Andrea E. Wurster

0001214128

Thesis Dissertation

Master of Science, eHealth

Supervisor: Dr. Norman Archer

Thesis Title: The Initial Development and Evaluation of iGeriCare Lessons

Committee Members: Dr. Cynthia Lokker, Dr. Richard Sztramko, and Geraldine Voros

The Initial Development and Evaluation of iGeriCare Lessons

Abstract

Informal caregivers (CGs) of people with dementia (PwD) in Ontario may provide upwards of 90 hours or more of caregiving (CG) or assistance to a loved one, per week. CGs of PwD often face increased social isolation, disrupted routines, and experience adverse health effects as this work is incredibly difficult and overwhelming, requiring knowledge, education, resources, and support. eHealth interventions can help to respond to the dynamic and changing needs of these CGs. To respond to these needs, Dr. Richard Sztramko conceptualized iGeriCare, an educational multimedia tool. 10 iGeriCare lessons were created and developed by Dr. Sztramko and Dr. Anthony J. Levinson and his team at the Division of e-Learning and Innovation.

The objective of this thesis is to review psychoeducational interventions aimed at CGs of patients with dementia and to evaluate the usability of iGeriCare learning modules. This thesis is comprised of two phases, a systematic literature review and an evaluation of the iGeriCare lessons. A systematic search was performed on MEDLINE, PubMed, CINAHL, and EMBASE. 31 articles and 23 prospective interventions were included in the final analysis. These interventions were generally perceived positively by CGs. Despite CG-perceived value, there is not enough evidence in the literature to clearly state whether online interventions improve CG stress, self-efficacy, or burden.

The Quality in Use Integrated Measurement Framework (QUIM) informs usability. Two experienced CGs agreed to participate. After they viewed the iGeriCare lessons on the eLearning management system (through the web-based system 360 Articulate), they were interviewed via telephone to gather their opinions of the usability of the iGeriCare modules. Qualitative interview data were analyzed, resulting in the following themes: relevance of content and information, slide design, ease of navigation, forward learning, educational tools, and accessibility. They perceived iGeriCare as an effective tool with online convenience and relished the thought of an online community whereby CGs can interact in a spirit of comradery and togetherness.

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LIST OF ABBREVIATIONS

Abbreviation	Definition
CGs	Informal Caregivers
PwD	People living with Dementia
LTC	Long-term care/nursing home
AW	Andrea Wurster
BS	Branavan Sivapathasundaram
RS	Dr. Richard Sztramko
SLR	Systematic Literature Review
RCT	Randomized Control Trial
CL	ComputerLink
ICSS	Internet-Based Support Services
MoD	Mastery Over Dementia
DEM-DISC	DEMentia-specific Digital Interactive
CARES	Social
STAR	Cares for Families
MOOC	STAR Training Program
DAC	Massive Open Online Course
NICHE	Digital Alzheimer's Centre
	Nurses Improving Care for Health System
	Elders

CHAPTER 1

INTRODUCTION

1.1 Rationale. The Canadian Health Institute for Health Information (CIHI) predicts older adults age 65+ will exceed 20% of the Canadian population by 2025 (2016). The Province of Ontario is moving to a home-care model to ultimately decrease the current bottleneck existing in long-term care (LTC) homes.

Older adults living in the community have similar needs to those admitted into LTC (CIHI, 2011). Canadian seniors are living longer in their private homes with multiple, chronic comorbidities. Older adults require more health services, incur increased costs, and require additional care (CIHI, 2011). The Province of Ontario is therefore encouraging seniors to age in their communities, ultimately relying more on informal caregivers (CGs), families, and kin.

Approximately 33% of CGs in Ontario claim to provide upwards of 90 hours or more of caregiving or assistance to a loved one, per week (CIHI, 2016; Sink, Covinsky & Barnes, 2006). CGs–the majority being women— provide up to 80% of community care to loved ones with multiple comorbidities (Markle-Reid et al., 2016). CGs are often the spouses or children of the persons with dementia (PwD) and although caregiving is perceived as a noble role, it is incredibly overwhelming (Schulz, 2000). CGs often face increased social isolation, disrupted routine, and experience adverse health effects (Schulz, 2000). Caregiving is difficult, it requires knowledge, education, resources, as well as social and emotional support. As the Canadian population continues to age, eHealth and

healthcare applications are being developed, innovated, and applied to respond to the dynamic and changing needs of CGs.

CGs continue to be the main source of care for older adults with dementia (Alzheimer's Association, 2014). CGs consist of family members, friends, and/or loved ones who provide an array of support (i.e. accompanying to appointments, driving, shopping, cooking, dressing, hygiene tasks etc.). Spouses and families of PwD are expected to care for their loved ones, therefore involving family members in roles as informal CGs. This is not only a drastic role change, but one that requires education about the disease and its prognosis, as well as development of daily coping strategies.

Dementia is caused by a group of diseases which result in damage to the brain. This damage can result in difficulties with memory, speech and language, problem solving, as well as other cognitive skills that interfere with a person's ability to perform daily functional activities (Alzheimer's Society, 2017). Aside from the most prevalent cause of dementia, Alzheimer's Disease, common causes of dementia include Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, and Parkinson's Disease (Alzheimer's Society, 2017).

According to Dr. Richard Sztramko, a Geriatric Specialist at Hamilton Health Sciences, it is frustrating to diagnose and provide information to patients and families within the time constraints of a one hour-long appointment. Overall, the healthcare system is fragmented between care providers, so continuity is often lacking in support provided to CGs having to deal with PwD. This issue is exacerbated as there are long wait-times between appointments. This fragmentation of care often leaves patient care incomplete and

inefficient, ultimately affecting CGs in addition to the patients (Markle-Reid et al., 2016). Interventions for home care often lack inclusiveness as well as appropriate skill and educational level required by the CG (Markle-Reid et al., 2016). Multimedia interventions are one way to allow CGs to access support, education, and tools at a time and place convenient for them. This is important as CGs simply do not own their time since they are influenced by the needs of their loved one. These common frustrations led to the idea of *iGeriCare*: A multimedia education tool for CGs of PwD.

iGeriCare is an initiative spearheaded by Dr. Sztramko, who responded to family/CG feedback at the Centre for Healthy Aging. Specifically, preliminary research conducted by Dr. Thom Ringer, a Research Assistant at the GERAS (Geriatric Educational and Research in Aging Sciences), determined CGs' overall desire for geriatrician-curated and prescribed online information; they particularly emphasized the value of both online support and eLearning.

Dr. Sztramko is an Assistant Professor in the Department of Medicine at McMaster University. Dr. Sztramko practices both geriatrics and internal medicine at St. Peter's Hospital, Hamilton General, and Juravinski Hospitals in Hamilton Ontario.

1.2 Evaluations of Health Interventions. As per the Medical Research Council (MRC) framework for the development and evaluations of complex healthcare interventions, said interventions should be developed and measured robustly (Boots et al., 2016; Craig et al., 2008). Complex initiatives include those which consist of multiple parts and components, for example, educational interventions consist of modules, forums, community pages, and additional links to resources (Craig et al., 2008). The first step

outlined by MRC is to assess current practices; this is followed by initial development and evaluation. Interventions should be evaluated by intended end-users (i.e. CGs or patients) throughout the development lifecycle to ensure meaningful use and accurate delivery (Craig et al., 2008).

1.3 Purpose. The objective of this thesis is to review psychoeducational interventions aimed at CGs of patients with dementia and to evaluate the usability of iGeriCare learning modules. The thesis is comprised of two phases, [1] a systematic literature review, and [2] an evaluation of *iGeriCare* lesson usability by informal CGs.

1.4 Research Questions. The research question for the systematic literature review is: *What is the effect of educational platforms for dementia CGs on stress/burden, depression or self-efficacy?* The research question for the usability component is: *Do informal CGs in the Hamilton community perceive the iGeriCare intervention as a viable, usable, and useful educational tool for CGs of PwD?*

CHAPTER 2

PHASE 1: SYSTEMATIC LITERATURE REVIEW

2.1 BACKGROUND

2.1.1 Introduction. Canadians are aging in the community and informal CGs are providing the majority of health-based care (Markle-Reid et al., 2016). Providing care requires training and education which CGs often do not receive; a prominent mindset in caregiving embodies the *learn as you go* mentality. As our world continues to digitize,

there is opportunity to provide CG-based support and educational interventions online. Dementia-based educational information is not customized for CGs, nor readily available; current sources of information are reported to be either diluted or intense. On the other hand, some resources found online are insufficient, illegitimate, and are not evidence-based.

This systematic review focuses on educational interventions as opposed to social support interventions, the Alzheimer's Association (US) offers the following definition:

Psychoeducational interventions are structured programs that provide information about the disease, resources, and services, and about how to expand skills to effectively respond to symptoms of the disease (i.e. cognitive impairment, behavioural symptoms, and care-related needs).

(Table 7; as cited in Gaugler et al., 2015).

This systematic literature review has been structured through a PRISMA framework. PRISMA is a 27-item checklist created to inform the robust presentation of systematic reviews and meta-analyses (Liberati et al., 2009). Certain items have been omitted as they did not apply to this type of review.

2.1.2 Objective. The objective of this systematic literature review is to summarize robust evidence on the effectiveness of online educational-based supports for CGs of PwD. This review includes RCTs, cohort studies, case-control studies, case studies and proof of concept studies. This review includes articles from inception to February 2018.

2.2 METHODS

   2.2.1 Protocol. The methods used in the analysis, as well as the inclusion/exclusion criteria were specified beforehand and are included in the following protocol. As this is a unique topic, the inclusion and exclusion criteria were created to properly and thoroughly address the research question.

   2.2.2 Inclusion and Exclusion Criteria. The inclusion and exclusion criteria were chosen to efficiently indicate articles most pertinent to the research topic and question. Inclusion criteria were any web-based or internet-delivered educational interventions for dementia CGs; randomized controlled trials (RCTs), cohort studies, case-control studies, case studies, and proof of concepts. Exclusion criteria consists of any non-web-based educational intervention for dementia CGs, psychosocial or social online support groups, telemedicine or tele counselling interventions, and interventions targeted at patients that have dementia opposed to their CGs.

   2.2.3 Information Sources. Articles were identified by searching electronic databases with the guidance of a professional librarian. MEDLINE, PubMed, CINAHL, and EMBASE were the included databases.

   2.2.4 Search Strategy. A systematic search was performed on MEDLINE, PubMed, CINAHL, and EMBASE for the following MeSH terms: "dementia" (including dementia as a keyword), "caregivers", "telemedicine" (including eHealth as a keyword), "Programmed Instruction as Topic", and "Software." Each MeSH term was exploded, and all sub-headings were included. The following terms were used as keywords:

"Alzheimer*", "caregiv*", "carer.*", "eLearning", "online intervention", "mobile app". "Dementia", "telemedicine", and "Internet" were also included as keywords.

"Dementia" OR "Alzheimer" were combined (4). "Caregivers" OR "caregiv*" OR "carer*" were combined (8). "Telemedicine" OR "eHealth" OR "Internet" OR "Computer Communication Networks" OR "Programmed Instruction as Topic" OR "software" OR "Internet" OR "elearn*" OR "module*" OR "online intervention*" OR "mobile app*" were combined (22). Lastly, final concepts were added (4 AND 8 AND 22) (Please view Table 1). All yielded articles were uploaded into RefWorks.

The search strategy gathered an initial yield of 1237 articles. After deleting duplicates, 601 articles remained across MEDLINE, PubMed, CINAHL, and EMBASE.

TABLE 1: SEARCH STRATEGY	
MEDLINE Search Terms	
	((dementia (MeSH) OR dementia (keyword) OR Alzheimer (keyword)) AND (Caregiv* (MeSH), carer* (MeSH), Caregivers (keyword)) AND (Telemedicine (MeSH) OR eHealth (keyword) OR Telemedicine (keyword) OR Internet (MeSH) OR Computer Communication Networks (MeSH) OR Programmed Instruction as Topic (MeSH) OR Software (MeSH) OR internet (keyword) OR eLearn* (keyword) OR module (keyword) OR online intervention* (keyword) OR mobile app* (keyword))
PubMed Search Terms	
1	(((dementia OR dementia OR Alzheimer*)) AND (caregivers OR caregiv* OR carer*)) AND (Telemedicine OR internet OR Computer Communication

	Networks OR software OR internet OR elearn OR module OR online intervention OR mobile app OR mobile application)
CINAHL Search Terms	
	("dementia OR Alzheimer*" OR (MH "Dementia+")) AND (((MH "Caregiver Burden")) OR ("caregiver OR carer*")) AND ("telemedicine" OR ("ehealth or e-health or telecare or telemedicine or telehealth") OR ((MH "Internet")) OR ((MH "Computer Communication Networks")) OR ((MH "Software")) OR "software" OR "elearn*" OR "module*" OR ("online intervention") OR ("mobile app*") OR ("mobile application") OR ((MH "Telehealth+") OR "ehealth"))
EMBASE Search Terms	
1	MEDLINE: dementia (MeSH) OR dementia (keyword) OR Alzheimer (keyword)
2	Caregiv* (MeSH), carer* (MeSH), Caregivers (keyword)
3	Telemedicine (MeSH) OR eHealth (keyword) OR Telemedicine (keyword) OR Internet (MeSH) OR Computer Communication Networks (MeSH) OR Programmed Instruction as Topic (MeSH) OR Software (MeSH) OR internet (keyword) OR eLearn* (keyword) OR module (keyword) OR online
6	intervention* (keyword) OR mobile app* (keyword)
	1 AND 2 AND 3

2.2.5 Study Selection. All articles were downloaded into RefWorks by Andrea Wurster (AW) and the authors AW and BS (Branavan Sivapathasundaram) respectively assessed eligibility criteria against the articles' titles and abstracts. Any disagreements

between reviewers were resolved by consensus. If consensus could not be reached, a third reviewer, Dr. Richard Sztramko (RS), would be asked to decide. After full consensus, the 85 articles were read in full, with inclusion and exclusion criteria applied once again. A final 31 articles were included in the review.

2.2.6 Data Collection. An individual review author (AW) extracted appropriate data from included articles and a second author checked the extracted data (BS). A data extraction sheet on Google Sheets was used to track included articles and data. Any disagreements were solved between the two authors (AW and BS), and when necessary, a third author would decide (RS).

2.2.7 Data Items. Information was extracted from the 31 articles. Please see Table 2 (below) to view the data extracted from the respective articles, organized by type.

