THE FIRST TIME DELIVERY OF THE FIRST LINK LEARNING SERIES USING SKYPE AND YOUTUBE

by

© Elizabeth McNaughton Wallack

Dissertation submitted to the

School of Graduate Studies

in partial fulfillment of the requirements for the degree of

Master of Science in Medicine (Community Health)

Division of Community Health & Humanities, Faculty of Medicine

Memorial University

May, 2016

St. John's, NL

i

Abstract

Introduction: This case study documented the experiences of informal and service providers who participated in the first time delivery of the First Link Learning Series from May–August 2013 in Newfoundland and Labrador. The aim of this study was to understand how informal caregivers of people with dementia experience this Internet mediated health resource, and how Skype and YouTube can be used as tools for the Alzheimer Society of Newfoundland and Labrador to effectively deliver the First Link Learning Series. **Methods:** Sources of data included key informant interviews (n=3), pre-study and post-study interviews with informal dementia caregivers (n=2), institutional documentation, field notes, and YouTube analytics. Framework Analysis was used to make meaning of the qualitative data, and descriptive statistics were used to report on quantitative outcomes. **Findings:** Between 3% and 17% of registered First Link clients attended the learning series sessions, however only two caregivers participated using Skype or YouTube. Framework Analysis revealed three shared themes: access, connection and privacy. **Discussion:** The themes helped to begin building theory about barriers and facilitators to Internet mediated health resources for informal dementia caregivers. Experiences of service providers using the Internet to support clients served to begin building a case for the appropriateness of these media. A modified version of Dansky et al.'s (2006) theoretical framework for evaluating E-Health research that situates the person/user in the model, helped guide discussion and propose future directions for the study of Internet based health resources for informal dementia caregivers.

Acknowledgements

Contents

List of Tables

List of Figures

List of Abbreviations

ASNL – Alzheimer Society of Newfoundland and Labrador

NL – Newfoundland and Labrador

TAM – Technology Acceptance Model

List of Appendices

Appendix

Introduction

The primary focus of this case study is to describe the experiences of dementia caregivers who accessed Internet-based health resources provided by the Alzheimer Society of Newfoundland and Labrador (ASNL). Using a naturalist paradigm, I have explored this phenomenon within its context, using a variety of data sources. This approach ensures that issues are not explored through one lens, but instead that multiple aspects of a phenomenon can be understood through a multiplicity of lenses. In carrying out this research, my goal was to focus on people's individual experiences as dementia caregivers, service providers, and technology users. By doing this I have identified a working hypothesis for how Internet-based health resources can address central issues surrounding three overarching themes present in my data: access, privacy and connection.

I refer to the term 'dementia caregiver' in my research and define it as an informal caregiver, who could be a spouse, child, friend or other relative of the person with dementia who is providing care. This definition excludes paid or professional caregivers who are not friends or family members. The term 'service provider' in this research specifically refers to people who work for non-profit organizations that provide information and/or support to individuals living with dementia and their families. Internet-based health resources are a type of E-Health and are defined as health information on websites or activities via communication technologies. I have specifically focused on Skype and YouTube as vehicles or ways to deliver health resources online. These terms will be discussed in greater detail later in this chapter and also in Chapter 2.

In this chapter I will position myself within the research. Subsequently, I will provide a description of the research problem, identify my research questions and discuss my rationale, goals and purpose of the research project.

I will then outline the context of this case study, focusing on issues in Newfoundland and Labrador (NL). These issues include: aging and dementia, resources for people with dementia, the ASNL and the First Link Program, and telemedicine and E-Health in the NL context. Finally, after discussing these contextual elements, I will consolidate these areas in order to illustrate the gaps my research has identified and addressed and demonstrate the significance of this study.

Ontology

Critics of traditional scientific constructions of knowledge have described limitations to methods of inquiry that examine reality as a single, knowable and defined object (Clark, 1998; Guba & Lincoln, 1994; Holton, 1993). While there are many benefits to knowledge creation that follow an empirical approach, traditional scientific paradigms cannot always be applied to real-world settings in which researchers have limited influence or ability to manipulate conditions and behaviours. Naturalistic inquiry, however, provides an alternate paradigm for researchers who wish to study dynamic phenomena in the field. Willems and Raush (1969) described two dimensions that help to define the naturalistic approach to research: the degree of influence on the conditions and behaviours studied, and that efforts are made to ensure the researcher does not impose an a priori set of outcomes (Willems & Raush, 1969, p. 46). Taking this into consideration,

Willems and Rush (1969) help to direct what the naturalistic researcher does, or the set of activities that are undertaken during the research process.

Lincoln and Guba (1985) argue that naturalistic inquiry can be considered analogous to other terms including post-positivism, phenomenology and the case study. Constructivism is a more contemporary term often used. While these terms have subtle differences and those that use them take different views of what they imply, Lincoln and Guba (1985) suggest that naturalism is an overarching term under which the other aforementioned terms fall. To help further develop our understanding of naturalistic inquiry, Lincoln and Guba (1985) describe the assumptions that underlie this method of inquiry. I have adopted these assumptions to guide my research process. The following are five propositions of the naturalist paradigm:

- "Realities are multiple, constructed and holistic,

- Knower and known are interactive, inseparable,

- Only time and context bound working hypotheses are possible,

- All entities are in a state of simultaneous shaping, so that it is impossible to distinguish cause from effects,

- Inquiry is value bound" (Lincoln & Guba, 1985, p. 37)

These five assumptions shape study design, the types of questions asked by the researcher, as well as data analysis and interpretation. Specific methodological issues will be addressed in the following chapter. As a starting point, however, it is important for me to orient myself within the research in order to situate myself to the problem statement,

research questions and rationale, goals, and purpose of the study, which follow this section.

The subject of supporting dementia caregivers is very close to me. Both of my maternal grandparents had dementia before they died and I spent time caring for my grandfather over the course of my master's program. My mother's side of the family lives in Toronto, Ontario (the largest city in the country). At times over the course of my grandparents' journey with Alzheimer's, our family found itself searching for resources and support, working hard to understand what was happening to our cherished family members.

Early in my grandmother's journey with Alzheimer's disease, I realized how fortunate we were for her to be living in a large city like Toronto, where there are opportunities for people with dementia including adequate numbers of home care workers and dementia tailored day programs. I was born and raised in St. John's, NL and during the time I spent caring for my grandparents I became very interested in understanding the needs of people with dementia and the family members who care for them in my home province. Before beginning my master's program, I worked at the Alzheimer Society of Newfoundland and Labrador (ASNL), the organization I partnered with for this project.

I am in a unique position in relation to my research topic and my passion for understanding the experiences of Alzheimer's caregivers because of these two very important aspects of my life history, This has, of course, shaped the epistemological underpinnings of my research. Throughout the research process I was careful to consider my possible biases as someone who has both worked for the organization I partnered with, and as someone who lived as a dementia caregiver. In my role as the researcher I

have attempted not to make any assumptions about other people's experiences based on my own subjective thoughts and feelings. Having said that, I did use my personal connections to the subject matter to help build trust and rapport with the people I interviewed. This unique perspective also helped to shape my understanding of the problem I hope to begin to address with this research.

Problem Statement

There are currently limited ways to address the informational needs of caregivers of people with dementia in NL. There is a gap in the literature around understanding ways to use technology in order to support caregivers of people with dementia in this province. There is also a sense of urgency requiring the people of NL to address this problem, which relates to the aging demographics in our province and our unique geographical challenges, and includes people living in rural and remote communities who wish to age in place.

Research Questions

1. How do informal caregivers of people with dementia experience the First Link Learning Series online using Skype and YouTube?

2. How can Skype and YouTube be used as tools for the ASNL to effectively deliver the First Link Learning Series?

Rationale, Goal and Purpose

During the fall of 2011 when I began my master's program, the ASNL was searching for low cost options to deliver education and support to caregivers of people

with dementia throughout the province. I formed a partnership with the ASNL in order to provide online options for the learning series, which I will discuss briefly later in this chapter and also in the methods section. This partnership formed the basis for my research study. We mutually agreed that using Skype and YouTube had the potential to create sustainable solutions for delivering the learning series online. The purpose of my involvement was to document the experiences of First Link clients who used Skype and YouTube to access the learning series online.

Understanding Dementia and Dementia Caregivers

Dementia is a syndrome that is diagnosed when cognitive deficits are sufficient enough to interfere with social or occupational functioning (Rockwood et al., 2014). These cognitive deficits generally affect thinking, remembering and reasoning. Dementia is not a specific disease. Many diseases can cause dementia. Common dementing disorders include Alzheimer's disease (accounting for 60% of cases in Canada); Vascular dementia; Fronto-temporal dementia; and Dementia with Lewy bodies (Smetanin et al., 2009). An individual can live with dementia for between 2–18 years after diagnosis, with an average life expectancy of 7 years (Mark, 2015). Carone, Asgharian and Jewell (2014) estimate that more than two out of every five Canadians reaching the age of 65 develops dementia before death, which means that the lifetime risk of dementia among elderly Canadians is 42.6%. Nearly 80% of all cases of dementia in Canada occur between the ages of 75 and 95, with 9.6% of the Canadian population developing dementia by age 80 and 28.7% by age 90 (Carone et al., 2014).

Dementia is progressive, which means the symptoms will gradually get worse over time. Dementia is generally divided into three stages: mild, moderate and severe. They can also sometimes be called early, middle, and late stages ("Living with Dementia," 2015; Lopez et al., 2003). Common symptoms in the early stages of dementia include forgetfulness, communication difficulties, and changes in mood and behaviour (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; "Living with Dementia," 2015; Lopez et al., 2003). People in this stage can maintain many of their functional abilities with minimum assistance. They may have insight into their changing abilities, and can help to plan and direct their current and future care. In the middle stages of the disease memory and other cognitive abilities will continue to decline although many people at this stage still have some awareness of their condition (Cerejeira et al., 2012; "Living with Dementia," 2015; Lopez et al., 2003). Assistance with daily tasks such as: shopping, housekeeping, dressing, bathing and toileting can become necessary as this stage progresses. In the late stage people eventually become unable to communicate verbally or look after themselves and care is required twenty four hours a day (Cerejeira et al., 2012; "Living with Dementia," 2015; Lopez et al., 2003).

While there are general stages that people with dementia progress through, research suggests that people experience a wide range of symptoms and many common symptoms can occur at different stages of the disease (Rockwood, Richard, Leibman, Mucha, & Mitnitski, 2013). The individual differences in people with dementia mean that there can also be a lot of uncertainty about what the future will hold. Because of the progressive nature of the disease people with dementia eventually become reliant on caregivers to help them in their daily lives.

In 2012, 480,000 Canadians reported that they were providing informal care for someone living with dementia (Sinha, 2013). Dementia was the 5th most common problem requiring help from caregivers in Canada behind aging, cancer, cardiovascular disease and mental illness. Family caregiving also comes at a personal and financial cost to families. In 2011, family caregivers spent in excess of 444 million unpaid hours looking after someone with cognitive impairment, including those with dementia (Sinha, 2013). These hours represent personal and financial sacrifices made by caregivers who may have otherwise been working or caring for their own young families.

A dementia caregiver's main role is to provide day-to-day care for the person with dementia. This may include support with activities of daily living, such as personal care or ambulation; instrumental activities of daily living, such as shopping, banking or preparing meals; managing other aspects of care, such as safety concerns and hiring and supervising professional care services; and helping the person to access medical care through activities such as providing transportation, and arranging appointments (Smetanin et al., 2009). People with dementia and their informal caregivers are sometimes referred to as a caregiving dyad (Morrison, Winter, & Gitlin, 2014). The term 'dyad' refers to two individuals who are regarded as a pair. Dementia caregivers are intrinsically linked to the person they are caring for because much of their day is centered on providing care for the individual. This link is also accentuated because informal caregivers have a personal connection to the person they care for and have history together as family or friends prior to the onset of dementia. Many interventions for people with dementia also focus on supporting the caregiver, acknowledging the intrinsic link between the health and well-being of both members of the dyad (Boots, de Vugt, van Knippenberg, Kempen, &

Verhey, 2014). For this reason, when considering ways to support people living with dementia, I suggest that it is equally important to consider the needs of the dementia caregiver. In the next chapter, I will describe the needs of dementia caregivers in greater detail, but for now I move to a discussion of how NL is impacted by dementia and how this relates to an aging population.

Aging and Dementia in NL

There are extremely limited statistics describing the incidence rates of dementia in this province. According to the ASNL, there are currently approximately 7,680 people living with dementia in NL. This incidence rate is extrapolated by applying incidence rates from work done by the Canadian Study of Health and Aging Working Group (2000) to population statistics in NL. The accuracy of this estimate is not well understood. In 1996, a legal interpretation of NL's advance directives legislation barred the use of proxy consent for individuals unable to give full, informed consent for research (Lindsay et al., 2002). This decision caused NL to exclude itself from this important foundational study on the incidence of dementia in Canada, limiting access to accurate and reliable statistics on dementia in NL.

One of the greatest risk factors for dementia is age (Gardner, Valcour, & Yaffe, 2013) and NL has the fastest growing aging population in Canada. Because of NL's rapidly aging population, we can also expect an increase in the number of people living with dementia. In 2015 there were 91,059 adults over the age of 65 in our province (Economic Research and Analysis, Department of Finance, n.d.). By 2026 there will be 130,055 adults over the age of 65 (Economic Research and Analysis, Department of

Finance, n.d.). This represents a growth rate of 43% over 12 years. Some of the fastest growing rates of older adults in NL are in rural and remote areas of the province.

Having limited statistics about people living with dementia in NL makes it challenging to plan and deliver services to these individuals. This is currently a major barrier to supporting individuals with dementia in NL. From what we already know, the number of community-dwelling older adults in this province, including those with dementia, is expected to increase at a greater rate than that of the resources required to provide services to them in the community (Chappell, Bornstein, & Kean, 2014). Caregivers of people with dementia in this province will require increased support and services to help manage the disease and help those with dementia live comfortably in the community, and there will be a need to find new and innovative ways to address this issue.

NL's geographical features influence people's perspectives and experiences. NL has a sparse population spread out over a large landmass with many people living in remote and rural areas with limited access to amenities or health facilities. In addition, the physical terrain of NL is rugged and is often characterized by unpredictable weather. It is, therefore, essential to understand these contextual factors as they relate to older adults and people with dementia in our province. Communities in this province were originally established as fishing villages that dot the coastlines. Many communities could only be accessed by boat until as recently as the 1970s. Even when connected by roadways, people in many rural and remote communities throughout the province still have to travel long hours to access services including shopping, banks and hospitals. This becomes even

more complex because of the long winters, road conditions and the high price of fuel that can make driving long distances dangerous and expensive.

Geography has caused people in NL to adapt in a number of ways. Some research suggests that historically, people in NL have had a tendency to segregate themselves geographically by communities, or even within a community itself along cultural and religious lines (Philpott, 2002). Self-sufficiency is also a highly valued trait among Newfoundlanders and connects to the rural culture, where lifestyles were based on the primary industries of fishing and forestry (Philpott, 2002). The uniqueness of place and its influence on the people who live here is also important for understanding the needs of dementia caregivers in NL.

Resources for People with Dementia and Their Caregivers in NL

There are very limited resources for people with dementia in NL, and the people who care for them. The two main resource providers in NL are the provincial government and the non-profit sector. Resources provided by the provincial government are offered through the Department of Health and Community Services. Of these services, most focus on supporting people in the community, as opposed to an institutional model of care. Many of these resources are also not designed specifically for individuals with dementia. Notable government programs include the Provincial Home Support Program and the Paid Family Caregiving Option. The Provincial Home Support Program is intended to supplement care provided by a family member for a child or an adult in need of care, including those with dementia. Home support services include personal and behavioural supports, household management and respite. There is a maximum financial ceiling to be

eligible for this program and individuals must undergo a functional and financial assessment before qualifying for services and subsidy (Provincial Home Support Services Program Paid Family Caregiving Option Health and Community Services, n.d.).

The Paid Family Caregiving Option provides subsidies for new Provincial Home Support Program clients. This program allows a member of the family who lives with the individual to be paid for part the care they provide. As with the Provincial Home Support Program, there is a maximum financial ceiling to be eligible for this program and individuals must undergo a functional and financial assessment before qualifying for services and subsidy (Provincial Home Support Services Program Paid Family Caregiving Option Health and Community Services, n.d.). Spouses of the individual in need of care are also not eligible for this program.

These resources are important to the current study because they demonstrate the government's recognition of the need for instrumental supports as well as respite and financial support for informal caregivers, including dementia caregivers. Despite this acknowledgement, there are no programs or mechanisms that provide education and skill-building opportunities for these individuals, demonstrating a clear gap in government services that support informal caregivers in our province.

The non-profit sector also has limited resources for individuals with dementia in NL. Some organizations offer services that are not exclusively for individuals with dementia, but that still help people to manage the disease and live comfortably in the community. One example is the Canadian Red Cross Community Transportation Service. This service is available on the Avalon Peninsula and offers drives to clients facing barriers such as mobility issues or limited access to public transportation. This service is

particularly helpful for individuals with dementia because Red Cross volunteers not only provide rides for clients, but also accompany individuals on these outings. This service is not exclusively for medical appointments. Clients can also access rides for grocery shopping and other essential activities of daily living (Newfoundland and Labrador, n.d). Another example is the Canadian Red Cross Health Equipment Loan Program. This service offers equipment to support mobility, independence, and safety. It is available in Corner Brook, Gander, Grand Falls-Windsor and St. John's, NL's larger towns and cities. However, many people are located in rural and remote locations quite a distance outside of these areas (e.g. some rural areas are at least 4-5 hours away from a small town/ city). The Seniors Resource Centre of NL also offers programs that are not exclusively designed for individuals with dementia, but that can help to address some of their needs in the community. One program of note is the Provincial Community Peer Support Volunteer Program. This program allows individuals to use their own life experiences to connect other seniors with services and resources. Another program of note is Caregivers Out of Isolation, which is a provincial program supported by the Seniors Resource Centre of NL. This program targets informal family caregivers of people of all ages including individuals with dementia. Their programs include the Caregiver Line (a toll free information line available 8:30 - 4:30, Monday to Friday), Caring Solutions (a provincial newsletter and e-bulletin), caregivers groups (located in the St. John's area and communities in the Central and Western health regions), a website, The Caregiver Guide (information and resources that can be mailed anywhere in NL), a referral service, and one on one support available in person in St. John's and over the phone in the rest of the province. Together, these non-profit services are important because they illustrate the

ways non-profit organizations are able to help address gaps in the system, however there are still limited resources for people in NL who want to care for someone at home, including those with dementia.

The ASNL is the only non-profit organization that exclusively supports individuals with dementia in NL. They offer a resource center, family support groups, one on one family meetings in the St. John's area, information packages, a newsletter, 1-800 number, and website. They are also introducing a new program called the First Link Program, which I will now discuss in detail.

The ASNL and the First Link Program

In the previous section, I have outlined the limited support options for dementia caregivers in NL. In 2012, the ASNL began implementing a pilot phase of the First Link program in NL. As the name suggests, First Link's goal is to connect individuals with dementia, their families, and caregivers as early as possible to local dementia-specific supports and learning opportunities (McAiney, Hillier, & Stolee, 2010). The ASNL receives referrals of newly diagnosed patients from health care professionals. Individuals can also self-refer to the program. Once individuals are referred, the ASNL makes first contact with the individual with dementia and the family in order to connect them to resources and support throughout the progression of the disease.

First Link also offers families a 16-week learning series in the form of face-to-face, 1-hour PowerPoint presentations. This learning series follows the progression of the disease: beginning with topics such as "What is dementia?" and then moving on to topics related to the later stages of the disease such as managing challenging behaviours,

navigating the health care system, and end of life care. Table 1 provides the full list of topics covered in the learning series.

Table 1

First Link Learning Series topics

Series	Topic
First Steps	Memory Loss and the Brain
	Communication and Coping Strategies
	Navigating the System
	Legal and Financial Matters
	Resources and Support
Care Essentials	What to Expect
	Day-to-Day-Care
	Understanding Behaviour
	The Caregiver Journey
	Community Resources
Options for Care	When Care Needs are Increasing
	How the System Works
	Coping with Change
Care in the Later Stages	What to Expect: Advanced Dementia
	Looking for Clues: Pain and Distress
	Understanding Grief

The First Link Learning Series has been implemented elsewhere in Canada. In 2010, McAiney and colleagues published an evaluation report detailing the First Link Demonstration Project that took place in Ontario, Canada. They looked at use of First Link from November 1 2007 to June 30 2009 across four demonstration sites (n=3562) (McAiney et al., 2010). They found that only 16% of registered Alzheimer Society First Link clients attended the learning series during that time (McAiney et al., 2010). This low rate of attendance was suggested to be in part due to caregivers' inability to leave their care receiver at home untended, "one caregiver reported that he was unable to leave his care receiver alone in order to attend the sessions and he has declined respite because his

care receiver becomes agitated in new situations" (McAiney et al., 2010, p. 74). Distance and travel costs were also found to be a barrier to attendance: "a second caregiver reported that she lives at a distance from the center where the session are held and is unable to obtain transportation to travel there" (McAiney et al., 2010, p. 74).

In the spring of 2013, the ASNL planned to deliver the First Link Learning Series for the first time in the province. Health care professionals and ASNL staff would deliver face-to-face information sessions over three months in Mount Pearl, NL. Clients of the First Link Program were invited to participate in person or by teleconference. The partnership I formed with the ASNL allowed me to explore online options for the learning series. I chose to partner with the ASNL because it allowed me to focus my case study on a high quality health resource that had been previously tested in other provinces but that had never been delivered online. At the outset of the study the ASNL agreed to assist with recruitment of participants for my study, however this proved to be a challenge and a major limitation of my study that I will discuss further along in the methods section. This partnership offered benefits to the ASNL in that I acted as a volunteer online facilitator, providing assistance with the Skype technology for the 16-week learning series. I also recorded the learning series so that the ASNL could upload it to their YouTube channel. In this manner, participants could choose to use Skype or YouTube to access the same learning series material. At the end of the project I created a Skype facilitator-training manual (Appendix A) and helped train a new volunteer in this position in an effort to promote project sustainability.

Telemedicine and E-Health in the NL Context

NL has a long history of using technology to reach rural areas of the province with education, support and health services. In the 1930's FM radios were used to broadcast course materials to teachers and students in rural areas of the province (Elford, 1998). In the 1960s videotapes on health topics were broadcast over CBC television to provide continued education for health care professionals. In 1975, Memorial University launched its first telemedicine project. There are many definitions of telemedicine, however Elford (1998) defines it "the use of communication and information technologies to deliver health services and exchange health information when distance separates the participants" (Elford, 1998, p. 208). Elford (1998) provided this definition when he described the telemedicine activities at Memorial University in a review that spanned from 1975 to 1997.

While Elford's (1998) definition of telemedicine may have been appropriate at the time, the growth of the Internet has caused this definition to become somewhat limited, as it seems to encompass what has more recently been called E-Health. Indeed, the term telemedicine existed long before the Internet (Maheu, Whitten, & Allen, 2002). The World Health Organization (WHO) offers a different definition of telemedicine, which helps to distinguish it from E-Health. Telemedicine is defined as "the use of telecommunications to diagnose and treat disease and ill health" ("E-Health", n.d.). Telehealth is another term that is commonly used. This term is described as a type of telemedicine that focuses specifically on interactive patient-physician consultations (Maheu et al., 2002). The term E-Health seems to have entered the literature around 1999

and is broader in scope (McLendon, 2000). According to the WHO, E-Health includes the delivery of health information for health professionals and health consumers, through the Internet and electronic telecommunications ("E-Health", n.d). To create a full picture of NL's historical use of technology to support the delivery of health information, I will discuss the relevant telemedicine, telehealth, and E-Heath initiatives at Memorial University. However, in my study I classify health resources for dementia caregivers delivered via the Internet as a type of E-Health.

At the time of Elford's (1998) publication there had been over 30 telemedicine projects in NL. Since then, there have been a number of initiatives at Memorial University that use technology to support different aspects of health care including the creation of the E-Health Research Unit. The E-Health Research Unit describes its work as geared towards physicians, working to apply new and emerging communications technology to health care in NL. This research unit has overseen over 20 projects, with an additional 16 projects currently in progress. In addition to projects lead by the E-Health Research Unit, there are three main areas Memorial's telemedicine and E-Health projects have offered people living in rural and remote areas of NL. These include: continuing medical education for physicians and nurses, consultations and diagnostic services and patient and family health education.

Of particular interest are three studies that delivered programs via Memorial's telemedicine center. The first was described as "one of the earliest and most successful distance education projects in the province", the *Special Programme for Parents of Preschool Deaf Children* was designed to help educate parents in remote areas about how to care for their child's needs in relation to their disability (Elford, 1998, p. 212). In the 1-

year study that began in 1977, parents were provided with educational videotapes that could be viewed at home and weekly telephone counseling. This remote support was complemented by residential workshops at the beginning and end of the 12-month program. Parent competence was found to have improved after the intervention and the children's language development was found to be significantly better than the development expected with no intervention – as predicted by a group of independent experts. Although the project was found to be successful, it only continued for a few years. This was attributed to lack of funding and recruitment of health professionals to some of the larger rural communities, which made the distance program unnecessary. This project illustrates the importance of considering sustainable E-Health projects that have the ability to carry on after the research has ended. By identifying free modes of communication (Skype and YouTube), and building on an existing service (First Link), I hope to address the shortcoming of this previous research.

