control group with measures at baseline and 2-months post-training	Informal; Participants completed on their own time	Meeting centers, memory clinics, an Alzheimer's café, and newspaper adds	Caregiver in the community for a PWD for 4 hours weekly; familiar with computers; lived in study area	*N*= 28; age=65.05; female (78.6%); spouses (39.3%); children (42.85%); high education (67.85%)	DEM DISC web based platform; self-pace through material	2 months	Engaged with intervention *M*=5.14 (*SD*=3.32) with sessions lasting *M*=14:36 mins (*SD*=10:46); 78.1% finished	CG (*n*=14)	Yes, the program provides both general and tailored info to participant

Note. Person with Dementia (PWD); Center for Epidemiological Studies Scale (CES-D); The Hospital Anxiety and Depression Scale (HADS); Self-Perceived Pressure From Informal Care Scale (SPPIC); Revised Memory and Behavioral Problem Checklist (RMBPC); Short Sense of Competence Questionnaire (SSCQ), Functional status of persons with dementia (IQCODE); State-Trait Anxiety Inventory (STA-I); Caregiver Management Style (CMS); General Health Questionnaire (GHQ-28); Neuropsychiatric Inventory (NPI); Mini-mental state exam (MMSE); Global Deterioration Scale (GDS); Camberwell Assessment of Need for the Elderly (CANE); Perceived Stress Scale (PSS); Perceived Quality of Life (PQoL); Perlin Mastery Scale (PMS); Video Situational Testing (VST); Camberwell Assessment of Need for the Elderly (CANE); Quality of Life Alzheimer's Disease scale (Qol-AD); Caregiver Strain Instrument (CSI); Positive Aspects of Caregiving (PAC); Caregiver's perceived stress (PSS-14); Revised Scale for Caregiving Self-Efficacy (RSCS); Beck Depression Inventory (BDI-II); Nottingham Health Profile (NHP); Alzheimer's Disease knowledge scale (ADKS); Approaches to Dementia Questionnaire (ADQ); Interpersonal reactivity index (IRI); Perceived stress scale (PSS); Self-Efficacy Scale (SES); Stress Appraisal Measure (SAM); Goal Attainment Scale (GAS); Carers' Assessment of Managing Index (CAMI); Satisfaction/relevance questionnaire (SRQ)

Table 3

Descriptions of Studies: Methodology and Outcomes

Methodological			Outcomes	
Author, year, location	Content Covered	Outcome Measures	Findings	Satisfaction measured
Beauchamp et al., 2005; USA	"Caregiver's friend: Dealing with dementia" covered being a caregiver, coping with emotions, common difficulties, cognitive and behavioral skills, and coping skills	Primary: CSI, PAC, CES-D, STAI; Secondary: Satisfaction	From pre-test to 30-day follow-up, stress (*p*<.001), self-efficacy (*p*=.016), intention to get support (*p*=.002), caregiver strain (*p*=.028), caregiver gain (*p*=.021), depressive symptoms (*p*=.009), and state anxiety (*p*=.030) improved with mostly small effect sizes. Ways of coping (*p*=.971) did not improve	Positive ratings in satisfaction, usefulness and enjoyment of material
Blom et al., 2015; the Netherlands	"Mastery of Dementia" covered 1) coping with behavior problems; 2) relaxation; 3) arranging help from others; 4) non-helpful to helpful thoughts; 5) communication with others	Primary: CES-D, HADS; Secondary: SPPIC, SSCQ, PMS, and RMBPC; IQCODE was measured of care recipient	Symptoms of depression (*p*=.034) and anxiety (*p*=.007) improved with effect sizes of .26 and .48	No
Cristancho-Lacroix et al., 2015; France	"Diapason" (12) sessions: 1) caregiver stress, 2) understanding the disease, 3) maintain autonomy, 4) understanding reactions, 5) coping with behavioral and emotional troubles, 6) communicating with loved ones, 7) improving daily lives, 8) avoiding falls, 9) pharmacological and nonpharmacological interventions, 10) social/financial support, 11) about the future, 12) summary	Primary: PSS-14; Secondary: RSCS, RMBPC, Zarit Burden Interview, BDI-II, NHP	Self-perceived stress (*p*=.98), care recipient memory and behavior frequency (*p*=.72) and reaction (*p*=.66), burden (*p*=.74), depressive symptoms (*p*=.56), social isolation (*p*=.79), emotions (*p*=.84), energy (*p*=.22), coping (*p*=.71) and quality of relationship (*p*=.36) did not change while knowledge (*p*=.008) and stress (*p*=.05) improved	Quantitative had positive results (i.e., training useful, comprehensive and clear) while qualitative feedback was mixed with main themes of 1) I expected something else; 2) It was useful for me; 3) This is not for me; 4) It would be better for others

Table 3 Continued: Descriptions of Studies: Methodology and Outcomes

Author, year, location	Content Covered	Outcome Measures	Findings	Satisfaction measured
Ducharme et al., 2011; Canada	“Online Stress Management Training Program” covered: 1) steps of the stress mgmt. process, 2) gaining awareness of the situation, 3) analyzing the problem, 4) analyzing the context, 5) coping strategies, 6) evaluation of goals, 7) summary	SES, SAM, health risks, GAS, CAMI	Self-efficacy (p=.005), stress appraisal perceived threat (p=.03), perceived challenge (p=.05), centrality (p=.29), control by self (p=.04), informal/formal support (p=.07), uncontrollability (p=.43), global stress (p=.06); health risks (p=.007); problem solving coping (p=.31), reframing (p=.12), stress management (p=.57)	Most liked component was role of coaches while the most common dislike was lack of interaction with other participants
Gaugler et al., 2015; USA	"CARES® Dementia Care for Families" covered 1) understanding memory loss, 2) living with dementia 3) using the CARES® approach	Primary: Dementia care knowledge; Secondary: satisfaction	Knowledge significantly changed (p<.05) with 81.5% of the sample increasing in knowledge	Yes, 90% of sample agreed or strongly agreed with measures of satisfaction (compared to in-person, easy to understand, confidence)
Griffiths et al., 2016; USA	The Tel-Savvy intervention focused on caregiver's primary and secondary appraisal of a stressors and problem-solving skills	Zarit Burden Inventory-Short form, CES-D, STA-I, PMS, RMBPC, evaluation questions proposed by research team	Intervention decreased caregiver burden (p<.05), depression (p<.005), anxiety (p<.005), BPSD frequency (p<.05), caregiver reaction to BPSD (p<.05) but caregiver competency (ns) did not increase	Evaluations of program found caregivers gave M=9.4 (SD=1.18) out of 10 ratings on overall program and the varying components (manual, video vignettes, videoconferencing, self-care exercises, video module classes)

Table 3 Continued: Descriptions of Studies: Methodology and Outcomes

Author, year, location	Content Covered	Outcome Measures	Findings	Satisfaction measured
Hattink et al., 2015; the Netherlands and the UK	"European Skills Training and Reskilling (STAR)" covering 1) what is dementia? 2) living with dementia, 3) why a diagnosis is important, 4) practical difficulties, 5) emotional impact of dementia, 6) support strategies, 7) positive and empathic communication, 8) emotional impact and looking after yourself	Primary: ADKS, ADQ; Secondary: IRI, quality of life, SSCQ	Attitudes toward dementia total score improved (*p*=.001) among informal caregivers with effect size of .19; Empathy subscales of distress decreased (*p*=.001; *p*<.001) and empathy (*p*<.001; *p*<.01) and perspective (*p*<.001; *p*<.02) increased among informal and formal caregivers; Sense of competency declined in the experimental group (*p*=.02) among informal caregivers	Usefulness and user friendliness were assessed with high ratings with the most useful modules being "practical difficulties in daily life" and "support strategies" while the least useful were "what is dementia" and "getting a diagnosis"
Hobday et al., 2010a; USA	Three modules covering introduction to dementia, rethinking activities, and toileting	Knowledge inventory; Perceptions of training	Knowledge improved from pre to post test (*p*<.001)	Overall positive ratings from both quantitative and qualitative questions on perceptions/satisfactions with program
Hobday et al., 2010b; USA	Introduction to dementia; behavior management; food and fluid intake; pain management in residents; communicating with residents	Dementia care knowledge, CARES® evaluation	Knowledge (*p*=.013); Majority (88%) responded they were more confident in skills, communication, and recognizing pain	Open-ended questions determined participants liked content and disliked difficulties accessing program
Irvine et al., 2007; USA	"Professional Dementia Care: Managing Aggression" with the Assess, Investigate, Do Something (A.I.D.) approach and person-centered care	VST knowledge; VST self-efficacy; attitudes; self-efficacy; behavioral intentions; satisfaction	VST knowledge, VST self-efficacy, Attitudes, Self-Efficacy and Behavioral Intention all significantly improved (*p*=.001) with effect sizes ranging from the lowest .17 (behavioral intention) to .40 (attitudes)	Quantitatively and qualitatively assessed satisfaction with largely positive responses that the training was helpful, enjoyable, and would recommend to a friend but did not like inability to explore website at will
Irvine et al., 2012; USA	Trials 1 & 2: "Caring skills: Working with mental illness" consisted of introducing mental health, dispelling common myths, building relationships, behavioral strategies, and skill building with video scenarios	VST knowledge; VST self-efficacy; myths; attitudes; self-efficacy; behavioral intentions	Trial 1: VST knowledge (*p*=.037), self-efficacy (*p*=.05), myths (*p*=.007), attitudes (*p*=.002) and behavioral intention (*p*=.038) improved while self-efficacy did not (*p*=.541)/ Trail 2: VST self-efficacy (*p*<.001), myths (*p*=.046), attitudes (*p*<.001), behavioral intention (*p*=.018), self-efficacy (*p*<.001) VST knowledge (*p*=.083) did not	User acceptance was rated both quantitatively and qualitatively with favorable and constructive feedback