TABLE 2: EXTRACTED DATA ITEMS			
Type	**Data Extracted**	**Articles**	**#**
Systematic Literature Reviews (SLR)	- Type of review (SLR/Meta-Analysis) - Interventions included - Results & conclusions	Boots et al., 2014; Wasilewski, Stinson & Cameron, 2017	2
Randomized Control Trials (RCTs)	- Intervention description - Methodology (experiment/control groups, participant details, measurement tools) - Results & conclusions	Bass et al., 1998; Beauchamp et al., 2005; Brennan, 1992; Cristancho-Lacroix et al., 2015; Kajiyama et al., 2013; Nunez-Naveira et al., 2016; Pagan-Ortiz et al., 2014; Pot, Blom & Willemse, 2015; van der Roest et al., 2010	9
Evaluation of intervention (usability, testing, feasibility, qualitative, quantitative, general, pre/post pilots)	- Intervention description - Methodology (evaluation tools, participant details, measurement) - Results & conclusions	Bhattacharyya, Benbow & Collins, 2017; Boots et al. 2016; Boyd et al., 2014; Brennan, Moore & Smyth, 1992; Brennan & Smyth, 1994; Chang, 2004; Chiu & Eysenbach, 2010; Chiu et al., 2009; Chiu & Eysenbach, 2011; Chiu & Lottridge, 2005; Gaugler et al., 2015; Glueckauf & Loomis, 2003; Goldberg et al., 2005; Hales & Fossey, 2017; Hattink et al., 2016; Kovaleva et al., 2017; Lai et al., 2013; Pleasant et al., 2017; Verywey et al., 2016	19

Explanation of intervention	- Intervention description Intention of the intervention - Funding details	Bricoli, 2015	1

2.2.8 Summary Measures. Although this systematic review will not employ meta-analyses, there were primary and secondary outcomes of interest. The primary outcome of interest included self-efficacy, and the secondary outcomes of interest include CG self-perceived quality of life and CG burden. Other measurements of interest included CG stress, CG depression, and CG anxiety.

2.2.9 Planned Methods of Analysis. The planned analysis was to organize articles through themes and similarities, specifically, parallel interventions, methods, findings, and results. For example, articles using the same summary measures were grouped; interventions with similar purposes were also grouped. In the following Results section, the interventions included will be introduced, followed by the general methodologies used in the respective articles.

2.3 RESULTS

2.3.1 Study Selection. Reasons for exclusion in the final round pertained to: articles/interventions which focused on formal CGs (i.e. nurses, PSWs, paid positions) opposed to informal CGs (4), articles/interventions designed for PwD/self-management, opposed to supporting the work of CGs (4), articles/interventions are not an online educational intervention/is considered psychosocial/is a smart home/mgmt./phone application (28), articles/interventions which focused on CGs of people with other ailments, not including dementia (i.e. AIDS, stroke) (1), the article could not be retrieved (10), and

the article was a repeat with a different title (1). An additional 7 articles were excluded during data extraction as they only presented the research protocol.

The entirety of the 31 final articles were read in detail. See flow diagram (Figure 1: Flow Diagram of Articles).

FIGURE 1: FLOW DIAGRAM OF ARTICLES
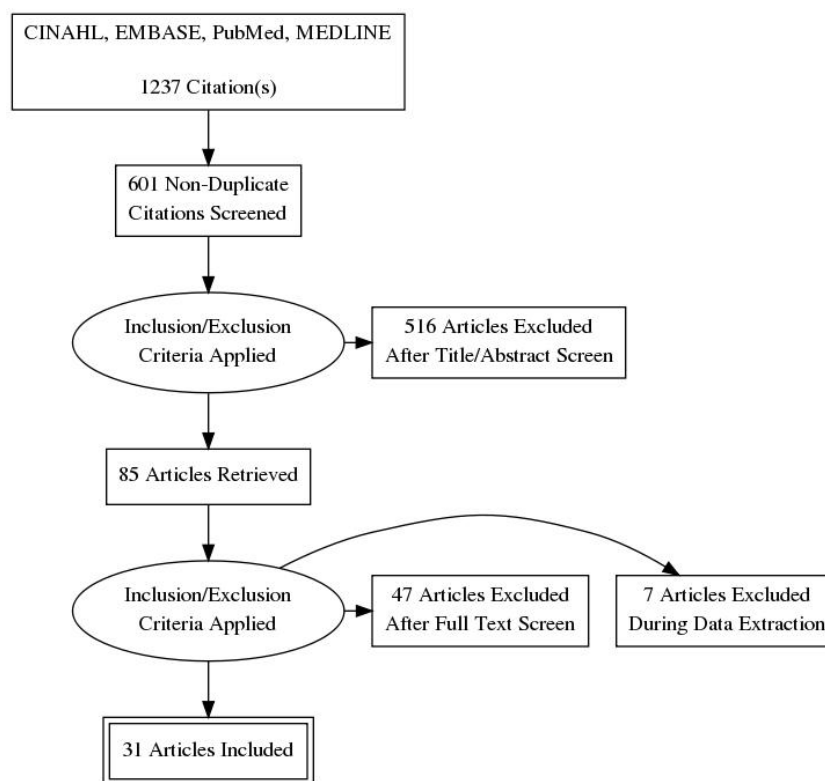
2.3.2 Included Interventions. The 31 articles included 23 interventions, not accounting for the interventions included in the 2 systematic literature reviews. This component will be structured in a way which complements the vastly unique studies and will be compared and contrasted thereafter. The vast majority of included articles assessed or explained the respective interventions. Full article details can be found in *Appendix A: SLR Article Details*. The interventions are as follows:

[1] *Partner in Balance* (PIB) was developed in order for CGs to set goals and evaluate their progress at achieving them. Featured modules focus on acceptance, balancing activities, communication, coping with stress, focusing on the positive, insecurities and remuneration, self-understanding, the changing family member, and social relations and support (Boots et al., 2016; & Boots et al., 2014).

[2] *ComputerLink* (CL), developed and tested throughout multiple articles during 1990-1996, was designed for CGs in the home. CL provides information, communication, and decision support for CGs. The nurse facilitates discussion forums and answers questions. CL was delivered through a terminal system, which was installed in the CG's home (Bass et al., 1998; Brennan, 1992; Brennan & Smyth, 1994; Brennan et al., 1992).

[3] *Internet Based Support Services* (ICSS) was created for bilingual Chinese CGs of people with dementia. Bilingual CGs desired online resources in both English and Chinese. The ICSS site consists of email support, 400 pages of dementia-specific information, and information about English and Chinese community resources (Chiu & Lottridge, 2005; Chiu & Eysenbach, 2010; Chiu & Eysenbach, 2011; Chiu et al., 2009).

[4] *Mastery Over Dementia* (MoD) consists of 8 modules and a booster session facilitated by an experienced psychologist. The purpose of the intervention is to assist with coping strategies, therapeutic techniques, as well as educational knowledge on dementia (Pot, Blom & Willemse, 2015).

[5] *Caregiver's Friend: Dealing with Dementia* features an array of texts and videos which emphasize positive CG strategies and practices. Designed by researchers and experts, the content is personalized, whereby CGs can fill out a survey which directs them

to an area or topic on the site. The site features three modules*: Being a Caregiver, Coping with Emotions,* and *Common Difficulties* (Beauchamp et al., 2005).

[6] *Diapason* is a fully automated site for CGs. The free tool consists of a platform where CGs can access thematically-organized information. The information is presented throughout a 12-week program, and features the following: CG stress, understanding the disease, maintaining autonomy, understanding reactions, coping with troubles, communicating, improving daily life, avoiding fall risks, interventions, social and financial support, the future, and an overall summary. The site also features relaxation videos, stories and testimonials, glossary for terms, and a forum monitored by a psychologist (Cristancho-Lacroix et al., 2015).

[7] *iCare,* a collection of modules, presents dementia-based content for CGs. Each module features actors portraying relevant situations (i.e. CG and loved one with dementia). The users are encouraged to finish a module within 7-10 days (Kajiyama et al., 2013).

[8] *UnderstAID* features 5 modules, focusing on 15 different topics. Module topics consist of cognitive declines (focused on attention, memory, and orientation), daily tasks (focused on bathing, incontinence, massage and touch, and physical exercise), behavioral changes (focused on anxiety and agitation, depression, manic symptoms, emotional control, and recognition), social activities (communication and apathy, and loss of motivation), and the CG (focused on coping with own stress and motivation) (Nunez-Naveira et al., 2016).

[9] *Cuidate Cuidador,* with a name that literally translates to *Caregiver, take care of yourself,* is a Spanish site and intervention which features information on dementia, including how to manage dementia-related behaviour, CG stories, and self-care. In an

attempt to respond to literacy issues in the area, the information can be accessed in either Spanish or English (Pagan-Ortiz et al., 2014).

[10] *DEMentia-specific Digital Interactive Social Chart (DEM-DISC),* an online intervention which features tailored information on dementia care and services, whereby CGs can ask questions about dementia, related needs, or services (van der Roest et al., 2010).

[11] *Cares for Families* (CARES) is an online site featuring information, created by experts and family CGs. The site features relevant modules which focus on caregiving strategies and dementia knowledge (Gaugler et al., 2015).

[12] *CARES Dementia Basics* presents multiple CG scenarios. The intervention consists of four modules, which focus on person-centered care, introductory information on dementia, understanding behaviour as communication, and the CARES approach (connect, assess, respond, evaluate, and share with other team members when providing care) (Pleasant et al., 2017).

[13] *Ginko,* a dementia-resource website, consists of a 7-week training workshop for CGs. Upon workshop completion, can join the online community and participate in the forum (Lai et al., 2013).

[14] *STAR Training Program* (STAR) consist of a site which hosts a training program. The featured modules aim to teach better care techniques, as well as facilitate dementia education (Boyd et al., 2014).

[15] *Living and Dying Well with Dementia: Mobile App* was developed as a free, accessible and easy-to-use resource. The app's mission is to promote understanding about

dementia and its key issues during end-of-life care through storytelling. Throughout *Jill's Journey,* the user experiences Jill aging, the onset of Jill's dementia, as well as Jill dying. As the user embarks on the journey, they can participate in various prompts and exercises (Bhattacharyya, Benbow & Collins, 2017).

[16] *AlzOnline* is a site which hosts relevant educational modules, live forums with experts, and room for companionship and connecting with other CGs. AlzOnline is also integrated with a telephone support service (Glueckauf & Loomis, 2003).

[17] *Massive Open Online Course: Understanding Dementia* (MOOC) is a 9 week, 9-unit online course. The MOOC is designed to support CGs with limited education. In order to move to the next unit, the user must pass a quiz. There is also a peer-to-peer forum, and an "Ask the Experts" discussion board (Goldberg et al., 2015).

[18] An Informative Website for Caregivers, conceptualized by Chang (2004) consists of four online modules, focusing on cognitive behavioural therapy in relation to CG for older adults with dementia. The site also features other links to resources. Although the educational resources in the intervention reportedly lack detail, the testing of the resources was quite robust (Chang, 2004).

[19] *Caring for Me and You*, a computerized cognitive behavioural therapy (cCBT) package, is a standalone intervention, which features an educational arm. The purpose of the intervention is to support CGs through the dementia journey (Hales & Fossey, 2017).

[20] *Digital Alzheimer's Centre* (DAC) is a website which offers dementia information, definitions, recent news, as well as community/forum and events sections. Alike similar resources, information is written in lay language. Any user can view the site's

home page; however, they are required to sign in to view the entire site (Hattink et al., 2016).

[21] *Tele-Savvy* is an online adaptation of a previous evidence-based, in-person dementia resource. The purpose of this psychoeducational resource is to expand users' knowledge, skills, and self-efficacy to overall improve their experience with caregiving (Kovaleva et al., 2017).

[22] *Network Support Dementia Project* aims to connect multiple multimedia resources onto one accessible site. Merging three care organizations which are already used in the region, the purpose was to provide related information about dementia, information exchange between CGs, as well as between CGs and healthcare professionals (Verwey et al., 2016).

[23] *Nurses Improving Care for Health System Elders* (NICHE) is a tool designed for nurses to teach CGs at home. NICHE was created to assist patients and families in the lifecycle of the disease—from diagnosis to death. Informative but not diagnostic, the app is designed to be used by older adults as its text is in lay terms and has an easy to navigate user interface (Bricoli, 2015).

2.3.3 Study Characteristics: *Literature Reviews.* Of the 31 included articles, two aimed to synthesize current eLearning interventions for CGs of PwD present in the literature. This included one systematic literature review (Boots et al., 2014) and one scoping review (Wasilewski et al., 2017).

With an overall aim of synthesizing the effectiveness and feasibility of educational interventions for CGs of PwD, Boots et al (2014) summarize the details, methodology, and

conclusions of 12 articles. The authors reported a rigorous systematic methodology to capture relevant and recent articles. The included articles all aimed to improve CG function and care provided, however varied significantly from one another. Boots et al (2014) determined that although online resources for CGs of PwD are a positive intervention, articles do not present large affect. The majority of the articles lacks methodological quality. They do address well-being, depression, burden, and self-efficacy (including Boots et al., 2014; Beauchamp et al., 2005; Glueckauf & Loomis, 2003).

Similarly, Wasilewski, Stinson and Cameron (2017) conceptualize 53 web-based interventions for CGs; although only half of the interventions focus on CGs of PwD, the authors conclude that CGs/end-users value interventions which tailor to their unique needs and context of illness; usage of the interventions declined over time, and therefore, interventions should address stage-specific needs across the caregiving and dementia journey (Wasilewski, Stinson & Cameron, 2017). Similar to Boots et al (2014), Wasilewski, Stinson and Cameron (2017) highlight depression and CG burden as the most common evaluated outcomes; reduction in CG burden was often observed across the included articles (Wasilewski, Stinson & Cameron, 2017). Overall, interventions were reported as effective.

2.3.4 Study Characteristics: General. The following tables present article information and outcome measures utilized. Please see Appendix B to view study characteristics, in full detail. The following tables only include articles which evaluate the intervention (Table 3), and those which only have robust outcome measures employed in RCTs or pilots (Table 4), respectively.