The second project of note is the Diabetes Distance Education Project, which began in 1994 at Memorial's telemedicine center. The project aimed to increase participants' knowledge of diabetes and self-care strategies; foster better attitudes towards diabetes and its management; promote greater self-care and glycemic control, and to assess the feasibility of using distance education technologies to deliver patient programs. Spanning a two-year period the project involved 85 people who participated in 15 hours of teleconferencing over five weeks. The sessions were delivered via print and video components supported by audio conferencing and telewriters – a piece of equipment that allows persons with speech and hearing impediments to communicate over telephone lines using typed messages. The study used a within-group, pre-test/post-test design with

follow up occurring at the end of the course and again at 3 months. The authors found that, "At the end of the course, participants demonstrated significant improvement in knowledge, attitude and behaviour" (Elford, 1998, p. 220). Also of note was that "69% of participants who had elevated glycated hemoglobin levels[1] at the beginning of the project improved towards the norm and 21% achieved normal levels" (Elford, 1998, p. 220). This study illustrates an intervention, which used multiple modes of communication to connect with participants. One reason for being able to attract such a large numbers of participants, may have been due to the choice in modes of communication, an important consideration for the present study.

In the third program, Curran and Church (1999) report on *A study of rural women's satisfaction with a breast cancer self-help network.* This project employed Memorial University's Telemedicine Centre to provide teleconferenced peer-support sessions from April to June of 1997. The equipment used consisted of push-button microphones and loudspeaker boxes, PC workstations, interface devices, and software for facilitating audio-graphic teleconferencing (Curran & Church, 1999). The sessions were offered on a bi-weekly basis. A facilitator guided each session by identifying who was speaking, and directed questions. Most topics of conversation were suggested by the participants and varied widely. The respondents' overall perception of the self-help support program was positive. Seventy-nine per cent strongly agreed or agreed that the teleconferencing sessions addressed their need for social support and information on breast cancer (Curran & Church, 1999). Sixty- four per cent strongly agreed and 29%

---

[1] The hemoglobin A1c test, also called HbA1c, glycated hemoglobin test, or glycohemoglobin, is an important blood test that shows how well an individual's diabetes is being controlled.

agreed to attend future sessions. Seventy-four per cent strongly agreed that it would be important for the teleconferencing sessions to continue. The authors stated that this suggests participants were satisfied with the program. Responses about the use of audio teleconferencing technology as a means of facilitating communication between participants were also positive. The responses suggested that unity felt among group members in a face-to-face self-help support program was as strong or stronger in the self-help support group facilitated through audio teleconferencing (Curran & Church, 1999). All participants strongly agreed or agreed that they were satisfied with the use of audio teleconferencing technology. Ninety-four per cent strongly agreed or agreed that teleconferencing helped them find emotional support and information from others. And 84% agreed that a sense of intimacy and safeness emerged within the group during the audio teleconferencing sessions (Curran & Church, 1999). This project is important because it illustrates a model that used existing provincial telehealth infrastructure. This may have been useful because it eliminated the need to purchase technology and created sustainability, because the technology continued to exist after the research ended. While this technology may reduce the amount of travel required to access a service such as Curran and Church's (1999) breast cancer self-help network, people still need to leave their homes to attend the program, which may not be possible for people who are sick or have other family obligations such as those living with dementia and their caregivers.

Past research at Memorial has largely focused on using the existing provincial telehealth infrastructure, even for the delivery of health education and information. NL's telehealth program currently provides services to clients in a number of specialty areas. There are 48 active clinical telehealth sites in the province, with many offering programs

in multiple chronic disease management areas and healthcare disciplines ("Newfoundland and Labrador Telehealth Program," 2015). Of special interest to my project is the program's provision of adult telepsychiatry services, which can help to address some of the needs of individuals living with dementia in their homes and communities in rural NL. Figure 1 provides a map of the province's telemedicine centers ("Newfoundland and Labrador Telehealth Program," 2015). In a 2010 evaluation report conducted by the NL Centre for Health Information, adult telepsychiatry services were reportedly offered from 6 sites, with at least one site in each of the four provincial health authorities ("Evaluating the Benefits Newfoundland and Labrador Provincial Telehealth Program: Chronic Disease Management," 2010). Major success of the program from the point of view of patients and families has centered on reducing the need to travel, and the costs associated with traveling to St. John's or other rural hubs where health services are available. Telehealth participants in NL have identified the need to further expand telehealth to other communities, as well as the need for more chronic health conditions to be managed under the current system ("Evaluating the Benefits Newfoundland and Labrador Provincial Telehealth Program: Chronic Disease Management," 2010).

Figure 1. Map of NL's Telemedicine Centers ("Newfoundland and Labrador Telehealth Program," 2015)

While telehealth is helping to address cost and travel time for patients in NL, these centralized locations still require individuals to leave their home to attend an appointment, much like a traditional face-to-face doctor's appointment. For the dementia caregiver, this may pose a barrier to accessing services as demonstrated by McAiney et al.'s (2010) findings. The current telehealth model in NL reduces the cost of travel, however it does not eliminate the need to travel entirely. My research differed from previous studies that have used existing provincial telehealth infrastructure, because it supports the delivery of health resources to dementia caregivers directly from their home via the Internet.

23

Study Significance

Because of the limited statistics about dementia in our province it is difficult to gauge the true impact of the illness and plan proper service delivery. There are also limited services available for people with dementia and their caregivers in this province. Caregivers of people with dementia in NL require increased support and services to help manage the disease and live comfortably in the community (Chappell et al., 2014). Because of the rapidly aging population there will be a need to find new and innovative ways to address this issue. There is a gap in the literature about understanding ways to use the Internet to support caregivers of people with dementia in this province. Past research in the NL context has largely focused on using the existing provincial telehealth infrastructure to provide services to people in rural areas. My research aims to address this by looking at a new E-Health model in NL, a model that makes health resources available to dementia caregivers directly from their home through the Internet.

Discussions with the ASNL revealed that they were seeking a new way to offer information to clients living in rural and remote areas of the province. Past research about First Link suggested that low attendance rates at the Fist Link Learning Series might have been in part due to caregivers' inability to leave their care receiver at home unattended as well as distance and travel costs (McAiney et al., 2010). My case study aims to build on this previous research by beginning to understand whether online options for the learning series can help to address these issues thereby addressing another gap in the literature, as well as addressing an identified need in the community.

Summary

My case study aims to understand how Skype and YouTube can be used to deliver online health resources to dementia caregivers. I am interested in understanding the experiences of these individuals within the NL context. The partnership I formed with the ASNL was instrumental in allowing me to take on these research questions, however barriers to recruitment have limited my ability to access a large number of dementia caregivers for this study. For this reason I expanded my study sample to include service providers as well as other sources of data in hopes of understanding this phenomena from multiple perspectives. The appropriateness of this research in the NL context is supported by the long-standing tradition of using telehealth in this province. It is also innovative because of the in-home E-Health model I examined, which differs from the existing provincial telehealth structure. The exploration of using Skype and YouTube to access the learning series will help to inform decisions with regards to the expansion of First Link in NL. It will help begin to inform whether these mediums are effective tools for non-profit organizations such as the ASNL to deliver information and health resources. My research will also help to build theory about how technology-enabled support can be delivered to dementia caregivers living in urban and rural areas who cannot access resources in person.

Literature Review

In this chapter, I will first discuss the needs of dementia caregivers in order to help convey the appropriateness of the First Link Learning Series as a health resource for dementia caregivers. Second, I will describe previous research exploring various delivery methods for Internet-based health resources for dementia caregivers. Subsequently, I will discuss how Skype and YouTube have both been mediums used in E-Health and medical education applications to help build a case for why they are appropriate in the present study. Finally, I will explain how community and nonprofit organizations are using the Internet in order to further a case for why my research is both timely and relevant.

Understanding the Needs of Dementia Caregivers

Although dementia caregivers sometimes develop positive coping strategies that help them manage the task of caregiving and may experience intrinsic reinforcement in their roles, such as the ability to keep the person they are caring for at home (Lloyd, Patterson, & Muers, 2014), caregiving roles can also be stressful and burdensome and caregivers themselves often need support (Mark, 2015; Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Informal caregivers of people with dementia have been reported to be at risk for adverse health outcomes including social isolation, depression, anxiety, stress, compromised immune responses, higher use of medication, and greater cognitive decline (Sorensen & Conwell, 2011). Moderators of stress for caregivers of people with dementia have been reported to include knowledge and information; and economic, social and community resources (Sorensen & Conwell, 2011). Lack of knowledge about dementia has been shown to cause dementia caregivers

to overestimate the person with dementia's abilities, which can lead to greater anger, frustration and depression for the caregiver (Ala, Berck, & Popovich, 2005). There is also evidence to suggest that cultural background may change the strength of relationships between certain caregiving stressors and their outcomes (Sorensen, Duberstein, Gill, & Pinquart, 2006). Most family caregivers play an advocacy role for individuals with dementia in areas including the community and health care system, and therefore seek out information to help them navigate the ever-changing day-to-day challenges associated with the disease (Mittelman, 2003).

Because both information and community resources are important moderators for controlling stress among dementia caregivers, it is important to know what types of information these individuals require. The literature suggests that there are a number of topics important to dementia caregivers; these include the need to understand dementia (Afram, Verbeek, Bleijlevens, & Hamers, 2014; Judge, Yarry, Looman, & Bass, 2013), how to communicate with the person with dementia (Bramble, Moyle, & McAllister, 2009; Ducharme et al., 2011; Judge et al., 2013; Paun & Farran, 2006; Seike et al., 2014) and information about medications and treatment options (Bogardus et al., 2004; Seike et al., 2014). Dementia caregivers have also reported the need for information about financial planning, (Afram, et al., 2014; Bogardus et al., 2004; Ducharme et al., 2011; Kelsey, Laditka, & Laditka, 2010; Liken, 2001; Park, Butcher, & Maas, 2004) and where to access support and how to make use of social resources (Afram, et al., 2014; Bogardus, Bradley, & Tinetti, 1998; Kwon & Tae, 2012; Park et al., 2004). Finally, dementia caregivers have reported the need for information about how to manage social and family

relationships (Afram, et al., 2014; Bogardus et al., 2004; Ducharme et al., 2011; Park et al., 2004; Sutter et al., 2014); and strategies for self-care (Jensen & Inker, 2015).

Research also suggests that how caregivers think about their needs as they relate to caring for the person with dementia can vary: some may present with problems or goals that are either broad or specific; others may identify short term or long term needs; and still others may also identify informational needs that can be relatively difficult or challenging to acquire, or that may be relatively easy to achieve (Bogardus et al., 1998). In addition to variations in scope, timeframe and level of difficulty, there is also evidence suggesting variability in issues facing caregivers of people with dementia. This means that all caregivers may not need the same types of information. While some caregivers may experience behavioural problems with the person they are caring for, others might place more emphasis on accessing social support, or reducing family conflict. This suggests that adaptive learning opportunities, which can be modified in scope and intensity, may play a key role in finding solutions to address heterogeneity among caregivers. A "one-size-fits-all" approach simply will not suffice nor fit the diverse needs of this highly variable population.

Improving education and skill-building opportunities for caregivers of people with dementia has also been identified as a priority by the Alzheimer Society of Canada (Smetanin et al., 2009) and there is research to suggest that caregivers can benefit from participating in education and support programs (Toseland, 2004). There have also been clear calls to action about the need to support informal caregivers (Mark, 2015; Smetanin et al., 2009). Mark (2015) suggests that in order to support dementia caregivers there should be "caregiver centered training and individual guidance based on the specific

situation" (p. 2). This statement is particularly significant in relation to my own research questions first, because it reflects the reality of life in NL for dementia caregivers where there is a lack of training to support them in their roles. Second, it is also important because it clearly points to the heterogeneity among dementia caregivers and how these individual differences should be considered when planning and delivering health resources to dementia caregivers in NL. This heterogeneity affects the types of supports that dementia caregivers require (Van't Leven et al., 2013). A heterogeneity of dementia caregiver needs led me to consider the value of previous literature describing individualized goal setting for the care of someone with dementia and how this concept can extend to the dementia caregiver in the current study.

Kiresuk and Sherman first described the concept of Goal Attainment Scaling (GAS) in 1968. Goal setting allows health care professionals to monitor an individual's progress towards specific, pre-established goals and allows them to assess the clinical meaningfulness of the treatments being received. Since Kiresuk and Sherman (1968) proposed GAS many studies have used the measure. For example, The Victorian Order of Nurses of Canada's Functional Fitness Continuum Project Evaluation Report used GAS as a way for program participants to set their own goals in the program, as well as a flexible evaluation approach (Connelly & London, 2008). However, they reported problems with the method they employed noting that the "'self-completing' GAS was not found to be 'user-friendly' nor readily understandable" by the older adults in the VON SMART Group Program (Connelly & London, 2008, p. 32). The use of GAS has been shown to successfully support dementia caregiver decision making during end of life care for people with advanced dementia (Einterz, 2014), although this version of GAS differed

from the VON's model because it used a decision aid video to help guide participant goal setting. Together Connelly and London (2008) and Einterz et al. (2014)'s work illustrates the importance of having a guide to help direct GAS for older adults and dementia caregivers.

A notable study by Rockwood and colleagues (2006) used GAS to assess the effectiveness of galantamine – a drug used to treat symptoms of dementia – by tracking its ability to affect both patient and physician set goals. Goal setters (patients/caregivers and physicians separately) identified common dementia-related symptoms and problems and were asked to set a minimum of 3 goals. Criteria were also set to help guide the goal setting process: 1) The problem areas must be evidently related to the patient's dementia; 2) The posited better and worse outcomes (i.e., the goals) must represent meaningful changes to patients/caregivers that could reasonably be influenced by the intervention (galantamine); and 3) The goals could reasonably be achieved within the study period (4-8 months) (Rockwood, Fay, Song, MacKnight, & Gorman, 2006). In a later study Rockwood and colleagues (2013) introduced SymptomGuide™, a tool that provides detailed descriptions of common symptoms of dementia. This tool enhanced the goal setting process by allowing caregivers to choose from a list of symptoms that were most troubling to them (Rockwood, Mitnitski, Black, Richard, & Defoy, 2013).

The methods employed in these studies are important for several reasons. First SymptomGuide™ provided patients and caregivers with a menu that facilitated conversation about the types of problems they were experiencing, addressing issues raised by Connolly (2008). Second, the criteria used to guide the goal setting process helped to explain the purpose of the goal setting. Finally, the use of both caregiver/patient and

physician goals is important because it acknowledges the potential differences between physician and patient/caregiver goals.

Taking an approach to care that places the person at the center of the model means considering the goals of the patient or caregiver in addition to the goals of the physician. This concept extends to a program like First Link, where the program itself identifies certain goals for participants (topics in the learning series) that may or may not differ from the goals of dementia caregivers. In order to address these important ideas about the individualized needs of dementia caregivers, I have incorporated these concepts into my study design. Briefly, I have used Rockwood et al.'s (2006) and Rockwood et al.'s (2013) descriptions of GAS to design my pre-study interview with dementia caregivers to help understand their experiences caring for someone with dementia and to direct conversation about what specific information they are seeking from the First Link Learning Series. GAS is not used as an outcome measure in this study, but rather as a tool to address ethical considerations (time required to participate). By selecting topics in the learning series that fit their individual needs, rather than suggesting they participate in the full 16-week series, which may include topics that are not relevant to their individual experiences, participant caregivers can save time and inconveniences that come with taking time out of their days to participate in the learning series. In the methods section I will describe in detail how I have incorporated GAS into this case study.

Internet-based Health Resources for Dementia Caregivers

There are clear and well-developed accounts of the types of issues dementia caregivers face, and the types of information they require. Access to this information can

have positive impacts on caregivers' health and well-being (Mittelman, 2003). In this case study I am looking specifically at the use of Internet-based health resources. Kim (2015) defined Internet-based health resources as health information on websites and activities via communication technologies. This definition is important because it excludes specific health interventions based on information and communication technology explicitly designed for clinical research (Kim, 2015). I have also made this distinction in my research, narrowing my focus to look specifically at using Skype and YouTube (Internet-based mediums) to deliver the First Link series – a health resource for dementia caregivers.

Use of the Internet to access health information is a new and emerging area of research. Caregivers are using the Internet as a tool to assist with caregiving activities and seeking information for the people they are caring for, referred to in one study as "surrogate seeking" (Sadasivam et al., 2011). Internet as a modality for delivering health information may help to overcome the limits of a face-to-face approach, specifically time constraints, geographic limitations, and transportation issues.

The topic of what makes a dementia caregiver likely to use the Internet to access health resources is still under investigation, however, there is some evidence to suggest that there are specific characteristics of dementia caregivers that make them more likely to use the Internet. An American study of Internet use among dementia caregivers, the first of its kind in the literature, found that 59% of respondents (n=450) identified as health-related Internet users (Kim, 2015). These dementia caregiver Internet users were more likely than non-users to be younger, more educated, have a higher household income, and spent less time caregiving than their non-user counterparts. Dementia

caregivers who were health-related Internet users were also more likely to be a child or grandchild of persons with dementia rather than their spouse. Notably, those experiencing higher emotional stress also reported more health-related Internet use and when caregivers reported taking care of totally dependent persons with dementia they were 2.99 times less likely to be health-related Internet users than those taking care of totally independent persons with dementia (Kim, 2015).

Despite limited knowledge of why dementia caregivers are likely to use the Internet, there is research spanning several decades investigating the role of Internet based health resources in dementia caregiving. One of the earliest Internet-based health resources for caregivers of people with dementia was designed to meet the needs of caregivers of dementia patients in Cleveland, USA (Smyth & Harris, 1993). The Alzheimer's Disease Support Center contained five online modules, including an "information rack" with an electronic library of materials, and bulletin board forums (Smyth & Harris, 1993, p. 125). Many health resources since this time have focused on web content , which offers information on various aspects of caregiving (Brennan, Moore, & Smyth, 1995; Chiu & Eysenbach, 2011; Coulehan, Rossie, & Ross, 2008; Ducharme et al., 2009; Lauriks et al., 2007; Marziali & Donahue, 2006; Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008; van der Roest, Meiland, Jonker, & Droes, 2010). The strength of this type of information is that it can be accessed at any time of day or night, which can be important for someone in a caregiving role because of demanding schedules and limited time. A drawback of this method is that it is a static form of information that requires updates to remain timely and relevant. This communication method is also a one way street, with information going out to caregivers, but no

opportunities for sharing and communication among users or those creating and posting information.

There has also been work exploring the use of a website combined with telephone support (Glueckauf et al., 2012). Some studies have offered information via a website with additional e-mail support, (Chiu et al., 2009) while other have used a website in combination with individual work and exchange with other caregivers online (Coulehan et al., 2008; Ducharme et al., 2011; Lai et al., 2013; Torp et al., 2008). There is a limited body of research that explores the use of videophone for supporting dementia caregivers' learning needs. In one recent Canadian intervention, participants received access to a password-protected website with links to information, e-mail, and threaded discussion (Tanner et al., 2015). Unique to the website was a video-conferencing link that supported caregivers' participation in a 10-session, manual-guided psychosocial support group (Tanner et al., 2015).

A recent meta-analysis of the effectiveness of computer-mediated interventions for informal caregivers of people with dementia reported that in general, these interventions offer a range of potential benefits including increased self-efficacy and intention to get support as well as reductions in caregiver stress, strain, depressive symptomatology, and anxiety when examined from the perspective of quantitative outcome measures (McKechnie, Barker, & Stott, 2014). Notably, the authors called for more research exploring the qualitative components of caregivers' experiences with computer-mediated interventions, indicating that information gathered from interviews with caregivers who have used computer-mediated interventions offers an important supplement to quantitative outcome measures.

Skype and YouTube

The history of Internet-based health resources for dementia caregivers indicates that there is limited knowledge about how dementia caregivers experience videophone mediated health resources, however there is stronger evidence to suggest that dementia caregivers are interested in having resources available online. In addition to the previously mentioned ways the Internet as a modality for delivering health information may help to overcome the limits of a face-to-face approach, which include time constraints, geographic limitations, and transportation issues, we also know that financial constraints serve as a barrier to accessing information online for dementia caregivers (Boots et al., 2014).

Skype is a free, web-based videoconferencing tool with well over 560 million registered users (Safei, Amin, Rose, & Rahman, 2011). The use of Skype by healthcare professionals entered the literature as early as 2009, in an article by Hori et al. (2009) a small, pilot study with 7 participants used Skype to facilitate communication between nursing staff, family caregivers and individuals with dementia (Hori et al., 2009). From 2008 to 2013, a handful of health research had been published regarding the use of Skype. The use of Skype among medical professionals can be divided into three major categories: instructional support for medical students and other trainees (Boedeker et al., 2011; Zolfo et al., 2010) physician-to-patient communication (diagnostics, clinical assessments and therapy delivery) (Constantinescu et al., 2014); and patient-to-family communication (Boedeker et al., 2011; Constantinescu et al., 2014; Good, Lui, Leonard, Morris, & McElwain, 2012; Zolfo et al., 2010). Furthermore, recent publications continue

to focus more heavily on instructional support for medical students and other trainees (O'donovan & Maruthappu, 2015), and physician-to-patient communication (Clarke & Mars, 2015), while the use of Skype for delivering health resources has been largely overlooked.

YouTube is a media-sharing site that allows users to upload videos and share videos them both privately and publically. It differs from Skype in that it is not videophone but rather a website with pre-recorded and live streaming videos that do not offer two-way communication. YouTube shares a large number of attributes with other social media – profiles, friends, comments, and private messaging/ sharing of content (Grajales, Sheps, Ho, Novak-Lauscher, & Eysenbach, 2014). YouTube has been used to support resource sharing, community building, marketing of medical products, delivering information, disseminating research findings, and presenting educational materials (Grajales et al., 2014). YouTube has been described as being easy to use, having little or no cost, and being accessible from both desktop and mobile devices (Grajales et al., 2014).

Several articles have been published about the use of YouTube as it relates to health information. Fernandez-Luque, and colleagues (2014) found that virtual communities developed through the "comment" feature of the site. Patients responded to each other's videos, described the progression of their disease, and endorsed specific medications. Keelan and colleagues explored videos that contained misinformation about vaccinations (Keelan, Pavri-Garcia, Tomlinson, & Wilson, 2007). Harmful videos (such as those that contradicted the Canadian Immunization Guide) were found to receive a higher number of views and user ratings – accounting for almost 50% of total YouTube

immunization videos. Because YouTube does not discriminate video ranking based on content (unless the video violates copyright policy) the number of times a video is viewed is the main driver behind search result rankings (Grajales et al., 2014).

Skype offers a live delivery option, connecting participants directly by online video link. YouTube offers a delivery option that is pre-recorded and allows caregivers to access videos whenever they have time available. Previous research has explored how Skype can be used to deliver health resources, however, not specifically to dementia caregivers. This is another identified gap in the literature, which my study attempts to address in the upcoming chapters. Previous research has criticized YouTube as a means for delivering health resources because some videos available online have harmful or misleading information that may be easily found and viewed due to search result rankings (Grajales et al., 2014). Having said that, technology, like any medium, has the potential for promoting both useful and misleading information but for the purposes of this study, my goal is to understand the potential positive impact technology can have for dementia caregivers as well as how they experience using such technology. This can also be seen as a gap in the literature that my study aims to address by offering appropriate, trustworthy information to participants and understanding their use of YouTube to access health information.

How Community and Nonprofit Organizations are using the Internet

The potential of the Internet to support the work of non-profit organizations has been discussed by a number of commentators over the past two decades. Landesmann (1995) identified publicity, public education, fundraising, volunteer recruitment, service

delivery, advocacy, research and communication as ways the Internet could be put to work for non-profit organizations (Landesmann, 1995).

Fundraising dominates much of the popular literature addressing the potential of the Internet for the non-profit sector with a focus on how to use websites to elicit donations (Dean, 2015). Some organizations also advertise volunteer opportunities online. Cravens (2003) described the concept of "virtual volunteering," where volunteers provide services online such as bookkeeping, writing or web site management.

Many non-profit organizations are committed to educating and creating supportive relationships in the community. The Internet offers the opportunity to provide tailored information with a professional appearance. Quality design and content have been said to add to perceptions of organizational credibility and improve rates of donations (Pitts, Blose, & Mack, 2014). How information is presented and organized on a website has also been shown to impact the processing of information and therefore the quality of the learning processes itself (Jones, Fitzpatrick, & Chassy, 2015). However specialist design considerations and quality content requires special skill sets and constant updating, tasks often difficult for smaller non-profit organizations (Chapman, Miller-Stevens, Morris, & O'Hallarn, 2015).