Table 3 Continued: Descriptions of Studies: Methodology and Outcomes

Author, year, location	Content Covered	Outcome Measures	Findings	Satisfaction measured
Irvine et al., 2013; USA	"Caring Skills: Working with Mental Illness" consisted of: About mental illness, the A.I.D. care strategy, care strategies for manipulative behavior and care strategies for aggressive behavior	Situational self-efficacy, situational knowledge, knowledge of mental illness, program acceptance	Self-efficacy (*p*<.001) and knowledge (*p*<.001) significantly improved at all three sites; program acceptance was positive (90% agreed or strongly agreed)	Program acceptability evaluated with 90% of participants agreed to statements about the program's content, usefulness, and influence on job skills
Kajiyama et al., 2013; USA	Online version of 'Coping with Caregiving' consisted of 1) about dementia, 2) dealing with stress, 3) how to relax, 4) pleasant activities, 5) new communication skills, 6) managing difficult behaviors, 7) healthy habits, 8) planning for the future	Primary: PSS, Secondary: RMBPC, CES-D, PQOL	Perceived stress (*p*=.003) declined; No significant change in the memory and behavioral problems (*p*=.06), depressive symptoms (*p*=.259), or perceived quality of life (*p*=.118)	Greater numbers of participants in the intervention group reported they were using the materials in real life and found it helpful
Rosen et al., 2002; USA	"Solutions of Long-Term Care" covered 1) the aging process; 2) understanding depression; 3) behavioral management of depression; 4) dementia and Alzheimer's Disease; 5) behavioral management; 6) agitation and aggression with dementia; 7) communication and the MDS; 8) medications and OBRA; 9) restraint reduction; 10) elder abuse and resident rights; 11) fire and safety; 12) pressure ulcers and skin care	Compliance, SRQ, knowledge	Compliance stronger at computer site (66%) than the lecture site (22%); Knowledge was higher for the computer site compared to the lecture site (*p*=.005)	Satisfaction was rated higher in the computer site than the lecture site (*p*=.0001)

Table 3 Continued: Descriptions of Studies: Methodology and Outcomes

Author, year, location	Content Covered	Outcome Measures	Findings	Satisfaction measured
van der Roest et al., 2010; the Netherlands	Dementia diagnosis, practical support, coping, finding company	Primary: CANE, SSCQ, PMS; Secondary: QoL-AD, USE questionnaire; Caregiver Background: CMS, GHQ-28, CES-D; Care recipient background: NPI, MMSE, GDS	Caregivers and care recipients in experimental group reported more met needs (*p*=.05), fewer unmet needs (*p*=.05), higher feelings of competency (*p*=.03) and were more likely to contact pharmacist or general practitioner (*p*<.05); There were no significant changes in reported needs by PWD (*p*=.45), total number of caregiver needs (*p*=.15), self-efficacy (*p*=.34), number of used formal services (*p*=.42), amount of professional care per week (*p*=.33), quality of life reported by caregiver (*p*=.27) and knowledge and care and welfare (*p*=.14)	Yes, friendliness, usefulness and satisfaction measured. Participants said the program was user friendly and useful, but ratings on satisfactions were neutral.

Note. Person with Dementia (PWD); Center for Epidemiological Studies Scale (CES-D); The Hospital Anxiety and Depression Scale (HADS); Self-Perceived Pressure From Informal Care Scale (SPPIC); Revised Memory and Behavioral Problem Checklist (RMBPC); Short Sense of Competence Questionnaire (SSCQ), Functional status of persons with dementia (IQCODE); State-Trait Anxiety Inventory (STA-I); Caregiver Management Style (CMS); General Health Questionnaire (GHQ-28); Neuropsychiatric Inventory (NPI); Mini-mental state exam (MMSE); Global Deterioration Scale (GDS); Camberwell Assessment of Need for the Elderly (CANE); Perceived Stress Scale (PSS); Perceived Quality of Life (PQoL); Perlin Mastery Scale (PMS); Video Situational Testing (VST); Camberwell Assessment of Need for the Elderly (CANE); Quality of Life Alzheimer's Disease scale (Qol-AD); Caregiver Strain Instrument (CSI); Positive Aspects of Caregiving (PAC); Caregiver's perceived stress (PSS-14); Revised Scale for Caregiving Self-Efficacy (RSCS); Beck Depression Inventory (BDI-II); Nottingham Health Profile (NHP); Alzheimer's Disease knowledge scale (ADKS); Approaches to Dementia Questionnaire (ADQ); Interpersonal reactivity index (IRI); Perceived stress scale (PSS); Self-Efficacy Scale (SES); Stress Appraisal Measure (SAM); Goal Attainment Scale (GAS); Carers' Assessment of Managing Index (CAMI); Satisfaction/relevance questionnaire (SRQ

Table 4

Internal, Descriptive and Statistical Validity Criteria

	Author and Year of Publication							
Criteria Quality Index	Beauchamp et al., 2005	Blom et al., 2015	Crostancho-Lacroix et al., 2015	Ducharme et al., 2011	Gaugler et al., 2015	Griffiths et al., 2016	Hattink et al., 2015	Hobday et al., 2010a
Participant Selection								
a. Eligibility criteria specified*	Y	Y	Y	Y	Y	Y	Y	DK
b. A method of randomization performed$^+$	Y	Y	Y	N	N	N	Y	N
c. Groups similar at baseline for main demographic and outcome variables*	Y	Y	Y	NA	NA	NA	Y	NA
Interventions								
d. Index and control interventions described*	Y	Y	Y	Y^x	Y^x	Y^x	Y	Y^x
e. Treatment allocation concealed$^+$	N	Y	N	NA	NA	NA	N	NA
f. Co-interventions avoided or comparable$^+$	NA	NA	NA	NA	NA	NA	NA	NA
g. Compliance acceptable in all groups$^+$	Y	Y	Y	Y^x	Y^x	Y^x	Y	Y^x
Outcome Measures								
h. Outcome assessor blinded to the intervention$^+$	DK	DK	DK	NA	NA	NA	DK	NA
i. Outcome measures relevant$^+$	Y	Y	Y	Y	Y	Y	Y	Y
j. Adverse effects described*	NA	NA	NA	NA	NA	NA	NA	NA

Table 4 Continued: Internal, Descriptive and Statistical Validity Criteria

Criteria Quality Index	Author and Year of Publication							
	Beauchamp et al., 2005	Blom et al., 2015	Crostancho-Lacroix et al., 2015	Ducharme et al., 2011	Gaugler et al., 2015	Griffiths et al., 2016	Hattink et al., 2015	Hobday et al., 2010a
k. Withdrawal/drop-out rate described and acceptable^{+}	Y	Y	Y	Y	N	Y	Y	Y
l. Short-term follow-up measurement performed*	Y	Y	Y	Y	Y	Y	Y	Y
m. Long-term follow-up measure performed*	N	N	Y	N	N	N	N	N
n. Time of the outcome assessment in both groups comparable^{+}	Y	Y	Y	NA	NA	NA	Y	NA
Statistics								
o. Sample size for each group described$^{\wedge}$	Y	Y	Y	Y^{x}	Y^{x}	Y^{x}	Y	Y^{x}
p. Analysis include an intention-to-treat analysis^{+}	N	Y	Y	NA	NA	NA	N	NA
q. Point estimates and measures of variability presented for the primary outcome measures^	Y	Y	Y	Y	Y	Y	Y	Y
Internal Validity Score	5	7	6	3	2	3	4	3

Note. Descriptive criteria*; Statistical criteria$^{\wedge}$; Internal validity criteria^{+};
Y= Yes; N=No; DN= Do not know because data/article unclear; NA= not applicable; Y on items =1 point on total scale
^{x}= No control group;
Total Score= Sum of ‘Y’ for internal validity items^{+} (b, e, f, g, h, i, k, n, p) from 0-9;
Hobday 2010a is Hobday, Savik & Gaugler; Hobday 2010b is Hobdat, Savik, Smith & Gaugler;
Irvine et al., 2012a refers to Trial 1 and 2012b to Trial 2

Table 4 Continued: Internal, Descriptive and Statistical Validity Criteria

Descriptive Items	Hobday et al., 2010b	Irvine et al., 2007	Irvine et al., 2012a	Irvine et al., 2012b	Irvine et al., 2013	Kaijyama et al., 2013	Rosen et al., 2012	van der roest et al., 2010
	Author and Year of Publication							
Participant Selection								
a. Eligibility criteria specified*	DK	Y	Y	Y	Y	Y	DK	Y
b. A method of randomization performed^{+}	N	Y	Y	N	N	Y	Y	N
c. Groups similar at baseline for main demographic and outcome variables*	NA	Y	Y	NA	NA	Y	DK	Y
Interventions								
d. Index and control interventions described*	Y^{x}	Y	Y	Y^{x}	Y^{x}	Y	Y	Y
e. Treatment allocation concealed^{+}	NA	N	N	NA	NA	DK	DK	NA
f. Co-interventions avoided or comparable^{+}	NA	NA	NA	NA	NA	NA	NA	NA
g. Compliance acceptable in all groups^{+}	Y^{x}	Y	Y	Y^{x}	Y	Y	Y	Y
Outcome Measures								
h. Outcome assessor blinded to the intervention^{+}	NA	DK	DK	NA	NA	DK	DK	DK
i. Outcome measures relevant^{+}	Y	Y	Y	Y	Y	Y	Y	Y

Table 4 Continued: Internal, Descriptive and Statistical Validity Criteria

	Author and Year of Publication							
Descriptive Items	Hobday et al., 2010b	Irvine et al., 2007	Irvine et al., 2012a	Irvine et al., 2012b	Irvine et al., 2013	Kajiyama et al., 2013	Rosen et al., 2012	van der roest et al., 2010
j. Adverse effects described*	NA	NA	NA	NA	NA	NA	NA	NA
k. Withdrawal/drop-out rate described and acceptable^{+}	Y	Y	Y	Y	Y	Y	Y	Y
l. Short-term follow-up measurement performed*	Y	Y	Y	Y	Y	Y	Y	Y
m. Long-term follow-up measure performed*	N	N	N	N	N	N	N	N
n. Time of the outcome assessment in both groups comparable^{+}	NA	Y	Y	NA	NA	Y	Y	Y
Statistics								
o. Sample size for each group described$^{\wedge}$	Y^{x}	Y	Y	Y^{x}	Y^{x}	Y	Y	Y
p. Analysis include an intention-to-treat analysis^{+}	NA	N	N	NA	NA	N	N	NA
q. Point estimates and measures of variability presented for the primary outcome measures^	Y	Y	Y	Y	Y	Y	Y	Y
Internal validity Score	3	5	5	3	3	5	5	4