TABLE 3: ARTICLE INFORMATION					
Intervention	Type	Methodology	N=#	Results	Reference
Partner in Balance (PIB)	Intervention Evaluation, Mixed Methods	Focus groups with CGs, individual interviews with healthcare professionals, usability tests with CGs and professionals, and an initial pilot with CGs.	n=47 CGs; n=13 professionals	CGs appreciated completing the intervention at home. The content and guided sessions was perceived positively. Preliminary effects of self-efficacy were positive.	Boots et al., 2016
ComputerLink (CL)	RCT	Conducted an RCT to evaluate CLs effect on CG strain.	n=102	CL reduced certain types of strain. CL is declared as an effective tool.	Bass et al., 1998
	RCT	Conducted an RCT with CGs, where 47 had access to CL for 12 months, to evaluate interaction.	n=102	CGs accessed CL 3888 times. Behavioral indicators demonstrate that CL promotes collaboration between CGs. CGs sought info over 500 times and spent an average of 10 minutes upon entry. CGs posted 749 messages on the forum.	Brennan, 1992
	Intervention Evaluation, General Methods	CL terminal modem system was installed in participating CGs homes. CGs used CL 1-8 months, 1 week during this timeline was analyzed.	n=47	Observance week: CL was accessed 98x, 29 respective participants logged-in. Mean log-ins to all participants (n=47) was 2, ranging from 0-13. Most frequently used component was the forum (used 80x), and the private mail was used 56x.	Brennan, Moore & Smyth, 1992
	Intervention Evaluation, General Methods	CG attitudes towards CL was measured with a researcher-developed self-administered 20-item survey. Participants were prompted with an adjective and were asked to indicate a Likert format the extent to which they agreed.	n=35	75% interested, 36% distressed; 29% Excited, 26% afraid. Overall, CGs/participants perceived CL as positive.	Brennan & Smyth, 1994
Internet-Based Support Services (ICSS)	Intervention Evaluation, Usability	Bilingual Chinese CGs participated in usability testing. A think-a-loud approach was used while participants worked their way through the intervention.	n=3	The interface was perceived as functional and the large icons on the email prompted participants appropriately. The text and site design provided context to facilitate use.	Chiu & Lottridge, 2005
	Intervention Evaluation, Qualitative	Qualitative methods used to understand CGs use of intervention. In-depth interviews explored CGs attitudes.	n=14	A needs factor must be present for use; needs of CGs must change over time as does their use; CGs are desperate for information as there is so much information out there and they do not know which/who to trust.	Chiu & Eysenbach, 2011
	Intervention Evaluation,	To explore attrition, the authors utilized a multi-	n=46	Needs factor must be present for service use. The site was redesigned according to feedback, including use of	Chiu & Eysenbach, 2010

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	Mixed Methods	phased, longitudinal study design.		narratives for education, addressing multilingual needs.	
	Intervention Evaluation, Mixed Methods	To explore Chinese-CGs use of ICSS, as well as the effects on the CGs health outcomes. Interviews were conducted, recorded, translated to English, and transcribed.	n=28	19 CGs who had higher scores started the service earlier than those with lower scores. Nonusers had increased perceived burden post; occasional users had minimal changes.	Chiu et al., 2009
Mastery Over Dementia (MoD)	RCT	The feasibility and effectiveness of MoD was evaluated with CGs. Measures were collected at baseline/during intervention. After viewing each lesson, CGs were asked to rate the comprehensibility and usefulness of the lesson.	n=149	68 CGs completed all lessons within 6 months, 81 did not finish all. 6 did not start at all. Those who did not finish reported the material wasn't relevant/faced too much CG burden. PRE-POST CHANGES REPORTED IN NEXT ARTICLE (below).	Pot, Blom & Willemse, 2015
Caregiver's Friend: Dealing with Dementia	RCT	Ensued a control waitlist with family CGs who were also employed, to test the effectiveness of the intervention.	n=299	7 CGs experienced significant positive results post-intervention. Use of intervention reduced depression, anxiety, and strain, whilst increasing perception of CG gain; the frequency of coping skills did not seem to improve.	Beauchamp, 2005
Living and Dying Well with Dementia	Intervention Evaluation (general)	Workshop/focus groups with CGs were held to provide an initial evaluation. Sample size and participant details not reported.	Not reported	The participants appreciated usability and usefulness; participants felt the app would be useful for CGs who had little access to education. The participants felt that the app could help prepare CGs for future events.	Boyd, 2014
Diapason	RCT	Unblinded RCT consisted with CGs. 25 CGs, included in the experimental group, were given Diapason to use at home for 3 mo. Control group received usual care (n=24).	n=49	CGs who improved their understanding of dementia reported feeling less stressed. CGs with a perceived personal time restriction/poor social support suffered from more stress, burden, and depression.	Cristancho-Lacroix et al., 2015
iCare	RCT	Participants were randomized (75 & 75) and required to complete a set of baseline questionnaires pre-and-post intervention. Participants in the experimental group interacted with the intervention for 3 months. Qualitative information was also gathered.	n=150	CGs in the experimental group experienced less stress, post intervention (statistically significant). The other outcome measures also improved, however was not statistically significant. 47 participants withdrew.	Kajiyama et al., 2013
UnderstAID	RCT	Participants were randomly assigned to experimental	n=103	The experimental group did experience statistically significant changes in depressive symptoms. 33.3% of CGs	Nunez-Naveira et al., 2016

		(n=36) or control group (n=41). 16 withdrew.		were satisfied with the application and 50% assessed as technically acceptable; UnderstAID was iterated to suit said suggestions.	
Cuidate Cuidador	RCT	Quasi-experimental 2-group design with baseline and post-test. Participants were given 1 hour to observe the intervention. Following, participants participated in a focus group re: usability and features. Participants were assigned to a control (n=23) or experimental group (n=17).	n=23	Majority of participants visited the site 3 times, and others up to 10 times daily. Usability measures were at half and improved the intervention thereafter. All measures were not statistically significant although improvement was observed. Sought the input of younger CGs as well.	Pagán-Ortiz et al., 2014
DEMentia-specific Digital Interactive Social Chart (DEM-DISC)	RCT	Participants were randomized; experimental participants (n=14 CGs and 12 PwD) were given DEM-DISC for two months. Those in the control group (n=14 CGs and 11 PwD) relied on their typical info sources.	n=51	The participants appreciated usability and usefulness; participants felt the app would be useful for CGs who had little access to education. The participants felt that the app could help prepare CGs for future events.	van der Roest et al., 2010
Cares for Families (CARES)	Pre-post pilot	Outcome measures were assessed at baseline, post intervention, and after 30 days of the intervention of CARES.	n=51	Improved CGs knowledge and components of CG; participants appreciated the vast topics including person-centred care, behaviour modification, and framework.	Pleasant et al., 2017
CARES Dementia Basics	Pre-post pilot	Pre-and-post-test pilot ensued with CGs. The purpose of the pilot was to assess improvement in dementia knowledge. Descriptive qualitative and quantitative data was sought through open-ended questions.	n=41	Knowledge was improved post intervention. CGs appreciated the content and flexibility of the online intervention; they also appreciated the vignettes. The intervention reportedly provided sufficient and needed information to the CGs.	Gaugler et al., 2015
Ginko	Pre-post pilot	To examine the outcomes Ginko has on CG's knowledge of dementia, in addition to their perceived social support, Chinese CG participated. n= 8 participants attended a 7-week face to face workshop and joined the forum thereafter. n=3 participants took the courses online.	n=11	Knowledge gained by the online workshop participants after attending the workshop was significantly greater than that gained by onsite workshop only participants. The onsite participants' anxiety and depression dropped significantly after the workshop.	Lai et al., 2013
STAR Training Program	Intervention Evaluation, Usability	To test usability of STAR as well as mitigate any user obstacles. Involved CGs (2 males, 3 females; mean	n=5	60% of the participants were able to perform half or more of the tasks; 80% completed the course, games, and quiz; 0 participants were able to find the page	Boyd, 2014

		age=45) CGs of PwD. Participants were asked to perform the same tasks on STAR, whilst gaze and heat maps recorded navigability.		guide. Task efficiency was also recorded; as the participant worked their way through the site, they became more efficient.	
Living and Dying Well with Dementia	Intervention Evaluation (general)	Focus groups with CGs were conducted to provide an initial evaluation. Sample size and participant details not reported.	Not reported	The participants appreciated usability and usefulness; participants felt the app would be useful for CGs who had little access to education. The participants felt that the app could help prepare CGs for future events.	Bhattacharyya, Benbow & Collins, 2017
AlzOnline	Intervention Evaluation (general)	3-Phase Evaluation: 1) integration of services as well as development of the lessons and website. 2 & 3) evaluation where constructive feedback was gained from their first group of graduates.	n=9	Feedback alluded to iterating the intervention to be more usable and useful. Home page changes were suggested as CGs desired direct links to the website specs (i.e. direct link to the forum).	Glueckauf & Loomis, 2003
Massive Open Online Course: Understanding Dementia (MOOC)	Intervention Evaluation (general)	Participants completed understanding dementia MOOC. Information was collected to understand educational background and user demographics. Completion per background was assessed.	n=9500	A total of 4409 individuals engaged in the discussion forums and made a total of 45,955 discussion posts. Of these, 2896 completed the MOOC. Participants with low education levels (elementary-vocational training) were just as likely to complete the MOOC as educated individuals.	Goldberg et al., 2015
Informative Website for Caregivers (name undisclosed)	Intervention Evaluation, Feasibility	To determine the feasibility of the intervention, CGs were given the intervention for 6 months. CG self-reported surveys and feedback.	n=21	CGs reported they used the site from 2-30 times. Some \were able to view the information and could respond to questionnaires. Recommends longitudinal studies be conducted with broader participations/ varying levels of education. Outcome measures not reported.	Chang, 2004
Caring for Me and You	Intervention Evaluation, Mixed-Methods	Consists of three phases. Third phase= pilot testing where end-users tested the intervention.	n=3	Authors believe the intervention was developed in a way which represents the needs of CGs. Specifically, content, style, and format of delivery compliments best practices of experts. RCT is now underway.	Hales & Fossey, 2017
Digital Alzheimer's Centre (DAC)	Intervention Evaluation, Mixed-Methods	PwD, CGs and professionals were sampled. Mixed-methods include observations, an online survey, semi-structured interviews. During observations, participants performed 5 tasks where speed, errors, and navigation was noted.	n=10; 4 PwD and 6 CGs/ n=287;88 PwD and 199 CGs/ n=18; 6 PwD, 6 CGs, 6 professional	A slight majority of participants appreciated the layout of the site; all participants felt the material was understandable and clear; ease-of-use with the site was noted. Survey results show 145 reported using the site at least twice; of these 145, majority were CGs. Interview responses also indicated	Hattink et al., 2016

			s, respectively	regular use; overall response was positive.	
Tele-Savvy	Intervention Evaluation (Qualitative)	To explore the acceptability of the intervention, CGs were recruited to test the intervention of which 36 completed. The CGs who completed were interviewed via semi-structured telephone (or skype) interviews. Conventional content analysis allowed for theme identification.	n=46	Themes: connectedness, distracted participants, different CG situations, technical difficulties, stage specific information, CG strategies. Authors conclude that interventions like Tele-Savvy is feasible for CG-distant-training.	Kovaleva et al., 2017
Network Support Dementia Project	Intervention Evaluation (Qualitative)	Used semi-structured interviews. Informal and formal CGs participated to gain insight and first impressions. Components of the site were evaluated, including 'Dementia info', 'Contacts/Clients', 'Messages' and 'Forums'.	n=24 (9 CGs and 15 professionals); n=16 (9 CGs and 7 professionals), respectively	Impressions were overall positive; participants felt the use of the platform would promote cooperation with other members of the care network, and in turn, improve the quality and efficiency of care PwD receive.	Verwey et al., 2016

TABLE 4: OUTCOME MEASURES AND SIGNIFICANCE			
Intervention	Type	Outcome Measures	Reference
Partner in Balance (PIB)	Intervention Evaluation, Mixed Methods	Self-efficacy and goal attainment **Significance not reported**	Boots et al., 2016
ComputerLink (CL)	RCT	CG strain (physical strain, emotional strain, relationship strain, activity restriction) **Not statistically significant in any measures**	Bass et al., 1998
	RCT	Behavioural indicators of use (count of access, content of messages posted) **Not statistically significant in any measures**	Brennan, 1992
Mastery Over Dementia (MOD)	RCT	Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), depressive symptoms (CES-	Pot, Blom & Willemse 2015

		D), Anxiety and Depression (7-item anxiety subscale of the Hospital Anxiety and Depression Scale), and CG burden (1-item scale) **Not statistically significant in any measures**	
Caregiver's Friend: Dealing with Dementia	RCT	CG strain, CG gain (Positive aspects of CG survey), depression (CES-D), and Anxiety (10-item sub scale) **Not statistically significant in any measures**	Beauchamp, 2005
Diapason	RCT	Primary outcome is perceived stress of CGs (PSS-14; not statistically significant). Secondary outcomes include: self-efficacy (RSCS; not statistically significant), perception and reaction to cognitive/behaviour symptoms (RMBPC; not statistically significant), CG burden (ZBI; not statistically significant), depressive symptoms (BDI-II; not statistically significant), and self-perceived health (NHP; not statistically significant), **dementia knowledge (VAS; improved, statistically significant)**	Cristancho-Lacroix et al., 2015
iCare	RCT	**Perceived stress (PSS; improved; statistically significant, p=0.003)**, level of depression (CES-D; not statistically significant), perceived quality of life (PQoL; not statistically significant), level of bother due to disruptive behaviours (RMBPC; not statistically significant).	Kajiyama et al., 2013
UnderstAID	RCT	**Depression (CES-D; improved; statistically significant, p=0.037).**	Nunez-Naveira et al., 2016
Cuidate Cuidador	RCT	Perceived mastery and competence (Personal Mastery Scale; PMS), perceived social support (Lubben Social Network Scale), CG burden (ZBI), and emotional distress, (CES-D). **Not statistically significant in any measures**	Pagán-Ortiz et al., 2014
DEMentia-specific Digital Interactive Social Chart (DEM-DISC)	RCT	Outcome measures: **CG mgmt. style (CMS; improved; statistically significant, p=0.05), CG wellbeing (GHQ-28; improved; statistically significant, p=0.03), and depression (CES-D; improved; statistically significant, p=0.03).**	van der Roest et al., 2010
CARES Dementia Basics	Pre-post pilot	Outcome measures: **dementia knowledge questionnaire (improved; statistically significant,**	Pleasant et al., 2017

		p=0.001) and **competency** (Sense of Competence in Dementia Care Staff Scale; **improved; statistically significant, p=0.01**).	
Cares for Families (CARES)	Pre-post pilot	**Dementia knowledge** (measured by developed 20-item, multiple-choice and true/false measure; **improved; statistically significant, p<0.05**).	Gaugler et al., 2015
Ginko	Pre-post pilot	**Dementia knowledge** (Alzheimer's Disease Knowledge Test; **improved; statistically significant, p=0.03**), anxiety (GHQ-30) not statistically significant) and depression (CES-D; not statistically significant)	Lai et al., 2013
Informative Website for Caregivers (name undisclosed)	Intervention Evaluation, Feasibility	CGs emotional status (Brief Symptom Inventory (BSI), CG Burden, CG social support, care recipient-functional rating as reported by CG. **Significance not reported**	Chang, 2004

2.4 SYNTHESIS OF RESULTS

The majority of articles assessed the effectiveness of the intervention presented. While many evaluated the usability, usefulness, CGs attitude towards, or described the development as well as the specifications of the intervention.

2.4.1 Outcome Measures.

CG Stress/Burden. Six of the thirteen articles featured in Table 4 measured CG stress/burden (Beauchamp, 2005; Chang, 2004; Cristancho-Lacroix et al., 2015; Kajiyama et al., 2013; Pagan-Ortiz et al., 2014; & Pot, Blom & Willemse, 2015). Common scales include the Zarit Burden Interview (ZBI; Ankri et al., 2005) and the Perceived Stress Scale (PSS; Cohen & Williamson, 1988). Only Kajiyama et al (2013) reported statistical significance for perceived stress (PSS). Similar to the outcome of CG burden, Bass et al

(1998) and Beauchamp (2005) measured CG strain and found no significant change/improvement.