Since the 1990s, the non-profit sector has become increasingly aware of the potential of the Internet as a tool for advocacy efforts. Kingsley et al. (2000) identified e-mail, list serves and the web as the most common tools for Internet advocacy. More recent research has noted the importance of social media in advocacy, and its ability to provide new opportunities to non-profit organizations. Özdemir (2012) suggests that social media reduce non-profit organizations' dependency on mass media; enable them to

reach a broader section of the public; provide a platform for developing two-way, mutual communication; and facilitate participation in their advocacy campaigns. Many small non-profit organizations are found to be using multiple social media sites to engage with different stakeholders. However, recent research suggests that these smaller non-profit organizations are not using social media to its full potential with regard to community-building and action mobilization (Hou & Lampe, 2015). These researchers also found that non-profit agencies face challenges when using social media to engage with the public, such as ineffective measurement of social media performance, and deficient organizational resources. Having the appropriate knowledge and understanding of how to use these tools will be particularly important if non-profit organizations are to make the most of what these tools have to offer.

Costello et al. (2013) identified the role of the Internet in community building for non-profit organizations. Online communities supported by non-profit organizations have been found to provide an important social space for the exchange of peer-to-peer support (Ancker et al., 2009; Nambisan, 2011). The social support offered by online communities, and the opportunities provided for engagement with others, are reported to have a positive impact on users' sense of well-being and their quality of life (Lieberman & Goldstein, 2005; Witney, Green, Costello, & Bradshaw, 2013). Bonniface and Green (2007) found that online communities promote improved psychosocial well-being, while van Uden-Kraan et al. (2009) suggested that online communities enhance users' self-efficacy in managing acute health conditions. Online communities can support positive behavioural change such as exercise participation, weight loss and smoking cessation and can play a role in educational activities (Bonniface & Green, 2007). There has also been some work

regarding the potential drawbacks for non-profit organizations using the Internet to support online community building; these include personal safety, protection of intellectual property, security of reputation, right of privacy and safeguarding from potential crime (Herman, Head, Jackson, & Fogarty, 2004).

Summary

Together, these four bodies of literature build a case for the importance of understanding how the Internet can be used to deliver health resources for dementia caregivers. While there is a strong body of literature about the needs of dementia caregivers, there is still limited knowledge about how dementia caregivers navigate and experience Internet-based health resources.

Skype and YouTube have been used successfully to deliver information and support in E-Health and medical education, however, little is known about the usefulness of these mediums for dementia caregivers and non-profit organizations that wish to capitalize on free web-based video conferencing options to deliver health resources. Non-profit organizations have used the Internet to support actives such as advocacy and fundraising for the last two decades. Non-profit organizations have also successfully capitalized on the Internet's ability to build community and offer social support and there is a growing body of research that is seeking to understand how non-profit organizations utilize social media. Nevertheless, there is still a gap in the literature about understanding how non-profit organizations are using the Internet to deliver health information over new media such as Skype and YouTube. Perhaps more importantly is McKechnie, Barker and Stott's (2014) call for more research exploring the qualitative components of caregivers'

experiences with computer-mediated interventions, indicating that information gathered from interviews with caregivers who have used computer-mediated interventions offers an important supplement to quantitative outcome measures. I intended to address this gap while also considering the perspective of those delivering health resources to dementia caregivers, uniquely positioning my research within the current body of knowledge on these topics.

Methodology and Methods

Research methodology is the study of methods, which includes the philosophical principles that inform approaches to research, as well as the technical issues of how to generate and analyze data. Green and Thorogood (2013) explain that methodology differs from research methods in that it provides an account of *why* particular approaches were taken, rather than just the "recipe" or the *how* of the techniques that were used in a particular study (p. 286). In the following section, I will discuss the methodology and methods used in this case study.

My initial study design was not a case study, but rather I hoped to conduct an experimental quantitative pretest posttest study looking at the impact of First Link delivered via Skype and YouTube on dementia caregiver goals. Working with the ASNL, I aimed to recruit 30 participants in three months, during the first time delivery of First Link. We were only successful in recruiting two caregiver participants, which will be further addressed in the study limitations section of my discussion. Because of this limitation, my study design shifted from an explanatory pretest posttest study to an exploratory case study. As previously mentioned, a case study allows for the use of multiple data sources. I added interviews with service providers, as well as data from institutional documents, YouTube analytics and field notes. Case studies allow for flexible integration of data as it arises through the course of the study process. The modification to my study design is important because it helps to demonstrate how community-based research is not always able to follow pre-defined research methods and needs to adapt to the real world boundaries of the data that are accessible to the

researcher. It also helps to illustrate the significance of naturalistic inquiry in community health research.

Stake (1995) and Yin (2003) describe two central approaches that guide case study methodology. Stake (1995) describes case research as an investigation and analysis of a single or collective case, intended to capture the complexity of the object of study. For Stake (1995), case studies draw on "naturalistic, holistic, ethnographic, phenomenological and biographic methods" (p. xi–xii.). The case study is defined by interest in the individual case or cases, not by the methods used to direct research. According to Yin (2003), a case study approach is appropriate when the study seeks to answer "how" and "why" questions. It is also selected in instances when there is no intention to manipulate the behaviour of those involved in the study, but rather observe the phenomenon at hand. The researcher also aims to include contextual factors such as descriptions of place and time because of their relevance to the case.

Both Yin (2003) and Stake (1995) base their approaches on a constructivist model, which recognizes the importance of subjective creation of meaning without totally rejecting some form of objectivity (Baxter & Jack, 2008). This is also in line with the naturalist paradigm described by Lincoln and Guba (1985). Yin's (2003) primary focus is on methods and the process of conducting sound case study research, while Stake (1995) places his focus on interpretation of phenomena. For Yin (2003), the focus of good case study research is on preparing for data collection, collection of evidence, analysis of the evidence, and composition of the case study report. But for Stake (1995), the focus is on building a clearer view of the phenomenon through explanation and descriptions. Case studies have been used to explore the phenomenon of providing community-based

support to dementia caregivers (Mittelman & Bartels, 2014). The case study method has also been used to understand how information and communication technology can support elderly family caregivers of people with dementia or stroke (Lundberg, 2014). The use of case studies in settings similar to the present study suggests that it is an appropriate method for understanding if Skype and YouTube can be used to effectively deliver the First Link Learning Series, in addition to the real world limitations that lead me to use this approach.

Theoretical Frameworks and Case Study Research

Theoretical frameworks are identified by Yin (2003) and Stake (1995) as important to the development of case study research, however Baxter and Jack (2008) note that even Yin (2003) and Stake (1995) fail to fully describe or provide a model of a conceptual framework for reference. Critiques of case study research in the health sciences focus on the lack of a clear methodological description or justification. Indeed, Mittelman and Bartels (2014) and Lundberg (2014) did not explicitly use a theoretical framework in their case studies (Mittelman, 2014; Lundberg, 2014). Researchers have called for better use of specialist methodological advice when designing case studies and for a clearer description of the theoretical framework in case study research (Hyett, Kenny & Dickson-Swift, 2014; Kleinert & Wager, 2010).

The theoretical framework serves as an anchor for the case study and is particularly important for guiding data interpretation (Baxter & Jack, 2008). The purpose of a theoretical framework is to identify the various constructs of interest in the study. At first, the framework might not display the relationships between all of the constructs, but

as the study progresses and data are analyzed, themes that have emerged can be integrated and a new, more fulsome framework, which includes various relationships between constructs. While there is strong evidence to suggest that theoretical framing is an important element to include in case study research, critics note that these frameworks may limit the inductive approach when exploring phenomena. Baxter and Jack (2008) suggest that the novice researcher safeguard against becoming deductive during data analysis by journaling thoughts and decisions in order to discuss these with other researchers to establish if their analysis and framing has become too driven by the framework. By practicing this type of reflexivity throughout the study process the researcher is able to link with the naturalist's paradigm, acknowledging the existence of multiple realities and how they are constructed, the interactions between the knower and the known, and the notion that all entities of interest within the case study are in a state of simultaneous shaping.

A Framework for Understanding E-Health Research

To address the concerns outlined by Hyett, Kenny and Dickson-Swift (2014), Kleinert and Wanger (2010), and Baxter and Jack (2008), I have drawn from Dansky, Thompson, and Sanner's (2006) *Framework for Understanding eHealth Research* to guide this case study. Baker, Gustafson and Shah (2014) have identified this framework as useful for its ability to provide a holistic perspective for designing and implementing E-Health research projects.

Dansky et al. (2006) proposed a framework for evaluating E-Health research that addresses four dimensions of E-Health evaluation. The first dimension is design and

methodological issues. These issues include recruitment, randomization, adequate sample sizes, retention, and study protocols. Dansky et al. (2006) suggest an integrative approach that includes qualitative data to help address some of the challenges of conducting this type of research. Among its strengths Dansky et al. (2006) note that a qualitative approach to E-Health research allows the researcher to use inductive logic, building and revising research questions and theory from experience in the field. Dansky et al. (2006) suggest that a combined approach drawing from both qualitative and quantitative methods is likely to foster a more holistic basis for understanding this complex phenomenon.

The second dimension is environmental constraints, such as limitations imposed by ethical review boards and considerations of privacy, confidentiality and security. Dansky et al. (2006) note the importance of considering these issues at the outset of the study, and having clear protocols in place in order to address potential concerns at the implementation phase.

The third dimension is technology. Issues with technology can include technical requirements related to hardware and software, infrastructure and resources to support the technology, changing requirements of the system, vendor relations, user issues such as training and satisfaction with the system and overall system maintenance and performance. Dansky and colleagues (2006) caution that organizations are often faced with the challenge of assessing both the technology itself and the impact of what is being delivered via the technology simultaneously during an evaluation. Thus, it is important to sort out issues that are related to the technology itself as opposed to those that are part of its implementation into an organization, or its "deployment" (Dansky et al., 2006, p. 401).

The fourth dimension of the framework is logistics. Dansky et al. (2006) consider areas such as staffing and skill requirements, a need for multidisciplinary teamwork, shared understanding of roles and responsibilities, obtaining buy-in from stakeholders, and timelines that are often unrealistic.

Critics of research that evaluates E-Health suggest that there tends to be a focus on specific interventions, which often become dated very quickly, in turn restricting their relevance and contribution to the field. Baker, Gustafson and Shah (2014) identify the importance of studying "universals" in E-Health research and "anticipat[ing] the next big thing"(p.3). Baker and colleagues (2014) believe that focusing research in these areas can help to develop strategies for increasing the timeliness and usefulness of E-Health research. These authors cite Dansky et al. (2006), emphasizing the value of the Framework for Understanding eHealth Research for its ability to help researchers focus universalities and future directions in E-Health research.

Applying Dansky et al.'s Framework to the Research Design

Design. This case study was theoretically framed using elements from Dansky et al.'s (2006) Framework as well as Yin's (2003) approach to case study research. Yin (2003) described the single embedded case study design, which looks at multiple units of analysis within a single case. Figure 2 illustrates the traditional single embedded case study design described by Yin (2003). According to Baxter and Jack (2008), the power of this method of inquiry is that it allows researchers to analyze data within the units separately but also allows for analysis between these units, and across all the units. While the single embedded case study has benefits, Baxter and Jack (2008) caution novice

researchers not to lose focus on the global issue as they analyze the subunits. I describe

this case study as a modified single embedded case study design because of the way in ,

which I have used the embedded units to understand the phenomena. Figure 3 illustrates

how some of the units are used to understand the case itself, however, some of the units

of analysis are used to describe and provide information about the context in which the

study has occurred. Also, in the case of institutional documents this source provides

information about both the context and the case as shown by its placement overlapping

the two areas.
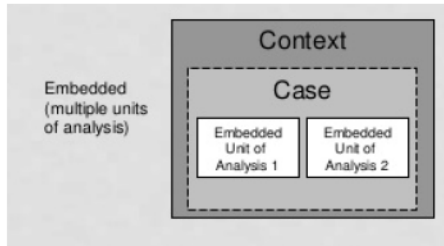
Figure 2. Embedded Case Study Design (Yin, 2003). This figure illustrates the location of the units of
analysis within the case.

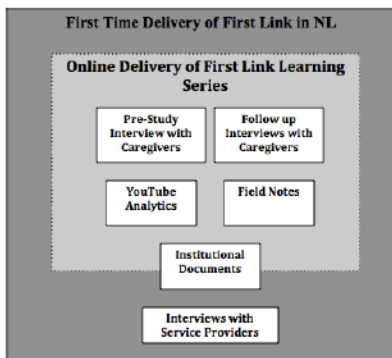*Figure 3.* Modified Embedded Case Study Design. This figure illustrates the location of the units
of analysis within this case study.

This case study explores the first time delivery of the First Link Learning Series

via Skype and YouTube, as media for the delivery of health resources to dementia

caregivers and attempts to address two primary questions:

1. How do informal caregivers of people with dementia experience the First Link Learning Series online using Skype and YouTube?

2. How can Skype and YouTube be used as tools for the ASNL to effectively deliver the First Link Learning Series?

The context of the present study is the first time delivery of the First Link Learning Series in NL. The case is the online delivery of the First Link Learning Series. In the previous chapters I have discussed major contextual elements that help situate the case including issues facing caregivers of people with dementia, support for dementia caregivers in the NL context, and previous research using technology to provide informational resources. These over-arching elements contribute to the big picture of how my study addresses gaps in the literature, specifically, understanding an in-home option for Internet-based health resources in NL, focusing on the delivery of a high quality health resource, and discovering if these new options address previously identified shortcomings of the in-person version of the learning series.

A feature of a sound case study design is the establishment of clear boundaries that bind the case. "Binding a case," involves setting limits around what is included in the research study and is similar to the development of inclusion and exclusion criteria found in other kinds of qualitative research (Green & Thorogood, 2009). An important distinction between the two is that boundaries also indicate the breadth and depth of the study as opposed to just the sample to be included (Baxter & Jack, 2008). Binding a case helps ensure that the study is reasonable in scope, focused and stays on track.

Binding a case can be done in a number of ways. For example, Creswell (2012) uses time and place, while Miles and Huberman (1994) use definitions and the context of

the case. I chose to bind my case study by time and place, which is in line with the underlying naturalistic assumptions of this case study. The time and place of the case also helps to define its context. In this case, the investigation was limited to the first time delivery of the learning series that was in the pilot-testing phase in NL. The provincial ASNL launched pilot testing of First Link in September 2012 with the hiring of the First Link Coordinator. The Coordinator began recruiting family physicians to refer individuals with dementia to the First Link Program. The program had been recruiting clients and their families for less than 5 months when this study was initiated in the spring of 2013 in St. John's and Mount Pearl, NL. Data collection with First Link clients continued for the duration of the 16-week program. However, binding the case by the duration of the program presented a problem because of challenges with recruitment. These and other methodological issues are discussed later.

Units of analysis in this case study include, caregiver interviews, key informant interviews, YouTube analytics data, institutional documents, and field notes. Data collection was an iterative process that was influenced by how my study changed over time. I began by conducting the pre-study interviews with two dementia caregivers. Next, the learning series started. Once it became clear I would only have two dementia caregiver participants, I added interviews with service providers. In this way, the service provider interviews were influenced by my experience talking to the dementia caregivers and my observations of the learning series. Field notes were collected from the time of recruitment until the end of caregiver post study interviews. After the learning series was complete I conducted the post study interviews with the dementia caregivers. The focus of these interviews shifted from the original GAS follow up to their experiences with

technology during the learning series. Next I collected data from YouTube analytics, and finally the ASNL released an institutional report of First Link, which was also included as a data source. I will now describe the data sources and process of data collection for each of these units in detail followed by a discussion of data analysis.

Pre-study interviews with caregivers aimed to understand the individual experiences of participants in their role as a dementia caregiver. The secondary purpose was to help them decide, which topics in the learning series were relevant to them. The interview protocol designed for this study is based on the work of Rockwood et al. (2006) and Kiresuk and Sherman(1968), and is outlined in Appendix B. The GAS interview process described by Rockwood et al. (2006) follows 5 steps: (a) identifying the goal (b) defining the goal in plain language (c) identifying potentially better and worse outcomes (d) weighting the goals relative to each other (e) follow up. I used this protocol to guide the first interview with participant caregivers. Interviews lasted between 30-90 minutes and were audio recorded using GarageBand by Apple Inc. version 6.0.4 and later transcribed. A summary of individual participant goals was prepared based on a collation of the data from the interviews (Appendix C). I sent a copy of the goals to participants to validate my interpretation of their individual goals. Participants received a list of First Link Learning Series Sessions and used their identified goals to direct selection of appropriate First Link Learning Series sessions, which they took part in by Skype or watched on YouTube.

Key informant interviews were used to understand how dementia caregiver service providers are using the Internet to serve clients, what the providers' perceptions are surrounding the need for service delivery via the Internet, as well as their perceptions

of the impact current online service provision has had on their clients. An 11-question interview guide (Appendix D) developed in consultation with my supervisory committee, guided interviews with service providers. The interviews were conducted in a private room at the service providers' workplace. Interviews lasted between 30-90 minutes and were audio recorded using GarageBand by Apple Inc. version 6.0.4 and later transcribed. During the interview, I restated and summarized information and then further questioned the participant to determine accuracy of understanding. This is a form of member checking (see page 56). Participants were also sent copies of the transcripts for feedback as part of the continued member checking

Skype and YouTube follow up interviews with dementia caregivers were conducted on Skype. Interviews lasted approximately 30 minutes, were audio recorded using GarageBand by Apple Inc. version 6.0.4 and later transcribed. The interview protocol was comprised of five subsections (Appendix E). I will discuss these subsections in detail during my discussion of technology.

I was granted access to the ASNL's YouTube Analytics profile for one time data collection in November of 2013. YouTube analytics provides reports on video views, audience demographics, playback locations, audience retention, and traffic sources. I downloaded these reports in an Excel format and later analyzed the data in order to provide contextual information, helping to situate the YouTube option of the learning series within the case.

The First Link Learning Series Report was an institutional document reporting on the First Link Learning Series in NL, and was published in November 2013. The report included information about caregivers participating in the in-person sessions as well as

online (Appendix F). I analyzed this report in order to provide contextual information, situating the Skype and YouTube options of the learning series within the case.

I collected field notes during the recruitment process and as I observed the 16-week learning series, keeping detailed records through the in-person and Skype sessions. I also kept notes that described my interactions with study participants, including trouble-shooting problems with technology and conversations that we had before and after the learning series sessions. Field notes were typed and stored as Microsoft word files (Microsoft Word for Apple Inc. version 14.2.0).

After collection, the data was analyzed using the Framework Analysis approach described by Gale, Heath, Cameron, Rashid, and Redwood (2013). The Framework Analysis approach is situated within a broad family of analysis methods termed thematic analysis or qualitative content analysis. It was first developed by researchers from the Qualitative Research Unit at the National Centre for Social Research in the late 1980s for use in large-scale policy research (Ives, Damery, & Redwod, 2012). It is now commonly used in other areas, including health research (Gale et al., 2013). The approach involves reviewing the data, identifying key themes and issues present in the data, coding, and arranging those concepts into thematic frameworks (Rockwood, Fay, Jarrett, & Asp, 2007). The Framework Method is most commonly used for the thematic analysis of semi-structured interview transcripts (Gale et al., 2013). Framework analysis is not a purely technical process. It can be influenced by the characteristics of the researchers and their individual epistemic stance and worldviews. As with many types of qualitative methods, critical reflection throughout the research process is essential. The researcher must remain reflexive, considering impressions of the data and thoughts about analysis throughout the

process. Gale et al. (2013) cautions researchers using qualitative content analysis methods such as Framework Analysis to remain flexible and adaptive. This flexibility allows the researcher to develop rich and nuanced findings that embrace and explain the complexity of real social life, and can be applied to complex social issues (Gale, 2013). When using the Framework Method it is important to acknowledge an ongoing interchange between data collection, analysis, and theory development. This method of analysis is appropriate because it is in line with the assumptions of naturalistic inquiry that underpin this case study.

The seven steps to the framework analysis process are: (a) transcription, (b) familiarization with the interview, (c) coding, (d) developing a working analytical framework, (e) creating a framework matrix, (f) applying the analytical framework, and (g) interpreting the data. All audio recordings were first transcribed using Microsoft Word for Apple Inc. version 14.2.0. During the familiarization stage both my primary supervisor and I independently reviewed the data and identified the key themes and issues present in the data. This was done by reading and re-reading responses from the first two transcripts and recording initial thoughts and impressions. During the coding stage both coders read each line of text and independently created categories that described what was important about each passage. Next, I met with my supervisor to develop a working analytical framework. In this stage we compared the labels that were applied to the coded categories to ensure inter-rater reliability. Some codes were grouped together into larger categories and some coding names were changed to reflect a shared perspective on the category. This formed the working analytical framework that was used to code the remainder of the responses and included three overarching themes: access, connection

54

and privacy. After this stage, I applied the analytical framework to the data. During this stage I indexed all remaining responses using the existing categories and codes in the analytical framework. Next, data is summarized into the framework matrix. This step is used to manage the data in order to better describe the data, flag interesting and illustrative quotations, and generate a framework matrix. The last stage in the framework method is interpreting the data. In this step I integrated findings into a conceptual model in order to develop an understanding of the "big picture" provided by the accounts. Quantitative data downloaded from YouTube Analytics and data from the First Link Learning Series Report, were analyzed using descriptive statistics including tabulations or total counts, mean values, and percentages, which allowed me to describe how people accessed the learning series both in person and online. The use of quantitative data in these forms also allows for the comparison of findings with previous research describing the First Link program.

As Gale et al. (2013) noted, my data analysis was an iterative process influenced by the order in which the units were analyzed. Pre–study interviews with dementia caregivers were analyzed first, followed by the post study interviews. Next, service provider interviews were analyzed using the framework matrix, looking for common themes shared between the experiences of dementia caregivers and the service providers, as well as divergent themes. Subsequently, YouTube analytics were examined, again building on the findings from both caregiver and service provider interviews and the working analytical framework. Finally, the First Link Learning Series Report was reviewed in depth.

There are choices researchers can make to improve the quality and trustworthiness of the case study that are also important design considerations. It is essential that the study questions are clearly written, the design is appropriate to answer the research question, sampling is carefully considered when designing the research protocol, data are collected and managed systematically, and that there is transparent analysis of the data (Yin, 2003). Furthermore, Lincoln and Guba (1985) proposed criteria of trustworthiness to guide naturalistic inquiry – including case studies, which can help to enhance the quality of research. For credibility, or confidence in the "truth" of the findings, Lincoln and Guba (1985) suggest prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, and member checking. For transferability, or the extent to , which findings are applicable in other contexts, the authors note the need for 'thick' descriptive data (Lincoln & Guba, 1985). Finally, for dependability and confirmability, or replicability and lack of bias respectively, the development of an audit trail and an external audit is required (Lincoln & Guba, 1985).

Throughout the research process I undertook a number of steps to address credibility. I took on the role of Skype facilitator, observing 16 weeks of learning series sessions as well as follow up with participants in an attempt to engage in prolonged observation. In the role of Skype facilitator I was able to observe the presentations in-person, while also acting as a link to the participants online. Observing the sessions over a period of 16-weeks allowed for intensive contact with participants in the field and opportunities for different challenges and obstacles to arise. In this manner I also attempted to engage in persistent observation, seeking to understand the phenomena in a more in-depth way. By being in the room during the presentations I was able to observe

the learning series from the point of view of the service providers, who were presenting the First Link Learning Series to clients in-person for the first time, while also communicating with an online participant. As the Skype facilitator, I was communicating with the online participant throughout the presentation, allowing them to communicate technical issues, type questions and relay the experience of participating via Skype in real time. By including multiple data sources I also attempted to use data triangulation to increase rigor and credibility. The data sources included different types of data (quantitative and qualitative) as well as different points of view (service providers and participants) of the same phenomena. Throughout the research process I also attended monthly meetings with my primary supervisor as well as student colleagues in the Division of Community Health and Humanities to engage in peer debriefing, exposing myself to individuals outside the research process to help develop and test working hypotheses and emerging design (Lincoln & Guba, 1985). Because of limited data, I was not fully able to conduct negative case analysis, which seeks to find divergent or contradicting explanations emerging from the data (Lincoln & Guba, 1985), however, the small sample size may in itself act as a negative case , which I will address further in my discussion. Finally, in order to address credibility of my findings I conducted member checking. Although some critics of member checking suggest that it can cause the researcher to presuppose a "true" picture of the world, Green and Thorogood (2009) suggest that member checking can be particularly useful when the aim of the research is to report participants' accounts of the world, as is the case in this study. After each interview was transcribed, participants were provided with a copy of the transcript and I briefly explained what I thought to be the themes present in our conversations, which

would form the basis of my analysis. Participants had the opportunity to reflect on and react to my reconstructions of their responses and clarify responses if they felt I had misinterpreted or misrepresented their experiences.

I was not fully able to address transferability in this study because of the small sample of dementia caregivers I accessed. In order to avoid a superficial account of the phenomena, I attempted to address this issue by adding additional sources of data. While this allowed me to explore the phenomena from different points of view and describe the study context more fully, this was still a primary limitation of my study, which I will address further in the discussion.