Note. *Note*. Descriptive criteria*; Statistical criteria$^{\wedge}$; Internal validity criteria^{+}; Y on items =1 point on total scale
Y= Yes; N=No; DN= Do not know because data/article unclear; NA= not available;
^{x}= No control group;
Total Score= Sum of ‘Y’ for internal validity items^{+} (b, e, f, g, h, i, k, n, p) from 0-9;
Hobday 2010a is Hobday, Savik & Gaugler; Hobday 2010b is Hobdat, Savik, Smith & Gaugler
Irvine et al., 2012a refers to Trial 1 and 2012b to Trial 2

Table 5

Criteria List for Methodological Quality

Criteria	Explication of Criteria
a. Eligibility Criteria Specified*	Criteria for study participation described.
b. A method of randomization performed+	A random assignment of participants to control or intervention groups was described.
c. Groups similar at baseline for main demographic and outcome variables*	Groups are similar at baseline regarding age, caregiving descriptors and outcome values. If not similar, study address methods to correct imbalance.
d. Intervention and Control interventions described*	Adequately describes intervention and control interventions (type, duration, content).
e. Treatment allocation concealed	Group assignment unknown to participants.
f. Co-interventions avoided or comparable+	If present, a co-intervention should be comparable to intervention and control groups.
g. Compliance acceptable in all groups+	Participant compliance to intervention was adequately described or addressed.
h. Outcome assessor blinded to the intervention+	Reviewer determines if description for analysis of outcomes was provided to determine if blinding occurred.
i. Outcome measures relevant+	Reviewer determines if outcomes assessed are relevant to the intervention.
j. Adverse effects described*	Each adverse event described or stated that no adverse events occurred.
k. Withdrawal/drop-out rate described +	Participants who did not complete the intervention must be described and documented.
l. Short-term follow-up measurement performed*	Outcome assessment at the end of the intervention period.
m. Long-term follow-up measure performed*	Outcome assessment >3 months after the end of the intervention period.
n. Time of the outcome assessment in both groups comparable+	Timing of outcome assessment should be the same for both the intervention and control groups.
o. Sample size for each group described^	Sample size for each group described.
p. Analysis include an intention-to-treat analysis+	Intention-to-treat analysis included to determine change in outcomes based on participants who did not finish study.
q. Point estimates and measures of variability presented for the primary outcome measures^	Point estimates (means, medians, modes, etc.) and measures of variability (standard deviations, 95% CI, etc.) are present in description of main outcome measures.

Note. Descriptive criteria*; Statistical criteria^; Internal validity criteria+

CHAPTER FIVE:

THE CARES® DEMENTIA BASICS PROGRAM EVALUATION

To summarize the evidence presented so far, in Chapter Two, caregiver training programs were described as positively contributing to quality improvement and online dementia training programs have been successful among formal and informal caregivers. In Chapter Three, it was argued, based on the tenets of the Empowerment Theory, that psychoeducational interventions lead to caregivers that are more confident. It was also posited, based on the Quality Health Care Model, that client and system factors influence interventions in health care environments. Moreover, the systematic review of online training interventions in Chapter Four identified core educational content found within formal and informal caregiver training programs (i.e., knowledge, behavioral management, skills, systematic approaches) with largely positive change in caregiver knowledge, self-efficacy, anxiety, depression, burden and satisfaction.

To explore the themes identified in the previous four chapters, the present study evaluates the CARES® Dementia Basics Program among formal and informal caregivers as previous studies show support for the effectiveness of the CARES® program (Hobday, Savik, Smith, et al., 2010; Pleasant et al., 2016). Further, the potential influence of participants' demographic (age, education, race) and caregiving characteristics (type, location, relationship) on intervention outcomes will be examined in this study over three time points. The overall effectiveness and influence of participant characteristics will provide insight for future online training programs.

Research Aims and Hypotheses

The present study examined the effectiveness of the CARES$^{®}$ Dementia Basics Program and influence of participant caregiving or demographic characteristics on outcomes. The following hypotheses were tested:

Hypothesis 1: Both formal and informal caregivers will improve in knowledge, competency, and person-centered care identification after completing the CARES$^{®}$ Dementia Basics Program.

Hypothesis 2: Formal caregivers will demonstrate larger overall gains than informal caregivers from the training program because CARES$^{®}$ was developed for formal caregivers.

Hypothesis 3: Demographic (age, race, education) and caregiving characteristics (experience, license, care recipient, and care location) will influence the trajectory of participant scores over time.

Method

Intervention

The CARES$^{®}$ Dementia Basics Program is an online, interactive training for dementia caregivers. The training utilizes video clips of caregivers, interviews with real staff members within LTC, and various healthcare perspectives. The online program consists of four one-hour modules. The CARES$^{®}$ modules are the following: 1) Meet Clara Jones, an introduction to person-centered care; 2) Introduction to Dementia; 3), Understanding Behavior as Communication; and 4) The CARES$^{®}$ approach to <u>C</u>onnect, <u>A</u>ssess, <u>R</u>espond, <u>E</u>valuate and <u>S</u>hare with others when providing care. CARES$^{®}$ emphasizes the importance of patient connection in daily life and during care routines. The program is user friendly, developed for individuals with minimal computer experience and requires only a mouse click to progress through the program. Previous evaluations of the CARES® Dementia Basics Program provide preliminary evidence for the success of the training in pre-post dementia-based knowledge, mastery of caregiving skills, and positive qualitative feedback (Hobday, Savik, Smith, et al., 2010; Hobday, Savik, & Gaugler, 2010; Pleasant et al., 2016).

Research Design

Primary data collection ranged from March 2015 to August 2016 with support from the National Alzheimer's Association. The primary data collection timeline is below.

All changes were approved by the USF IRB (Pro 19196). Oregon Care Partners was established in 2014 to implement free training for all caregivers in the state, reflecting the Oregon Alzheimer's Disease State Plan recommendations (SPADO Force, 2012). Equal opportunity training among caregivers was funded to promote better quality care for all Oregonians with Alzheimer's disease regardless of setting. The study initially began by randomizing participants into an immediate or delayed-training protocol. Within weeks of the start of data collection, participants in the delayed-training arm of the study were dropping from the study at high rates. In an effort to disseminate the CARES® Dementia Basics training to widest audience in Oregon, as was the objectives of the grant funded project, the research team elected to stop the delayed-training arm of the study and funnel all new participants into the immediate training arm at the end of March 2015. Figure 2 illustrates the two arms of the study.

The study expanded in April 2015 to caregivers from WA, IL, CA, and TX. The immediate-training and delayed-training arms (Figure 3) were reintroduced in the additional four states. Participants from Texas and California were randomized into the immediate-training arm and participants from Illinois and Washington were randomized into the delayed-training arm.

Enrollment and Inclusion Criteria

Recruitment of participants occurred through existing consumers of CARES® in Oregon and through networking with the Oregon Health Care Association. Recruitment advertisements asked participants to go to either www.hcinteractive.com/oregon or www.oregoncarepartners.com to learn more about the research study. HCI interactive advertised to potential participants in the additional states through existing networks. Recruitment efforts were not successful in Texas and thus all participants are from OR, WA, IL, and CA.

The target population was either formal or informal caregivers of PWD. Inclusion criteria included: 1) high speed internet access from any location; 2) access to a phone; 3) fluent in English; 4) not taken previously the CARES® Dementia Basics Program; 5) currently caregiving for someone with memory loss, cognitive impairment, or dementia.

Study Protocol

After completing the informed consent and demographic questionnaire, participants in the immediate study protocol (OR, CA) were emailed a pre-test. The access code for the CARES® Dementia Basics training was emailed to participants within 24-48 hours after completing the pre-test. The CARES® access code was valid for a period of two weeks, but extensions were granted when requested. Once the CARES® training was completed, the study coordinator emailed a post-test and a completion certificate within a span of 24-48 hours. After the post-test was complete, participants were emailed a thank you and date to expect the follow-up email (30 days from completion of post-test). To encourage movement through the study protocol, participants were sent emails reminding them to either complete the pre-test, post-test or follow-up test. A gift card lottery was started for Oregon participants in month 3 of the study.

Participants who had completed either the post-test or follow-up test were entered into a bi-weekly lottery for a $20 gift card.

Participants in the delayed-training condition (WA, IL) followed a similar protocol with the exception of a two-week delay after completing the initial pre-test and addition of a second pre-test before receiving the CARES® access codes. All contact occurred via email within the same 24-48 hour window as the immediate arm of the study (Figure 3) and the questionnaires used in assessment were the same. It was estimated the immediate training arm would take 1½-2 months and the delayed-training arm would take 2 ½-3 months to complete.

Study Measures

Participants answered the same study survey at pre-test, post-test and follow-up test. The individual survey items can be found in Appendix A.

Dementia Knowledge

The 16-item dementia-based knowledge questionnaire was adapted from the CARES® EsssentiALZ certification exam by the research team with dementia expertise.

Dementia Competency

The 5-item Sense of Competence in Dementia Care Staff (SCIDS) Professionalism subscale gauged changes in caregiving attitudes and self-efficacy. Internal consistency for this measure was previously established with a Cronbach’s alpha of =.91 and a test-retest reliability of ICC= .74 (Schepers, Orrell, Shanahan, & Spector, 2012). The 5-items asked participants how well one could keep up a positive attitude towards the care recipient, the care recipient’s family, keep motivated, play an active role in the care team and deal with personal care (such as incontinence care).

Person-Centered Care Identification

Participants identified person-centered care tasks after viewing a video clip that showed a caregiver assisting a resident with dentures before a meal. HCI Interactive developed the video clip and it was not a part of the CARES® Dementia Basics Training. Participants chose from eight options in this question, of which five were correct person-centered caregiving techniques.

Analysis

Descriptive statistics were performed on all variables of interest. The main outcomes of the dementia knowledge questionnaire, the SCIDS subscale, and the person-centered care identification video vignette were analyzed over three time points. A multi-level ordinal model was used to best fit the distribution of the outcome variables.