CG Depression. Eight of the thirteen articles featured in Table 4 measured CG depression (Beauchamp, 2005; Cristancho-Lacroix et al., 2015; Kajiyama et al., 2013; Lai et al., 2013; Nunez- Naveira et al., 2016; Pot, Blom & Willemse, 2015; Pagan-Ortiz et al., 2014; & van der Roest et al., 2010). All but one article which measured CG depression utilized the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The other instrument utilized by Cristancho-Lacroix et al (2015) to measure depression was the Beck Depression Inventory (BDI-II; Beck, 1996). Only two articles reported decreased levels of depression and significant improvement (Nunez-Naveira et al., 2016; & van der Roest et al., 2010).

CG Self-efficacy. Only two of thirteen articles in Table 4 measured self-efficacy (Boots et al., 2016 & Cristancho-Lacroix et al., 2015). Revised Scale for CG Self-Efficacy was a noted survey for this outcome (RSCS; Steffen et al., 2002). Statistical significance was not reported by Boots et al (2016); significant improvement was not found by Cristancho-Lacroix et al (2015).

CG Anxiety. Three articles measured anxiety and one article measured emotional status (Beauchamp, 2005; Pot, Blom & Willemse, 2015; Chang, 2004; & Lai et al., 2013). An array of survey instruments was utilized, including a 7-item subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and a 10-item subscale of the State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch & Lushene, 1970).

Emotional status was measured through the Brief Symptom Inventory (BSI; Derogotis, 1992). No articles reported statistical significance for anxiety/emotional status.

CG Perceived Quality of Life. Kajiyama et al (2013) measured perceived quality of life (PQoL; Patrick et al., 1988) and did not find statistical significance.

Dementia Knowledge. Interestingly, four articles assessed CG-dementia knowledge (Cristancho-Lacroix et al., 2015; Gaugler et al., 2015; Lai et al., 2013; & Pleasant et al., 2017). All four articles found increased dementia knowledge and statistical significance in their outcome measures, however, two surveys were created for the sole purpose of testing the intervention, and one survey source was not cited; this ultimately questions the validity of the knowledge survey tools used and questions the statistical significance.

Goal Setting, Competence and Mastery. Lastly, three articles assessed goal setting, competence and mastery. Boots et al (2016) assessed goal attainment through Goal Attainment Scale (GAS; Kiresuk & Sherman, 1968). Pagan-Oritz et al., 2014 assessed mastery and competence through the Perceived Mastery Scale (PMS; Aneshensel, Pearlin & Schooler, 1978). Lastly, Pleasant et al (2017) evaluated perceived-competence through the Sense of Competence in Dementia Care Staff Scale (SCIDS; Schepers et al., 2012). Only Pleasant et al (2017) found statistical significance in their competence measure.

Overall, the bulk of literature suggests that there may be a benefit by using online CG education modules, however, robust RCTs are encouraged to replicate statistically significant outcome measures in future in order to prove or disprove hypotheses.

2.4.2 Development of Intervention. Most (29/31) articles briefly explain the intervention developmental methodology and process. Interventions were developed by

medical experts, content experts, as well as professionals (i.e. instructional designers) (Beauchamp et al., 2005; Bhattacharyya, Benbow & Collins, 2017; Boyd et al., 2014; Chang, 2004). Four interventions were also developed with CG and PwD input through focus groups and/or interviews (Beachamp et al., 2005; Bhattacharyya, Benbow & Collins, 2017; Boots et al., 2016; Chang, 2004). Interestingly, Bhattacharyya, Benbow and Collins (2017) sought general feedback from CGs post-development to gauge attitudes towards *Living and Dying Well with Dementia*. Boots et al (2016) gathered themes from CGs and healthcare professionals through in-person semi structured interviews. The themes thereafter informed the topics included in their *PIB* intervention (Boots et al., 2016).

2.4.3 Iterative Developmental Framework. Four interventions were iterated to suit feedback collected from participants. Articles utilize an iterative-feedback developmental methodology whereby feedback was sought and later applied (Boyd et al., 2014; Chiu & Lottridge, 2005; Glueckauf & Loomis, 2003; Nunez-Naveira et al., 2016).

2.4.4 Perceived Value. Interventions, including *CL, MoD, Caregiver's Friend, Diapason, iCare and UnderstAID*, were deemed effective tools by the participating CGs (Bass et al., 1998; Beauchamp et al., 2005; Brennan et al., 1992; Cristancho-Lacroix et al., 2015; Kajiyama et al., 2013; Nunez-Naveira et al., 2016; Pot, Blom & Willemse, 2015).

Interventions that were evaluated sans robust RCT design (*CL, Living and Dying Well with Dementia* App, *AlzOnline*, and *Caring for Me and You*) were also deemed as favourable interventions by CGs; interventions were believed to be helpful, useful, and usable by the older population (Brennan & Smyth, 1994; Bhattacharyya, Benbow & Collins, 2017; Glueckauf & Loomis, 2003; Hattink et al., 2016). Although the majority of

articles were evaluated according to the needs of older CGs, Pagan-Ortiz et al (2014) evaluated *Cuidate Cuidator* with younger CGs and older CGs. This is notable as younger CGs are significantly overlooked in the CG and dementia literature. More interventions should seek feedback and evaluate with diverse CG populations and characteristics.

Pleasant et al (2017) evaluated increase of dementia knowledge among participants. In addition to increased knowledge in this study, participants appreciated the vast majority of topics offered, including person-centred care and behaviour modification.

2.4.5 Testing and Usability. Articles which focused on assessing the usability of the interventions (*STAR* and *ICSS*) used both task-instructed measures, measuring eye gaze and mouse movements, as well as think-a-loud measures, respectively (Boyd et al., 2014; Chiu & Lottridge, 2005). Both of these studies of usability testing used a small number of participants (3, and 5) respectively (Boyd et al., 2014; Chiu & Lottridge, 2005). In both instances, it was reported that the participants could mostly complete the majority of the tasks; as participants made their way through the sites, they tended to improve in ability to use the system (Chiu & Lottridge, 2005). CGs of all ages can learn how to use complex interventions – some will learn faster than others. However, the intervention needs to be learnable and consistent for this to occur.

2.4.6 Attrition. Chiu and Lottridge (2005), and Chiu and Eysenbach (2011), through Andersen's Behavioral Model of Health Service Utilization (BMHSU) and Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT), confirmed that CGs must feel the need to *want* or *have* to use an intervention (Andersen, 1995; Venkatesh et al., 2003). This alludes to attrition, an issue which eHealth developers and innovators of

healthcare interventions face. Attrition, as per Eysenbach's (2005) Law of Attrition, conceptualizes the term in two parts. Participants who do not follow-up by completing post-intervention questionnaires are called *dropout attrition* and participants who stop using the intervention are referred to as *non-usage attrition*.

Dropout attrition was experienced in pilot and testing trials (Kurz et al., 2016; Kajiyama et al., 2003; Goldberg et al., 2015). Noted reasons for dropout attrition include the CGs spouse/loved one passed away, time conflicts, uselessness of the application, or CG suffered from a disease (Chiu & Eysenbach, 2010; Nunez-Naveira et al., 2016). Ensuring meaningful use with interventions is important when designing, developing, and testing interventions to mitigate attrition.

2.4.7 The Importance of Stage-Specific Information. As usage of the interventions declined over time, interventions should address stage-specific needs across the caregiving and dementia journey (Wasilewski, Stinson & Cameron, 2017). Kovaleva et al (2017) complement this finding with the theme of 'stage specific information.' Chiu and Eysenbach (2011) recognize how the CG journey changes, alters, and adapts over time; CGs do not encounter the same experiences either. For example, CGs who evaluated *PIB* emphasized the need to have stage-specific information readily available, as opposed to information tailored simply to coping with the disease and to stigmatizing topics (Boots et al., 2016).

Online educational interventions that are personalized to the needs of the CG as well as the state of the PwD are seldom available (Hales & Fossey, 2017). *DemDisc* addressed this through specific questions which, in steps, lead the users to material relevant

to their needs. Similarly, *Caregiver's Friend* features a survey, which assesses the needs and stage of the CG/PwD, and in turn, directs the user to the correct and relevant material on the site per the quiz result (Beachamp et al., 2005). This is critical as the CG and dementia journey is unique for all dyads; therefore, interventions should be designed to be applicable to CGs beginning the journey, as well as those who are further along.

2.4.8 Featured Material and Use of Vignettes. CGs require information that is both lay and relevant. Bhattacharyya, Benbow and Collins (2017) highlighted the CG's preference for 'bite-sized chunks' of information so the size of the delivered material was comprehensive; participants were thus not as likely to be intimidated by the amount or difficulty of the content that was delivered. Participants who interacted with *CARES* appreciated the lay delivery yet the actual complexity of the content; the information was sufficient to gain a thorough understanding of concepts (Gaugler et al., 2015). Interventions should also highlight the use of vignettes, which create a lifelike comparison and personal connection to the material (Gaugler et al., 2015; Kajiyama et al., 2013).

2.4.9 Online Flexibility. The purpose of many interventions was to provide an accessible and reachable set of educational information for CGs. Hosting the intervention online is flexible for CGs and PwD alike, as their days are not their own; CGs cannot commit to a time to meet online (i.e. for a live event) so taking advantage of daily events is uncertain. This emphasizes the importance of online asynchronous forums whereby CGs and end-users can connect, give and receive support (Brennan, 1992; Brennan, Moore & Smyth, 1992; Gaugler et al., 2015; Glueckauf & Loomis, 2003).

Some interventions also feature live forums or 'ask the expert' where a healthcare professional will lead and disseminate sessions; however, it may be difficult for CGs to be online at any specific time. It is therefore recommended to archive expert live forums so CGs can log-on and review them at a time that is convenient.

2.4.10 Importance of Community Forums. Community forums were of importance to CGs as they are a way of communicating with likeminded peers (Brennan et al., 1994; Glueckauf & Loomis, 2003; Goldberg et al., 2015). This spirit of comradery allows CGs to bond with and support one another through relatable experiences. Although forums are not considered to be educational interventions, a vast number of interventions did feature forums, which also have merit in a social sense, thereby helping to support CG wellness by reducing their susceptibility to social isolation and loneliness.

2.4.11 Intervention Research Lifecycle. The majority of articles assessed the early usability, likeability, and CG-perceived usefulness of the interventions during or shortly after development; the effectiveness was assessed thereafter using robust methods. This lengthy and quintessential assessment method has merit, as it attempts to ensure meaningful use of the intervention over time. It is critical to develop interventions with the proposed end-users to ensure this meaningful use. In the past, eHealth interventions have too often ignored the needs of their intended users. Unfortunately, the articles reviewed seldom presented the developmental methodology that was used.

2.5 CONCLUSION

Overall, the 23 respective interventions and 31 related articles attempt to respond to the dynamic needs of CGs of PwD, as well as support the educational gaps of CGs and PwD, alike. The interventions were generally perceived positively and helpful by those assessing them, whether that included healthcare professionals or intended end-users. The RCT's published on this topic evaluated their interventions through the following outcome measures: CG-burden, depression, stress, anxiety, self-efficacy and improvement of dementia knowledge. At this time, there is not enough evidence in the literature to clearly state whether online interventions improve CG stress, self-efficacy, or CG burden, albeit many authors continue to use said outcome measures to evaluate effectiveness. Because the interventions are all so different, their effectiveness needs to be evaluated on an intervention-to-intervention basis, hence the array of evaluation methods and tools.

Interestingly, the vast majority of interventions and articles acknowledge that online interventions are convenient to CGs alike, as their days are often unpredictable; CGs cannot always commit to a certain day and time. A missing component within the literature involves testing the intervention with potential end-users during development. As per the MRC framework, the development of healthcare interventions should include the input of its intended end-users (Boots et al., 2016; Craig et al., 2008).

Similarly, most of the interventions included more aspects than just educational materials. Other aspects included community spaces and online forums, both of which are incumbent to coping with CG tasks, experience, and the overall journey. This importance of comradery available in a convenient place (online). CGs are able to create meaningful

relationships with one another online, which informs their CG experience. This thesis will highlight the usability testing of the suite of *iGeriCare* lessons with CGs of PwD This, in turn, will attempt to ensure meaningful use of the *iGeriCare* educational platform.

CHAPTER 3

PHASE 2: LESSON USABILITY

3.1 METHODOLOGY

3.1.1 Ethics. This study is directed towards CG-perceived usability and impact of *iGeriCare*, based on the iterative development of the *iGeriCare* lessons This study was approved by the Hamilton Integrated Research Ethics Board (HiREB).

3.1.2 *iGeriCare*. Ten *iGeriCare* lessons were designed by Dr. Sztramko and developed by Dr. Anthony J. Levinson and his team at the Division of eLearning Innovation (*DeLI*) at McMaster University. *DeLI* also developed the *iGeriCare* site. Dr. Anthony J. Levinson is the John R. Evans Chair in Health Sciences Educational Research focusing on the development and testing of learning technologies. *iGeriCare* was designed with early feedback collected from healthcare professionals (case managers and geriatricians).

The *iGeriCare* intervention can be accessed at: www.iGeriCare.ca. The *iGeriCare* site features the following landing pages: *'Home', 'Lessons', 'Resources', 'Discussions', 'About Us',* and *'Help.'* The site design is simple, clean, and inviting. The *'Home'* page introduces the purpose and elements of the site, which is *Bringing Clarity to Dementia: A*

diagnosis of dementia can be challenging for patients, families and caregivers. This thesis will only focus on the evaluation of the lessons and does not focus on the site.

Each lesson follows a similar structure, beginning and concluding with a vignette focused on a relatable experience (a PwD and a CG), and features closing true/false and multiple-choice questions. Lesson content is designed to build from other lessons. The following 10 lessons have been published on the *iGeriCare* site:

TABLE 5: IGERICARE LESSONS	
Lesson	**Description**
[1] What is Dementia?	- Teaches CGs about cognition, and how it is impacted by dementia - CGs will learn about the most common causes of dementia and other causes of dementia-like symptoms
[2] What is Mild Cognitive Impairment?	- Presents the difference between normal aging and mild cognitive impairment (MCI) - CGs will discover what causes MCI, how it is diagnosed, and the treatment options
[3] How to Promote Brain Health	- Explores how diet, exercise, supplements, blood vessel health and lifestyle choices affect the brain
[4] The Different Types of Dementia	- Presents similarities and differences between dementias (Alzheimer's Disease, vascular, Lewy Body, Frontotemporal, and Parkinson's disease dementias).
[5] How is Dementia Treated?	- Distinguishes between managing the symptoms of dementia and modifying the disease itself - Discusses what prescription drugs and other therapies are available
[6] Safety and Dementia	- Covers risks of wandering, driving, fire, improper use of medications, and managing personal finances - CGs will also be introduced to strategies in order to mitigate these risks
[7] Caring for the Person with Dementia at Home	- Presents the types of services available in the CGs' home and community.
[8] Apathy, Depression, and Anxiety in Dementia	- Covers psychiatric issues which may affect those with dementia - CGs learn how to cope and will discover available treatments
[9] Behavioural Issues in Dementia	- Building upon lesson 8, this lesson delves into additional issues which may affect those with dementia

[10] Caregiver Wellness	-	Presents coping mechanisms, as well as the importance of self-care

3.1.3 Research Question and Aim. The purpose of this thesis component is to understand the perceived usability, usefulness, and feasibility of the *iGeriCare* lessons, and whether *iGeriCare* is perceived as an effective intervention to be utilized in both clinical and home settings.