In an effort to address and uphold the tenants of dependability and confirmability in my research, I provided a detailed account of the research process including the steps taken from the beginning of my research to the development and reporting of the findings in order to produce an audit trail. I also provided documentation of the research tools I have used including interview guides as appendices to this document.

Environment. Dansky et al. (2006) describes environment in terms of environmental constraints, which the E-Health researcher should consider, namely ethical guidelines for research, such as considerations of privacy, confidentiality and security. Before this research began, and once the provincial research ethics board reviewed my project, I received ethics approval from the Health Research Ethics Authority of NL. The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2010) aims to support researchers by identifying key ethical considerations in the design, conduct and oversight of research. These principles guided my research process and considerations of environmental constraints.

Respect for human dignity is the core value of the Policy (p.8), which advocates for researchers to be chiefly concerned with respecting the inherent worth of all human beings though respect and consideration during all phases of the research process. TCPS2 guidelines are based on 3 core principles: a) respect for persons, b) concern for welfare, and c) justice (CIHR, N, 2010).

Respect for persons involves respecting personal autonomy and allowing a person to choose freely without interference (CIHR, N, 2010). A key consideration when designing this research was the knowledge that caregivers of people with dementia have limited time and can experience high levels of stress (Sorensen & Conwell, 2011). There is also evidence that the informational needs of caregivers are heterogeneous (Zarit & Femia, 2008). The First Link Learning Series was designed as a progressive learning series. The ASNL encourages clients of First Link participate in the full 16-week series. As previously discussed, Zarit and Femia (2008) suggest that being offered treatment that does not fit an individual's profile will not be of benefit to a person and may in fact cause some type of harm or distress to the individual. To address this ethical consideration, I offered study participants a planning tool not offered to regular First Link clients and used the goal attainment scaling process in an effort to help study participants identify topics in the learning series that were relevant to their individual needs as caregivers rather than encouraging them to participate in the full 16 sessions. Study participants were also told that they could leave the study at any time and that this would not impact their access to the learning series or ASNL support services.

Informed consent is an important way to address respect for persons during research. During the informed consent process for caregivers, I explained the study

objectives, the information that would be collected about the participant as well as the person with dementia they were caring for, and described potential risks and discomforts they may experience. In addition I told participants that there was no obligation for them to stay in the research study, and that withdrawal from the study would not affect the services they would be able to receive from the ASNL. I also gave study participants the opportunity to ask questions about the study before signing the consent form. During the consent process for service providers, I explained the study objectives, the information that would be collected about the participant, and described potential risks they may experience.

Personal welfare is another core principle to consider when undertaking research. There are many aspects to consideration of a person's welfare. A person's welfare is the quality of the person's experience of life in all its aspects (CIHR, N, 2010). They can include consideration of factors that impact on person's physical, mental and spiritual health, as well as economic and social circumstances. Other aspects of welfare can include concern for privacy and control of information about the person. I carefully considered the feasibility of using Skype to deliver health resources to dementia caregivers through a thorough search of the literature to address Skype security.

Skype uses encryption, cryptography, a digital certificate and authentication to maintain security and prevent data theft (Good et al., 2012). I provided each participant with instructions about how to manage Skype security, including how to change her password, how to her edit profile information, and how to block calls from people not in their Skype contact list. I also gave participants the opportunity to ask questions and practice changing their settings during a test call.

The study consent form also identified Internet security as a potential risk. The study procedures also addressed participant privacy and confidentiality through the careful storage and retention of study data. All data was anonymized and names were replaced with study codes, in order to de-identify study materials. Pseudonyms for participants were also used in the body of the manuscript text and place names were not identified. Because the ASNL publicly advertised their involvement in the study and also provided letters of support for my MSc funding, the organization name was not withheld in this manuscript, however the names of service providers that I interviewed were not identified.

Justice refers to the obligation to treat people equitability and fairly (CIHR, N, 2010). When attempting to address issues of justice, it is important to consider potential vulnerability. Vulnerability can be caused by limited capacity, or limited access to social goods such as rights, opportunities, and power (Kitchin, 2008). People with dementia can lack capacity. Capacity is the ability to understand information about your care and appreciate the consequences of giving or refusing consent. According to provincial legislation, a Substitute Decision-Maker is needed when a person lacks capacity. I addressed this issue in my study by including consent forms that recognized the complexity of consent and capacity for people living with dementia and their caregivers. I provided three options for study consent: (a) the individual with dementia who had capacity could consent for their caregiver to participate in the research study, (b) a substitute decision maker could consent on behalf of a person living with dementia who lacked capacity, or (c) in a case where an individual with dementia lacked capacity but still had knowledge or understanding of their surroundings such that they could appreciate

the fact that their caregiver was providing information about them to the research study, an individual with dementia could assent to the research taking place. This third option in particular speaks to the ideals behind the TCPS2 of justice because it continues to respect the ideas and opinions of the individual with dementia even if they are officially seen to lack capacity in the eyes of the law.

Logistics. The third element in Dansky et al.'s (2006) framework is logistics. Logistics refers to areas such as staffing and skill requirements, a need for multidisciplinary teamwork, shared understanding of roles and responsibilities, obtaining "buy-in" from stakeholders, and timelines that are often unrealistic (Dansky et al., 2006).

Very early in the planning stages of this project, my committee members felt that my project would have difficulty getting through ethics if we structured the study in such that I was the one delivering a health intervention. This was for two reasons: a) because I was not a health professional and b) by delivering the intervention I would have a dual relationship within the research that could bias my findings. I needed a community partner that employed health care professionals in the delivery of dementia education. It was in this way that I approached the ASNL and negotiated the partnership that formed the basis of my research project.

I signed a confidentiality agreement that allowed me access to certain information about the program's clients and project planning. My role would be to facilitate the Skype sessions with clients of the program, edit the video recordings of the sessions, and provide the videos for the ASNL to post on YouTube. The First Link Coordinator would provide proxy recruitment for potential participants, helping me to connect with people who may want to participate in my study.

The ASNL received funding in order to help deliver their program. This funding came with a set of expectations that included meeting specific timelines for the delivery of the learning series. The ASNL was one of the last provinces in Canada to implement the program, and so there was also pressure from the national office to roll out the program within a particular time frame. These time constraints, combined with the need to receive ethics approval before beginning my research meant that there were only four months to recruit participants before the beginning of the learning series.

There were specific criteria that helped guide caregiver recruitment for this study. In order to be eligible to participate, an individual had to be a family caregiver of a person with dementia in NL, who was a client or wanted to become a client of the provincial Alzheimer Society' First Link Program and participate in the First Link Learning Series between May and August of 2013. This individual also needed to have access to a computer and the Internet. Finally, the person needed to be the substitute decision maker for the individual with dementia that they were caring for, or the person living with Alzheimer's disease or a related dementia also had to provide consent. These criteria were a result of negotiations between myself and the Health Research Ethics Board and also myself and the ASNL.

The First Link coordinator was asked to use a contact script (Appendix G) and offer the Skype and YouTube option when describing the First Link Learning Series to newly registered clients. Other methods to promote recruitment included distribution of posters through the Alzheimer Society's communication channels over a period of four months, inclusion of posters in electronic newsletters of other local service providers such as the Seniors Resource Center of NL, Caregivers Out of Isolation NL and The Salvation

Army, as well as an article in a local newspaper featuring my study titled, *A modern approach to confronting Alzheimer's disease* (Appendix H).

Time limits, inclusion criteria and the proxy recruitment strategy through the ASNL proved to be significant challenges through the recruitment process, resulting in low numbers of participants in this study. With respect to time, a number of potential participants did not want to make a time commitment over the summer months, and some people could also not commit to the sessions because they took place during regular work hours.

The inclusion criteria and consent process was structured such that an individual had to be an appointed substitute decision maker for the individual with dementia, or the person living with dementia had to provide consent for their caregiver to participate in the study. Through the recruitment process I discovered that many people are stuck in a grey area when providing care for an individual with dementia. While the person with dementia may be exhibiting symptoms that are causing caregivers to want to seek information and support, they are not the official substitute decision makers. The dynamic can be such that they do not want the person with dementia to know they are seeking information and support. In these situations, people were not able to participate in the research. This was the case on two occasions during my recruitment efforts.

I was not able to contact clients directly about participating in my research until after the First Link Coordinator had explained the study and obtained verbal consent allowing me to contact them. And while this is seen as a standard ethical procedure to ensure voluntary participation and privacy, it was still a major challenge mostly because the First Link coordinator devoted limited time to recruitment, which fell behind the

major priority of launching the First Link Program for the first time in the province. There was also some evidence of gatekeeping during the recruitment process. Hudson and colleagues define gatekeeping as the process by, which people's capacity to be invited into a research project, or to make an informed decision regarding research participation, is inhibited by others (Hudson, Aranda, Kristjanson, & Quinn, 2005). The First Link Coordinator only attempted to contact a subset of the total number of clients in the First Link program that she felt were a "good fit" for the project, which resulted in less than one quarter of total First Link clients being contacted about participating in my study. This will be discussed further in my findings.

The service provider recruitment used purposive sampling, which involves selecting participants "purposefully" in order to include a pre-determined range (Green & Thorogood, 2009). To be included in the sample, participants had to be directly involved in providing services to dementia caregivers in NL. I selected staff at the ASNL and one member of another local organization that was involved in providing services to caregivers of people with dementia in NL. In order to provide further information about how the community partner played a role in the logistics of this study, I included two sources of data to help describe their role in relation to the case – key informant interviews and the First Link Learning Series Report.

Technology. The primary focus of this case is on the dementia caregivers' use of the technology – namely Skype and YouTube. Participants completed Skype familiarization and pre-session test calls before participating in the online learning series. All sessions were recorded and later edited into 15-minute segments before being uploaded to YouTube. Finally, I used follow up interviews and an analysis of YouTube

analytics as sources of data to help describe people's experiences using technology to participate in the learning series.

Both participants already had Skype installed on their computers prior to participating in the research study. Participants were asked to take part in one additional Skype test call prior to the First Link Learning Series. The call was placed by the researcher from the designated First Link computer at the ASNL office. Participants were given an overview of privacy features available on Skype, including how to make their profiles private and improving password security. Participants were also shown how to mute and un-mute their microphones and turn on and off the webcam feature.

Over 16 weeks beginning in May of 2013, participants were invited to Skype-in to the First Link Learning Series. Learning series topics follow the course of Alzheimer's disease from diagnosis to advanced dementia. A list of First Link Learning Series topics is provided in Table 1. Each session was delivered in person at the ASNL Provincial Office in Mount Pearl, NL between 1-3pm in the afternoon. The presentations were delivered by both health care professionals and ASNL staff using PowerPoint for visual aids. Each session lasted on to one and a half hours and included time for participants to ask questions and discuss topics together. A webcam allowed participants to see the presenter on Skype and the "share screen" feature was used so that participants could clearly see the PowerPoint slides during the presentation. For the duration of the project, I acted as Skype facilitator.

The ASNL YouTube channel was launched in August of 2013. I edited videos and uploaded them to the YouTube channel. The ASNL First Link Coordinator was responsible for making the videos public and promoting the video's availability online to

First Link clients and the general public. The researcher sent study participants direct links to the YouTube videos via e-mail as they were uploaded.

Dansky et al. (2006) cautions that organizations are often faced with the challenge of assessing both the technology itself and the impact of what is being delivered via the technology simultaneously during an evaluation. The focus of the case was understanding the utility of using Skype and YouTube, the technology itself, when delivering informational resources for dementia caregivers. However, because I adopted a naturalistic perspective, assuming that people construct their own understanding of the world though their experiences, I attempted to include dimensions in the follow up interview that take into account the context in, which the technology was experienced. The Skype and YouTube follow-up interview is the primary source of data used to understand the participants' experience of using technology in this project. The qualitative interview was comprised of five subsections: a) exploring practical aspects of using Skype and YouTube, b) social aspects of the program, c) experiences participating online, d) experiences being at home during the session, and e) other thoughts from participants.

Summary

I sought to understand the experiences of caregivers of people with dementia who accessed the First Link Learning Series, and whether Skype and YouTube can be used to effectively deliver the First Link Learning Series. I used a modified version of a case study in, which some of the units of analysis helped to further develop the context in, which the research took place and some helped to explore the case itself. One of the

critiques of the case study approach is the lack of theoretical framing. This chapter provided a clear description of Dansky et al.'s (2006) framework for evaluating E-Health and identified four key elements, design, environment, technology and logistics. I explain how this case study addressed those elements as a step towards better understanding the use of Internet-based health resources by dementia caregivers.

Findings

In this section I will first describe the context in, which individuals participated in the First Link Learning Series, both online and in person, in order to help frame my findings. Next I will describe the two groups of participants – service providers and dementia caregivers, who provided insight into how Internet-based health resources can be provided online. Characteristics about the data obtained from YouTube analytics and Field notes will also be described. I will then discuss shared themes that began to develop from my data. These themes include access, connection and privacy.

First Link Learning Series

The First Link Learning Series started on May 1, 2013. Health care professionals and ASNL staff delivered one presentation every week for 16 weeks, with the last session on August 28, 2013. At the time of learning series, the First Link Coordinator identified 23 clients who could be contacted to participate in the learning series online. Twelve clients were successfully contacted and asked to participate in my study. There were 52 First Link clients at the time of the learning series. The First Link Learning Series Report and field notes were used to describe attendance. Between 2 and 7 caregivers attended each session of the learning series in person. One caregiver who participated in my study favored Skype as a medium to access the learning series, while the other favored YouTube. Table 2 (p.69) is a summary of attendance for the First Link Learning Series, May–August 2013. Between 3% and 17% of registered First Link clients attended the learning series sessions. Additionally, the 2 online participants accounted for up to 28% of those in attendance at any given session.

Table 2

Attendance of the First Link Learning Series May–August 2013

Session Title	In Person (n=7)	Via Skype (n=1)	Via YouTube (n=1)
Memory Loss and the Brain	n/a	0	1
Communication and Coping Strategies	n/a	0	1
Navigating the System	n/a	0	1
Legal and Financial Matters	n/a	1	0
Resources and Support	n/a	0	1
What to Expect	4	0	1
Community Resources	3	0	0
Understanding Behaviour	7	1*	1
Day-to-Day Care	4	0	0
The Caregiver Journey	5	0	0
When Care Needs are Increasing	4	1	1
How the System Works	3	1	0
Coping With Change	4	1	0
What to Expect: Advanced Dementia	3	1	1
Looking for Clues: Pain and Distress	5	0	1
Understanding Grief	2	0	0

Note. * denotes Skype troubleshooting.

Description of Online Caregiver Participants

The first participant, Stella, was a 50-year-old woman caring for her 84-year-old father with Alzheimer's disease. She and her father lived together in an urban area. Stella worked from home. Her father had access to two home support workers who provided care 6 hours a day 7 days a week. Her father was in the late stages of Alzheimer's disease. When asked to describe her father's condition she said, "He doesn't really know me at this point." During the interview Stella identified three issues related to the care of her father that were most important to her: personal care (problems with toileting); social support (for herself); and getting information about placement into long term care.

The second participant, Mary was a 53-year-old woman caring for her 83-year-old mother, who had been diagnosed with mixed dementia (Alzheimer's disease and vascular dementia). Mary and her mother had lived together in a rural area for some time, but at the time of our interview her mother was in a long-term care facility an hour's drive from where she was living. Almost daily Mary was making the hour-long drive to visit and help care for her mother. Mary's mother was in the late stages of dementia, no longer able to walk and confined to a Geri-Chair, she was often not able to recognize her daughter or the staff who would see her daily, and became easily agitated and confused during daily activities such as grooming and eating. When describing her mother's condition Mary explained, "She doesn't know what's happening. She doesn't know who they [hospital staff] are, even though she sees them every day, right?" During the GAS process, Mary identified three issues that were important to her: Staff Interactions; Communication; and Understanding Medications. Table 3 summarizes the patient and caregiver demographics.

Table 3

Online dementia caregiver participant characteristics

Characteristic		Mary	Stella
Participant	Gender	Female	Female
	Age	53	66
	Relationship to person with dementia	Daughter	Daughter
	Location	Rural	Urban
Person with dementia	Gender	Female	Male
	Age	83	84
	Living arrangement	Long Term Care	At home (with daughter)
	Location	Rural	Urban
	Type of dementia	Mixed Dementia (AD and Vascular)	Alzheimer's disease
	Year of diagnosis	2005	Unknown
	Services in place	Social Worker	Home support 7 days a week, 5 hours a day

Description of Service Providers

The service providers interviewed for this project were all working for provincial organizations whose aim is to support, among others, caregivers of people with dementia and included staff at the ASNL, as well as another organization. The age of service providers ranged from 21–54 years old, with a combined 26.5 years' experience supporting caregivers across the province. The organizations these service providers worked for offered a range of services, which included both online, print and in-person resources. Table 4 is a summary of service provider characteristics. Due to the small size of the organization SP1 worked for, the name of the organization has been withheld to preserve anonymity at the individual's request.

Table 4

Service provider characteristics

Characteristic	SP1	SP2, SP3
Population served	Caregivers of all ages, including dementia caregivers	Individuals with dementia and their families/caregivers, health care professionals.
Service area	NL	NL
Services provided	Information Sessions, newsletter, e-bulletin, support group, website, 1-800 number, information and resources, referral, one on one support.	Resource center, family support groups, information packages, newsletter, 1800 number, website, First Link Program, information sessions, one on one family meetings

YouTube Analytics

In November of 2013 I was granted access to the ASNL's YouTube Analytics and downloaded data from the YouTube website into Excel output files. Data was analyzed

from these files. I collected video view reports for all posted videos, which included information about the dates each video was posted and the number of views each video had received. I also collected data on playback locations for each video, which provided information about where in the world people had been viewing the videos. Finally, I collected a sample of audience retention data from one video that had been posted for the longest amount of time on the ASNL YouTube site.

Field Notes

A total of 24 notes were kept throughout the research study. The notes contained personal reflections about my interaction with study participants, as well as observations about their use of Skype. There was one note for each of the 16 First Link Learning Series Sessions and 8 additional notes describing first contact with participants, problems using Skype, and other details from our conversations that were relevant to their use of technology and caregiving experiences. The first note was created on May 1, 2013 and the last note was written August 28, 2013.

Themes

The sources of evidence in this case study revealed three shared themes that help to describe how Internet-based health resources can be delivered online. These themes included: access, connection and privacy.

Access. The first theme that was identified in my data is "access", which extends beyond simple access to technology. Warschauer and Matuchniak (2010) define technology access as first, the physical availability of Internet-connected computers and also, the factors that support or constrain this technology access. In my findings, access

goes beyond simply considering access to the technology itself, and also includes how the Internet facilitates opportunities for participation, and the use of resources.

Service providers and caregivers viewed the Internet as an important way to access health resources. They cited its ease of use, ability to help overcome barriers and flexibility. These subthemes, while distinct, are also interrelated and help to form the bigger picture of what supported or hindered access to the First Link Learning Series online for participants.

Ease of use. Service providers viewed the Internet as an easy way to reach clients. They were already providing information and health resources to their clients through websites, e-mails, e-bulletins, and in some cases, social media. They used words such as "fast" and "instantaneous" to describe interactions they were having with clients over the Internet. Both caregivers reported that using technology to connect to the learning series was easy. Stella said, "...it was all easy, it's not things that were unfamiliar to me, I did not have any problems." Mary did experience a problem using Skype during the course of the learning series. She reported positive feelings about using the technology overall and said she was not deterred from using Skype again. However, she used YouTube for the remainder of the series. This was due in part to a scheduling conflict with the time of day of the learning series sessions. She described using YouTube as easy, saying:

> Really I didn't even have to, it just sort of all popped up I didn't have to do
> anything, I didn't even have to navigate really I just took the link and put it in the
> browser, and it was right there.

She also successfully used Skype during the follow up interview.

Overcoming barriers. Service providers and caregiver participants seemed to share the view that technology was a way to overcome barriers to accessing information and health resources. Barriers to access for both groups included time, money, and distance/geography. When asked if it would be helpful for more services to become available over the Internet, one service provider said, "I think it would be really good to be able to extend our ability to be able to provide services, because over the Internet it's pretty cost effective." Cost as a barrier to access also came up for caregivers. When explaining the difference between attending a face-to-face learning series session and an online session Mary explained:

> It will be an expense traveling, right? It would be an additional trip and it would be a burden on me and I would probably weigh it back and forth and think, "Can I really get enough useful information from the session for me to make that commitment?" You know, it's a big time and financial commitment to go for a presentation and I might think oh, it might not be worth it.

For this caregiver, the cost of traveling was intertwined with the value of time and the distance/geographical limitations of living in a rural area. Considering ways to overcome geographical limitations was also important to service providers and technology was the seen as a way to address these barriers. One service provider explained:

> ...that's what it's all about, when you're trying to be provincial, and you only have one, two, three or four offices, like the Cancer Society or the VON, you have to figure out how to reach the rural and the remote.

This service provider explained that her existing clients were asking for more services to be available over the Internet. They also told her that there were opportunities to use existing networks like colleges and schools as a means of facilitating these connections. I considered using community-based locations to facilitate technology for this project, but dementia caregivers have reported leaving care recipients at home as a barrier to participating in outside activities in previous research on First Link (McAiney et al., 2010). For this reason, this option was not explored. Indeed, this particular barrier to access came up for Mary and Stella in this study. Being able to access the learning series from home was very important too for Stella:

Ya, it worked for me because I work from home and I had a very limited amount of time that I could, that I can get out. Because I have 6 hours a day in, which I have to work, and be around the house for the homecare worker and Dad, so to be able to stay home rather than use the travel time to get to the office and to get to the ASNL and get back, wasn't wasted time for me. My time is, you know, is very limited so I thought it was excellent. I could just go to the computer, and just get on and it was really good.

Despite the ability for Skype to overcome these time and geographical barriers, the solution was imperfect. Field notes revealed one of the ways Skype was still limited in its ability to overcome barriers to access, particularly time and geography for this participant.

During week 14 of my project Stella expressed a desire to have more social support and time to communicate with other caregivers who were sharing her experience. After having a few successful Skype sessions during the learning series, Stella requested

if the Family Support Group, offered in the Provincial Office of the ASNL in Mount Pearl, could also be made available to her via Skype. I made this request known to the First Link Coordinator who worked with this participant to facilitate this request.

During the follow up interview I asked Stella about her experiences accessing the Family Support Group via Skype: "that didn't work because that was in the evening and I didn't have any help then and I just never could seem to put it together because of that." She described that without the homecare worker available, her attention had to be focused on the needs of her father.

While time of day facilitated this participants' ability to access the learning series it also conversely inhibited her from accessing the Family Support Group. In this way the real time, time sensitive aspect of the Skype delivery can either work either as a barrier or a facilitator to accessing information and health resources online. YouTube was found to be a better option than Skype for Mary, who was living in a rural area.

> ...it [the Skype sessions] was often the time of day when I was traveling to and from the nursing home to see my mother, which is why the YouTube alternative is good for me too. Then I can just watch them at my leisure.

YouTube Analytics also provided insight into just how far this medium was able to reach geographically. Of the 718 views that the First Link Learning Series videos received during the first 3 months they were posted online, 70% of the videos' audience was located in Canada, 14% was from the United States, 3% was from the United Kingdom, 2.9% was from Australia. The remaining 10.1% was from some 30 countries around the world. In total people from 32 countries viewed videos from the First Link Learning Series. The top 10 YouTube Views by Country are described in Table 5.

Table 5

Top 10 YouTube Views by Country

Country	Views
Canada	504
United States	101
United Kingdom	26
Australia	21
Hungary	9
Oman	8
Philippines	7
New Zealand	5
Saudi Arabia	5

These findings supported reports from a service provider who talked about the role of the Internet in reaching long distance caregivers who are helping to support someone living in another province or country. She described providing phone calls and e-mails to "the long distance component" of their clients. "...we definitely get calls from Ontario, Alberta, those are the two main ones, and I've had calls from other parts of the country as well." YouTube is also not limited by time in the same way as the live Skype option. When describing the needs of caregivers and how the Internet can overcome barriers, one service provider explained,

> It's about options, it's about, um when I think about the Internet and beyond just webinars, because that is real time often, I am thinking caregivers are prowling around in the middle of the night, or they might not get a chance to think or

breathe, or do, until 11 o'clock at night and that is when the clicking around can happen.

Flexible and individualized. Service providers and caregiver participants also indicated that the Internet facilitated access to information and health resources by being individualized and flexible. One service provider described e-mail as a way people could ask about their "specific situation." One caregiver also described how the shorter 15-minute YouTube segments were important to her in this way:

> ...it's an awful lot of information to hear and I like the YouTube better because I can stop it and a couple of things that [the presenter] said that I didn't quite get, I was able to, you know, just go back a bit and rewind… which was good.