Multi-level Ordinal Models

Hierarchical Generalized Linear Modeling (HGLM), also known as Multi-Level Modeling (MLM) allows an extension of regression analyses to be performed on data that is nested or hierarchical in nature. Multi-level models are appropriate for outcome data that is categorical or ordinal by transforming the outcome with a nonlinear link function (cumulative logit link) and non-normal error distribution (multinomial distribution) (Ene, Leighton, Blue, & Bell, 2015). By transforming the outcome variables and error distribution, the model building process and interpretation remains similar to multi-level linear models with continuous outcomes (Leke, 2004).

There are many strengths when using multi-level modeling to evaluate longitudinal repeated measures data. Multi-level models minimize the risk of an underestimated standard error and reduce the risk of Type I error by accounting for error at all levels of the nested model (Ene et al., 2015; Moerbeek, 2004). Multi-level models are also flexible with time between observations and can accommodate missing data whereas within other methods, missing data would exclude participants from analysis (Nich & Carroll, 1997). Within the two-level model of the present longitudinal repeated measures design, the level-one factor of time varies during the study period and is nested within the second-level of the participant. Specifically, the first-level factor of time consists of baseline, post-test, and 30-days post-test. The second-level includes nine possible invariant participant factors that are described in more detail in the next section. Proc Glimmix within SAS 9.4 was used for the multi-level ordinal models.

Predictor and Dependent Variables

The dependent variables had the following range in scores, with higher scores indicating better performance. The 16-item dementia questionnaire ranged in score from 3 to 16. The SCIDS questionnaire ranged from 11-20. The person-centered had a range of 2-8. The distributions of the three main dependent variables were right skewed. To enhance clarity in model interpretation, the ordinal dependent variables were divided into binary or tertile outcomes based on the distributions of each dependent variable. Knowledge and sense of competency were appropriate as tertile outcomes and person-centered care was appropriate for a binary outcome.

Within the two-level model of the present study, the level-one factor of time included baseline, post-test and follow-up test. Additionally there were nine possible level-two invariant participant factors. The majority of the demographic and caregiving characteristics of the participant sample were multinomial and dichotomized based on their distributions. Participants who answered with qualitative response in the questions regarding license, highest education, location and relationship to care recipient were categorized into the dichotomized predictor variables. The dichotomized predictor variables were sex [male=0 (*n*=27), female=1 (*n*=203)] race [other=0 (*n*=51), white=1 (*n*=174)] type of caregiver [informal=0 (*n*=49), formal=1(*n*=184)], license for caregiving [no=0 (*n*=133), yes=1 (*n*=98)], highest education [high school=0 (*n*=55), college coursework=1 (*n*=177)], location [home=0 (*n*=84), other=1 (*n*=148)], state [CA/WA/IL=0, OR=1], and relationship to care recipient [family/friend=0 (*n*=56), paid=1 (*n*=176)]. Age and previous experience (years) remain continuous factors.

Model Fit

The Maximum Likelihood (ML) method is traditionally used to estimate multi-level linear models. Other estimation methods, however, are more appropriate for non-normal outcomes, such as the skewed distributions in the present analysis. The Laplace estimation in SAS Proc Glimmix was utilized as it is appropriate for non-normal data (Smiley, Leighton, Guo, Ene, & Bell, 2015). The Laplace estimation allows one to assess model fit in the same manner as multi-level linear models. The fit indices of AIC and BIC were used to assess model fit, with lower estimates suggestive of a better fit. When estimating best fit, differences of 0-2 points is considered weak evidence to favor the more complex model and changes of 3-6 are considered strong evidence for the more complex model (O'Connell & McCoach, 2008; Smiley et al., 2015).

The first hypothesis examined if caregivers improved in all outcomes from the intervention. The second hypothesis examined if formal caregivers had larger improvements from the intervention compared to informal caregivers. The first and second hypotheses were evaluated in the following model building sequence (as seen in Tables 8, 9 and 10): Model 1 is the unconditional model, consisting of no predictors and only the random effects of the intercept. The unconditional model allows us to calculate the Intra Class Correlation (ICC), or an estimate of how much of the variance in the dependent variable exists between participants. Model 2 consists of Model 1 and the random slope for the level-1 predictor (time). Model 3 builds upon Model 2 by adding the level-2 fixed effects of state and caregiver and the level-1 predictor of time. Model 4 builds upon Model 3 with the addition of the interaction term, caregiver type*time.

The third hypothesis examined if participant caregiving or demographic characteristics differed at baseline or influenced the trajectory of performance. This hypothesis was examined by the following model building sequence (as seen in Tables 11, 12, and 13): Model 1 is the unconditional model, consisting of no predictors and only the random effects of the intercept. The unconditional model allows us to calculate the Intra Class Correlation (ICC), to estimate the variance between participants in the dependent variable. Model 2 consists of Model 1 and the random slope for the level-1 predictor of time. Model 3 builds upon Model 2 by adding the level-2 fixed effects pertinent to each outcome variable and level-1 predictor of time. Model 4 builds upon Model 3 with the addition of interactions of the significant level-2 variable(s) by time.

Results

Participant Sample

Chi-Square Test of Independence and t-tests were performed to assess potential differences between participants who signed up for study but did not continue with participants who completed the baseline and pre-test. There were no significant differences in age, previous experience, education, caregiver type, license, care recipient and care setting. There was, however, a significant differences in race between groups, x^2 (1, N=334)=4.53, p=.03. Non-responders had a greater representation of participants who were white (87%) and lower representation of participants who were other race (13%) compared to the analytic sample. Please see Figure 4 for participant flow.

The analytic sample of participants totaled N=233. There were 145 participants from the state of Oregon, 16 from California, 29 from Washington and 42 from Illinois. Oregon and

California participants were entered into the immediate-training protocol, and participants from Washington and Illinois were entered into the delayed-control protocol. Baseline scores were used for the delayed-control group as there were no significant differences between the baseline and repeated baseline survey (two-weeks later) in knowledge $t(110) = -1.78$, $p=.08$, sense of competency $t(107) = 1.33$, $p=.3$, or person-centered care identification $t(110) = 1.26$, $p=.4$.

The average age of the analytic sample was *M*=45.4 (*SD*=15.3). The majority of participants were female (87%) and white (77%) with some college or higher (76%). When asked about caregiving type, 79% of the sample identified as a formal caregiver, 21% as an informal caregiver. When asked about type of healthcare license, 53% of the sample stated they had no license for caregiving. Formal caregivers reported current job experience at *M*=3.3 (*SD*=4.4) years while informal caregivers reported *M*=3.1 (SD=3.7) years of experience.

When asked about their current caregiving setting, 42% reported an assisted living facility, 34% a home setting, 12% in a nursing home, 6% hospice and 22% reported ‘other’. When asked about specific workplace names, few participants were from the same setting with the exception of a cluster of (*n*=10) participants from Illinois who were from the same assisted living facility chain. All demographic and caregiving characteristics can be found in Tables 6 and 7.

First and Second Hypothesis

The outcomes of knowledge, sense of competency and person-centered care identification were assessed by multi-level ordinal models presented in Tables 8-10. Models were assessed by the AIC and BIC indices, with smaller estimates (greater than a change of 2) indicative of a better fit (O'Connell & McCoach, 2008; Smiley et al., 2015). To test the first and second hypotheses, the fixed effects of time, state, caregiver type and the interaction term of caregiver type*time were included in the models.

The first hypothesis that both formal and informal caregivers will improve in knowledge, competency, and person-centered care identification after the CARES® Dementia Basics Program was partially supported. For the outcome of knowledge, model 4 of Table 8 was used for interpretation. Across participants there was a positive, significant relationship between knowledge and the level-1 factor of time in the study (*b*=1.4, *p*<.001). This positive and significant relationship showed as time in the study progressed, participants' likelihood of achieving a higher knowledge score improved.

For the sense of competency outcome seen in model 4 of Table 9, the level-1 factor of time (*b*=.31, *p*=.43) was positive but not significant in the model. In the outcome of person-centered care identification on Table 10, the fixed effect of time was positive (*b*=.39, *p*=.27), but not statistically significant. In summary, the first hypothesis that all caregivers would improve due to the CARES® program was partially supported due to the significant, positive effect found in the outcome of knowledge across participants. Knowledge scores were more likely to increase during the duration of the intervention. Although competency and person-centered care identification had positive estimates of time, neither indicated significant change.

The second hypothesis that formal caregivers would demonstrate larger overall gains compared to informal caregivers was not supported. An interaction term of time*caregiver type was conducted in model 4 of Tables 8, 9, and 10 to assess if caregiver type affected participants' performance during the study period. The caregiver type by time interaction was not significant in either knowledge (*b*= -.45, *p*=.30), sense of competency (*b*= -.14, *p*=.76), or person-centered care (*b*= -.14, *p*=.72), which suggests caregiver type was not influential on participant outcomes.

The fixed effect, however, of caregiver type, demonstrated a positive, significant relationship (*b*=2.4, *p*=.003) at baseline for the sense of competency outcome as shown in model 4 of Table 9. Formal caregivers started at a higher level compared to informal caregivers in their sense of competency rating as baseline. In summary, there was no evidence to support the second hypothesis that formal caregivers would demonstrate larger overall gains compared to informal caregivers after the CARES® intervention.

Third Hypothesis

The third hypothesis tested if caregiving and demographic characteristics influenced the trajectory of participant scores in the study period. To first assess the relationship between demographic and caregiving characteristics with the main outcomes, exploratory analyses were conducted between each individual predictor variable and the three dependent variables. Predictors that contributed to model fit were included in the model building sequence shown in Tables 11, 12, and 13.

The third hypothesis that demographic and caregiving characteristics would influence the trajectory of participant outcomes was not supported. There were, however, baseline differences reported in all outcomes. The addition of the interaction terms did not enhance the model fit assessed by AIC and BIC in knowledge (Table 11), competency (Table 12), or person-centered care identification (Table 13).