The research question is: Do informal CGs in the Hamilton community perceive the *iGeriCare* intervention as a viable, usable, and useful educational tool?

3.1.4 Sampling and Recruitment. CGs heavily involved in the McMaster and Hamilton community were purposely recruited to participate as *'super-users.'* These community CGs (n=2) facilitate support groups at the Alzheimer Society of Hamilton and volunteer in the community. The purpose of involving the super-users was to evaluate the initial usability and content of the lessons; it was critical to involve the super-users to provide an initial opinion and evaluation deriving from the larger target user base.

3.1.5 Participant Characteristics. The super-users are well equipped with dementia-based knowledge; they have provided informal care in the past and both are in their early eighties. Additionally, they are both very knowledgeable on the topics of caregiving and dementias. These participants were recruited by the Division of eLearning Innovation (*DeLI*) and worked closely with me during the evaluation process. The super-users have both previously been CGs to loved ones who had dementia at home, as well as in LTC facilities. As seniors in their third age, both live very fulfilling and meaningful lives. The third age, as per gerontology literature, conceptualizes older adults who are active in

education, volunteerism, and meaningful activity to be in the third age—something that has seldom to occur in past generations (Twigg, 2004). The super-users lead and have led support groups at the local Alzheimer's Society, as well as volunteer daily and weekly at local LTC homes and hospitals.

3.1.6 Development of the Lessons. The purpose of the study was to inform the development and evaluation of the lessons. Dr. Sztramko drafted the content of the lessons which Dr. Anthony J. Levinson edited, and his team at the Division of e-Learning Innovation (*DeLI*) developed. Dr. Anthony J. Levinson and his team brought the *iGeriCare* concept to reality.

Lessons were developed through an iterative framework facilitating consistent end-user feedback. Iterative development enables evaluators to consistently provide subjective feedback, ultimately influencing the overall development (Leslie et al., 2006). To inform the framework, lessons were evaluated online through *360 Articulate*. 360 Articulate features a web-based application, enabling users to create and evaluate eLearning modules. Geriatricians, clinicians, case managers and community CGs (total n=12) evaluated. Evaluators commented as they watched the lessons being developed; both content and style were assessed. However, only data collected from the CGs (n=2) were included in this thesis.

3.1.7 QUIM Framework. The Quality in Use Integrated Measurement (QUIM) Framework informed lesson usability. QUIM consists of 10 factors and subsequent intersecting criteria (Seffah, Donyaee, Kline & Padda, 2006). As per the usability literature, certain studies have attempted to support usability aspects appropriate to older adult end-

users and testers (Holzinger, Searle, Kleinberger, Seffah & Javahery, 2008). Holzinger et al (2008) generated an 11th factor of *acceptability* to represent older end-users. *Acceptability* has many common criteria with other factors, but it also introduces criteria appropriate for older adult users/testers, including safety, discretion, dependability, non-obtrusiveness, appropriateness, understandability, and trustworthiness (the ability to inspire confidence) (Holzinger et al., 2008). Table 2 depicts QUIM and the 11th factor. The usability questions derive from the factor and criteria definitions featured in Holzinger et al (2008).

QUIM was chosen as it encompasses a comprehensive list of usability components and factors. Moreover, QUIM allows for qualitative feedback and enables a fluid and natural interview script. The magnitude of factors and criteria avoided constant repetition, although some criteria were replicated as they were applicable (e.g. controllability). Although results generated through QUIM factors and criteria can be quantified, QUIM offers qualitative-based results, which were used in this study (Seffah et al., 2006). At this point of the intervention development, qualitative data was desired as the feedback could be more easily communicated to various stakeholders (physicians, CGs, case-managers), project sponsors, and grant agencies.

TABLE 6: Relations Between Factors and Criteria & The 11th Factor* *adapted from Seffah et al., 2006*											
	Factors										
Criteria	Efficiency	Effectiveness	Satisfaction	Productivity	Learnability	Safety	Trustfulness	Accessibility	Universality	Usefulness	*Acceptability*
Time behavior	X			X							*X*

Resource utilization	X			X						X	*X*
Attractiveness			X						X		*X*
Likeability			X								*X*
Flexibility		X	X					X	X	X	*X*
Minimal action	X		X		X			X			*X*
Minimal memory load	X		X		X			X	X	X	*X*
Operability	X		X				X	X		X	*X*
User guidance			X		X			X	X		*X*
Consistency		X			X	X		X	X		*X*
Self-descriptiveness					X		X	X	X		*X*
Feedback	X	X						X	X	X	*X*
Accuracy		X				X		X		X	*X*
Completeness		X				X		X			*X*
Fault-tolerance						X	X			X	*X*
Resource safety						X					*X*
Readability								X	X		*X*
Controllability							X	X	X	X	*X*
Navigability	X	X						X	X	X	*X*
Simplicity					X			X	X		*X*
Privacy							X		X	X	*X*
Security						X	X			X	*X*
Insurance						X	X				*X*
Familiarity					X	X					*X*
Loading Time	X			X					X	X	*X*
…											
Safety											*X*
Discretion											*X*
Dependability											*X*
Non-Obtrusiveness											*X*
Appropriateness											*X*
Understandability											*X*
Trustworthiness											*X*

3.1.8 Telephone Interviews. As previously mentioned, CGs from the community (n=2) participated as 'super-users.' Post-online view and evaluation, super-users participated in semi-structured telephone interviews to evaluate each lesson's respective usability. The super-users participated in 11 and 6 telephone interviews, respectively. One

super-user only participated in 6 interviews (evaluating 8 lessons) as she started the review process later on. Both super-users were involved in their respective communities.

Each interview involved a telephone interview script (TIS), with each featuring 2-3 factors, and 5-8 subsequent criteria from QUIM. Factors and criteria included in the TIS were chosen at random (and repeated) to avoid repetition. Not all factors/criteria were used as not all were relevant in the scope of the intervention.

Telephone interviews lasted anywhere from 8-20 minutes in total. Telephone interviews took place 1-2 days after the super-users (and the RA; myself) evaluated the lessons on 360 Articulate. The super-users had the lessons in front of them during interviews, for reference. One super-user participated in 11 interviews (1 initial welcome interview/10 lesson interviews), and the other in 6 (1 initial welcome interview/5 interviews for 1-8 lessons, total). Please see Figure 2 for the factors and criteria used in the respective interviews.

During the telephone interviews, factors were defined to the super-user (e.g. "*Efficiency: the capability of the software application (being the iGeriCare lesson) to allow you to use appropriate time to achieve the related goal (i.e. clicking 'next' to move onto the next component, and the lesson fulfilling this 'next' command by moving on).* After the definition was provided, the criteria-based questions were asked (e.g. *Resource Utilization: When entering a command to the lesson, for example, clicking 'next' to move on to the next component, does the lesson fulfill this command?).* The respective TIS were unique but they followed the same structure. Please see Appendix C to view a TIS example.

3.1.9 Data Collection and Planned Analysis. During the interviews, the super-user responses were transcribed verbatim on a PDF in real-time. Transcriptions were collected into a comprehensive word document which presented the factors, criteria-based questions, and answers in tabular form. Completed documents were fed back to *DeLI* to inform refinement, subsequent development and validation of specifications.

The qualitative data collected during the telephone interviews were thematically analyzed for recurring themes, words, and attitudes. Inductive analysis was applied when applicable (i.e. with instances of themes). Recurring themes that were found included: relevance of content and information, slide design, ease of navigation, forward learning, and educational tools.

Figure 2: Interview QUIM Criteria & Factors

Factors	Tally
Satisfaction	4
Trustfulness	3
Usefulness	2
Efficiency	1
Effectiveness	2
Accessibility	3
Learnability	2
Universality	3
Productivity	3
Acceptability	3
Criteria	Tally
Attractiveness	6
Likeability	3
User-Guidance	5
Self-descriptiveness	4
Navigability	4
Loading Time	4
Resource Utilization	3
Minimal Action	3
Consistency	3
Completeness	4
Readability	2
Simplicity	2
Familiarity	2
Minimal Action	3
Feedback	2
Controllability	3
Appropriateness	2
Trustworthiness	2
Understandability	2
Consistency	1
Safety	1
Dependability	1
Operability	2
Accuracy	1
Time Behavior	1

TIS&L#	Factors	Criteria
TIS 1	Satisfaction	Attractiveness, likeability, user-guidance
Lesson 1	Trustfulness	Self-descriptiveness, navigability
	Usefulness	Loading time
TIS 2	Efficiency	Resource utilization, minimal action
Lesson 2	Effectiveness	Consistency, navigability, completeness
	Accessibility	User-guidance, readability, simplicity
TIS 3	Learnability	Self-descriptiveness, familiarity, minimal action
Lesson 3	Universality	Attractiveness, feedback, controllability
TIS 4	Productivity	Resource utilization, loading time
Lesson 4	Universality	Attractiveness, controllability
	Satisfaction	Likeability, user-guidance
TIS 5	Trustfulness	Self-descriptiveness, navigability
Lesson 5	Usefulness	Loading time
	Satisfaction	Attractiveness, likeability, user-guidance
TIS 6	Productivity	Resource utilization, loading time
Lesson 6	Universality	Attractiveness, feedback, controllability
TIS 7	Trustfulness	Readability, familiarity
Lesson 7	Acceptability	Appropriateness, trustworthiness, understandability
TIS 8	Learnability	Minimal action, consistency, simplicity
Lesson 8	Accessibility	Operability, completeness
	Acceptability	Dependability, trustworthiness, safety
TIS 9	Satisfaction	Operability, attractiveness
Lesson 9	Effectiveness	Completeness, navigability
	Acceptability	Consistency, appropriateness
TIS 10	Productivity	Time behavior
Lesson 10	Accessibility	User-Guidance, self-descriptiveness, completeness
	Acceptability	Accuracy, dependability, understandability

Explanation of Figure 2:
- *The factors and subsequent criteria used against the lessons and telephone interview scripts (TIS) are featured in the orange and white table.*
- *The tally which each factor and criteria was used, in total, are presented in the green and white rows.*
- *The 11th factor, Acceptability, and its subsequent criterion are shaded in grey.*

3.2 RESULTS

Themes became apparent during the usability interview of Lesson 8 and theoretical saturation was reached. Theoretical saturation occurs when no new insights are added to the collected data and themes become repetitive and apparent (Bowen, 2008). Saturation became apparent on many aspects of the lessons, including the bite-sized bits of information, appropriate language usage, and lesson comprehensiveness. Lesson usability evaluation still continued thereafter despite theoretical saturation. Thoughts, experiences, and opinions of the lessons were often presented in a narrative and storytelling manner. The super-users often related their thoughts to their past and current situations and shared them openly. The analysis of the collected data highlighted relevant themes, including: relevance of content and information, slide design, ease of navigation, forward learning, use of educational tools, and accessibility.

3.2.1 Relevance of Content and Information. As the super-users were experienced within their respective caregiving communities, they confidently attested to the importance and relevance of the content. When asked whether the respective lessons were relevant, the super-users agreed that all lessons were relevant to caregiving. The content presented in each lesson built upon previous material, as one super-user mentioned: *"What I learned from lesson 1…carried on to lessons 2 and 3."* The super-users emphasized the importance and relevance of the various topics:

"It is a terrifically relevant topic, this one… caring for the person with dementia at home. So many caregivers are doing it and doing it well. So many

people have difficulties all across the board. It is really relevant as this is what the government and healthcare institutions are expecting us to do…we need this education."

<div align="center">…</div>

"The info was organized very well. Some think dementia is the disease, but the graphic shows that it is not the disease, it is the result. Some people have a lot of confusion on this topic. This kind of program would help people that haven't gone out for other research. You need to know if its Alzheimer's or frontal temporal."

<div align="center">…</div>

Each lesson began and ended with personal vignettes, which were usually focused around a couple—usually a CG and their loved one (using pseudonyms), being the PwD. The vignettes were appreciated by the super-users:

"I like the personal illustration with the people and their stories, and how they come back at the end and pull the information at the end. It makes it personal, and it makes the information easy to grasp."

<div align="center">…</div>

"…and the fact that it connected to a real person makes it more understandable. You actually talk about "Russ (pseudonym)."

<div align="center">…</div>

3.2.2 Slide Design. Likeability and attractiveness are two critical components of usability (Seffah et al., 2006). Overall, the super-users perceived the lessons as attractive, inviting, and overall positive:

> *"The spacing, colours, are all enjoyable to look at... it had enough information, but was not too cluttered Not too much text and simple graphics… I would watch another lesson!"*

<div align="center">...</div>

3.2.3 Ease of Navigation. The super-users found the lessons easy to navigate. Although one super-user initially had trouble operating the lesson, they were able to 'pick up' the navigation easily. This speaks to the learnability of the software. By the third and fourth lessons, the super-users were very comfortable, *"...I now know what to expect."* In regard to the criteria of operability, *"...yes! [The lesson] follows the same patterns as the others!"* Comments on navigation include:

<div align="center">...</div>

> *"[The lessons] are easy to navigate through…you can't really make a mistake going to the next one."*

<div align="center">...</div>

> *"I think I could teach someone else how to use the lesson."*

<div align="center">...</div>

"It's very easy to finish, manageable, and easy to work through. The way it

is set up, not just the content or information. The mechanics also work

well… once you get started."

<div align="center">…</div>

A super-user thought the structure of the lesson specs were helpful (i.e. the menu on the left-hand side—please see Figure 3, below):

"Everything is very clear. The menu on the left-hand side is very helpful as

you know where you are in the lesson. You know where you're headed. The

next button is easy to hit, and it's easy to head back to the previous

component."