There is evidence in the YouTube Analytics that also suggests people are viewing the videos in different /individualized patterns. While views is a measure of every time a person clicks to watch a video, watch time indicates how many minutes the viewer let the video play before clicking away from the page. A sample of watch time data was selected for in-depth analysis. Table 6 reports "watch time" statistics for the video Memory Loss and the Brain, Part 1 over a one-month period from February 1, 2014 to March 1, 2014.

Memory Loss and the Brain, Part 1 was selected for in depth analysis because it was the most viewed video and was posted for the longest period of time. The total duration of the Memory Loss and the Brain Part 1 video is 14:17. On February 20 and 22, one user watched over 80% of the total video on each day. On March 1 one user watched only 0.38 seconds of the video before clicking away. On February 26, the video was viewed 3 times for a total of 16 minutes. The average view duration was 5:13 – only 36% of the video's total duration.

While it is not known why these individuals watched the videos in these patterns, data from service providers and caregiver participants suggest a number of possible reasons. For instance, the individual viewer may be seeking specific information in the video that they may or may not have received during the partial viewing. When a viewer quickly clicked away from the video, they may have decided that the information they were seeking did not match with the video's content. On February 26, where there are 3 separate views of the same video, it may in fact be the case that 3 people viewed the video for a total of 16 minutes, or it could also be, as was the case with Mary, that the same segment of the video was watched multiple times to improve comprehension.

Table 6

Watch Time for Memory Loss and the Brain Part 1, February 1 – March 1, 2014

Date	Views	Estimated minutes watched	Average view duration (minutes)	Average percentage viewed
Feb 01, 2014	0	0	0	0
Feb 02, 2014	0	0	0	0
Feb 03, 2014	0	0	0	0
Feb 04, 2014	0	0	0	0
Feb 05, 2014	0	0	0	0
Feb 06, 2014	0	0	0	0
Feb 07, 2014	0	0	0	0
Feb 08, 2014	0	0	0	0
Feb 09, 2014	0	0	0	0
Feb 10, 2014	0	0	0	0
Feb 11, 2014	0	0	0	0
Feb 12, 2014	11	32	2.94	20.56
Feb 13, 2014	1	0	0.28	1.99
Feb 14, 2014	2	1	0.68	4.79
Feb 15, 2014	0	0	0	0
Feb 16, 2014	0	0	0	0
Feb 17, 2014	0	0	0	0
Feb 18, 2014	0	0	0	0
Feb 19, 2014	0	0	0	0
Feb 20, 2014	1	12	12.04	84.27
Feb 21, 2014	0	0	0	0
Feb 22, 2014	1	14	14.28	99.98
Feb 23, 2014	0	0	0	0
Feb 24, 2014	1	1	0.86	6
Feb 25, 2014	2	2	1.06	7.45
Feb 26, 2014	3	16	5.18	36.25
Feb 27, 2014	3	19	6.19	43.33
Feb 28, 2014	0	0	0	0
Mar 01, 2014	1	0	0.38	2.65

Both the service providers and caregivers viewed using the Internet to access information and health resources online as important and useful. Both participants viewed using the Internet as generally easy. Impressions of using Skype and YouTube to access the learning series were positive, even in the face of technical difficulties experienced by one caregiver participant. Both service providers and caregiver participants identified barriers to access. These included time, money and distance/geography. For service providers, the Internet is seen as a means to overcome barriers and extend the reach of their services to rural and remote communities. For caregiver participants in this study, the use of Skype and YouTube were not a perfect solution for overcoming barriers. Both service providers and participants expressed the importance of having flexible and individualized options available over the Internet that allow people to control when they receive information and health resources, and how much information they are exposed to at a time.

Connection. Connection often refers to "connectivity" or the ability of a computer to link to a server that provides Internet access ("Connectivity," 2015). Connection in the present context refers to links made between people, and how the Internet facilitates those links. Making connections with people through the Internet was an important aspect of using technology for both caregivers and service providers, although the way the caregivers and service providers experienced connection differed in some areas.

Information sharing and professional connections. The value of connections for service providers was split into two areas: promotion and information sharing. The Internet was used as a tool to share important messages as well as resources with clients. One service provider explained,

...we use Facebook and we use Twitter to be able to, I guess, get the message out

there and do promotion of the great things people are doing with regards to the

disease as well as letting people know what's available if we're offering sessions,

we'll promote it through those venues, we will promote any good news stories, we

use it to just get the message out there so people will know how to get involved.

In addition to connecting with clients, service providers also described the value

of being able to connect and share information with other service providers:

And I guess that's one of the huge things, we can pull from other provinces on

their social media and tag or repost it to ours so that the volume of information we

have accessible to us is a lot higher...we're able to do a better job of education

because we're tapping into other areas of expertise across the country.

Social and personal connections. Caregivers also valued connection, but these

connections were more focused on a social and personal level. Before participating in the

learning series, one caregiver explained,

...I'd love to go to the Alzheimer courses that they have, you know in the evenings

they have chats or whatever it is that they have, but I can't get out. So that for me

is hard, so if that was online, something like that, it would be lovely.

While Skype was useful for providing some degree of personal connection for

Stella, the experience was still not the same as, or a replacement for, being there in

person. Stella noted, "I found that it was very helpful to be part of the group." She

explained that Skype still lacked a "personal touch" but also noted, "That works for me

you know, that wasn't what I was looking for." Despite this difference between being

there in person and participating online, both participants still reported that using the

Internet to join the learning series provided some level of connection to other people. Stella explained:

> ...I enjoyed that live experience. You can get to ask a question if you want to, you have the group even though I was at home, it offered me the opportunity to be a part of something and I appreciated that, you know that somebody was out there that actually wanted to help me get though some of the stuff, ya it was excellent.

Another shared experience both caregivers had when using the Internet to connect to the learning series was the desire to see the presenter. When describing why this was important both participants explained that body language was important to them, and that seeing the person made them feel more connected to the experience.

Both participants also explained how they viewed the Internet and the availability of the learning series online as a tool for helping other caregivers in their social circles. Stella explained that having the videos available on YouTube was an easy way to share information with other caregivers she had met:

> Well I'm in a position now where I'm meeting people all the time and that's what happens when you get into a position like this, you start to meet people that are having the same journey, and I would love to be able to say this is all on YouTube and go watch these seminars because they were great, you know?

> Mary also expressed a similar desire to tell other caregivers about the learning series:

> ...there is one family I know who has Alzheimer's and talks about it quite openly, and ya I told them. I, don't know if she uses the Internet and things like this but I'm sure she has family members that do.

This illustrates how YouTube can facilitate information sharing by providing a tool to help caregivers support one another.

Both service providers and caregivers viewed technology as a tool to share information with others. For service providers whose job it is to share information and resources, this concept is understandable. However it is interesting that caregivers also shared this view. Caregivers are often seen as those in need of help and support, but the Internet, and having access to information and health resources online, seems to have empowered Stella and Mary to want to connect with other caregivers in this new way, as a purveyor of this newly acquired resource.

Both service providers and caregivers also viewed technology as a way to connect with others. For service providers it was about connecting to their clients, but it was also about connecting to other service providers and experts that had additional resources that they could share. For caregivers, the need and desire for a personal and social outlet was the driving force behind a desire to connect. The fact that service providers did not identify technology as a way to connect on a more personal level with clients, or a way to foster social connections among clients, may indicate there are still new ways for service providers to use technology to support clients.

Privacy. Privacy was the third theme that emerged for the data. Internet privacy involves the right to, or obligation to protect personal privacy concerning the storing, repurposing, delivery to third parties, and displaying of information relating to oneself via the Internet (Culnan, 2000). Internet privacy was a shared concern for both service providers and caregiver participants, with two interconnected sub-themes emerging – control and fear and discomfort. My data suggests that the Internet can act as a tool for

controlling what and how information is shared with others. Despite the positive associations with the Internet as it relates to addressing access and connection, both the service providers and caregiver participants also expressed some fear and discomfort around the use of e-mail and Skype, as it related to their personal privacy.

Control. The Internet was found to be a way for people to control what information they shared with one another and how they chose to share this information. E-mail was a common tool for caregivers and service providers to communicate anonymously. One service provider explained, "I have communicated with someone, I didn't know if it was a man or a woman, I didn't know where they were e-mailing from." Another explained, "There are sometimes that people won't even call, it can be an exchange, with one answer, it can be three or four lengthy exchanges where I don't know the person's name." These service providers reported experiencing anonymous exchanges via e-mail, where clients are able to request specific health resources and information without disclosing personal information such as their name or where they live.

This anonymity was also illustrated by a caregiver who used e-mail during the learning series to ask a question she did not feel comfortable asking in person by Skype. This question involved sensitive legal and financial information that the participant did not feel comfortable disclosing during the live Skype session. E-mail provided an option for her to control how and when she asked this question, and to access information she otherwise may not have felt comfortable asking for in person.

Fear and discomfort. Both the caregiver participants and the service providers also raised issues surrounding fear and discomfort when using the Internet to access or deliver health resources online. While e-mail was seen as a way for dementia caregivers

to ask questions anonymously, service providers seemed to be leery of sending answers into cyberspace, not knowing exactly how they would be used and interpreted, "I have an e-mail that could be forwarded to about 500 people, or 20 people and um, you know, this is what the lady from the [deleted] office said." Another service provider explained, "I always put a waiver at the bottom of the e-mail, I can only answer this question based on the information you've provided, if there is more information not provided, the answer may be different." These experiences offer a somewhat paradoxical account of how the Internet can both address privacy concerns in terms of control, and how lack of control can create fear and discomfort.

The caregiver participants also expressed discomfort using Skype to access the learning series. Mary described feeling "funny" seeing herself on the screen. Throughout the study she had alluded to her reservations about using the webcam, and I spent some time showing her how to turn it off and on during Skype calls. When asked if this solution had worked for her Mary said,

> Yes that was a good solution because I felt more comfortable then, and too I
> didn't feel I had to tidy up my house, and that I was on display in anyway, which
> is kind of ridiculous but it's the way that I felt... So I was fine with just being a,
> you know, audio participant.

Discomfort using the webcam also came up for Stella although not as consistently. Most days she was happy to have the webcam on and even chatted with other participants prior to the sessions. However before one session, she indicated that she had not slept well the previous night because her father was having problems sleeping. She said that

she didn't feel up to being on the webcam and she was given instructions about how to disable it.

I was able to address discomfort for both participants by introducing control of the webcam feature. This example illustrates the push-pull of the privacy factor: introducing control seems to mitigate the perceptions of discomfort and fear on the part of the caregiver, however, control in the hands of the caregiver can also be seen as somewhat of a risk for service providers when they do not know the person on the other end of the e-mail communications.

Conclusion

Access, connection, and privacy are three distinct themes that began to develop and kept emerging within the data in this case study. Both service providers and caregiver participants viewed the Internet as an important way to access health resources. In order for the Internet to facilitate access, the tools had to be easy to use, able to overcome barriers, and flexible and individualized. For service providers, the Internet is seen as a means to overcome barriers and extend the reach of their services to rural and remote communities. For participants in this study, the use of Skype and YouTube were not a perfect solution for overcoming barriers. Feedback about using Skype and YouTube to access the learning series was generally positive, however, one participant did experience difficulty using Skype. Both participants and service providers expressed the importance of having flexible and individualized options available over the Internet that allow people to control when they receive health resources, and how much information they are exposed to at a time. This supports the subjective experiences of caregivers that

highlighted the fact that Skype was a better fit for one caregiver participant, while the other participant favored YouTube to access the learning series.

Connection was a shared theme for caregivers and service providers, but while these connections revolved around promotion and information sharing for service providers, caregivers of people with dementia valued social and personal connections. The mismatch between how service providers view making connections and what caregivers value the most about the connections that were offered by Skype and YouTube presents an opportunity to explore new ways for these two groups to interact using the Internet.

Finally, privacy as it relates to the ability to control personal information, as well as a fear and discomfort when transmitting data over the Internet offers a paradox that connects back to the previous themes of access and connection. Access and connection were highly valued by service providers and dementia caregivers – qualities that seem, in some ways, to directly oppose privacy concerns. Both service providers and caregivers addressed feelings of fear and discomfort by introducing more control into situations. For service providers this meant carefully crafting e-mails, or adding a waiver to mitigate responsibility for potentially misused or misinterpreted information. I helped to address this issue with caregivers by showing them how to turn the webcam off and on, introducing an additional way to help them manage their own privacy and feel in control.

These themes, when compared and contrasted help to describe important aspects of how Internet-based health resources can be delivered online. Access, connection, and privacy will be important considerations for future work that aims to support caregivers

of people with dementia, and my findings suggest that Skype and YouTube may help to address some of these issues.

Discussion

E-Health is a broad term, which can include interventions, clinical research, delivery of health services, and health information resources. I chose to narrow my focus in this case study to look specifically at Internet-based health resources. The First Link Learning Series is a health resource for dementia caregivers that has traditionally been delivered face-to-face, but was offered online for the first time anywhere in Canada as part of my research project.

This case study documented the experiences of service providers and dementia caregivers who participated in the First Link Learning Series using Skype and YouTube. I used a modified version of a case study, described by Yin (2003) to explore this phenomenon using naturalistic inquiry. The modified case study design I used is imperative because it helps to demonstrate how community-based research needs to be able to adapt to the real world boundaries of the data, which are accessible to the researcher. I included key informant interviews, pre-study and post-study interviews with dementia caregivers, institutional documentation, YouTube analytics, and field notes as sources of data to help answer my research questions and describe the context surrounding the case.

Of particular significance to the context were the key informant interviews, which revealed the views non-profit dementia caregiver service providers who participated in my study had about using the Internet to support their clients. Previous research has identified a lack of qualitative inquiry addressing components of caregivers' experiences with computer-mediated options for support (McKechnie et al., 2014). My research

provided an opportunity to begin to address this gap in the literature. An important element of high quality qualitative research is to provide a clear description of one's theoretical framework. By adopting Dansky et al.'s (2006) framework for understanding E-Health research I attempted to address previous critiques of case study research, which suggests that case studies in the health sciences have tended to lack a clear methodological description or justification. In this chapter I will begin by addressing my two research questions. Subsequently I will discuss future considerations for understanding the delivery of Internet mediated health resources, the study limitations, and recommendations for future research on this topic.

How do informal caregivers of people with dementia experience the First Link Learning Series online using Skype and YouTube?

My limited sample did not allow me to fully answer this question, as I was unable to reach data saturation and present findings that could be considered generalizable. However, in an effort to begin to unpack the experiences of dementia caregivers who access Internet-based health resources online, I offer the following as a working hypothesis on, which to build future work. The caregivers of individuals with dementia who participated in this study experienced both barriers and facilitators to accessing Internet-based health resources. These experiences relate to the three themes identified in my findings: access, connection and privacy. Figure 4 represents a balance between the negative and positive aspects of the user experience. I will now discuss these elements in detail.

Dementia Caregivers'
Experiences of Internet
Mediated Health
Resources

Barriers

Privacy
-Fear and/or discomfort
Access
-Time
- Caregiving duties
-Technology Failures

Connection
-Social and personal connections
Privacy
-Control of sending/receiving
information
Access
-Easy to use
-Low cost
-No need to travel
-Medium of choice

Facilitators
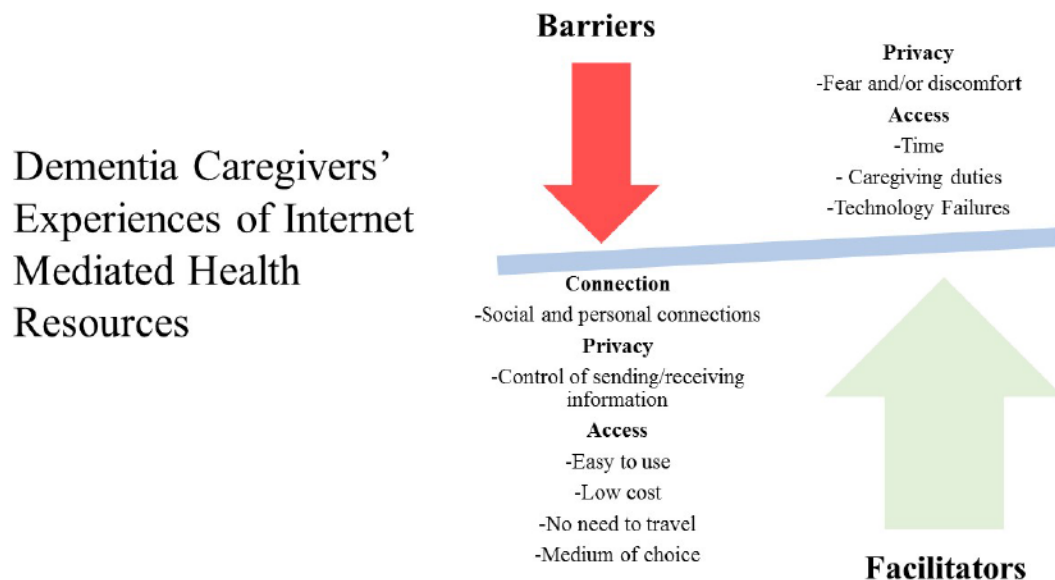
Figure 4. Dementia Caregivers' Experiences of Internet Mediated Health Resources. The green arrow is larger because participants described more ways in, which Skype and YouTube were of benefit to them as opposed to the drawbacks of the medium. Never the less, there were still some negative aspects of the experience that may threaten to "tip the scales" towards a negative experience of Internet-based health resources if these elements are not considered by service providers.

Access barriers. Time was highly valued by caregivers. Decisions about accessing health resources were weighted against the sacrifice of time away from other important parts of their lives including work, day-to-day activities, and most importantly caregiving duties. Despite offering online options, time was still a major barrier for both participants trying to access the First Link Learning Series. Living in rural Newfoundland was found to impact one participant's perception of the value of time, and was intertwined with the cost of traveling and distance from in-person health resources. Even in an urban area barriers related to time were still present and the participant's caregiving experiences shared similarities with the rural experience. While YouTube was able to

address some of the issues associated with the real time delivery of the learning series, social connection was lacking. Fernandez-Luque and colleagues (2014) found that virtual communities developed through the "comment" feature of YouTube. My findings differed from those of Fernandez-Luque et al. (2014), in that there was no evidence of virtual community building through the comments section of YouTube. However, the ASNL's YouTube channel was only active for a short period during my data collection, which may have contributed to the lack of comments and communication between users. My study suggests that while online options can help to overcome some barriers related to time, the demands of caregiving still make time a limited and valued commodity. Caregivers view time costs and conflicts with their caregiving role as barriers to accessing health resources online.

During my study, we experienced a technology failure. Despite this problem, the participant still reported positive feelings about using the technology overall and was not deterred from using Skype in the future. Skype has appeared in the literature since 2009 (Hori et al., 2009). The use of Skype for health related research is in three major categories, instructional support for medical students and other trainees; physician-to-patient communication (diagnostics, clinical assessments and therapy delivery); and patient-to-family communication (Brecher, 2013; Boedeker et al. 2011; Good et. al, 2012; Constantinescu et al., 2014; Zolfo et al., 2010). To the best of my knowledge, there are no accounts of Skype technology failures in the literature, and also no accounts of how users reacted to experiencing such a problem. My findings demonstrate that technology failures can act as a barrier to the delivery of health resource online, and illustrate important factors related to technology and logistics that should be addressed in future research.

Access as a facilitator. Both participants who used Skype and YouTube to connect to the learning series reported that using this technology was generally easy, notwithstanding one participant's experience of a technical failure. Ease of use has been previously cited as a motivational factor for accessing health resources online (Ajuwon & Popoola, 2015) and is a foundational factor in the Technology Acceptance Model. The TAM defines perceived ease of use as a belief about using technology that involves little effort (Davis, 1993). Ahadzadeh, Sharif, Ong, and Khong (2015) explain that perceived ease of use can affect attitude toward using technology, which in turn can influence the behavioural intention to adopt or reject it. Previous research has also shown that perceiving technology as easy to use and having a positive attitude about technology can influence one's intention to use health information online (Lim et al., 2011; Wong, Yeung, Ho, Tse, & Lam, 2012). This previous research supports my findings, which suggest ease of use supports access and acts as a facilitator for the delivery of Internet mediated heath resources for dementia caregivers.

Caregivers identified financial concerns as potential barriers to participating in the in-person First Link Learning Series and described how the online options helped to overcome these barriers. Skype and YouTube are free services and participants already had the equipment required (computer, webcam, microphone and Internet) to access the learning series online. Because caregivers had access to the basic technology, there was no additional cost when accessing these Internet mediated health resources, and no need to travel to access these resources. The notion that caregivers of people with dementia in my study face financial barriers to accessing services are in line with an American study by Rattinger et al. (2015), who identified financial concerns among dementia caregivers.

The authors found that the costs of daily care for dementia caregivers increased by 18% for each year spent caring for an individual with dementia and that individuals with more advanced dementia had high costs of care. The Alzheimer Society of Canada also identified financial concerns faced by caregivers. They describe "opportunity costs" as the wages caregivers could have earned had they been able to participate in the labor force (Smetanin et al., 2009). My findings are also in line with McAiney, et al. (2010) who reported challenges experienced by First Link clients living in rural and remote areas of Ontario when trying to access services and supports. They suggested that using technology, such as E-Health should be explored as an opportunity to increase access to the learning series and support groups without the need to travel long-distances. This evidence echoes the experiences reported by the dementia caregivers in my study. Participants valued Skype and YouTube's ability to provide access to health resources from home, removing the cost of travel and time off work (potential lost opportunity costs). This demonstrates how using Skype and YouTube facilitated access to health resources for participants in my study by removing financial and geographical barriers to participation.

I have also demonstrated that the live, time sensitive aspect of Skype can either work as a barrier or a facilitator to accessing information and health resources online and that the experiences of the individual in their role as a caregiver can have an impact on the utility of the medium. While the ability to speak directly with presenters and participants was highly valued by one participant, her caregiving duties kept her from participating via Skype during times she did not have a paid caregiver present for her father. My findings also demonstrated YouTube's value as a medium, offering an

alternative to Skype in, which videos could be paused and rewound to help improve comprehension of material. Dementia caregivers need adaptable approaches to health resource delivery that are able to change with their needs (Zarit & Femia, 2008). These considerations also relate to the needs of the person with dementia. It is not enough to simply offer health resources online; the modes of delivery need to be adaptable and individualized.

There is previous research supporting my findings that multi-modal delivery methods facilitate the delivery of Internet-based health resources. In 2012 Ghosh and Ahadome suggested that the future of E-Health interventions would be "multi-modal," incorporating multiple channels of communication, and recent work by Lai et al. (2013), Glueckauf et al. (2012), Ducharme et al. (2011), Chiu et al. (2009), Coulehan et al. (2008), and Torp et al. (2008) have demonstrated the effectiveness of multimodal approaches to Internet based health resource delivery. My findings support the idea that having a choice of delivery mode, which can accommodate individual differences related to day-to-day caregiving experiences, facilitates access to Internet based health resource for dementia caregivers.

Privacy barriers. Both participants experienced some discomfort using the webcam when accessing the learning series via Skype. Participants' discomfort with the webcam tied directly to their experiences caring for the individual with dementia. There have been previous reports of discomfort with webcams during videoconferencing. A recent study by Kilpi et al. (2013) described participants having a "vague feeling of discomfort of viewing oneself on the screen" (p. 320). The authors recognized these feelings of discomfort using the webcam as a form of privacy concerns. The authors

suggest that if participants are not comfortable with the videoconferencing technology there may be a loss of trust for the medium, which in turn can affect an individuals' likeliness to use the technology. These participants were not accessing health resources and were also not dementia caregivers however, feelings of discomfort using a webcam have also been previously described in E-Health research. In another study exploring the use of technology to connect people at the end of life, an individual dying of cancer reportedly chose not to appear onscreen when being Skyped into his daughter's wedding due to his failing health (Johnston, Hillier, Purdon, Pears, & Robson, 2012). Discomfort using the webcam was directly related to the individual's failing health. My findings are unique because caregivers' feelings of discomfort were not directly related to their own health but rather the health of the individual with dementia. My findings illustrate how caring for an individual with dementia, and the individual's health and behaviours can influence acceptance and comfort with accessing health resources online. My findings also illustrate how the dementia caregiver's experiences in their role as caregiver have potential to act as a barrier to accessing health resources online.

Privacy as a facilitator. Making choices about what to share and when to share it helped participants in my study overcome feelings of discomfort and fear with regards to Internet privacy. Previous research about privacy for health-related social networking suggests that users may not have the knowledge and technical skills to understand settings and therefore can't change their own settings appropriately (Li, 2015). I found that participants required a small amount of support in the form of step-by-step directions in order to learn skills to help control their privacy online and manage Skype's privacy settings. One caregiver also used a strategy – switching to e-mail – a form of online

communication she felt most comfortable with, to help introduce more control and improve her feelings of security in the online environment. Introducing control in the online environment acted as a facilitator for the online delivery of health resources because it improved the user experience by addressing concerns about privacy.