The following results will describe model 4 of knowledge (Tables 11), sense of competency (Table 12) and person-centered care (Table 13). For the outcome of knowledge, the level-2 factors of education (*b*=1.4 *p*=.001) and race (*b*=1.5, *p*<.001) were significantly different at baseline. Caregivers who were White with more than a high school education had a higher score in knowledge at baseline. Similar to the results for the first and second hypothesis, a positive, level-1 factor of time was reported for Knowledge also in these models (*b*=.82, *p*=.07). The interaction terms in model 4 (Table 11) of time*education (*b*=.11, *p*=.79) and time*race (*b*=.14, *p*=.73) were not significant. Although the level-1 effect of time was not significant in model 4 for the Knowledge outcome, this is likely due to multi-collinearity of time within the model (entered in as Time, Time*Education and Time*Race). In model 3 of Table 11, the level-1 factor of time demonstrated a positive, significant effect in the model (*b*=1.0, p<.001).

For the sense of competency outcome, the level-2 factor of caregiving type (*b*=2.1, *p*=.01) was significantly different at baseline in model 4. Formal caregivers started with higher ratings in self-reported competency at baseline compared to informal caregivers. The interaction term in model 4 of time*caregiver type (*b*= -.12, *p*=.78) was not significant.

For the outcome of person-centered care identification, education (*b*=1.2, *p*=.004) was significantly different at baseline among caregivers. Caregivers with more than a high school education were more accurate in their person-centered care assessment at baseline compared to those with a higher school education or less. The interaction term in model 4 of time*caregiver type (*b*= -.53, *p*=.17) was not significant.

In summary, although no evidence supported the influence of participant factors on the intervention outcomes over time as demonstrated by the nonsignificant interaction terms, differences existed between participants at baseline for all outcomes. Education and race were significantly different at baseline in the outcome of knowledge while education differed at baseline in the outcome of person-centered care identification. Differences existed between formal and informal caregivers in sense of competency in dementia care at baseline.

Discussion

The present study aimed to evaluate the CARES® Dementia Basics Program and explore the potential influence of participant factors on study outcomes. Results indicate that across caregivers, positive and significant growth in knowledge occurred during the intervention. Growth in knowledge among caregivers is encouraging for the use of the CARES® Dementia Basics Program among both formal and informal caregivers. CARES® was designed for formal caregivers, yet both groups improved modestly in knowledge after the intervention. No differences in outcomes appeared related to demographic or caregiving characteristics, however, baseline differences in education, race, and caregiver type existed. This study assessed outcomes over three time points and offers insight to improve future study designs, content and methods.

Outcomes

The CARES® Dementia Basics Program is based on an A-B-C behavioral approach to increase the use of person-centered philosophy in dementia care. Caregivers are encouraged to incorporate the care recipient's history, likes/dislikes, and hobbies when performing care tasks in partnership with the care recipient. Enhanced relationships foster better care and communication throughout the long-term care continuum.

Dementia care knowledge is a main outcome in the majority of online training program evaluations. Similar to current literature (e.g., Cristancho-Lacroix et al., 2015; Gaugler et al., 2015), the present study demonstrated dementia knowledge improvement as a result of the psychoeducational intervention. Although gains in knowledge were modest among the sample, improvements held between both groups of caregivers in separate sensitivity analysis not reported here. Knowledge of Alzheimer's disease, the disease trajectory, and communication strategies are foundational components to increase caregivers' empowerment and sense of competency to perform care. The four empowerment constructs of meaning, competency, self-determination, and impact are inherently linked to comprehension. Caregivers begin to gain greater control of their situation with increased knowledge of Alzheimer's disease and its progressive symptomology (Spreitzer, 1995; Thomas & Velthouse, 1990). Fostering specific caregiving skills is possible with increased knowledge as a foundation.

Caregivers' sense of competency did not significantly change in response to the psychoeducational intervention in contrast to other training interventions that reported improvement in competency and perceived self-efficacy among formal (Irvine, Billow, et al., 2012) and informal (Beauchamp et al., 2005; Ducharme et al., 2011; van der Roest et al., 2010) caregivers. Caregivers sampled in this study started at baseline with high sense of competency and maintained their high scores during the study period, leaving little room for improvement. A more comprehensive sense of competency measure beyond the 5-item SCIDS Professionalism scale could provide a more nuanced look at this construct. Interestingly though, baseline differences were noted in the sense of competency ratings favoring formal caregivers. Formal caregivers are more likely to interact with a greater number of PWD in a workplace compared to a home setting and this may have contributed to baseline differences.

The person-centered care measure asked participants to identify the caregivers' actions in the video reflecting person-centered care philosophy. This measure was created after the success of the video situational testing measures that query caregivers on situational self-efficacy and knowledge after watching a short video vignette (Irvine, Billow, et al., 2012) or photo depiction of a resident behavior or caregiving scenario (Irvine et al., 2013). To improve the current measure, additional systematic questions that ask about steps to handle a caregiving situation would be beneficial. It is a complex task to evaluate caregiver skill within an online intervention. Additional investigation into alternative methods that are reliable and assess change beyond the study period is necessary to enhance the validity of online psychoeducational interventions.

Overall scores among participants for all three outcomes displayed little variation throughout the study period. At baseline, the outcomes were right skewed, suggestive of a high score on knowledge, sense of competency, and person-centered care identification. When assessed for normal distribution, all three items violated the skewness and kurtosis estimates, confirming the lack of a normal distribution. A few possibilities exist for the high scores at baseline. One possibility is that the participant sample was more experienced (~3 years) and more educated (65% some college or higher) than what was expected for an introductory dementia care intervention. The participant sample likely came with knowledge of dementia, the disease process, and symptom progression, all topics covered in the CARES® Dementia Basics Program. The combination of experienced and educated caregivers may have contributed to a ceiling effect in the outcome data.

Another possibility for the distributions seen in the present study could have involved the outcome measures. Two of the three outcomes created, in part, by the research team were not piloted before the study period. The knowledge assessment was adapted from the Alzheimer’s Association essentiALZ certification and the research team created the person-centered care identification video question. The SCIDS professionalism subscale utilized to assess caregiver self-efficacy was validated among formal, professional caregivers and the present sample included informal caregivers. Inclusion of a measure in addition to the SCIDS professional subscale tailored to the specific needs of informal caregivers (i.e., emotional, psychological, self-care) could have additionally enhanced the results. In a previous assessment of perceived self-efficacy among informal caregivers, questionnaire items were grouped into self-management and community support services and a relationship existed between lower rates of psychological and physical burden and higher perceived self-efficacy (Fortinsky et al., 2002). Follow-up item analysis to confirm the assessments' content and construct validity would also enrich the discussion and future use of these measures.

Limitations and Future Directions

Interventions conducted online face unique obstacles in monitoring the success of an intervention. Three components of treatment implementation—treatment delivery, treatment receipt, and treatment enactment should be monitored in behavioral interventions (Burgio, Corcoran, et al., 2001) to enhance validity. Treatment delivery, or monitoring of the interventionist and treatment procedure, was standardized in the present study by the use of online training modules. Treatment receipt, or understanding the degree of intervention absorption, can be evaluated through knowledge or skill gain, which was assessed, in part, by the knowledge questionnaire in the present study. The last component, treatment enactment, is the evaluation of skill change outside of the study period. The person-centered care measure was created to assess skill enactment in absence of participant observation in the current study. Treatment enactment, however, is measured best through direct observation, a challenge for online interventions. Potential ways to implement treatment enactment online could be to increase participant feedback post-intervention or include a remote video session where an interventionist could query on skill use in the workplace or home environment (Burgio, Corcoran, et al., 2001). Asking participants in follow-up if they have been able to incorporate the new skills into practice would also be useful. Qualitative findings from a recent evaluation of the four hour CARES Serious Mental Illness training among certified nurse assistants suggested participants enjoyed the convenience and real-world examples presented in the online training, but also disliked the length of training and technical issues they faced (Molinari et al., 2016). Additional qualitative feedback from participants can help to inform future program development and allow for a better understanding of the implementation of training lessons. Meaningful evaluations remain one of the largest challenge in the future of online training programs.

Compliance and spillover during the training period are important assessment components to be mindful of in an online research study. In the present study, it was unknown how engaged participants were or if participants were exposed to other information regarding dementia care. Participants from ALFs were from some states that had additional training requirements and we are unaware if any mandatory training took place during the study period. The present sample may not be generalizable to all caregivers; although they are predominately female, sample does not reflect what we know in terms of racial/ethnic makeup or education levels for formal caregivers (Squillace et al., 2009) but is similar to the makeup of informal caregivers (Bouldin & Andresen, 2014). Our present sample is predominately white (77%) and most have had at least some college (65%).

Recommendations for Future Studies

It is possible to create an online dementia based training program targeting both formal and informal caregivers. As this study demonstrated, all participants improved in knowledge. There are, however, strategic changes that could enhance the reach and depth of information. Online formats can be widely disseminated and still be customized to the caregiver type, location, and previous experience. Online formats also have the potential to provide continuous support for caregivers through personal consultation or booster sessions.

One method to enhance to psychoeducational interventions would be to create more interactive and personalized components. One way to achieve this would be to include a coach or facilitator to review homework exercises or answer personal caregiving questions as done in Blom et al., (2015), Ducharme et al., (2011), in Griffiths et al., (2016). If that is not feasible for widespread dissemination, another successful technique described in the literature was the ability to customize the content to an individual's needs as in Hattink et al., (2015) and Beauchamp et al., (2005). In the study by Hattink and colleagues (2015), learners filled out an 'about me' form and an algorithm set them on a unique learning path based on their caregiving experience. Further, being able to identify as a parent, spouse, or professional caregiver at the start of a training as in Beauchamp et al., (2005), allowed the learner to view content specific to their role instead of generalized material for all caregivers. Past research (e.g., Gitlin et al., 2003; Schultz et al., 2003) suggests informal caregivers respond to tailored content and these options are deserving of further exploration.