<div align="center">…</div>

FIGURE 3: Menu with Lesson Specs
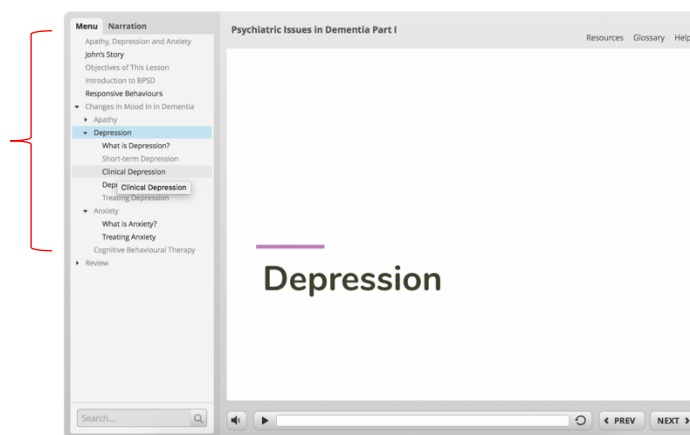
3.2.4 Forward Learning. The super-users felt encouraged to pursue further information on topics, as well as share with their friends, family, and peers who were

experiencing dementia and caregiving. CGs felt the resources as invaluable, and that as time progresses, more and more CGs will be online for support, education and information:

"I can see people in the future, going online and wondering if I am alone in this and they go to Alzheimer's Society to see others… but this is a fantastic beginning!"

...

One super-user relished the opportunity to review various information:

"If there was anything I wanted to look at again, I could just back up. Once you have that figured out, you can do it easily."

...

3.2.5 Educational Tools. The developers at *DeLI* utilized educational tools to facilitate learning, education, as well as enjoyment. Visual learning tools such as interactive graphics, images, interactive charts were all used to present information:

"The graphics on the slide 'what causes apathy' (lesson 9) …the [graphic] of the brain, was particularly helpful for me. I am a visual [learner], so any graphics help me, really."

...

When asked about the comprehensibility and understandability of lesson 10, a super-user emphasized how an interactive graphic helped her understand a topic about CG wellness:

"Especially the graphic about caregiver wellness, that was really well done.

It has six areas… the center is caregiver wellness. The information in each

is so relevant. When you click on an area, it's another important topic!"

...

Each lesson featured at its conclusion 2-3 true or false, or multiple-choice questions whereby end-users could test their knowledge. This was perceived as a positive and effective tool, where CGs can gain confidence in themselves:

"It is good to have something to do with the material that you just heard. It

is a good learning exercise… they are a really good review, a fun little quiz."

...

"As each lesson goes on, I become more and more confident. Now, I have

learned a new thing!"

...

3.2.6 Accessibility. Accessibility is one of QUIMs factors; in addition to the 11th factor of acceptability, being accessible is pertinent to reaching family CGs as well as PwD (Holzinger et al., 2008). In relation to the helpful bite-sized bits of information, this theme

not only speaks to the accessibility of *iGeriCare* being online, it speaks to the accessibility of the information in the way it is organized and presented:

"It was organized in a way that helped me remember. I think if it was new information for someone, it was organized. You did not have to digest a big large text, it was very simple. Particularly, with an older person, you can't pay attention to a large article, so small bits of photographs and text work best."

...

"It is a good way to summarize. This information is so important to know. Lots of times people are in denial and they don't get help. It is such good information… it is not given in a way that is over your head either… it is very accessible. Anyone who can work the computer can understand totally what is being taught"

...

The content was also delivered well, in small, bite-sized bits. The concept of comprehensive bits was a theme that arose in almost every interview. The bite-sized bits allowed the super-users' attention to be kept on the lesson:

"...partly because of the small sections and because it is not too long. It doesn't go into great lengthy details and long explanations. It gets the info down in sizeable bits that you can get it and move onto the next."

...

"...the short information 'bite' and [the way the] sentences [are

structured] would be accessible for a person with ESL. If you can work

a computer, you would be able to access this information."

...

Overall, *iGeriCare* is perceived as a very effective tool:

"If I were backing up several years and was in the middle of [my husband's]

crises with Alzheimer's, I would find this very helpful. This program would

be very useful and is not stressful to use…"

3.3 ITERATION OF LESSONS PER FEEDBACK

The above feedback was fed back to *DeLI* and the developers. The feedback influenced a few minor changes to the lessons. Typically, *DeLI* would iterate the lesson content until the complete version was created and accepted.

DeLI developed an avatar of Dr. Sztramko to help host and narrate the lessons (Figure 4, below). During the evaluation of the first lesson, one of the super-users did not appreciate the way the avatar's hands were moving as she found him to be too distracting. The avatar was re-designed and improved by lesson 2:

"I find the little icon of the lecturer [Dr. Sztramko] waggling his arms and mouth a little bit distracting. That may just be me…but my eyes just want to go down to him, but I want to read the words. It looks like he is trying to plan an air guitar… I found it distracting."

There was also a documented instance from Lesson 7 where the words on the lesson slide overlapped with a stock photo (a stand-in photo that would be replaced by an image in a later version). This issue was fixed thereafter and would have been fixed by the developers without the feedback.

Figure 4: Dr. Sztramko's Avatar

CHAPTER 4

DISCUSSION

This thesis has attempted to evaluate the usability of the *iGeriCare* lessons, an eHealth intervention, through the QUIM usability framework. Through a qualitative usability perspective, the super-users applied their personal experiences to inform their assessments (i.e. reflecting on the Alzheimer's support groups that they lead to justify how they felt about the lesson content, design, and structure).

Similar to other interventions assessed in the systematic literature review (Phase 1), the methodology involved in this thesis complements the usability testing of the *STAR* and *ICSS* training programs (Boyd et al., 2014; Chiu & Lottridge, 2005). However, the usability

testing we used was much more detailed as it sought an array of usability components, and assessed every lesson, individually. Like *STAR* and *ICSS*, the usability component of this thesis involved a small number of participants (n=2 CGs). *iGeriCare* has been developed in a way where CGs can choose which topics are most relevant to their stage and information needs; although the information presented in the lessons builds upon one another, CGs are still able to determine their own needs, and select just what they want to access.

Similarly, to Bhattacharyya, Benbow and Collins (2017), the *iGeriCare* lessons do feature information bites or 'bite-sized information'. This delivery of information is not only complete and thorough, it also allows the end-user to comprehend the information well. This conclusion parallels Gaugler et al (2015), who determined that information that is sufficient yet clear is best for CG education. The use of vignettes in the *iGeriCare* lessons were appreciated by the super-users as it allows a personal connection to the material, similar to the *CARES* and *iCare* interventions (Gaugler et al., 2015; Kajiyama et al., 2013).

The accessible online presence of *iGeriCare* is also a positive aspect of the intervention. This finding was represented in the evaluation and presentation of similar interventions (Brennan, 1992; Brennan, Moore & Smyth, 1992; Gaugler et al., 2015; & Glueckauf & Loomis, 2003). As more and more older adults are searching for educational information and support online, multimedia interventions will be at the forefront of support. This was highlighted by the super-users who explained the importance and relevance of the *iGeriCare* information, as well as the convenience of the information being presented on one comprehensive, accessible, and usable site. They emphasized how some of their more

'tech-savvy' friends, family, and comrades from their support groups would thrive with *iGeriCare*, and how as our society ages and more older adults are familiar with searching online, *iGeriCare* will be invaluable.

The *iGeriCare* developmental methodology paralleled similar interventions. Alike *Caregiver's Friend, Living and Dying Well with Dementia, STAR*, and Chang's (2004) informative website, the lesson material was conceptualized and developed by medical and content experts (Beauchamp et al., 2005; Bhattacharyya, Benbow & Collins, 2017; Boyd et al., 2014; Chang, 2004). The super-users expressed how *iGeriCare* has merit because of the involvement of the content experts and medical personnel.

As the 11th factor of QUIM, acceptability, was developed to represent the needs of older adult users, it was applied against the lessons. The super-users found *iGeriCare* to be a safe resource, despite being online. The super-users emphasized the hesitance older adults experience when interacting online, specifically, when being asked for email addresses and passwords. This hesitance is mitigated by providing users information about the team involved in developing the system (i.e. Hamilton Health Sciences, McMaster University, St. Peter's Hospital, Alzheimer's Society, etc.). The super-users also felt they could depend on the integrity and accuracy of information presented. The consistency of the lesson structure and specifications allowed the super-users to retain the know-how of operating the lessons. This speaks to the content and lesson development; the lessons were structured in an effective way wherein the super-users understood the structure and where therefore able to follow along well.

CHAPTER 5

CONCLUSION

This comprehensive thesis offers an extensive review of existing published works on online systems for training CGs, linking their results to an initial usability evaluation of *iGeriCare*, as well as its CG-perceived effectiveness and potential. Dr. Richard Sztramko, Dr. Anthony J. Levinson and the *DeLI* team conceptualized the lesson content and design. The lessons were deemed as a relevant, acceptable, and usable resource by the super-user reviewers. The super-users concluded that *iGeriCare* is an effective intervention for communicating relevant information from the clinic to the home, and perceived it to be viable, usable, and useful.

The next steps will include a more robust pre-post-test evaluation of the *iGeriCare* resource (including the site). In this manner, *iGeriCare* is following research lifecycles similar to the interventions featured in the literature review. Additionally, as interventions for CGs continue to be developed and evolve, they should be studied from a usability and CG-perceived usefulness perspective.

5.1 Limitations. The super-users participated in 11 and 6 telephone interviews (evaluating 10 and 8 lessons, respectively). The super-user who participated in 6 telephone interviews was unavailable for the consecutive interviews due to unexpected health events. Two super-users are a small sample size, but their participation allowed an in-depth analysis and the ability to confirm findings. Additionally, the super-users experience is not equivalent to new CGs, however it allows us to test initial concepts and gain valuable information from a less vulnerable population; the super-users have had extensive training,

experience, and education on the dementia and PwD. They were also new to the learning management system (360 Articulate), which may have impacted their experiences. Additionally, the interviews took place over the phone as the CGs experienced some mobility issues. Lastly, the QUIM Framework was not quantified. Although a limitation, a qualitative perspective was desired.

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Appendix A: Systematic Literature Review, Articles in Detail

Systematic Literature Review, All Articles in Detail							
Intervention	Type	Details	Methodology	Variables/ Measurements	Results/ Conclusions	Extracted Data	Reference
N/A	Scoping Review	The aim was to understand current educational interventions for CGs. Authors conceptualized 53 web-based interventions for CGs.	Followed a systematic approach to the research questions	N/A	The authors conclude that CGs value interventions which tailor to their unique needs and illness context; usage of the interventions declined over time, and therefore, interventions should address stage-specific needs.	Type of review; included interventions; conclusions reached	Wasilewski, Stinson & Cameron, 2017

Partner in Balance (PIB)	Systematic Literature Review	A systematic literature review was conducted. Purpose: to evaluate previous interventions for CGs of PwD.		N/A	Although online resources for CGs of PwD are positive interventions, articles do not present large affect; the majority of the articles lack methodological quality however often affect well-being, depression, burden, and self-efficacy.	Type of review; included interventions; conclusions reached	Boots et al., 2014
	Intervention Evaluation, Mixed Methods	To explore CG attitudes and views towards PIB; a pragmatic study was conducted	In-depth focus group interviews were conducted to explore CGs views on content; in-depth independent interviews to explore internet use and testing and feasibility with CGs (n=4). Baseline and post-tests (8 weeks) were conducted.	Self-efficacy and goal attainment	CGs appreciated completing the intervention at home. The content and guided sessions was perceived positively. Preliminary effects of self-efficacy were positive.	Intervention description, methodology (participants, sample size, evaluation tools/measurements), results/conclusions	Boots et al., 2016
ComputerLink	RCT	To evaluate CLs effect on CG strain	RCT (n= 102 CGs; 51 control & 51 experimental group). Experimental group interacted with CL for 12 months. Rigorous pre-and-post-test used. Utilized an initial in-person interview.	Caregiver strain (including physical strain, emotional strain, relationship strain, activity restriction). Each type of strain was measured through three items.	CL reduced certain types of strain if CGs also had large networks, were spouses, or did not live alone with their receivers. Frequent use of communication function reduced strain for CGs who were initially more strained. CL is declared as an effective tool.	Intervention description, methodology (participants, sample size, evaluation tools/measurements), results/conclusions	Bass et al., 1998
	RCT	To evaluate CG interaction with the CL intervention	RCT (n=102) CGs, where 47 had access to CL for 12 months.	Behavioural indicators of use (count of access, content of messages posted)	CGs accessed CL 3888 times. Behavioral indicators demonstrate that CL promotes collaboration between CGs. CGs sought info over 500 times and spent an average of 10 minutes upon entry. CGs posted 749 messages on the forum.		Brennan, 1992
	Intervention Evaluation (general)	To understand CG use of CL	Using a convenience sample of CGs from a Research Registry, all participants got a CL terminal modem system installed in their homes. Participants used CL 1-8 months, 1 week during this timeline was analyzed.	CL website analytics (count of log-ins, forum-use)	During week of observance, CL was accessed 98 times, 29 respective participants logged-in. Mean log-ins to all participants (n=47) was 2, ranging from 0-13. Most frequently used component was the forum (used 80x),		Brennan, Moore & Smyth, 1992

					and the private mail was used 56 times.		
	Intervention Evaluation (general)	To explore CG attitudes towards CL	CG attitudes towards CL was measured with a researcher-developed self-administered 20-item survey. Participants were prompted with an adjective and were asked to indicate a Likert format the extent to which they agreed with the term.	Positive items: interested, excited, strong, inspired, enthusiastic, proud, alert, determined, attentive, active. Negative items: extremely distressed, upset, guilty, hostile, irritable, ashamed, nervous, scared, jittery, afraid.	75% interested, 36% distressed; 29% Excited, 26% afraid. Overall, CGs/participants perceived CL as positive.		Brennan & Smyth, 1994
Internet-Based Support Services (ICSS)	Intervention Evaluation, Usability	To evaluate ICSS usability with bilingual Chinese CGs	Bilingual Chinese CGs (n=3) participated in usability testing; a think-a-loud approach was used.	Frameworks: Andersen's Behavioral Model of Health Service Utilization (BMHSU); Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT)	The interface was perceived as functional and the large icons on the email prompted participants appropriately. The text and site design provided context to facilitate use.	Intervention description, methods, results	Chiu & Lottridge, 2005
	Intervention Evaluation, Qualitative	To understand CG use of ICSS	Qualitative interviewing methods used to understand CGs (n=14) use of intervention. In-depth interviews explored CGs attitudes.		A needs factor must be present for use; needs of CGs must change over time as does their use; CGs are desperate for information as there is so much information out there and they do not know which/who to trust.		Chiu & Eysenbach, 2011
	Intervention Evaluation, Mixed Methods	To explore attrition of interventions for CG of PwD (n=46)	To explore attrition, the authors utilized a multi-phased, longitudinal study design. BMHSU is the most used model of understanding attrition; model consists of three factors: predisposing, enabling, and needs factors.	Andersen's Behavioral Model of Health Service Utilization (BMHSU)	Needs factor must be present for service use. The site was redesigned according to feedback, including use of narratives for education, addressing multilingual needs.		Chiu & Eysenbach, 2010
	Intervention Evaluation, Mixed Methods	To evaluate CG-use of ICSS, as well as effects on CG health outcomes	To explore Chinese-CGs use of ICSS, as well as the effects on the CGs health outcomes. Interviews were conducted, recorded, translated to English, and transcribed.	CG burden (BSFC), memory and behaviour (RMBPC), depression (CES-D), perceived health (SRH), perceived social support (MSPSS), positive aspects of CG (PAC), functional level (OARS), CG	The 19 CGs who had a higher score started the service earlier than those with lower scores. Nonusers had an increase in perceived burden at postintervention; occasional users had minimal changes.		Chiu et al., 2009