Connection as a facilitator. My findings suggest that participants placed high value in building social context and interactivity. Tu and McIsaac (2002) described social presence as a measure of the feeling of community that a learner experiences in an online environment. Because caregivers of people with dementia in my study are accessing health resources online, they can also be considered online learners. Tu and McIsaac (2002) described social context as the relationships "senders" of information have with "recipients", online communication as the characteristics of real time discussion, and interactivity as communication styles participants use when interacting online. He considered these elements to be important in establishing a sense of community among online learners. My findings are in line with Tu and McIsaac (2002), as participants in my study (recipients) placed a high value on building relationships with presenters (senders) as well as other in-person participants. They valued a visual representation of the sender and indicated that body language helped them understand and interpret the health information they received. They also expressed that communicating with other participants gave them a feeling of community and belonging. These experiences facilitated the delivery of online health resources.

Participants explained that they viewed the Internet and the availability of the First Link Learning Series online as a tool for helping other caregivers in their social circles. These findings support previous work by Grajales et al. (2014) who found that YouTube

has been used to support resource sharing, community building, and delivering information. However, my findings suggest that in addition to being a way for service providers to share information with clients and the general public, the caregivers I interviewed viewed YouTube as a tool to help other caregivers by directing them to information about dementia. This novel finding is particularly interesting because it illustrates how YouTube can act as a tool for caregivers to support one another. As one of my participants described, caregivers are often in a unique position because they meet people who are on a similar journey as they are. Caregivers are often seen as those in need of help and support, but the Internet, and having access to information and health resources online, seems to have empowered caregivers in my study to want to connect with other caregivers. It is possible that this type of empowerment may offer a source of intrinsic reinforcement in their role as caregivers, similar what Cohen, Colantonio, and Vernich (2002) described. The positive associations that come with offering help and support to others is another way in, which social connections can facilitate the online delivery of health resources.

How can Skype and YouTube be used as tools for the ASNL to effectively deliver the First Link Learning Series?

This case study suggests that dementia caregivers can experience barriers and facilitators when using the First Link Learning Series through Skype and YouTube. The presence of facilitators related to access, connection and privacy illustrated the ways in, which Skype and YouTube can be effective media for the delivery of online health resources. Barriers experienced by these dementia caregivers illustrate some of the

challenges of using these media. The limited number of caregivers who participated in the online delivery of the First Link Learning Series may be related to some of the barriers experienced by my study's participants, particularly issues related to time and balancing caregiving duties. Due to the small sample size of dementia caregivers in my study, limited conclusions can be drawn about the true effectiveness of Skype and YouTube as tools for the ASNL to deliver online health resources, and future research will need to be conducted in order to fully answer this research question.

Despite this limitation in my research, the inclusion of service providers' perceptions of using the Internet to deliver health resources to dementia caregivers offered an additional, valuable dimension to understanding the potential for Skype and YouTube to be effective media for delivering Internet mediated health resources. Dansky et al. (2006) identifies staffing skill requirements and obtaining "buy-in" from stakeholders as important considerations for what makes E-Health successful. The service providers I interviewed were already using the Internet to provide information and health resources to their clients through websites, e-mails, e-bulletins, and in some cases, social media. This is similar to findings of Özdemir (2012) who found that social media reduced community-based organizations' dependency on mass media; enabled them to reach a broader section of the public; provided a platform for developing two-way, mutual communication; and facilitated participation in their advocacy campaigns.

Service providers were also using the Internet to connect and share credible information with other service providers, as well as their clients. Concerns about the credibility of health information online are well documented in the literature (Metzger & Flanagin, 2013; Westerman, Spence, & Van Der Heide, 2012). My findings suggest that

the service providers I interviewed are aware of the presence of inaccurate and untrustworthy information online as well as the need to seek out credible sources of information in order to support their clients. This is important because it demonstrates a level of knowledge appropriate to effectively deliver health resources online. These findings are also in line with a foundational article by Spencer (2002) who discussed the potential of the Internet for non-profit organizations. She recognized the Internet as a potentially powerful tool community-based organization can use to improve information credibility. This was illustrated by how the service providers tapped into expertise across the country. Service providers also identified the Internet as a way to extend the services they provided, and improve access to services because of cost effectiveness of the medium. This finding is also in line with the previously mentioned work of Özdemir (2012).

As a whole, these experiences demonstrate a climate of acceptance by service providers for introducing new ways to provide Internet based health resources for clients of the First Link program. This buy-in is an important aspect of why Skype and YouTube have future potential to effectively delivery online health resources to dementia caregivers (Dansky et al., 2006). My findings also suggest that service providers understand that information sharing should promote the proliferation of credible information. Together, service provider "buy-in", knowledge and abilities point towards the potential of Skype and YouTube for effective delivery of online health resources.

Future Considerations for Understanding the Delivery of Internet Mediated Health Resources for Dementia Caregivers – Modifying Dansky et al.'s (2006) Framework

Dansky et al.'s (2006) framework for evaluating E-Health research guided the analysis of my findings and helped me to make meaning from my data. Dansky et al.'s (2006) framework has been identified in the literature for its ability to help study "universals" in eHealth research (Baker et al., 2014). However through the research process I identified three shortcomings of this framework for, which I propose modifications. First, Dansky et al. (2006) does not locate the participant or "the user" in the framework. I propose that the person/user is a missing element in the framework and should be added because it was found to be a central feature for understanding the delivery of Internet mediated health resources for dementia caregivers in this study. For example, participants' availability, perceptions of technology, desires to connect with others, and personal preferences influenced how they used Skype and YouTube to access the learning series. The addition of the person to the framework also helps to better align it with my epistemic stance that accepts that people construct their own understanding of the world though their experiences, which in turn influences the ways we as researchers can come to understand a phenomena.

Second, while Dansky et al. (2006) treat design, environment, logistics and technology as four separate but equal elements to be considered throughout the research process, I have treated design as an overarching element, under, which the other elements in the framework fall. The elements of study design influenced and in some instances dictated how the remaining elements in the research developed. The third shortcoming of

Dansky et al.'s (2006) framework is the lack of attention to how the elements interact

with one another. Study design was also reciprocally influenced by environmental,

technological and logistical considerations. For example, recruitment and study protocols

both influenced and were influenced by ethical considerations (environment); technology

and resource requirements (technology); staffing/skill requirements, and timelines

(logistics); and individual participant factors (person). Using Dansky et al.'s (2006)

framework helped to address criticism of research focusing on technology, which

suggested a tendency to focus on specifics that restrict their relevance and contribution to

the field. This is important because it has helped me to consider lessons related to using

Skype and YouTube for delivering the First Link Learning Series that can translate to the

delivery of future online health resources. Figure 5 illustrates the modified version of

Dansky et al.'s (2006) framework that I am proposing. Table 7 provides a summary of

how the take away messages from the thematic analysis of my findings fit with the

modified version of Dansky et al. (2006) framework. I will now discuss how these key

messages could be applied to future research in the field.

A Framework for Understanding E-Health Research
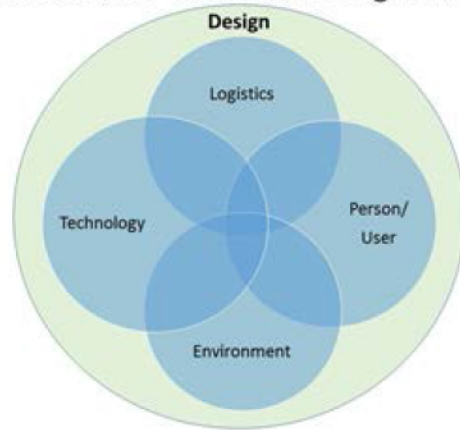
Figure 5. A Modified version of Dansky et al.'s (2006) Framework for Understanding E-Health Research. This figure illustrates the elements that emerged as important considerations for conducting E-Health research. The circles represent separate elements, however the area of overlap illustrates the ways in, which these constructs influence and interact with one another, with Design as an overarching element under, which the others fall.

Table 7

Placement of themes into modified Dansky et al. (2006) Framework

Framework element	Thematic Analysis: Barriers	Thematic Analysis: Facilitators
Design	*Access barriers.* Time is a limited and precious commodity for dementia caregivers, which relates to balancing caregiving duties.	*Access facilitators.* Participants valued multi-modal delivery methods when accessing the learning series online.
Logistics	*Access barriers.* Technology can fail.	*Privacy as a facilitator.* Control allowed participants to feel secure in the online environment.
Environment	*Privacy barriers.* Fear and discomfort with technology relates directly to caregiving experiences	*Privacy as a facilitator.* Control allowed participants to feel secure in the online environment.
Technology	*Access barriers* Technology can fail.	*Access as a facilitator.* Participants found Skype and YouTube easy to use. No cost to participants and removal of geographical barriers Participants valued multi-modal delivery methods when accessing the learning series online. *Privacy as a facilitator.* Control allowed participants to feel secure in the online environment. *Connection as a facilitator.* Skype and YouTube were used as tools for making connections.
Person	*Access barriers.* Time is a limited and precious commodity for dementia caregivers, which relates to balancing caregiving duties. *Privacy barriers.* Fear and discomfort with technology relates directly to caregiving experiences	*Access as a facilitator.* Participants found Skype and YouTube easy to use. Participants valued multi-modal delivery methods when accessing the learning series online. *Privacy as a facilitator.* Control allowed participants to feel secure in the online environment. *Connection as a facilitator.* Participants valued social and personal connections.

One key design consideration for future studies that seek to understand dementia caregivers' experiences of Internet-based health resources should be to consider ways to minimize time burdens on participants. This means offering programs and interventions that fit within the busy schedules of caregivers who often both work during the day and care for an individual with dementia. Recruitment challenges will likely continue to be a major barrier for conducting research in NL for this population. Improved long-term connections with individuals living with dementia and their families to the ASNL may help to facilitate access to this population for future research partnerships. Future research that wishes to access larger sample sizes in NL should seek partnerships with other entities that may have stronger long term connections to individuals living with dementia and their caregivers such as primary care physicians and clinics, public health nurses, and community-based social workers.

Key logistical considerations for future development of Internet mediated health resources for dementia caregivers might consider insuring service providers have adequate skills and training to deal with problems like technical failures. Service providers should also consider ways to help participants develop their own skills to manage their privacy online. Key environmental considerations revolve around better understanding the needs of dementia caregivers as they relate to feelings of security, privacy and trust for the media they are using to access health resources online. More work is also needed to fund ways to include dementia caregivers in research who fall in the "grey" area of providing care for individuals with dementia without express substitute decision making authority. Future considerations related to technology should address ways to mediate the impact of technology failures on the delivery of health information

online. This may require considering options that allow the research team to have more control of overall system maintenance and performance. Dementia caregivers saw Skype and YouTube as tools for making connections. This differed from the tools' intended use, as ways to deliver health resources. Selecting media that can act as both tools that can provide education and information, but also work as ways for individuals to connect in a social setting or a more personal basis should be considered by service providers for future projects aiming to meet the needs of dementia caregivers.

Finally, considering the person who is accessing health information online is of vital importance to the future development of Internet mediated health resources for dementia caregivers. The person played a role in the development of each of the themes in my findings. Dementia caregivers' personal strengths and resources acted as facilitators to using the Internet to access health resources online, while personal struggles and challenges, often directly connected to their caregiving role, related to the challenges and barriers they faced to access health resources online. Future considerations for the delivery of Internet mediated health resources for dementia caregivers should focus on finding ways to work within the dementia caregiver's reality, which often involves limited time, variable schedules and accommodating the changing needs of the person they are caring for. We must also try to find ways to capitalize on dementia caregivers' strengths, which include the ability to connect with other caregivers in similar situations and their knowledge and experiences as dementia caregivers.

My participants were not the intended audience for the learning series. The series was designed to target newly diagnosed individuals with dementia and their caregivers. My participants were both in the late stages of caring for someone with dementia. As new

clients in First Link, they were offered the learning series in the same manner as all other clients when communicating with the ASNL. That is to say, they were encouraged by the First Link coordinator to participate in the full 16-week series that follows the progression of the disease from early to late stages of dementia. When I initially designed this study I was hoping to include a larger number of participants that would have allowed for the quantitative analysis of goal attainment over the course of the learning series. Because of my small study sample my use of GAS shifted from an outcome measure, to a tool to help address an ethical concern I had about the design of the First Link Learning Series. My initial review of the literature revealed that caregivers of people with dementia have limited time and can experience high levels of stress (Sorensen & Conwell, 2011). They also have heterogeneous profiles and learning needs (Zarit & Femia, 2008). I used the GAS interviews to help caregiver participants in my study select topics in the learning series that fit their needs. My knowledge that participants did not fit within the "normal" First Link client profile made the use of GAS all the more important in order to address this ethical consideration however, because of this my participants had a slightly different experience of the learning series than regular First Link clients.

For future development and implementation of First Link I suggest that there is a possible missing element, which would place more emphasis on individual differences among clients, rather than making assumptions that clients follow a homogeneous pattern of experiences as newly diagnosed individuals with dementia, family members and dementia caregivers. The structure of the First Link Program is ideal for the incorporation of Goal Attainment Scaling. The referral system provides a means for physicians to identify their goals for clients upon referral. The intake process provides a structure for

program coordinators to work with new clients to set individual goals. And the continuous check-ins with clients allows the program coordinator an opportunity to revisit goals, monitor progression towards goal attainment and modify the scope and intensity of the services being offered to clients, such as the learning series, based on their identified needs.

In addition to providing benefits to clients, Goal Attainment Scaling would act as a seamless evaluation tool for the First Link program. Gaps in services would easily be identified as clients present with goals that are not addressed by existing information and support options available through the Alzheimer Society. GAS would allow First Link to be evaluated for its ability to address meaningful outcomes for caregivers, and GAS would also help coordinators to identify when clients require services that fall outside their scope of practice and facilitate referrals to other health services. Although the current design of the learning series may have been a limitation in the present study, my research findings provide opportunity to build new methods of evaluation into the future development of the First Link Program.

Limitations and Future Research Recommendations

I attempted to be transparent in the research process by providing a clear account of the procedures I have used to collect and analyze data. Framework Analysis was used because it gave me the ability to analyze all data collected systematically and maintain a transparent audit trail. This approach to data analysis enhances rigour and therefore, the credibility of the findings (Smith & Firth, 2011). Despite the steps I have taken to address rigour in my case study, there are still several limitations to my study. Dansky et al.

(2006) cautions that unrealistic timelines can be a challenge in E-Health research. The main limitation of my case study was its small sample size. Only 2 people participated in the Skype and YouTube delivery of the sessions. It is possible that gatekeeping occurred during the recruitment process. Gatekeepers are individuals who control the researcher's access to study participants (Green & Thorogood, 2009). Green and Thorogood (2009) explain that the use of gatekeepers can either facilitate or restrict who is invited to participate in the research. Despite the fact that there were 52 clients registered for First Link at the time of the study, only 23 were identified by the First Link coordinator as being appropriate for contact about the learning series. Of those 23, only 12 were successfully contacted before the study began. The number of individuals who met the study inclusion/exclusion criteria (p.63) was not documented by the First Link Coordinator and I was not given detailed information as to whether additional exclusion criteria were used by the ASNL. Because of my small sample size I was not able to reach data saturation in my interviews with dementia caregivers. Data saturation is the intention to keep sampling data until nothing new is being generated (Green & Thorogood, 2009). Because of this, there are likely additional themes and constructs that have not been captured in my data. Future research should focus on accessing a larger sample size of dementia caregivers in order to gain a fuller picture of the experiences of online participation in the First Link Learning Series.

In order to address this limitation I added additional sources of data to triangulate my findings and improve trustworthiness. I added interviews with service providers to help add more data to my study. Triangulation involves using multiple sources of data in an investigation in order to help improve understanding of a phenomena, and is used to

increase our faith in the validity of findings (Green & Thorogood, 2009). I used purposive sampling to select service providers included in my study. There was a very small pool of experts in this area who could provide relevant information for my study. I used my judgment to select service providers who had relationships to caregivers of people with dementia. Nonetheless, the selection of these individuals may be biased by my own experiences and opinions and therefore it is possible that my findings as they related to the experiences of service providers have limited generalizability. The additional sources of data included in my case study and my attempt to triangulate my findings were an effort to address this limitation and increase the validity and trustworthiness of my findings.

The first time delivery of a health resource is often a unique event. In this instance the case study was bound by context: including participants, location, time and the learning series presenters. The clients that are referred to the First Link program during the initial phase of implementation (the first 6 months of development) may not be representative of the types of clients that will be referred to the program in the future – this includes the stage of dementia at, which the client accesses the learning series, and their corresponding educational needs. Findings should be interpreted with this in mind.

Technology is continuously changing. Time also dictated the versions of Skype and YouTube that were used for this research study. In this manner the findings of my study may have limited generalizability because the versions of Skype and YouTube are continuously changing. In order to address this limitation I attempted to focus my discussion on universal lessons that could be applied to E-Health and online health resource delivery in general, rather than having a narrow focus on technical aspects of

Skype and YouTube.

This study focused on the online delivery of the First Link Learning Series, however there were a number of participants who attended the in-person sessions and also a number of individuals who did not attend the learning series, but who were clients of the First Link program. The low attendance rates and small sample can potentially represent negative cases, or individuals with views other than those reflected in my findings. In retrospect there may have been an opportunity to conduct more preliminary work to understand what the needs of clients were, prior to beginning the learning series, including perceptions of technology, informational needs and issues around access. This should be seen as a limitation of the present study. Future research should focus on identifying the needs of all individuals eligible to participate in the learning series prior to the start of the series. This would allow for a better understanding regarding the uptake of the Skype and YouTube options of the learning series.

With respect to the technical issues that were experienced by a participant during the study, adequate details about the versions of Skype used by all parties in this research was not kept because I did not anticipate the high frequency of updates required by Skype. Although there were no issues with YouTube during my study, I also did not keep a record of YouTube updates. Future research that uses third party services such as Skype and YouTube to deliver online health resources, should take careful field notes documenting the versions of the programs that are used, as well as any change to the programs during the course of the research so that technology failures and other unanticipated issues can be accurately documented and later described.

Although I had formally entered into a partnership with the ASNL to recruit

participants and deliver the online version of the learning series, the nature of this partnership shifted over the course of the study. All First Link clients were not offered an opportunity to participate in my study, and I believe my value as perceived by the ASNL was as a volunteer facilitating the online sessions rather than a researcher hoping to answer an important question of benefit to the organization and ASNL clients. This should be seen as a limitation with respect to how the partnership was developed. Future students wishing to partner with a community organization for the purposes of a Master's project may wish to pursue formalized discussion with express support and oversight from the university. Particularly, in the case of novice researchers, a standard agreement or memorandum of understanding would facilitate a commitment to shared expectations and goals. Regular meetings that involve the student, supervisor, an institutional representative, and the community partner would formalize the process and help hold all parties accountable to the original parameters of the agreement. Senior researchers with community-based research experience could guide the development of a process and help create a framework that is both inclusive of the needs of the organization but also meets the institutional requirements for students to design and conduct a sound research study. Crucial to this recommendation is the need for clear communication, identification of shared goals and forming a partnership that is mutually beneficial to both the organization and the student.

Conclusion

This case study aimed to address two primary research questions to help understand whether or not Skype and YouTube could be used to effectively deliver online

health resources to dementia caregivers. I was interested in understanding the experiences these individuals within the NL context during the piloting of the First Link Program. Although I faced some challenges with accessing the dementia caregiver population, I was able to begin to identify barriers and facilitators to providing Internet mediated health resources. My findings should be viewed as an early account of the phenomena with opportunity for future research to build on this work.

In 2013, Dr. Roger Butler began a new project called *Telegerontology: A novel approach to optimize health and safety and to age in place among people with dementia in NL*. I was hired as a research assistant and my work developing consent forms for substitute decision makers of people with dementia, and using Skype to connect to individuals was the first of its kind in NL and was incorporated into this new project. Dr. Butler was able to build on my work, incorporating the online delivery of the First Link Learning Series into the Telegerontology project and using my consent forms as a template for his study. Dr. Butler is also using Skype to create a physician-patient link in order to closely monitor people living at home with dementia. This illustrates the way my preliminary work fits into the bigger picture of E-Health for people with dementia in NL. Dr. Butler`s work also helps to illustrate how multi-component online interventions that include the delivery of health resources are being considered as promising opportunities to support people living with dementia at home in NL. While my study had several limitations, my findings are still able to help contribute to future understandings how the Internet can be used to support dementia caregivers in NL and future research in this area.

References

Afram, B., Verbeek, H., Bleijlevens, M. H., & Hamers, J. P. (2014). Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies. *International Psychogeriatrics*, 1-12.

Ahadzadeh, A. S., Sharif, S. P., Ong, F. S., & Khong, K. W. (2015). Integrating health belief model and technology acceptance model: an investigation of health-related internet use. *Journal of Medical Internet Research, 17*(2).

Ajuwon, G. A., & Popoola, S. O. (2015). Influence of motivational factors on utilisation of Internet health information resources by resident doctors in Nigeria. *The Electronic library, 33*(1), 103-119.

Ala, T. A., Berck, L. G., & Popovich, A. M. (2005). Using the telephone to call for help and caregiver awareness in Alzheimer disease. *Alzheimer Disease & Associated Disorders, 19*(2), 79-84.

Ancker, J. S., Carpenter, K. M., Greene, P., Hoffman, R., Kukafka, R., Marlow, L. A., . . . Quillin, J. M. (2009). Peer-to-peer communication, cancer prevention, and the internet. *Journal of Health Communication, 14*(S1), 38-46.

Baker, T. B., Gustafson, D. H., & Shah, D. (2014). How can research keep up with eHealth? Ten strategies for increasing the timeliness and usefulness of eHealth research. *Journal of Medical Internet Research, 16*(2).

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report, 13*(4), 544-559.

Boedeker, B. H., Bernhagen, M., Miller, D. J., Miljkovic, N., Kuper, G. M., & Murray, W. B. (2011). The combined use of Skype and the STORZ CMAC video

laryngoscope in field intubation training with the Nebraska National Air Guard. *Studies in Health Technology and Informatics, 163*, 83-85.

Bogardus, S. T., Jr., Bradley, E. H., & Tinetti, M. E. (1998). A taxonomy for goal setting in the care of persons with dementia. *Journal of General Internal Medicine, 13*(10), 675-680.

Bogardus, S. T., Jr., Bradley, E. H., Williams, C. S., Maciejewski, P. K., Gallo, W. T., & Inouye, S. K. (2004). Achieving goals in geriatric assessment: role of caregiver agreement and adherence to recommendations. *Journal of the American Geriatrics Society, 52*(1), 99-105.

Bonniface, L., & Green, L. (2007). Finding a new kind of knowledge on the HeartNET website. *Health Information & Libraries Journal, 24*(s1), 67-76.

Boots, L. M., de Vugt, M. E., van Knippenberg, R. J., Kempen, G. I., & Verhey, F. R. (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Internation Journal of Geriatric Psychiatry, 29*(4), 331-344.

Bramble, M., Moyle, W., & McAllister, M. (2009). Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing, 18*(22), 3118-3125.

Brecher, D. B. (2013). The use of Skype in a community hospital inpatient palliative medicine consultation service. *Journal of Palliative Medicine, 16*(1), 110-112.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nursing Research, 44*(3), 166-172.

Newfoundland and Labrador. (n.d.). Retrieved August 10, 2015, from

    http://www.redcross.ca/in-your-community/newfoundland-and-labrador

Carone, M., Asgharian, M., & Jewell, N. P. (2014). Estimating the lifetime risk of

    dementia in the Canadian elderly population using cross-sectional cohort survival

    data. *Journal of the American Statistical Association, 109*(505), 24-35.

Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. (2012). Behavioral and

    psychological symptoms of dementia. *Frontiers in neurology, 3.*

Chapman, D., Miller-Stevens, K., Morris, J. C., & O'Hallarn, B. (2015). Social Media as

    a Tool for Nonprofit Advocacy and Civic Engagement: A Case Study of Blue Star

    Families. *Cases on Strategic Social Media Utilization in the Nonprofit Sector*, 66.

Chappell, N., Bornstein, S., & Kean, R. (2014). *Agitation and Aggression in Long-Term*

    Care Residents with Dementia in Newfoundland and Labrador. St. John's, NL:

    Newfoundland & Labrador Centtre for Applied Health Research, Memorial

    University.

Chiu, Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M., & Eysenbach, G.

    (2009). Internet-based caregiver support for Chinese Canadians taking care of a

    family member with alzheimer disease and related dementia. *Canadian Journal*

    on Aging, 28(4), 323-336.

Chiu, T. M., & Eysenbach, G. (2011). Theorizing the health service usage behavior of

    family caregivers: a qualitative study of an internet-based intervention.

    International Journal of Medical Informatics, 80(11), 754-764.

CIHR, N. (2010). SSHRC (Canadian Institutes of Health Research, Natural Sciences and

    Engineering Research Council of Canada and Social Sciences And Humanities

Research Council Of Canada) 2010 Tri-Council Policy Statement: Ethical

Conduct For Research Involving Humans. Retrieved January 21 from:

http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf

Clark, A. M. (1998). The qualitative-quantitative debate: moving from positivism and

confrontation to post-positivism and reconciliation. *Journal of Advanced Nursing,
27*(6), 1242-1249.