The baseline differences in education, race, and caregiver type observed in this study provides guidance for the conceptualization and design of future studies. Although there was no evidence that caregiver demographic or caregiving characteristics influenced the trajectory of participant outcomes, replication of this work is necessary. Baseline differences were apparent, but the null interactions observed could be due to either lack of a relationship or the lack of variance in the outcomes of the present sample. Without adequate variance in the outcomes over time, it is challenging to assess possible potential influence on scores over time. The Quality Health Care Model was the theoretical foundation for the third hypothesis and asserts that system and client factors moderate intervention outcomes in health care environments. It is plausible that the system and person-level factors throughout the long-term care system could reinforce or hinder an intervention as previous work details the challenges of incorporating educational initiatives in a long-term care environment (Broad, 1997; Kaasalanien, 2002; Stolee et al., 2005). Likewise, the support or lack of support when caregiving within the community can potentially affect intervention outcomes over time. Continual support, education, and mentorship is necessary to incorporate new caregiving initiatives into practice.

The current study evaluated change in knowledge, competency, and person-centered care identification as result of the CARES® Dementia Basics Training among both formal and informal caregivers across three time points. Results indicated modest growth in knowledge among all caregivers during the study period, and although not significant, change in the two other outcome measures were positive. This study demonstrates promising results and future replication studies should consider the degree of caregiving experience and psychometrics of outcome measurements to decrease the likelihood of a ceiling effect in the data. Similar to the current study, multiple time points to investigate the long-term effects of interventions are recommended. The CARES® program offers a systematic, yet customizable framework that encourages connection between caregivers and care recipients, and as detailed in this study, is a valuable tool to prepare and retain dementia caregivers in the coming years.

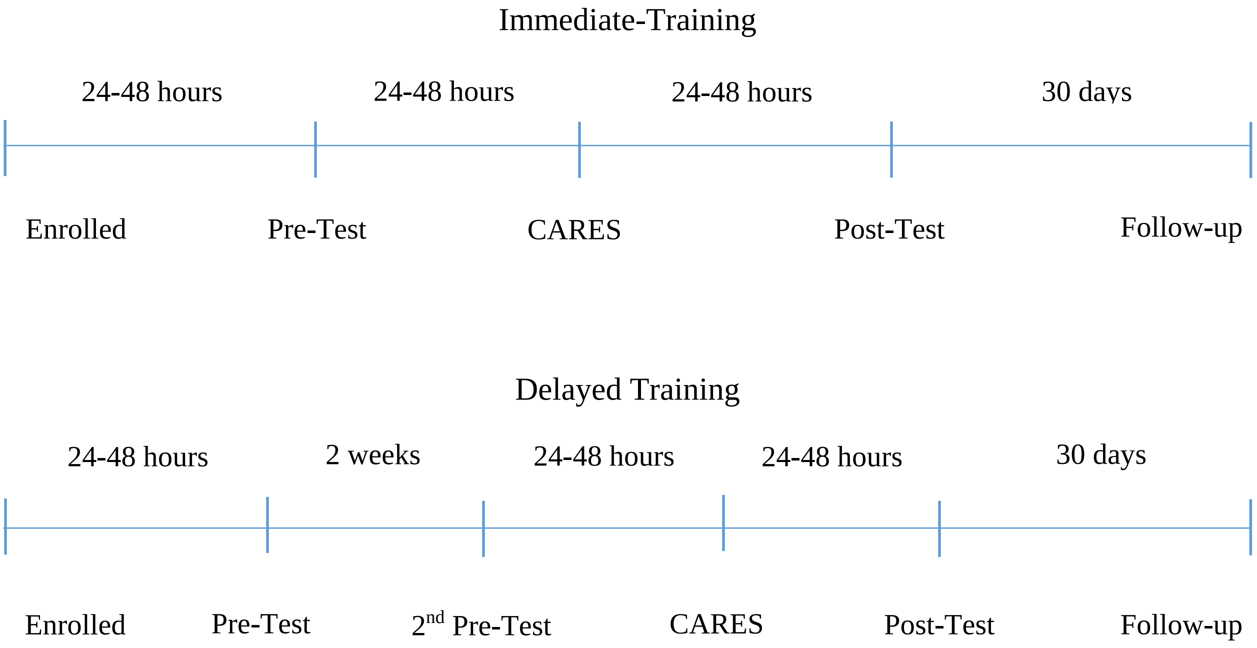

Figure 3. Immediate and Delayed-Training CARES® Study Protocols

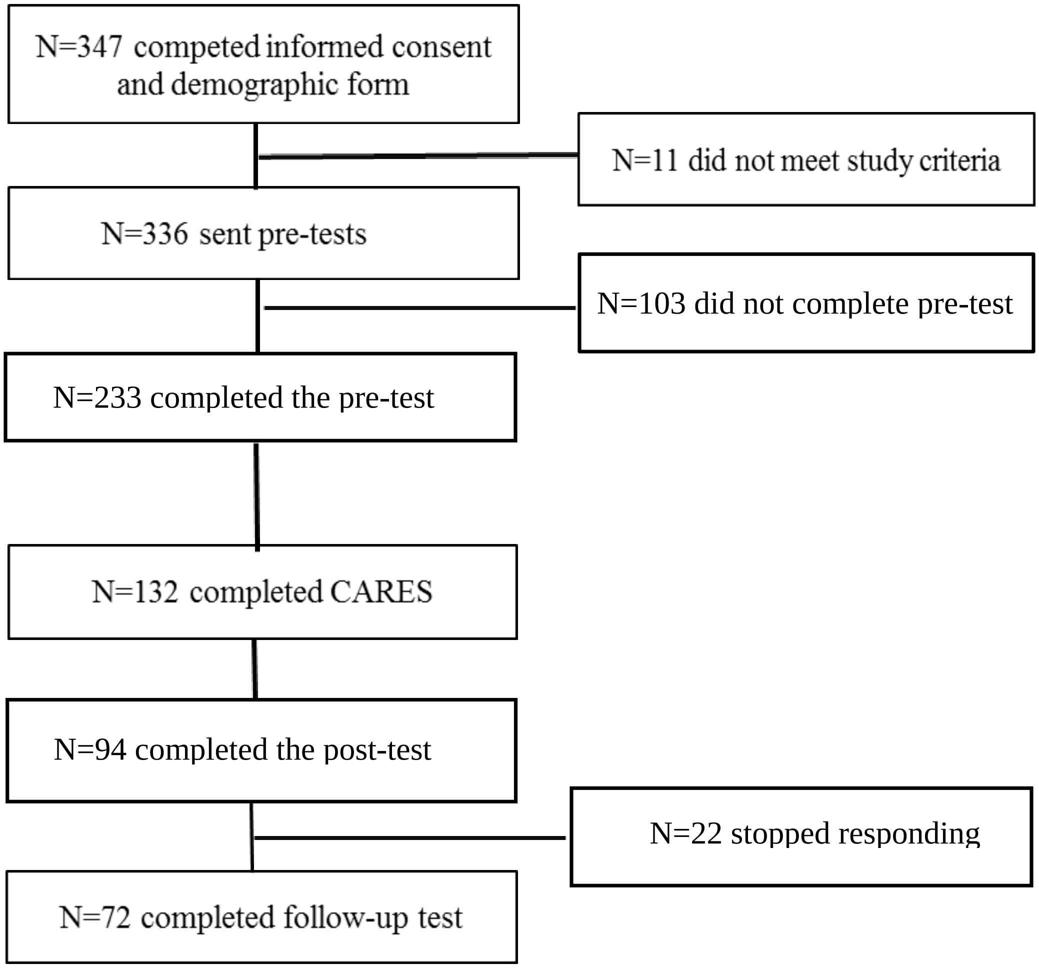

Figure 4. Flow Chart of Participants in the CARES® Online Evaluation

Table 6

Demographic Characteristics of Sample (N=233)

Characteristic	*M* or (n)	*SD* or (%)
Age	*45.4*	*15.3*
Sex		
Female	203	87%
Male	27	12%
Missing	3	1%
Race		
White	174	77%
Other Race	51	23%
Missing	8	2%
Ethnicity		
Hispanic	17	7%
Education		
High School	44	19%
GED	11	5%
Some college	82	35%
Associate's Degree	25	11%
Bachelor's Degree	45	19%
Other	26	11%
Missing	0	0
Knowledge		
Time 1	*12.4*	*2.4*
Time 2	*14*	*2*
Time 3	*14*	*1.8*
Sense of Competency		
Time 1	*17.7*	*2.3*
Time 2	*18.3*	*2.1*
Time 3	*18.1*	*2.1*
Person-Centered Care		
Time 1	*6.1*	*1.4*
Time 2	*6.6*	*1.3*
Time 3	*6.5*	*1.1*

Note. Other race consists of Black (32), Asian (12), American Indian (8), and Hawaiian (2); The 16-item dementia questionnaire score ranged from 3-16; The SCIDS questionnaire ranged from 11-20; The person-centered ranged from 2-8.

Table 7

Caregiving Characteristics of Sample (N=233)

Characteristic		*M* or (n)	*SD* or (%)
Type			
	Formal	184	79%
	Informal	49	21%
License			
	Certified Nurse Assistant	49	20%
	Certified Medication Aide	4	2%
	Home Health Aide	8	3%
	Licensed Practical Nurse	9	4%
	Registered Nurse	18	7%
	Other	28	11%
	No License	133	53%
Relationship to Care Recipient			
	Paid	156	67%
	Spouse	10	4%
	Child	21	9%
	Sibling	2	.01%
	Extended Family	8	3%
	Friend	6	3%
	Other	29	12%
	Missing	1	0%
Location of Caregiving			
	Home Setting	80	34%
	Nursing Home	27	12%
	Assisted Living Facility	97	42%
	Hospice	6	3%
	Other	22	9%
	Missing	1	0.4%
Current job experience (years)			
	Formal	*3.3*	*4.4*
	Informal	*3.1*	*3.7*

Note. License type is out of 249 because participants could choose more than one license

Table 8

Two-level Ordinal Model predicting Knowledge by Caregiving Type

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time			1.0* (.28)	1.4* (.47)
Level -2 Factors				
State (Oregon)			.36 (.34)	.36 (.34)
Caregiver type (Formal)			.02 (.39)	.21 (.43)
Time*Caregiver Type				-.45 (.43)
Intercept				
Intercept 2 (scores 14-16)	-.23 (.17)	-.23 (.17)	-1.0* (.47)	-1.2* (.5)
Intercept 1 (scores 12-13)	1.6* (.2)	1.6* (.2)	1.0* (.46)	.85 (.48)
Error Variance				
Intercept	2.1* (.78)	2.1* (.78)	2.2* (.85)	2.3* (.87)
Time		0	.01 (.49)	.03 (.49)
Model Fit				
AIC	908.97	807.97	774.27	775.08 [a]
BIC	818.29	818.29	798.36	802.65 [a]