				competence (CCS).			
Mastery Over Dementia (MoD)	RCT	To measure feasibility and effectiveness of MoD	The feasibility and effectiveness of MoD was evaluated with (n=149) CGs. Measures were collected at baseline/during intervention. After viewing each lesson, CGs were asked to rate the comprehensibility and usefulness of the lesson.	Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), depressive symptoms (CES-D), Anxiety and Depression (7-item anxiety subscale of the Hospital Anxiety and Depression Scale), and caregiver burden (1-item scale).	68 CGs completed all lessons within 6 months, 81 did not finish all. 6 did not start at all. Those who did not finish reported the material wasn't relevant/faced too much CG burden. PRE-POST CHANGES REPORTED IN NEXT ARTICLE (below).	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Pot, Blom & Willemse, 2015
Caregiver's Friend: Dealing with Dementia	RCT	To evaluate the effectiveness of Caregiver's Friend for CGs who were also employed, full time	Ensued a control waitlist with (n=299) family CGs who were also employed, to test the effectiveness of the intervention.	CG strain, CG gain (Positive aspects of CG survey), depression (CES-D), and Anxiety (10-item sub scale).	7 CGs experienced significant positive results post-intervention. Use of intervention reduced depression, anxiety, and strain, whilst increasing perception of CG gain; the frequency of coping skills did not seem to improve.	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Beauchamp et al., 2005
Diapason	RCT	To evaluate the effectiveness of Diapason with CGs	Unblinded RCT consisted of n=49 CGs. 25 CGs, included in the experimental group, were given Diapason to use at home for 3 mo. Control group received usual care (n=24).	Primary outcome is perceived stress of caregivers (PSS-14). Secondary outcomes include: self-efficacy (RSCS), perception and reaction to cognitive/behaviour symptoms (RMBPC), CG burden (ZBI), depressive symptoms (BDI-II), and self-perceived health (NHP).	CGs who improved their understanding of dementia reported feeling less stressed. CGs with a perceived personal time restriction/poor social support suffered from more stress, burden, and depression.	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Cristancho-Lacroix et al., 2015
iCare	RCT	To evaluate the effectiveness of iCare	Participants (n=150) were randomized (75 & 75) and required to complete a set of baseline questionnaires pre-and-post intervention. Participants in the experimental group interacted with the intervention for 3	Perceived stress, level of depression, perceived quality of life, level of bother due to disruptive behaviours	CGs in the experimental group experienced less stress, post intervention (statistically significant). The other outcome measures also improved, however	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Kajiyama et al., 2013

			months. Qualitative information was also gathered.		was not statistically significant. 47 participants withdrew.		
UnderstAID	RCT	To evaluate the effectiveness and feasibility of UnderstAID	Participants (n=103) were randomly assigned to experimental (n=36) or control group (n=41) as 16 dropped out to test UnderstAID.	Feasibility: 3 self-administered questionnaires developed for the intervention. Outcome measures reported: depression (CES-D).	The experimental group did experience statistically significant changes in depressive symptoms. 33.3% of CGs were satisfied with the application and 50% assessed as technically acceptable; UnderstAID was iterated to suit said suggestions.	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Nunez-Naveira et al., 2016
Cuidate Cuidador	RCT	To evaluate the usability and effectiveness of Cuidate Cuidador	Quasi-experimental 2-group design with baseline and post-test. n=23 CGs participated. Participants were given an hour to observe the intervention. Following, participants participated in a focus group re: usability and features. Participants were assigned to a control (n=23) or experimental group (n=17).	Perceived mastery and competence (Personal Mastery Scale; PMS), perceived social support, caregiver burden (ZBI), and emotional distress, (CES-D).	Majority of participants visited the site 3 times, and others up to 10 times daily. Usability measures were at half and improved the intervention thereafter. All measures were not statistically significant although improvement was observed. Sought the input of younger CGs as well.	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	Pagán-Ortiz et al., 2014
DEMentia-specific Digital Interactive Social Chart (DEM-DISC)	RCT	To evaluate the effectiveness and usefulness of DEM-DISC	Participants were randomized; experimental participants (n=14 CGs and 12 PwD) were given DEM-DISC for two months. Those in the control group (n=14 CGs and 11 PwD) relied on their typical info sources.	Outcome measures: CG mgmt. style (CMS, measured by questionnaire), CG wellbeing (measured by GHQ-28), and depression (CES-D).	CGs used DEM-DISC an average of 5 times; the most active at 14 visits. They consulted the questions a total of 105 times and followed the steps to obtain advice in 78.1% of those instances. CGs felt the system easy to use. No effects found with outcome measures.	Intervention description, experiment/control groups, participant details, measurement tools, results, and results/conclusions	van der Roest et al., 2010
CARES Dementia Basics	Pre-post pilot (randomized)	To provide an initial evaluation of CARES	CGs (n=51) interacted with CARES. Outcome measures were assessed at baseline, post intervention, and after 30 days of the	Outcome measures: dementia knowledge questionnaire (dementia knowledge	Improved CGs knowledge and components of CG; participants appreciated the vast topics including person-centred care,	Intervention description, methods, results/conclusions	Pleasant et al., 2017

			intervention of CARES.	questionnaire) and competency (Sense of Competence in Dementia Care Staff Scale).	behaviour modification, and framework.		
Cares for Families (CARES)	Pre-post pilot	To provide an initial evaluation of CARES impact on CG-dementia knowledge	Pre-and-post-test pilot ensued with n=41 CGs. The purpose of the pilot was to assess improvement in dementia knowledge. Descriptive qualitative and quantitative data was sought through open-ended questions.	Dementia knowledge (measured by developed 20-item, multiple-choice and true/false measure).	Knowledge was improved post intervention. CGs appreciated the content and flexibility of the online intervention; they also appreciated the vignettes. The intervention reportedly provided sufficient and needed information to the CGs.	Intervention description, methods, results/conclusions	Gaugler et al., 2015
Ginko	Pre-post pilot	To evaluate knowledge outcomes Ginko has on Chinese CGs	To examine the outcomes Ginko has on CG's knowledge of dementia, in addition to their perceived social support, Chinese CG participated. n= 8 participants attended a 7-week face to face workshop and joined the forum thereafter. n=3 participants took the courses online.	Dementia knowledge, anxiety, and depression	Knowledge gained by the online workshop participants after attending the workshop was significantly greater than that gained by onsite workshop only participants. The onsite participants' anxiety and depression dropped significantly after the workshop.	Intervention description, methods, results/conclusions	Lai et al., 2013
STAR Training Program	Intervention Evaluation, Usability	To test usability of STAR with CGs	To test usability of STAR as well as mitigate any user obstacles. Involved CGs (2 males, 3 females; mean age=45) CGs of PwD. Participants were asked to perform the same tasks on STAR (i.e. Find the Learning paths of the training), whilst gaze (to measure eye movements) and heat maps (to measure mouse movements on the screen) were recorded.	N/A	60% of the participants were able to perform half or more of the tasks; 80% completed the course, games, and quiz; 0 participants were able to find the page guide. Task efficiency was also recorded; as the participant worked their way through the site, they became more efficient.	Intervention description, methodology, results/conclusions	Boyd et al., 2014
Living and Dying Well with Dementia	Intervention Evaluation (general)	To provide an initial evaluation of	Focus groups with CGs were conducted to provide an initial evaluation. Sample size	N/A	The participants appreciated usability and usefulness; participants felt the app would be useful	Intervention description, methodology,	Bhattacharyya, Benbow & Collins, 2017

		the app	and participant details not reported.		for CGs who had little access to education. The participants felt that the app could help prepare CGs for future events.	results/conclusions	
AlzOnline	Intervention Evaluation (general)	To provide an initial evaluation of AlzOnline	3-Phase Evaluation: 1) integration of services as well as development of the lessons and website. 2 & 3) evaluation where constructive feedback was gained from their first group of graduates (n=9 CGs).	N/A	Feedback alluded to iterating the intervention to be more usable and useful. Home page changes were suggested as CGs desired direct links to the website specs (i.e. direct link to the forum).	Intervention description, methodology, results/conclusions	Glueckauf & Loomis, 2003
Massive Open Online Course: Understanding Dementia (MOOC)	Intervention Evaluation (general)	To evaluate user-completion per educational background	Over 9500 participants participated in the understanding dementia MOOC. Information was collected to understand educational background and user demographics. Completion per background was assessed.	Biographical information via questionnaire (geographical location, level of education, experience with PwD).	A total of 4409 individuals engaged in the discussion forums and made a total of 45,955 discussion posts. Of these, 2896 completed the MOOC. Participants with low education levels (elementary-vocational training) were just as likely to complete the MOOC as educated individuals.	Intervention description, methodology, results/conclusions	Goldberg et al., 2015
Informative Website for Caregivers (name undisclosed)	Intervention Evaluation, Feasibility	To evaluate the feasibility of the intervention	To determine the feasibility of the intervention, n=21 CGs were given the intervention for 6 months. CG self-reported surveys and feedback.	CGs emotional status (Brief Symptom Inventory (BSI), CG Burden, CG social support, care recipient-functional rating as reported by CG.	CGs reported they used the site from 2-30 times. Some \were able to view the information and could respond to questionnaires. Recommends longitudinal studies be conducted with broader participations/varying levels of education. Outcome measures not reported.	Intervention description, methodology, results/conclusions	Chang, 2004
Caring for Me and You	Intervention Evaluation, Mixed-Methods	To evaluate the intervention through CGs and a small pilot	Consist of three phases. Third phase= pilot testing where end-users (n=3 CGs) tested the intervention.	N/A	Authors believe the intervention was developed in a way which represents the needs of CGs. Specifically, content, style, and format of delivery compliments	Intervention description, methods, results	Hales & Fossey, 2017

					best practices of experts. RCT is now underway.		
Digital Alzheimer's Centre (DAC)	Intervention Evaluation, Mixed-Methods	To evaluate DAC with PwD, CGs and professionals	PwD, CGs and professionals were sampled. Mixed-methods include observations (n=10; 4 PwD and 6 CGs), an online survey (n=287;88 PwD and 199 CGs), semi structured interviews (n=18; 6 PwD, 6 CGs, 6 professionals). During observations, participants performed 5 tasks where speed, errors, and navigation was noted.	N/A	A slight majority of participants appreciated the layout of the site; all participants felt the material was understandable and clear; ease-of-use with the site was noted. Survey results show 145 reported using the site at least twice; of these 145, majority were CGs. Interview responses also indicated regular use; overall response was positive.	Intervention description, methods, results	Hattink et al., 2016
Tele-Savvy	Intervention Evaluation (Qualitative)	To explore acceptability of Tele-Savvy	To explore the acceptability of the intervention, n=46 CGs were recruited to test the intervention of which 36 completed. The CGs who completed were interviewed via semi-structured telephone (or skype) interviews. Conventional content analysis allowed for theme identification.	N/A	Themes: connectedness, distracted participants, different CG situations, technical difficulties, stage specific information, CG strategies. Authors conclude that interventions like Tele-Savvy is feasible for CG-distant-training.	Intervention description, methods, results	Kovaleva et al., 2017
Network Support Dementia Project	Intervention Evaluation (Qualitative)	To understand CG-attitudes towards Network Support Dementia Project	Used semi-structured interviews and focus groups. Informal and formal CGs (n=40) participated to gain insight and first impressions. Components of the site were evaluated, including 'Dementia info', 'Contacts/Clients', 'Messages' and 'Forums'.	N/A	Impressions were overall positive; participants felt the use of the platform would promote cooperation with other members of the care network, and in turn, improve the quality and efficiency of care PwD receive.	Intervention description, methods, results	Verwey et al., 2016
Nurses Improving Care for Health System Elders	Description of Intervention	The app contains information on 27 respective topics, including medication, delirium, dementia, depression, functional decline, transitions, and surgery. The purpose of the app is to assist families and patients in transitions in, and out of care, as well as to assist with	N/A	N/A	Intervention description	Bricoli, 2015

NICHE		communication between CGs and care providers.				

Appendix B: Study Characteristics

Partner in Balance (PIB). A substantial number of articles attempted to evaluate

PIB (see description in Intervention 4 above). To evaluate its feasibility and effectiveness,

Boots et al (2016) conducted focus groups with n=4 CGs. With an overall aim of evaluating

PIB via focus groups, CGs' views on the content, feasibility of the intervention, as well as

user-testing and evaluation was sought. Overall, CGs felt PIB was a usable and useful tool

(Boots et al., 2016).

Computer Link (CL). CL culminated with an RCT in a series of published articles.

With a motive of understanding CLs effect on CG strain, Bass et al conducted an RCT with

n=102 CGs (1998). The results of the RCT were also later reported on in Brennan (1992).

Bass et al had 51 CGs interact with CL for 12 months, and measured CG strain (consisting

of emotional, physical, relationship and activity strains) pre-and-post intervention (1998).

Bass et al (1998) found the intervention reduced certain types of strain if the CGs had large

social support networks, were spouses, or did not live alone with the PwD. CL was therefore

declared an effective, usable tool.

Mastery over Dementia (MoD). Pot, Blom, and Willemse (2015) developed a

similar RCT design. Pot, Blom, and Willemse (2015) recruited n=149 CGs to measure the

feasibility and effectiveness of MoD. All 149 participants utilized MoD for 6 months. Participants, including family members and spouses, were asked to rate the usefulness and comprehensibility of lessons (after viewing) on a Likert scale of 1 to 5. Participants rated usefulness between 1 and 5, 1 being not easy, and 5 being very easy. Participants also rated comprehensibility of the lessons between 1 and 5, 1 being not useful at all, and 5 being very useful. Pot, Blom, and Willemse conclude that 68 CGs completed all 8 MoD lessons within the 6 months, while 81 did not finish completely, and 6 did not begin (2015). Upon clarification, participants who did not finish/did not begin, claimed the information was irrelevant to their situations/they felt too overburdened to participate (Pot, Blom & Willemse, 2015).