Clarke, M., & Mars, M. (2015). An investigation into the use of 3G mobile

communications to provide telehealth services in rural KwaZulu-Natal.

Telemedicine and e-Health, 21(2), 115-119.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving:

rounding out the caregiver experience. *International Journal of Geriatric
Psychiatry, 17*(2), 184-188.

Connectivity. (n.d.). Retrieved January 17, 2016, from http://www.merriam-

webster.com/dictionary/connectivity

Connelly, D. M., & London, O. (2008). *VON Canada Functional Fitness Continuum
Project Evaluation Report*. Retrieved January 17, 2016 from

http://www.von.ca/en/special_projects/docs/SMART_Evaluation.pdf

Constantinescu, G., Waite, M., Dornan, D., Rushbrooke, E., Brown, J., McGovern, J., . . .

Hill, A. (2014). A pilot study of telepractice delivery for teaching listening and

spoken language to children with hearing loss. *Journal of Telemedicine and
Telecare, 20*(3), 135-140.

Costello, L. N., Dare, J. S., & Green, L. R. (2013). *Sustaining online communities in the charitable health sector: how to keep a good thing going.* In procedings of ANZCA conference 2013 'Global Networks - Global divides': Bridging new and traditional communication challenges. Gold Coast, Australia: Australian and New Zealand Communication Association.

Coulehan, M. B., Rossie, K. M., & Ross, A. J. (2008). *Developing a novel Internet-based psychoeducational intervention for dementia caregivers.* In proceedings from AMIA annual symposium, 915.

Cravens, J. (2003). Online mentoring: Programs and suggested practices as of February 2001. *Journal of Technology in Human Services, 21*(1-2), 85-109.

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches.* Thousand Oaks, California: Sage.

Culnan, M. J. (2000). Protecting privacy online: Is self-regulation working? *Journal of Public Policy & Marketing, 19*(1), 20-26.

Curran, V. R., & Church, J. G. (1999). A study of rural women's satisfaction with a breast cancer self-help network. *Journal of Telemedicine and Telecare, 5*(1), 47-54.

Dansky, K. H., Thompson, D., & Sanner, T. (2006). A framework for evaluating eHealth research. *Evaluation and Program Planning, 29*(4), 397-404.

Davis, F. D. (1993). User acceptance of information technology: system characteristics, user perceptions and behavioral impacts. *International Journal of Man-Machine Studies, 38*(3), 475-487.

Dean, A. (2015). *Digital Engagement in DC: How Nonprofits in the Nation's Capital Use Social Media for Fundraising* (Doctoral dissertation, American University).

Ducharme, F., Beaudet, L., Legault, A., Kergoat, M. J., Levesque, L., & Caron, C. (2009). Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure. *Clinical Nursing Research, 18*(1), 44-67.

Ducharme, F. C., Levesque, L. L., Lachance, L. M., Kergoat, M. J., Legault, A. J., Beaudet, L. M., & Zarit, S. H. (2011). "Learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *Gerontologist, 51*(4), 484-494.

Economic Research and Analysis, Department of Finance. (n.d.). Retrieved January 17, 2016, from http://www.economics.gov.nl.ca/POP-projections.asp

E-Health. (n.d.). Retrieved January 17, 2016, from http://www.who.int/trade/glossary/story021/en/

Einterz, S. F., Gilliam, R., Lin, F. C., McBride, J. M., & Hanson, L. C. (2014). Development and testing of a decision aid on goals of care for advanced dementia. *Journal of the American Medical Directors Association , 15*(4), 251-255.

Elford, R. (1998). Telemedicine activities at memorial University of Newfoundland: a historical review, 1975-1997. *Telemedicine Journal : The Official Journal of the American Telemedicine Association, 4*(3), 207-224.

Evaluating the Benefits Newfoundlland and Labrador Provincial Telehealth Program: Chronic Disease Management. (2010). Retrieved January 17, 2016, from http://nlchi.nl.ca/images/PDFs/Telehealth_BE_FinalReport.pdf

Fernandez-Luque, L., Karlsen, R., & Melton, G. B. (2011, October). HealthTrust: trust-based retrieval of you tube's diabetes channels. In Proceedings of *The 20th ACM*

international conference on Information and knowledge management (pp. 1917-1920). ACM.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology, 13*, 117.

Gardner, R. C., Valcour, V., & Yaffe, K. (2013). Dementia in the oldest old: a multi-factorial and growing public health issue. *Alzheimers Research & Therapy, 5*(4), 27.

Ghosh, R., & Ahadome, T. (2012). Telehealth's promising global future. *Analytics Magazine*, 39-45.

Glueckauf, R. L., Davis, W. S., Willis, F., Sharma, D., Gustafson, D. J., Hayes, J., . . . Springer, J. (2012). Telephone-based, cognitive-behavioral therapy for African American dementia caregivers with depression: initial findings. *Rehabilitation Psychology, 57*(2), 124-139.

Good, D. W., Lui, D. F., Leonard, M., Morris, S., & McElwain, J. P. (2012). Skype: a tool for functional assessment in orthopaedic research. *Journal of Telemedicine and Telecare, 18*(2), 94-98.

Grajales, F. J., 3rd, Sheps, S., Ho, K., Novak-Lauscher, H., & Eysenbach, G. (2014). Social media: a review and tutorial of applications in medicine and health care. *Journal of Medical Internet Research, 16*(2), e13.

Green, J., & Thorogood, T. (2009). Qualitative Research Methods for Health Research. Thousand Oaks: Sage.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of Qualitative Research, 2*(163-194).

Herman, M. L., Head, G. L., Jackson, P. M., & Fogarty, T. E. (2004). *Managing risk in nonprofit organizations: A comprehensive guide*. Hoboken, New Jersy: John Wiley & Sons.

Holton, G. J. (1993). *Science and anti-science*. Cambridge, Massachusetts: Harvard University Press.

Hori, M., Kubota, M., Ando, K., Kihara, T., Takahashi, R., & Kinoshita, A. (2009). The effect of videophone communication (with skype and webcam)for elderly patients with dementia and their caregivers. *Gan to kagaku ryoho. Cancer & Chemotherapy, 36 Suppl 1*, 36-38.

Hou, Y., & Lampe, C. (2015). Social Media Effectiveness for Public Engagement: Examples of Small Nonprofits. *Information Management, 27*, 32.

Hudson, P., Aranda, S., Kristjanson, L., & Quinn, K. (2005). Minimising gate-keeping in palliative care research. Reterieved January 17, 2016 from http://espace.library.curtin.edu.au/R?func=dbin-jump-full&local_base=gen01-era02&object_id=134574

Hyett, N., Kenny, A., & Virginia Dickson-Swift, D. (2014). Methodology or method? A critical review of qualitative case study reports. *International Journal of Qualitative Studies on Health and Well-Being, 9*. 23606.

Ives, J., Damery, S., & Redwod, S. (2012). PPI, paradoxes and Plato: who's sailing the ship?. *Journal of Medical Ethics*, medethics-2011.

Jensen, C. J., & Inker, J. (2015). Strengthening the Dementia Care Triad Identifying Knowledge Gaps and Linking to Resources. *American Journal of Alzheimer's Disease and Other Dementias*, 30(3), 268-275.

Johnston, J., Hillier, L. M., Purdon, M., Pears, D., & Robson, M. (2012). Opportunities for Improving the Quality of Life of Dying Persons: Use of technology to connect people at the end of life. *Journal of Palliative Care, 28*(3), 178.

Jones, J., Fitzpatrick, J., & Chassy, P. (2015). The cognitive engineering of memory in educational website design. *Advances in Social Sciences Research Journal, 2*(5).

Judge, K. S., Yarry, S. J., Looman, W. J., & Bass, D. M. (2013). Improved strain and psychosocial outcomes for caregivers of individuals with dementia: Findings from project ANSWERS. *Gerontologist, 53*(2), 280-292.

Kelsey, S. G., Laditka, S. B., & Laditka, J. N. (2010). Caregiver perspectives on transitions to assisted living and memory care. *American Journal of Alzheimer's Disease and Other Dementias, 25*(3), 255-264.

Kilpi, K., Elprama, S., & Jacobs, A. (2013, January). Exploring privacy and trust issues in a future immersive videoconferencing system. In proceedings from *System Sciences (HICSS), 2013 46th Hawaii International Conference* (pp. 315-324). IEEE.

Kim, H. (2015). Understanding internet use among dementia caregivers: results of secondary data analysis using the us caregiver survey data. *Interactive Journal of Medical Research*, 4(1).

Kingsley, E., Harmon, G., Pomeranz, J., & Guinane, K. (2000). *E-Advocacy for nonprofits: The Law of lobbying and election-related activity on the Net*: Alliance for Justice.

Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal, 4*(6), 443-453.

Kitchin, H. A. (2008). *Research ethics and the Internet: Negotiating Canada's Tri-Council policy statement*: Fernwood Publishing Co., Ltd.

Keelan, J., Pavri-Garcia, V., Tomlinson, G., & Wilson, K. (2007). YouTube as a source of information on immunization: a content analysis. *Jama, 298*(21), 2482-2484.

Kleinert, S., & Wager, E. (2011). Responsible research publication: international standards for editors. Promoting research integrity in a global environment, 319.

Kwon, S. H., & Tae, Y. S. (2012). Nursing home placement: The process of decision making and adaptation among adult children caregivers of demented parents in Korea. *Asian Nursing Research, 6*(4), 143-151.

Lai, C. K., Wong, L. F., Liu, K. H., Lui, W., Chan, M. F., & Yap, L. S. (2013). Online and onsite training for family caregivers of people with dementia: results from a pilot study. *Intnational Journal of Geriatric Psychiatry, 28*(1), 107-108.

Landesmann, C. (1995). *Nonprofits and the world wide web*. Retrieved January 17, 2016, from http://www.nonprofits.org/lib/website.html

Lauriks, S., Reinersmann, A., Van der Roest, H. G., Meiland, F. J., Davies, R. J., Moelaert, F., . . Droes, R. M. (2007). Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews, 6*(3), 223-246.

Li, J. (2015). A privacy preservation model for health-related social networking sites. *Journal of Medical Internet Research, 17*(7), e168.

Lieberman, M. A., & Goldstein, B. A. (2005). Self-help on-line: an outcome evaluation of breast cancer bulletin boards. *Journal of Health Psychology, 10*(6), 855-862.

Liken, M. A. (2001). Caregivers in crisis: moving a relative with Alzheimer's to assisted living. *Clinical Nursing Research, 10*(1), 52-68.

Lim, S., Xue, L., Yen, C. C., Chang, L., Chan, H. C., Tai, B. C., . . . Choolani, M. (2011). A study on Singaporean women's acceptance of using mobile phones to seek health information. *International Journal of Medical Informatics, 80*(12), e189-202.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Beverly Hills, CA: Sage.

Lindsay, J., Laurin, D., Verreault, R., Hébert, R., Helliwell, B., Hill, G. B., & McDowell, I. (2002). Risk factors for Alzheimer's disease: a prospective analysis from the Canadian Study of Health and Aging. *American Journal of Epidemiology, 156*(5), 445-453.

Living with Dementia. (2015). Retrieved January 17, 2016 from http://www.alzheimer.ca/en

Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London),0*(0), 1-27.

Lopez, O. L., Becker, J. T., Sweet, R. A., Klunk, W., Kaufer, D. I., Saxton, J., . . . DeKosky, S. T. (2003). Psychiatric symptoms vary with the severity of dementia

in probable Alzheimer's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences, 15*(3), 346-353.

Lundberg, S. (2014). The results from a two-year case study of an information and communication technology support system for family caregivers. *Disability and Rehabilitation: Assistive Technology, 9*(4), 353-358.

Maheu, M., Whitten, P., & Allen, A. (2002). *E-health, telehealth, and telemedicine: a guide to startup and success*: John Wiley & Sons.

Mark, R. E. (2015). Promote the health of dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 1533317515588182.

Marziali, E., & Donahue, P. (2006). Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist, 46*(3), 398-403.

McAiney, C. A., Hillier, L. M., & Stolee, P. (2010). *First Link Demonstration Project:Final Evaluation Report*. Retrieved January 17, 2016 from: http://brainxchange.ca/Public/Files/First-Link/First-Link-Evaluation-Report-ON-2010.aspx

McKechnie, Barker, & Stott. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review. *International Psychogeriatrics, 26*(10), 1619-1637.

McLendon, K. (2000). E-commerce and HIM: ready or not, here it comes. *Journal of AHIMA/American Health Information Management Association, 71*(1), 22-23.

Metzger, M. J., & Flanagin, A. J. (2013). Credibility and trust of information in online environments: The use of cognitive heuristics. *Journal of Pragmatics, 59*, 210-220.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage.

Mittelman, M. S. (2003). Psychosocial intervention for dementia caregivers: what can it accomplish?. *International Psychogeriatrics, 15*(S1), 247-249.

Mittelman, M. S., & Bartels, S. J. (2014). Translating research into practice: Case study of a community-based dementia caregiver intervention. *Health Affairs, 33*(4), 587-595.

Morrison, K., Winter, L., & Gitlin, L. N. (2014). Recruiting community-based dementia patients and caregivers in a nonpharmacologic randomized trial what works and how much does it cost?. *Journal of Applied Gerontology*, 0733464814532012.

Nambisan, P. (2011). Evaluating patient experience in online health communities: implications for health care organizations. *Health Care Management Review, 36*(2), 124-133.

Newfoundland and Labrador Telehealth Program. (2015). Retrieved September 10, 2015 from http://nlchi.nl.ca/index.php/telehealth

O'donovan, J., & Maruthappu, M. (2015). Distant peer-tutoring of clinical skills, using tablets with instructional videos and Skype: A pilot study in the UK and Malaysia. *Medical Teacher, 37*(5), 463-469.

Özdemir, B. P. (2012). Social media as a tool for online advocacy campaigns. *Global Media Journal – Canadian Edition 5*(2), 23-39.

Park, M., Butcher, H. K., & Maas, M. L. (2004). A thematic analysis of Korean family

    caregivers' experiences in making the decision to place a family member with

    dementia in a long-term care facility. *Research in Nursing & Health, 27*(5), 345-

    356.

Paun, O., & Farran, C. J. (2006). Nursing home placement of persons with alzheimer's

    disease. *Alzheimer's Care Today, 7*(2), 104-114.

Peeters, J. M., Van Beek, A. P., Meerveld, J. H., Spreeuwenberg, P. M., & Francke, A. L.

    (2010). Informal caregivers of persons with dementia, their use of and needs for

    specific professional support: a survey of the National Dementia Programme.

    BMC Nursing, 9(1), 9.

Philpott, D. (2002). A critical analysis of Newfoundland and Labrador's model of special

    education management. *International Journal of Disability, Community and*

    Rehabilitation, 1(3).

Pitts, R. E., Blose, J. E., & Mack, R. W. (2014). Exploring donation appeals in top not-

    for-profit websites. *MIS REVIEW: An International Journal, 19*(2), 15-38.

Provincial Home Support Services Program Paid Family Caregiving Option Health and

    Community Services. (n.d.). Retrieved January 17, 2016, from

    http://www.health.gov.nl.ca/health/long_term_care/family_caregiving.html

Rattinger, G. B., Schwartz, S., Mullins, C. D., Corcoran, C., Zuckerman, I. H., Sanders,

    C., . . . Lyketsos, C. G. (2015). Dementia severity and the longitudinal costs of

    informal care in the Cache County population. *Alzheimer's & Dementia, 11*(8).

    946-954.

Rockwood, K., Fay, S., Jarrett, P., & Asp, E. (2007). Effect of galantamine on verbal repetition in AD A secondary analysis of the VISTA trial. *Neurology, 68*(14), 1116-1121.

Rockwood, K., Fay, S., Song, X., MacKnight, C., & Gorman, M. (2006). Attainment of treatment goals by people with Alzheimer's disease receiving galantamine: a randomized controlled trial. *Canadian Medical Association Journal*, 174(8), 1099-1105.

Rockwood, K., Mitnitski, A., Black, S. E., Richard, M., & Defoy, I. (2013). Cognitive change in donepezil treated patients with vascular or mixed dementia. *The Canadian Journal of Neurological Sciences, 40*(04), 564-571.

Rockwood, K., Mitnitski, A., Richard, M., Kurth, M., Kesslak, P., & Abushakra, S. (2014). Neuropsychiatric symptom clusters targeted for treatment at earlier versus later stages of dementia. *International Journal of Geriatric Psychiatry 30*(4), 357-367.

Rockwood, K., Richard, M., Leibman, C., Mucha, L., & Mitnitski, A. (2013). Staging dementia from symptom profiles on a care partner website. *Journal of Medical Internet Research, 15*(8).

Sadasivam, R. S., Delaughter, K., Crenshaw, K., Sobko, H. J., Williams, J. H., Coley, H. L., . . . Houston, T. K. (2011). Development of an interactive, web-delivered system to increase provider–patient engagement in smoking cessation. *Journal of Medical Internet Research, 13*(4).

Safei, S., Amin, M. A. M., Rose, A. N. M., & Rahman, M. N. A. (2011). Instant e-teaching framework model for live online teaching. *ArXiv Preprint ArXiv:1107.4628.*

Seike, A., Sumigaki, C., Takeda, A., Endo, H., Sakurai, T., & Toba, K. (2014). Developing an interdisciplinary program of educational support for early-stage dementia patients and their family members: An investigation based on learning needs and attitude changes. *Geriatrics & Gerontology International, 14*(S2), 28-34.

Sinha, M. (2013). *Portrait of caregivers, 2012.* Retrieved January 17, 2016 from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf

Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., & Ahmad, S. (2009). *Rising Tide: The Impact of Dementia in Canada 2008 to 2038.* Retrieved January 17, 2016 from http://www.alzheimer.ca/~/media/Files/national/Advocacy/Rising_Tide_RiskAnalytica.pdf

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse Researcher, 18*(2), 52-62.

Smyth, K. A., & Harris, P. B. (1993). Using telecomputing to provide information and support to caregivers of persons with dementia. *Gerontologist, 33*(1), 123-127.

Sorensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry, 19*(6), 491-496.

Sorensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: mental
health effects, intervention strategies, and clinical implications. *Lancet Neurology,
5*(11), 961-973.

Spencer, T. (2002). The potential of the Internet for non-profit organizations. *First
Monday, 7*(8).

Stake, R. E. (1995). *The Art of Case Study Research*. Thousand Oaks: SAGE
Publications.

Stake, R. E. (2013). *Multiple case study analysis*. New York: Guilford Press.

Sutter, M., Perrin, P. B., Chang, Y. P., Hoyos, G. R., Buraye, J. A., & Arango-Lasprilla,
J. C. (2014). Linking family dynamics and the mental health of Colombian
dementia caregivers. *American Journal of Alzheimer's Disease and Other
Dementias, 29*(1), 67-75.

Tanner, J. A., Black, B. S., Johnston, D., Hess, E., Leoutsakos, J.-M., Gitlin, L. N., . . .
Samus, Q. M. (2015). A randomized controlled trial of a community-based
dementia care coordination intervention: Effects of MIND at home on caregiver
outcomes. *The American Journal of Geriatric Psychiatry, 23*(4), 391-402.

The incidence of dementia in Canada. The Canadian Study of Health and Aging Working
Group. (2000). *Neurology, 55*(1), 66-73.

Torp, S., Hanson, E., Hauge, S., Ulstein, I., & Magnusson, L. (2008). A pilot study of
how information and communication technology may contribute to health
promotion among elderly spousal carers in Norway. *Health Social Care in the
Community, 16*(1), 75-85.

Toseland, R. W. (2004). *Caregiver Education and Support Programs: Best Practice Models.* San Francisco: Family Caregiver Aliance.

Tu, C.-H., & McIsaac, M. (2002). The relationship of social presence and interaction in online classes. *The American Journal of Distance Education, 16*(3), 131-150.

Van't Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. *International Psychogeriatrics, 25*(10), 1581-1603.

van der Roest, H. G., Meiland, F. J., Jonker, C., & Droes, R. M. (2010). User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness. *Aging & Mental Health, 14*(4), 461-470.

Van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Seydel, E. R., & van de Laar, M. A. (2009). Participation in online patient support groups endorses patients' empowerment. *Patient Education and Counseling, 74*(1), 61-69.

Warschauer, M., & Matuchniak, T. (2010). New technology and digital worlds: Analyzing evidence of equity in access, use, and outcomes. *Review of Research in Education, 34*(1), 179-225.

Westerman, D., Spence, P. R., & Van Der Heide, B. (2012). A social network as information: The effect of system generated reports of connectedness on credibility on Twitter. *Computers in Human Behavior, 28*(1), 199-206.

Willems, E. P., & Raush, H. L. (1969). *Naturalistic viewpoints in psychological research.* New York: Holt, Rinehart and Winston.

Witney, C., Green, L., Costello, L., & Bradshaw, V. (2013). Creativity in an Online Community as a Response to the Chaos of a Breast Cancer Diagnosis. *M/C Journal, 16*(1).

Wong, C. K., Yeung, D. Y., Ho, H. C., Tse, K.-P., & Lam, C.-Y. (2012). Chinese older adults' Internet use for health information. *Journal of Applied Gerontology*, 0733464812463430.

Yin, R. K. (2003). *Case Study Research: Design and Methods*. Thousand Oaks: SAGE Publications.

Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging & Mental Health, 12*(1), 5-13.

Zolfo, M., Iglesias, D., Kiyan, C., Echevarria, J., Fucay, L., Llacsahuanga, E., . . . Lynen, L. (2010). Mobile learning for HIV/AIDS healthcare worker training in resource-limited settings. *AIDS Research and Therapy, 7*, 35-6405-6407-6435.

Using Skype 6.10 for Microsoft Windows XP Professional Version 2002

A Simple Guide

October 2013

Created for the Alzheimer Society of Newfoundland and Labrador

Starting Up

- Click the Skype icon, located on the desktop to open the program

Starting Up

- This will bring you to Skype's home screen, which looks like this:
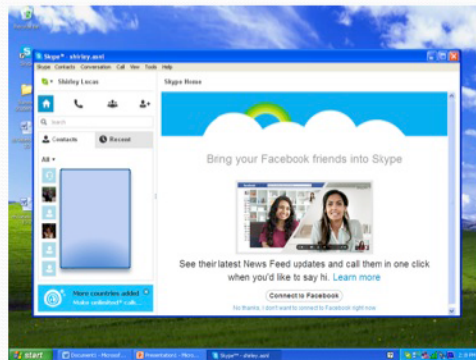
Contacts

- Your "contact list" is located on the left hand side of the screen:
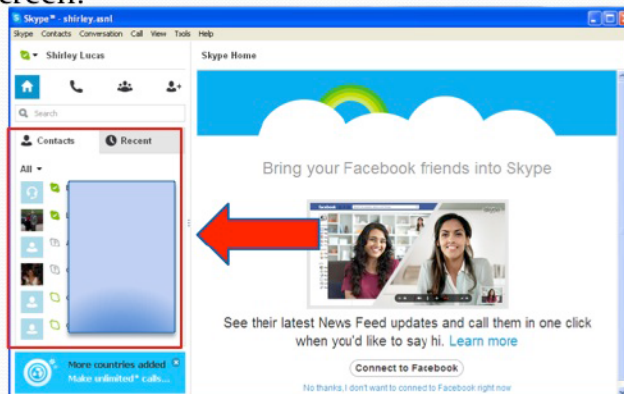
Contacts

- You can search your contact list by typing a name into the search bar located at the top of the contact list:
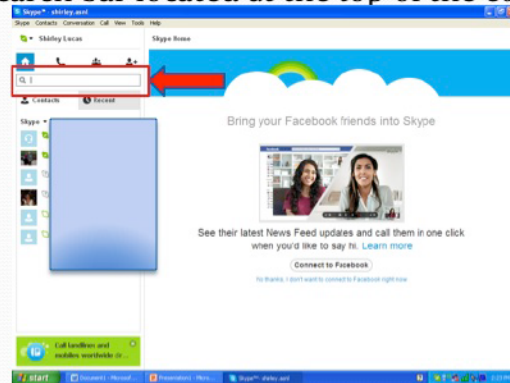
Making a call

- To make a Skype call, click on the name of the contact you wish to call. All names are located in the contact list:
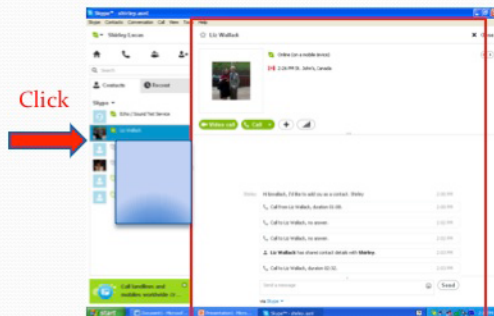
Click

- When you click on the person's name, it will appear with a blue rectangle around it. The person's profile will also appear on the right side of the window (indicated by the red rectangle).