Note: *p<.05; [a]Model used for interpretation. ICC=.39; Values based on SAS Proc Glimmix. Intercept 0 (scores 3-11) 31% of sample; Intercept 1 (scores 12-13) 33% of sample; Intercept 2 (scores 14-16) 36% of sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

Table 9

Two-level Ordinal Model predicting Sense of Competency by Caregiving Type

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time			.21 (.19)	.31 (.38)
Level-2 Factor				
State (Oregon)			-.73 (.54)	-.73 (.54)
Caregiver type (Formal)			2.3* (.75)	2.4* (.77)
Time*Caregiver Type				-.14 (.44)
Intercept				
Intercept 2 (score of 20)	-1.24* (.31)	-1.24* (.31)	-2.7* (.86)	-2.8* (.87)
Intercept 1 (scores 17-19)	1.9* (.34)	1.93 (.34)	.48 (.74)	.42 (.76)
Error Variance				
Intercept	9.4* (2.96)	9.4* (2.95)	8.9* (3.26)	8.9* (3.24)
Time		0	.03 (.54)	.01 (.53)
Model Fit				
AIC	776.05	776.05	764.23	766.14 [a]
BIC	786.35	786.35	788.27	793.61 [a]

Note: *p<.05; [a]Model used for interpretation. ICC=.74; Values based on SAS Proc Glimmix. Intercept 0 (scores 11-16): 30% of sample; Intercept 1 (scores 17-19) 35% of sample; Intercept 2 (score 20) 35% of sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

Table 10

Two-level Ordinal Model predicting Person-Centered Care by Caregiving Type

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time			.28 (.15)	.39 (.35)
Level-2 Factor				
State (Oregon)			.37 (.28)	.37 (.28)
Caregiver type (Formal)			-.23 (.32)	-.15 (.38)
Time*Caregiver Type				-.14 (.37)
Intercept				
Intercept 1 (scores 7-8)	.17 (.13)	.17 (.13)	-.03 (.37)	-.09 (.41)
Error Variance				
Intercept	.88* (.47)	.88* (.47)	.76* (.43)	.75 (.49)
Time		0	0	.01 (.35)
Model Fit				
AIC	544.28	544.28	543.59	547.45 [a]
BIC	551.17	551.17	560.81	571.55 [a]

Note: *p<.05; [a]Model used for interpretation. ICC= .21; Values based on SAS Proc Glimmix. Intercept 0 (scores 3-6) is 51.5% of the sample, Intercept 1 (scores 7-8) is 48.5% of the sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

Table 11

Two-level Ordinal Model of Knowledge by Caregiving Characteristics

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time		.	1.0* (.18)	.82 (.44)
Level-2 Factor				
Education (Some College +)			1.5* (.38)	1.4* (.42)
Race (White)			1.6* (.40)	1.5* (.43)
Time*Education				.11 (.4)
Time*Race				.14 (.4)
Intercept				
Intercept 2 (scores 15-16)	-.23 (.17)	-.23 (.17)	-3.1* (.66)	-3.0* (.55)
Intercept 1 (scores 12-13)	1.6 (.2)	1.6 (.2)	-1 (.59)	.91* (.47)
Error Variance				
Intercept	2.1* (.78)	2.1* (.78)	1.9* (.73)	1.9* (.74)
Time		0	0	0
Model Fit				
AIC	807.97	807.97	714.97	718.74 [a]
BIC	818.29	818.29	735.39	745.96 [a]

Note: *p<.05; [a]Model used for interpretation. ICC=.39; Values based on SAS Proc Glimmix. Intercept 0 (scores 3-11) 31% of sample, Intercept 1 (scores 12-13) 33% of sample, Intercept 2 (scores 14-16) 36% of sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

Table 12

Two-level Ordinal Model of Sense of Competency by Caregiving Characteristics

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time			.19 (.18)	.28 (.38)
Level-2 Factor				
Caregiver type (Formal)			2.1* (.81)	2.1* (.84)
License (Yes)			.68 (.53)	.68 (.53)
Setting (LTC spectrum)			.36 (.65)	.36 (.65)
Time*CG Type				-.12 (.44)
Intercept				
Intercept 2 (score of 20)	-1.2* (.31)	-1.2* (.31)	-3.3* (.73)	-3.6* (.75)
Intercept 1 (scores 17-19)	1.9* (.34)	1.9* (.34)	-.33 (.59)	-.38 (.61)
Error Variance				
Intercept	9.4* (2.96)	9.4* (2.96)	8.9* (2.86)	8.9* (2.58)
Time		0	0	0
Model Fit				
AIC	776.05	776.05	758.88	760.8[a]
BIC	786.35	786.35	782.85	788.2[a]

Note: *p<.05; [a]Model used for interpretation. ICC=.74; Values based on SAS Proc Glimmix. Intercept 0 (scores 11-16): 30% of sample, Intercept 1 (scores 17-19) 35% of sample, Intercept 2 (score 20) 35% of sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

Table 13

Two-level Ordinal Model of Person-Centered Care by Caregiving Characteristics

	Model 1	Model 2	Model 3	Model 4
Level-1 Factor				
Time			.3 (.18)	.7* (.34)
Level-2 Factor				
Education (Some College +)			.9* (.34)	1.2* (.39)
Time*Education				-.53 (.38)
Intercept				
Intercept 1 (scores 7-8)	.17 (.13)	.17 (.13)	-.68 * (.30)	-.88* (.34)
Error Variance				
Intercept	.88* (.47)	.88* (.47)	.80 (.52)	.82* (.46)
Time		0	.05 (.39)	0
Model Fit				
AIC	544.28	544.28	537.39	535.47[a]
BIC	551.17	551.17	554.58	552.67[a]

Note: *p<.05; [a]Model used for interpretation. ICC= .21; Values based on SAS Proc Glimmix. Intercept 0 (scores 3-6) is 51.5% of the sample, Intercept 1 (scores 7-8) is 48.5% of the sample. Entries show parameter estimates with standard errors in parentheses; Estimation method=Laplace.

CHAPTER SIX

DISCUSSION OF ONLINE DEMENTIA TRAINING PROGRAMS

All age groups use the internet (AARP, 2016; Cavanaugh et al., 2009; Liang & Chen, 2012). With increased internet consumption, the desire for tasks to become more efficient and convenient for users has grown. The interest in online learning parallels the accessibility and expectation of internet access in the daily lives of Americans. Opportunity exists to seize the convenience of online programs and to disseminate interactive, timely, and personalized content to caregivers of PWD. A strength of the internet is the possibility to reach caregivers across the globe and to disseminate high-quality content to caregivers. To build upon the strengths noted, the field must move towards stricter methodological design and continue to investigate innovate methods to measure change in an online setting.

As seen in the systematic review in first study, both formal and informal caregivers demonstrated improvements in knowledge, depression, anxiety, burden and satisfaction from multiple training programs. Questions, however, remain regarding the lasting impact of change measured in largely pre-post study designs. With a goal to educate and empower caregivers, continued mentorship and evaluation beyond pre-post testing is necessary. Further, designing and testing outcomes that assess caregiving skills (e.g., communicating with care recipients, performing care tasks) and usefulness of training (e.g., satisfaction and impact on job) within a virtual arena is key for future research.

Interestingly only one study in the systematic review examined a dose effect, and when examined, found a significant relationship between time spent and positive impact of training

(Beauchamp et al., 2005). The results of the PRISMA review and qualitative feedback from caregivers emphasize, however, the connection between the training program and participant as more important than a specific length of training. This makes sense, given recent research that shows the average internet attention span is approximately 6 minutes and programs that utilized multi-media approaches were more successful at maintaining engagement (Guo et al., 2014). Trainings of various lengths (approximately 1-6 hours) showed positive growth in outcome measures (Beauchamp et al., 2005; Irvine, Billow, et al., 2012; Rosen et al., 2002), so the challenge going forward is to strive to make content succinct, interactive, and personalized as best as possible. Criticisms of online training stem from being boring, outdated, or not engaging. However, the field is evolving as educators learn more about tailoring content to audiences and creating an interactive and engaging learning environment. Researchers in this area should turn to experts in education to capitalize on design and communication.

The results of the second study demonstrate a modest improvement in knowledge among all caregivers. It is hard, however, to say to what degree a modest increase in knowledge influences daily caregiving practices. The goal of the CARES® Dementia Basics training program is to promote person-centered care philosophy and encourage meaningful connections between caregivers and care recipients. Through the mechanism of improved communication and observation, behavioral symptoms of dementia will likely decrease. Given the second study's results in light of a growing body of literature that demonstrate knowledge gains from the CARES® training (Gaugler et al., 2015; Hobday, Savik, Smith, et al., 2010; Molinari et al., 2016; Pleasant et al., 2016), future work should evaluate how formal and informal caregivers incorporate knowledge into caregiving skills. The results of the second study demonstrate that indeed both formal and informal caregivers improve on knowledge; therefore, evaluation of each group’s caregiving skills in their care environment is an interesting and necessary next step for the field. In future evaluations of the CARES® program(s), one option for the observation of person-centered skill change would be the CARES® Observational Tool (Gaugler, Hobday, & Savik, 2013). Examples of person-centered caregiver practices included in this measure are the following: to introduce oneself with a name, smile/make eye contact, approach from the front at eyelevel, and continue conversation with the PWD for at least 15 seconds during the care task (Gaugler et al., 2013). This measure, however, requires observation of caregivers, which may be more plausible at an organization level in day-to-day practices, but comes with limitations in research studies that exist online. A subset of studies from the first study (Cristancho-Lacroix et al., 2015; Griffiths et al., 2016; van der Roest et al., 2010) asked participants to visit a university setting for assessment. Although this technique is not plausible for the widespread dissemination of material, it would enhance the literature base to have validated baseline and post-test psychometrics when intervention efficacy is first established. Additionally, exploring potential use of web-based interactive technology to observe and support caregivers is essential.