Caregiver's Friend. To evaluate the effectiveness of *Caregiver's Friend*, Beachamp et al (2005) employed a waitlist RCT with n=299 CGs, who were also employed outside of the home. Outcomes include CG strain (measured by CG strain instrument, developed by the Benjamin Rose Research Institute; Bass et al., 1998), CG gain (Positive aspects of CG survey; Tarlow et al., 2004), depression (CES-D; Radloff, 1977), and anxiety (10-item sub scale; Spielberger, Gorsuch & Lushene, 1970). The participants had an average exposure to the intervention of 32 minutes. Beachamp et al (2005) reported 7 participants who experienced significant positive results post-intervention. Use of intervention reduced depression, anxiety, and strain, whilst increasing perception of CG gain; the frequency of coping skills did not seem to improve (Beachamp et al., 2005).

Diapason. Alike measures noted above, Cristancho-Lacroix et al (2015) conducted a non-blinded pre-post-RCT where participating CGs (n=49) were randomized into the

experimental or control group. Those randomized into the experimental group (n=25) had access to Diapason for 3 months. CGs included in the control group received usual care and educational means. The primary outcome was CG stress (PSS-14; Cohen, Kamarck & Mermelstein, 1983). Secondary outcomes include: self-efficacy, perception and reaction to behaviours of PwD, CG burden, depression, and self-perceived health. The secondary outcomes were measured by: Revised Scale for CG Self-Efficacy (RSCS; Steffen et al., 2002), Revised Memory and Behaviour Problems Checklist (RMBPC; Teri et al., 1992), Zarit Burden Interview (ZBI; Ankri et al., 2005), Beck Depression Inventory (BDI; Beck, 1996), and Nottingham Health Profile (NHP; Bucquet, Condon & Ritchie, 1990), respectively. Outcomes were collected at baseline, post-intervention (3-month), and at a follow up (6-month post-baseline). Cristancho-Lacroix et al (2015) conclude Diapason an effective educational intervention, as CGs in the experimental group improved their dementia knowledge and felt less stressed.

iCare. In an RCT to prove the effectiveness of the intervention, n=150 CGs were randomized to a control or experimental group, where participants in the experimental group were given the intervention, iCare, for 3 months (Kajiyama et al., 2013). Qualitative and quantitative data was sought; outcome measures included perceived stress (PSS; Cohen & Williamson, 1988), depression (CES-D; Radloff, 1977), perceived quality of life (PQOL, Patrick et al., 1988), and level of bother due to disruptive behaviours (RMBPC; Teri et al., 1992). Although all outcome measures showed improvement post-intervention in the experimental group, only perceived stress was statistically significant across groups (Kajiyama et al., 2013).

UnderstAID. Nunez-Naveira et al (2016) evaluate the effectiveness of UnderstAID among CGs in a robustly-designed RCT. A total of n=103 CGs were randomly assigned to the experimental (n=36) or control group (n=41) whilst 16 withdrew. Feasibility was evaluated post-intervention through questionnaires developed for the intervention. Depression (CES-D) was the outcome measure (Nunez-Naveira et al., 2016). Attrition was reported; however, the experimental group did experience statistically significant changes in depressive symptoms. 33.3% of CGs were satisfied with the intervention and 50% assessed it as technically acceptable and usable; UnderstAID was iterated to suit suggestions (Nunez-Naveira et al., 2016).

Cuidate Cuidador. Pagan-Ortiz et al (2014) utilize a quasi-experimental RCT design to evaluate the intervention. The experimental group (n=17) completed four sessions which expanded 1 month, including: 1. Providing an overview, completing pre-tests, and familiarization with the intervention. 2 and 3. Ensuring the experimental participants could use the key features of the site, and 4. Administration of post-test and general debriefing of the study. The control group (n=23) participants were provided an overview of the study where administering of the pre-tests took place and received printed Spanish-language educational materials, with substance similar to topics offered in Cuidate Cuidador (Pagan-Ortiz et al., 2014).

Qualitative and quantitative data was collected through open-ended questions and standardized surveys, respectively (Pagan-Ortiz et al., 2014). Outcome measures include perceived mastery and competence (PMS; Aneshensel, Pearlin & Schooler, 1978), perceived social support (LSNS; Lubben, 1988), CG burden (Zarit, Reever & Bach-

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Peterson, 1980), and emotional distress (CES-D; Radloff, 1977). Participants were also administered a 20-item knowledge questionnaire, which was developed specifically for the study. Participants in the experimental group also participated in an open-ended focus group (Pagan-Ortiz et al., 2014). The majority of participants visited the site 3 times with other participants accessing the site 10 times or every other day. Usability was not perceived well by participants and the intervention was iterated accordingly (Pagan-Ortiz et al., 2014). Outcome measures were not significant, although self-master, social support, CG burden observed as improved in the experimental group (Pagan-Ortiz et al., 2014). Overall, CGs felt the site to be helpful and useful (Pagan-Ortiz et al., 2014).

DEMentia-Specific Digital Interactive Social Chart (DEM-DISC). van der Roest et al conducted an RCT to evaluate the intervention (2010). Participants included in the experimental group (n=14 CGs and 12 PwD) were given DEM-DISC for two months and were encouraged to access the system with their questions and concerns in mind (van der Roest et al., 2010). Participants included in the control group (n=14 CGs and 11 PwD) relied on their typical information sources. Outcome measures were: CG management style (CMS; De Vugt et al., 2004), CG well-being (GHQ-28; Goldberg & Hillier 1979), and depression (CES-D; Radloff, 1977).

During the intervention, CGs used DEM-DISC an average of 5 times, the most active participant accessing 14 unique visits (van der Roest et al., 2010). Participants consulted the questions a total of 105 times and followed the necessary steps to acquire the advice in 78.1% of instances. CGs felt the system easy to use; no statistically significant effects were found with outcome measures (van der Roest et al., 2010).

Internet-Based Support Services (ICSS). In a series of articles published from 2005-2011, Chiu et al evaluated the overall usability (Chiu & Lottridge, 2005), CG attitudes (Chiu & Eysenbach, 2011), attrition factors (Chiu & Eysenbach, 2010), and overall effectiveness (Chiu et al., 2009) of ICSS. CGs appreciated the layout and sizing of the website, ICSS was iterated per recommendations (Chiu & Lottridge, 2005). However, in order for CGs to use an educational intervention, the CG must feel that he/she needs the intervention; CGs require this educational information as it is seldom readily available and trustworthy (Chiu & Eysenbach, 2011; Chiu & Eysenbach, 2010). To understand ICSS effect on CG wellness, Chiu et al (2009) also employed CES-D to evaluate changes in CG burden; CGs who utilized ICSS for a longer period reported lower CG burden post-intervention, compared to occasional users.

CARES. In a pre-post-test pilot, Pleasant et al determine the participating CG improved their overall dementia-knowledge (2017). The CGs appreciated the vast number of topics, including person-centred care, behaviour modification, and frameworks (Pleasant et al., 2017).

CARES (Dementia Basics). To evaluate whether the intervention improves CG knowledge on dementia, Gaugler et al (2015) host a pre-post-test pilot with n=41 CGs. Both qualitative and quantitative data was sought to understand impact and dementia knowledge was the main outcome. Gaugler et al (2015) created a custom 20-item test to monitor changes in participants' dementia knowledge. Findings allude to knowledge improvement as CGs improved by an average of 3 points (Gaugler et al., 2015).

Ginko. Lai et al (2013) evaluated Ginko's effectiveness on Chinese CG knowledge through a pre-post-test pilot where n=8 participants attend 7, 2-hour in-person seminars, and n=3 participants took the courses solely online. Post pilot, both groups joined the online forum. Outcome measures included anxiety, depression, and knowledge. Participants who took the courses online had gained significantly higher knowledge than the in-person participants; the on-site group's anxiety and depression dropped significantly after the seminars (Lai et al., 2013).

AlzOnline. With an overall purpose of evaluating AlzOnline, Glueckauf and Loomis sought constructive feedback from the first group of graduates (n=9 CGs) (2003). CGs felt AlzOnline to be useful and usable and changes were made to reflect feedback, specifically, direct links were added to the home-page for ease-of-navigation (Glueckauf & Loomis, 2003).

Living and Dying Well with Dementia Mobile App. To offer an initial evaluation of the Living and Dying Well with Dementia App, Bhattacharyya, Benbow, and Collins held a workshop with CGs (2017). The participants appreciated the apps usability and usefulness and participants felt the app would be useful for CGs who had little access to education (Bhattacharyya, Benbow & Collins, 2017). Additionally, the participants felt that the app could help prepare CGs for future events (Bhattacharyya, Benbow & Collins, 2017). Future steps include a more thorough and rigorous analysis of impact and change in practice (Bhattacharyya, Benbow & Collins, 2017).

STAR. To test the usability of STAR, as well as mitigate any user obstacles, Boyd et al (2014) conducted usability testing with n=5 informal (2 males, 3 females; mean

age=45) CGs of PwD. Participants were asked to perform the same tasks on STAR (i.e. Find the Learning paths of the training), whilst gaze (to measure eye movements) and heat maps (to measure mouse movements on the screen) were recorded. The purpose of the gaze and heat maps are to determine whether the participant was looking at an appropriate object on the screen to perform the respective task (Boyd et al., 2014). Overall, 60% of the participants were able to perform half or more of the tasks, and 80% completed the course, games, and quiz; 0 participants were able to find the page guide (Boyd et al., 2014).

The efficiency of completing each task was also recorded; as the participant worked their way through the site, they became more efficient (Boyd et al., 2014). All participants self-reported satisfaction with STAR, however participants would only use the intervention because they need the information and support (Boyd et al., 2014). Recorded issues include: using text instead of icons for navigation, loading web pages in the current window opposed to a new window and not being able to navigate back to the original window, and not being able to find buttons due to small size and colour (Boyd et al., 2014). STAR was iterated to suit the feedback and participants agreed that STAR was a usable tool (Boyd et al., 2014).

Informative Website. To test feasibility, Chang (2004) provided the intervention (name unknown), to n=21 CGs for 6-months. The CGs self-reported surveys as well as feedback; outcome measures include the following: emotional status (measured by subscales of the Brief Symptom Inventory (BSI; Derogotis, 1992), CG burden (Aneshensel, Pearlin & Schuler, 1993), and CG support (Chang, 1999). Participating CGs reported using the website 2-30 times; the majority of CGs could complete the online intervention and submit surveys however some preferred to submit via mail (Chang, 2004). Pre-and-post

testing were not reported nor compared; participating CGs reportedly had scores similar to the norm (Chang, 2004).

Massive Open Online Course: Understanding Dementia (MOOC). As education levels affect completion of online eLearning, Goldberg et al (2015) collected user-demographics and educational backgrounds of n=9500 participants. Through a questionnaire, geographical location, level of education, and experience with dementia/PwD was all evaluated (Goldberg et al., 2015). A total of 4409 participants engaged in the online forum and composed over 45,000 discussion posts (Goldberg et al., 2015). Interestingly, Goldberg et al determined individuals with lower education levels (completed elementary school/vocational school) were just as likely to complete the MOOC as their higher-educated counterparts (university degrees and beyond) (2015).

Caring for Me and You. Hales & Fossey (2017) conducted multi-phased, mixed-methods study whereby n=3 CGs tested the usability of the intervention. Overall, authors determine the style, content, and delivery of Caring for Me and You was developed to the unique needs of CGs; an RCT is now underway (Hales & Fossey, 2017).

Network Support Dementia Project. Verwey et al (2016) utilized semi-structured interviews to gain qualitative insight and first impressions of the intervention. Components of the site were evaluated by CGs and feedback was overall positive. Participants felt the use of the intervention would allow better communication between informal and formal CGs in the network and would therefore allow for better care (Verwey et al., 2016).

Digital Alzheimer's Centre (DAC). Similarly, to Hales and Fossey (2017), Hattink et al utilize mixed-methods to evaluate DAC. PwD, CGs, and healthcare professionals

informed the descriptive data; methods included face-to-face usability testing (n=10; 4 PwD and 6 CGs), an online survey (n=287; 88 PwD and 199 CGs), and semi-structured interviews (n=18; 6 PwD, 6 CGs, 6 professionals) (2016). A slight majority of participants appreciated the layout of the site and all participants felt the material was delivered clearly; ease-of-use with the site was noted (Hattink et al., 2016). Survey results should n=145 reported using the site at least twice, the majority being CGs; the majority of participants had a positive outlook on the intervention (Hattink et al., 2016).

Tele-Savvy. Kovaleva et al explored the acceptability of the intervention where n=46 CGs were given the intervention for testing (2017). 36 participants completed the intervention in full and were interviewed about their experiences via skype afterwards. Overall, the themes allude to CG connectedness, importance of situations and stage specific information, and CG strategies; attitudes are overall positive (Kovaleva et al., 2017).

Niche. Bricoli (2015) offers a thorough explanation of the free NICHE patient and family app. Bricoli recognizes the criticality and importance of family CGs with respect to supporting the healthcare system (2015). In parallel, Bricoli created the app to provide a library of tools and resources for CGs (2015). As mentioned, the app contains information on 27 respective topics, including medication, delirium, dementia, depression, functional decline, transitions, and surgery. The purpose of the app is to assist families and patients in transitions in, and out of care, as well as to assist with communication between CGs and care providers (Bricoli, 2015). NICHE was developed in conjunction with Baylor Scott and White's Centre for Learning Innovation and Practice; the St. Louis Chapter of the

Alzheimer's Association and the International Collaboration of Orthopaedic Nursing (ICON) created content (Bricoli, 2015).

Appendix C: Telephone Interview Script 1

Semi-Structured Telephone Interviews

Introduction:

Hello. It's *[insert your name], the Research Assistant from iGeriCare at St. Peter's Hospital.* I am calling about the iGeriCare platform. Is this time okay to do a 20-minute interview about iGeriCare?

> *[If the participant says yes, RA will proceed]*

You have viewed the first lesson, "What is dementia?", correct?

IF NOT:
Okay, once you view it, we can schedule another conversation to speak to it. Schedule next call.

IF YES:
Okay, I just want to understand what you thought of that from a "usability" perspective.

QUIM FACTORS & CRITERIA
1. **Satisfaction:** the subjective responses from users about their feelings when using the software (e.g. happy/satisfied)
    a. In your opinion, is the lesson **attractive?**
        i. Why/why not?

    b. In your opinion, do you particularly **like** the look of the lesson?
        i. Why/why not?

    c. Did the layout of the lesson **guide** you to use it? (e.g. navigating to the next component).
        i. Why/why not?

2. **Trustfulness:** also, known as the faithfulness a software product offers to its users, the concept is pertinent concerning e-commerce websites. (may be a stretch)

    a. In your opinion, is the purpose of the lesson **self-descriptive**?
        i. Why/why not?

    b. Do you think you could easily **navigate** the lesson and would you be willing to interact with another one?

       i. Why/why not?

3. **Usefulness:** whether a software enables users to solve real problems in an acceptable way.
   a. Does the lesson **load** well?
      i. Do you find the lesson to be particularly slow, or fast?

Do you have any other thoughts or comments about the lesson you viewed?

Those are all the questions I have for you today. Do you have any questions for me?
I thank you for speaking with me today. I hope you have a wonderful [day, evening].

Goodbye.