Future Recommendations

Based on the overall results of the results of this dissertation, the following are recommendations for the future development and evaluation of online dementia-based interventions. Given the evidence that online interventions improve outcomes for caregivers, to continue progress, when designing the intervention content and delivery, attention to content that appeals broadly, but is customizable is key. One way to achieve this goal is by presenting a dementia-care training within a systematic framework while providing opportunities to personalize the information received, through either an algorithm or feedback from a training facilitator. Examples of studies that did this particularly well are Ducharme et al (2011), Hattink

(2015), Griffiths (2016), Blom (2015) and Beauchamp (2005). Further, capitalizing on the core content identified between formal and informal trainings (knowledge of dementia, behavioral management, caregiving skills, and systematic approaches) in the first study is another strategy to build programs that appeal to a wide audience of caregivers. Given the attention span for online content, continuing to present interactive online content through multiple formats (video, lecture, and activities) is ideal to encourage engagement during the training period. The literature examined in this dissertation suggests that online training programs are indeed interactive and use multiple formats to engage participants.

One area that is in need of future development of educational-based interventions is in the optimal timing/dose of training. Results of the first study detail that the "dose" of training was reported in multiple ways. To encourage a dose effect comparison, standardizing the reporting of time within an intervention is necessary. Online trainings need to utilize the embedded technology of online interventions and record the time participants spend in online training programs. Within an online environment, it is necessary to record and present the actual item spent by participants within the intervention. This additional data would permit analysis of dose effect and could help establish the minimum threshold of training needed in future training programs. To ensure the validity of future research designs, including a randomized design, control group, and potential blinding of treatment allocation would enhance the quality of studies, as seen in the internal validity ratings of the systematic review in study one.

Given the combined factors of increased longevity and the anticipated rise in Alzheimer's disease both in the U.S. and worldwide, it is overdue to increase the federal training requirements for direct care workers in nursing homes and establish national guidelines for dementia training along the long-term care continuum. Our minimum training standards for direct care works should be higher as a nation. If unsuccessful at the U.S. national level due to an increasingly partisan political climate, change should be pursued at the state level. Dementia training programs are an important tool to foster culture changes and improve caregiver knowledge and technique. Although the evidence from this dissertation supports the future design and evaluation of training programs, online training programs are only as effective as the environment in which they are introduced and reinforced. Continued learning, mentorship and support from caregivers' communities, research universities and public policy is necessary to improve care for PWD.

Future work, additionally, should be mindful to include the care recipient when evaluating the merits of online training programs. The overall goal of educational and training interventions is to improve the quality of life and experience for both the caregiver and the care recipient. Losing track of the human element in this process is a mistake. Four studies in the first study (Cristancho-Lacroix et al., 2015; Griffiths et al., 2016; Kajiyama et al., 2013; van der Roest et al., 2010) monitored behavioral changes in PWD during the study period with the Revised Memory and Behavioral Problems Checklist, where caregivers are asked to rate present behavior on a 5-point scale (Johnson, Wackerbarth, & Schmitt, 2001). Two studies demonstrated a significant reduction in inappropriate behavior during the intervention period (Griffiths et al., 2016; van der Roest et al., 2010), and interestingly, both studies included either a personalization or individualization component. Future projects must include evaluations of care recipients to verify the reach and usefulness of psychoeducational interventions. The internet is a powerful tool that can enhance connectedness to caregivers worldwide, and reinforcing the underlying human element will increase the likelihood of long-term success.

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APPENDIX A:

THE CARES® EVALUATION SURVEY

Knowledge Question (16-items)

1. Which of the following is most necessary for person-centered care?
    - a) A state-of-the-art, newly constructed nursing home
    - b) Caregivers who are well trained in addressing individual needs
    - c) Doubling the number of volunteers
    - d) Therapy pets

2. Which of the following is an example of person-centered care?
    - a) Providing baths two days per week
    - b) The person in charge of recreation chooses different types of music to play every evening
    - c) Asking what the person with dementia wants to eat
    - d) Serving a set menu with no substitutions so you don't play favorites

3. Which of the following is least important to know when caring for people with dementia?
    - a) What they enjoy for food or drink
    - b) Their likes and dislikes
    - c) Their prior income during their working years
    - d) Who they include in their family

4. To deliver person-centered care, which of the following would be most helpful to know about people with dementia?
    - a) The type of dementia they have
    - b) Their life history
    - c) How old they are
    - d) All of the above
    - e) None of the above

5. What does the CARES® Approach stand for?
    - a) Contact with the Resident, Assess their Health, Respond Appropriately, Evaluate What Works, Share with the Doctor
    - b) Connect with the Resident, Answer their Concerns, Request help from the Supervisor, Evaluate what works, Share with the family.
    - c) Connect with the Resident, Assess their Behavior, Respond Appropriately, Evaluate What Works, Share with the Team
    - d) Contact the Resident, Answer their Concerns, Respond Appropriately, Evaluate What Works, Share with the Team.

6.Alzheimer's disease, the most common form of dementia, is:
a) A normal part of aging
b) Not an illness
c) A progressive terminal disease
d) All of the above
e) None of the above

7. Symptoms of dementia usually tend to get worse over time.
a) Yes
b) No

8. In addition to memory, dementia can affect these areas of thinking:
a) Insight
b) Attention
c) Perception
d) Judgment
e) All of the above

9. For the thinking skill “Language,” which of the following behaviors may indicate a problem for the person with dementia?
a) Not wearing a coat in cold weather
b) Missing doctor’s appointment
c) Having difficulty climbing stairs
d) Referring to a banana as “that yellow thing”
e) Being distracted from gardening by a car that drives by

10. What are the stages of dementia, in correct order of progress?
a) The first signs, requires complete assistance, increasing problems, significant confusion, minimal self-care abilities
b) The first signs, increasing problems, significant confusion, minimal self-care abilities, requires complete assistance
c) The first signs, significant confusion, minimal self-care abilities, requires complete assistance, increasing problems
d) Increasing problems, the first signs, significant confusion, minimal self-care abilities, requires complete assistance

11. If a person with dementia requires complete assistance with activities of daily living (ADLs), what stage of the disease is he/she in?
a) Middle stage: wandering
b) Early stage: minor confusion
c) Late stage: forgetting how to swallow
d) None of the above

12. When a person with dementia hits you or someone else, what might they be trying to communicate?
    a) Fear
    b) Frustration
    c) Feeling overwhelmed
    d) All of the above
    e) None of the above

13. Which of the following does not directly cause sudden behavior changes in the person with dementia?
    a) His/her health and comfort
    b) His/her age
    c) His/her environment
    d) His/her ability to communicate
    e) None of the above

14. It is important that you be accurate and thorough when describing a resident's behavior. Which of the following is the best example of this?
    a) Mrs. Smith refused to go to the Bingo activity today.
    b) Mrs. Smith did not want to go to the Bingo activity today. She usually loves to go to Bingo. I noticed she was rubbing her ankle and had a painful expression. I asked her what was wrong and she said she couldn't walk.
    c) Mrs. Smith did not want to go to the Bingo activity today. This isn't like her. I will observe her again at tomorrow’s activity
    d) Mrs. Smith refused to go to Bingo today. She said she was tired but was rubbing her ankle. After lunch I will ask if she wants to go to the music program.
    e) All of the examples reflect accurate resident-centered descriptions of behavior

15. Which of the following is not one of the steps of the "positive physical approach?”
    a) Approach from the front
    b) Walk quickly
    c) Stand to the side
    d) Crouch low
    e) Offer them your hand

16. Which of the following is a good way to connect with a person with dementia?
    a) Use the person’s name when talking with him/her
    b) Introduce yourself during every interaction
    c) Know the person’s preferences
    d) All of the above
    e) None of the above

Dementia Competency (5-items)

17. How well do you feel you can deal with personal care, such as incontinence in a person with dementia?
    a) Not at all
    b) A little bit
    c) Quite a lot
    d) Very much

18. How well do you feel you can play an active role in your staff team?
    a) Not at all
    b) A little bit
    c) Quite a lot
    d) Very much

19. How well do you feel you can keep up a positive attitude towards the relatives of a person with dementia?
    a) Not at all
    b) A little bit
    c) Quite a lot
    d) Very much

20. How well do you feel you can keep up a positive attitude towards the people you care for?
    a) Not at all
    b) A little bit
    c) Quite a lot
    d) Very much

21. How well do you feel you can keep yourself motivated during a working day?
    a) Not at all
    b) A little bit
    c) Quite a lot
    d) Very much

Person-Centered Care Identification (1 item)

22. After watching the video clip, identify all behaviors in the video that demonstrate person-centered care. Please check all that apply.
    Aide guides resident toward dining room once grooming activity is accomplished
    Aide uses friendly, supportive tone
    Aide models behavior of opening her mouth to help resident
    Aide gently wipes resident’s mouth after dentures are inserted
    Aide tells resident to go to the dining room because her dentures are in place
    Aide acknowledges resident for successfully putting in dentures
    Aide concentrates mainly on completing the task of putting dentures in mouth
    Aide adjusts her approach in inserting dentures responding to resident behavior

APPENDIX B:

IRB APPROVAL LETTER

USF
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RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX(813)974-7091

3/4/2015

Kathryn Hyer, Ph.D.
USF School of Aging Studies
13301 Bruce B. Downs MHC 1300
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**
IRB#: Pro00019196
Title: Online Dementia Care Training for Oregon Caregivers

Study Approval Period: 3/4/2015 to 3/4/2016

Dear Dr. Hyer:

On 3/4/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

Approved
Item(s): Protocol
Document(s):
Protocol Guidelines Online Dementia Training for Oregon Caregivers Pro 19196.docx

Consent/Assent Document(s)*:
Informed Consent Online Dementia Care Training for Oregon Caregivers *granted a waiver

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s). **Waivers are not stamped.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR
56.110. The research proposed in this study is categorized under the following expedited review category:

(7) Research on individual or group characteristics or behavior (including, but not limited to,esearch on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have
any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Boar

APPENDIX C:

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Apr 27, 2017

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