Making a call

- Click the "video call" or "call" button, located in the profile window, to place a call.
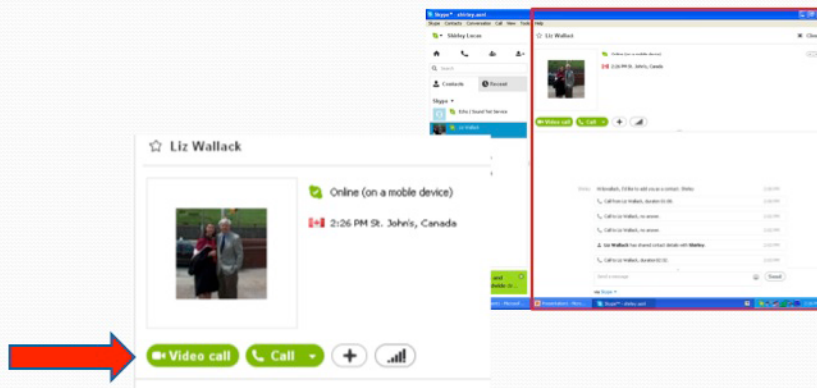
Making a call

- You will see this screen when you are placing the call:
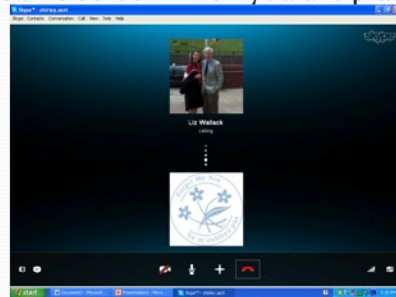
- The "Skype song" will play while you are calling. A log beep is also a normal sound to hear while you are connecting.

Making a call

- You will see this screen when the call is connected!

Making a call

- Your picture appears in the bottom right corner.
- The picture of the person you are calling will be the large central image.
- If they do not use a webcam, the profile picture of the person you are calling will be the central image.
- Even if they do not have a webcam, you can still use the webcam feature on your side of the call and select the "video call" option so they can see you!

Making a call - controls

- These are the buttons that let you control the call:

- They are located at the bottom of the screen during your call.
- **If they do not appear at the bottom of the screen during a call, simply hover your mouse near the bottom of the screen and they will pop up.**

Making a call - controls

- This button lets you turn the webcam off and on:

- When the webcam is **off**, there is a red strike through the image like the one above.

- This button controls the microphone and lets you mute your voice on the call by clicking on it (red strike through means off, just like the webcam image):

Ending a call

- To end the call click the red hang-up receiver:

- You will return to the profile screen:
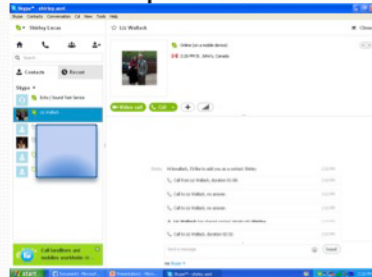
Making a call - summary

- Select the person you would like to call by clicking on their name, listed in the contact list. It will become highlighted by a blue rectangle.
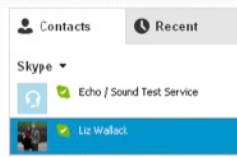
- To place a call click the green "video call" or "call" button

- To end a call use the red receiver hang up button

Using Skype and Other Functions

- You have just learned the basics of making a Skype call!
- There are other Skype features you can use once you are confortable making a basic call.
- Some of these features will be necessary to use when providing support for the First Link Learning Series.
- These include:
  - Share screen
  - Text chat
  - Adding a contact
  - Group calls

Share Screen

- Before a Learning Series session and your Skype call, you can open the PowerPoint presentation on your desktop that you will be sharing with the caller. Just leave it open on your desktop in the background.
- The "plus button" has a number of functions, including screen share:

Share Screen

- When you click the "plus button" while on a call, a menu will appear:
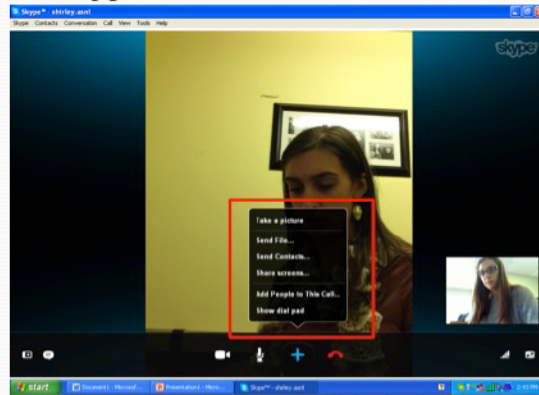
Share Screen

- Click the "Share screens" option, from the "plus button" menu.
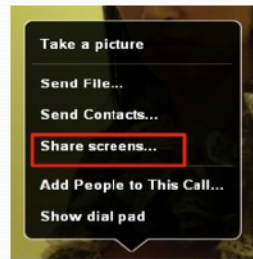
Share Screen

- You will be prompted to confirm the share screen:
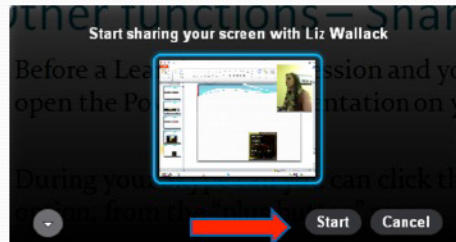
- Start sharing by clicking the "Start" button!

Share Screen

- After you have pressed "start", the person you are calling can see exactly what appears on your computer screen.
- Click back into the PowerPoint program, click the "slide show" tab located at the top of the screen.
- Click the "From Beginning" button to start the slideshow with the caller.
- As the presenter clicks though the sideshow on their laptop, you can also click along to allow your caller to participate in the presentation.

Share Screen

- You will continue to see your caller in the top right of the screen during screen share.
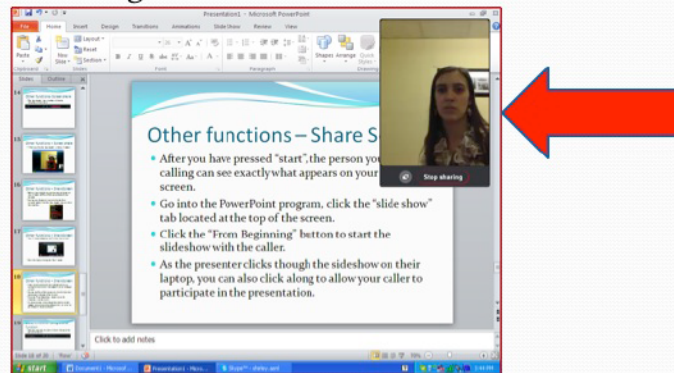
Share Screen

- To end the screen sharing, click the "stop sharing" button, located in the caller window.

- You will be returned to the full Skype call window, but you will still be connected to the caller.
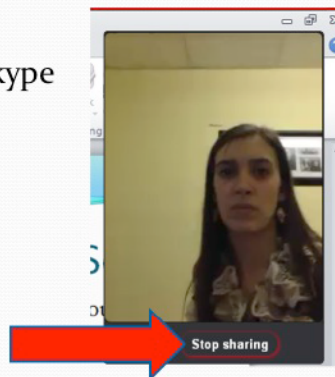
Share Screen

- Full Skype call window:

Share Screen

- To end the call click the red hang-up receiver:

- You will return to the profile screen:
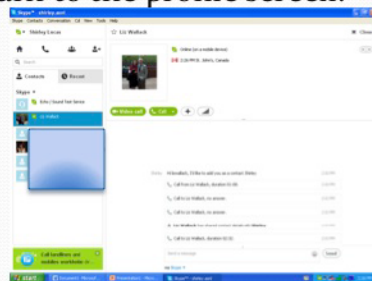
Using the text chat function

- The text chat icon lets you type an instant message to the person during the call:

Using the text chat function

- You can type text in the message box and then click the "send" button. The person can also type messages back to you.
- This comes in handy if you want to speak to someone during a presentation, or while other people are talking.

Type here

Click to send
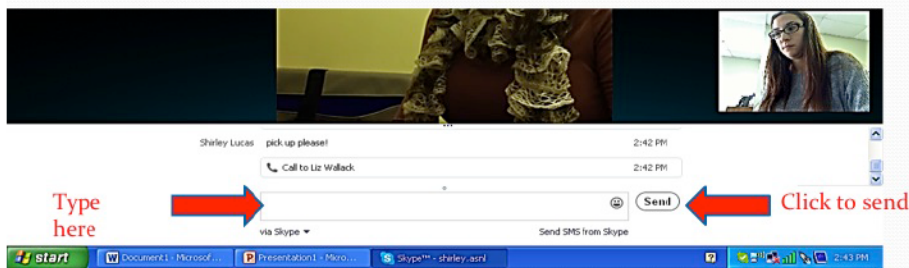
Adding a Contact

- Add a contact by clicking on the "person plus" button, located above the contact list.

Add a contact. Search for people you know using their name, Skype Name or email.
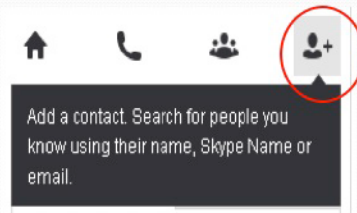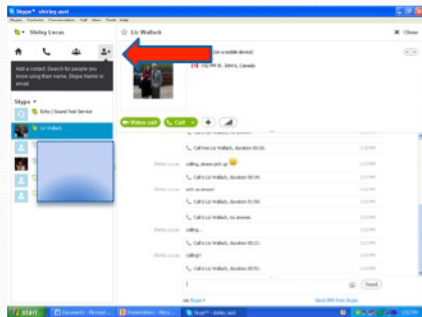
Adding a Contact

- You can type the person's name, Skype name, or e-mail in the search bar:
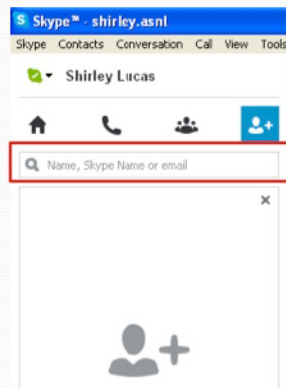
Adding a Contact

- Once you have found the person you want to add, select their name from the list by clicking on it. It will turn blue and the person's profile will appear on the right.
- Click "Add to Contacts" located in their profile box.
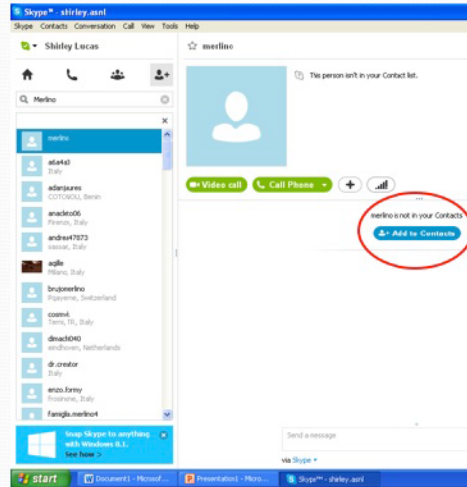
Adding a Contact

- You will be prompted to send the contact request.
- You can add a personal message, or simply click "send" to request the contact.
- You will receive a notice when the person has accepted your request.
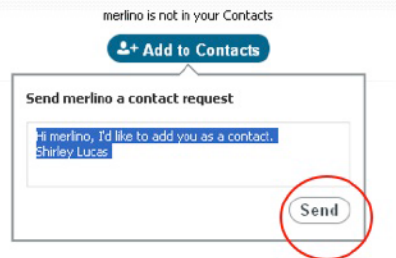
Group Chat

- You can have multiple people on the same call, this is called a "group chat".
- Start a group chat by selecting the first contact you would like to include. (click on the contact in the contact list)
- Their profile will appear on the right.

Group Chat

- Next, click the "plus button" located next to the call features.
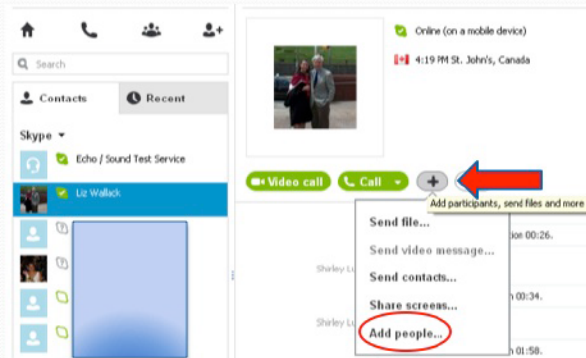
- Select "Add people" from the drop down menu.

Group Chat

- A window called "Add people" will appear.
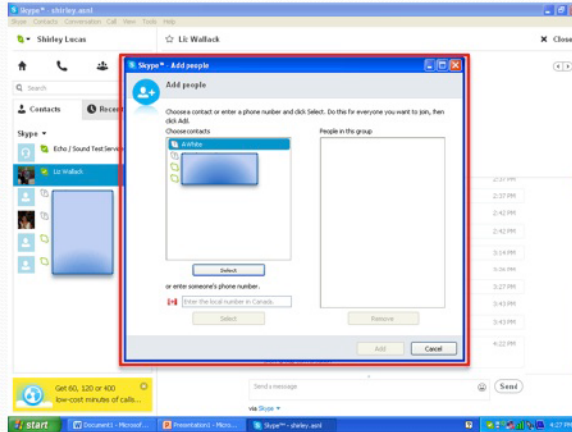
Group Chat

- Select contacts to add to the call by clicking on a name, and then clicking the "select" button.

Click the name of a contact
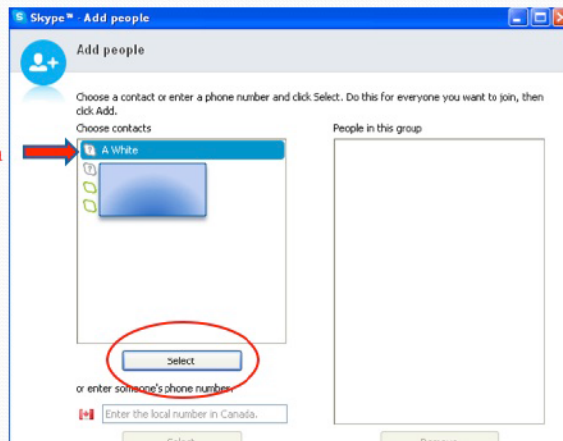
Group Chat

- You can also remove contacts you've selected by first clicking on their name and then by clicking the "remove" button.
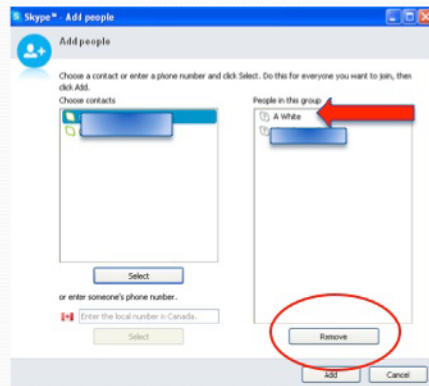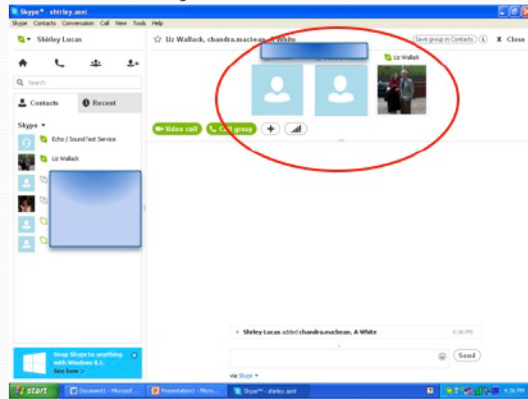
Click a name

Group Chat

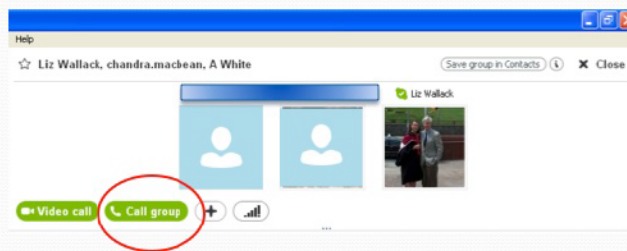- When you have selected the contacts you want to include in the group chat, click the "Add" button:
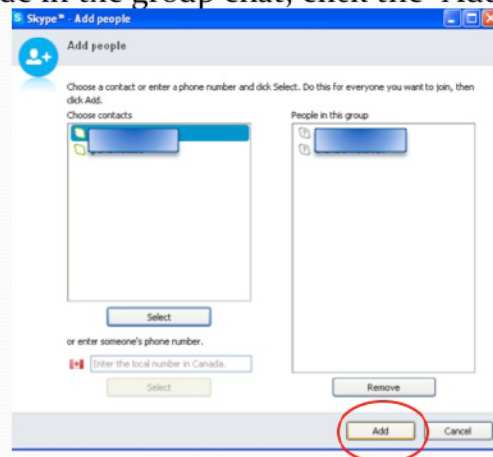
Group Chat

- You will now see a new profile window with pictures of all the contacts you've added

Group Chat

- Click on the "call group" button to start a group chat.

Group Chat

- You will see this window as you place your call.

Group Chat

- Everyone in the group can hear each other.
- Whether they can see each other will depend on who has their webcam turned on.
- You may use the "share screen" and "text based chat" features in the group chat.
- To end the call click the red receiver hang up button

Help

- If you are having problems with audio or video, a Skype test call can help determine the source of the problem.
- To make a Skype test call simply click on the "echo/sound test service" icon located in the contact list

- Make a call using the same steps as you would with a regular contact.
- Skype will provide you with prompts to test the service.
- This test call can give you information to determine if there is a problem with your webcam, microphone or speakers.

Help

- If there is no problem with your audio/video components check for program updates
- In the menu bar, click **Help** > **Check for Updates**. If an update is available, you will be asked to download it. Simply click **Download**.
- After the download is complete, click **Upgrade** in the pop-up window.
- Asking the person on the other end of the call to check for updates sometimes also resolves a technical problem, but check your end first.

Help

- For additional help please consult the Skype Support webpage at:

https://support.skype.com/en/

- Or call Elizabeth Wallack at 728-1610 or e-mail elizabethwallack@gmail.com

Acknowledgements

- This manual was created by Elizabeth Wallack as a part of the MSc. thesis project, *"Using Skype and Youtube to Facilitate Alzheimer Society First Link Education Sessions for Informal Caregivers of People with Dementia in Newfoundland and Labrador"*

- The project was funded by Memorial University of Newfoundland and Labrador and The Newfoundland and Labrador Centre for Applied Health Research (NLCAHR)

B

Initial GAS Interview Questions/protocol

0.0 Preamble

I'd like to briefly review your consent form with you. (Read signature page) Do you have any questions? I'd like to also remind you that you may withdraw at any time. To insure your privacy and the privacy of the person you are caring for, all identifying information, for example names and places, will be removed after this interview. My role in this study is that of student researcher. In addition, I have a personal connection to the disease. I helped care for my grandmother with Alzheimer's disease before she passed away in 2007 and I help with my Papa now who also lives with Alzheimer's disease. I am very proud of this role I am able to play in my family. I know there can be many rewarding aspects to being a caregiver. But I understand that this role also comes with challenges. I want to talk to you today about some of the challenges you may be facing in your role as caregiver.

The purpose of First Link is to increase understanding and awareness among individuals with dementia and their family members/caregivers of Alzheimer's disease and other dementias, provide community resources and to increase coping and confidence of caregivers and self-efficacy for self-management. What I want to do today is to obtain information from you on your goals related to education you'll be receiving from First Link. These goals can help you decide, which sessions fit your needs.

1.0 Brief introduction to the caregiver's experience

Please tell me about your experiences as a caregiver.

(Probe until there is a clear picture of the problems the caregiver is experiencing.)

1.1 Identifying the goal

One of the questions I am trying to answer is about what goals caregivers of people with Alzheimer's disease living in rural Newfoundland, set for themselves and their loved ones.

I sent you some information about setting goals for the First Link education sessions. Did you have a chance to review that information?

(If no) I'd like to just briefly go over that information with you because it will help us take these next steps.

(If yes) It sounds to me like you are having trouble with __answer from question 1____ did you chose that as a goal? What did you choose as a goal?

1.2 Describing the goal in plain language

How would you describe the current experience you are having with __Goal 1__?

(Record description)

We're going to try to make a 5-point scale. It goes from negative two to positive two. It looks like this: (show image via Skype)

-2	-1	0	1	2
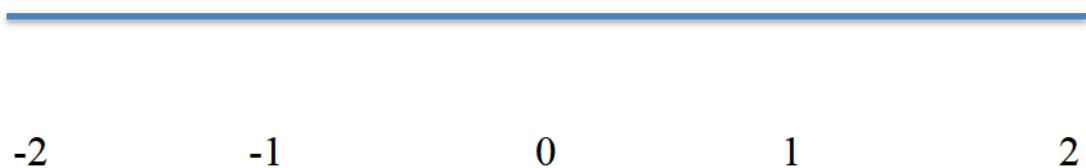
I wrote down what you just described to me. Let me read it back to you. (Read back the description) Does that accurately describe your current situation? (If no) How

would you like me to change it? (Re-read/re-write description until participant is satisfied) Does that accurately describe your current situation?

(If Yes) We are going to place the description you just gave me on the 5-point scale at zero here: (show image)

-2	-1	0	1	2
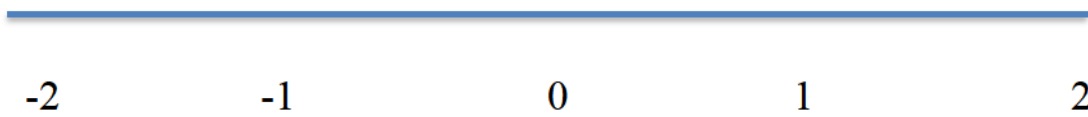
It will be the starting point for you, before you begin the First Link Education Sessions. After the sessions, it could be possible that you will see no change in your goal, or it could get better or worse.

1.3 Identify potentially better and worse outcomes

We're going to try to make a scale that describes what those better or worse outcomes might look like.

<u>"Much Worse"</u>

Now, can you please describe for me an outcome that would be very much worse than what you are currently dealing with? We're going to place that description at negative two. (Record description)

I'm going to read it back to you. (Read) Does that accurately describe your current situation? (If no)

How would you like me to change it? (Re-read/ re-write description until participant is satisfied)

Does that accurately describe your current situation?

<u>"Worse"</u>

(If Yes)

Now, can you please describe for me an outcome that would be worse than what you are currently dealing with? We're going to place that description at negative 1. (Record description)

I'm going to read it back to you. (Read) Does that accurately describe your current situation? (If no)

How would you like me to change it? (Re-read/ re-write description until participant is satisfied)

Does that accurately describe your current situation?

<u>"Munch Better"</u>

(If Yes)

Now, can you please describe for me an outcome that would be very much better than what you are currently dealing with? We're going to place that description at positive 2. (Record description)

I'm going to read it back to you. (Read) Does that accurately describe your current situation? (If no)

How would you like me to change it? (Re-read/ re-write description until participant is satisfied)

Does that accurately describe your current situation?

<u>"Better"</u>

(If yes)

Now, can you please describe for me an outcome that would be better than what you are currently dealing with? We're going to place that description at positive 1. (record description)

I'm going to read it back to you. (read) Does that accurately describe your current situation? (if no)

How would you like me to change it? (Re-read/ re-write description until participant is satisfied)

Does that accurately describe your current situation?

(If yes)

I'm going to read the five descriptions that you've just given me one more time in order from worst outcome to best outcome. (Read all five descriptions)

Would you like me to make any further changes? (If yes make changes)

Repeat this process for up to three goals

1.4 Weight Goals Relative to Each Other

I'd like now for you to try to rank the three goals we've just identified. Which of the goals is most important to you? Which is second most important? (Record order of goals)

1.5 Wrap up and explanation of follow up (step 5 of GAS)

I'm going to send you a file that has the scale we just made for each of your goals. Would you like me to send this via Skype or e-mail?

(Record answer)

I am also going to send you a list of the First Link Learning Series sessions so you can use our work here today to help you pick, which sessions you would like to attend.

Do you have any questions for me about the study?
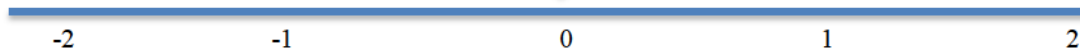
Thanks and sign off.

C

Stella's Goals

Goal 1: Personal Care (problems with toileting)

Current Status
He doesn't want me to help him, like when his underwear is dirty. He just doesn't want any female help for those things, and that's the problem.

| -2 | -1 | 0 | 1 | 2 |

Description of "Much Worse"
He would have to go in a home.

| -2 | -1 | 0 | 1 | 2 |

Description of "Worse"
Our communication breaks down. He just refuses to let me near him and he yells at me, and threatens me with his cane and all those things that they do. And eventually if he gets really agitated he'll just sit down and not look at me and not talk to me, he shuts completely off.

| -2 | -1 | 0 | 1 | 2 |

Description of "Better"
I think that there are a few things, like having someone to talk to, who understands where you are, is huge. When I went to the Alzheimer's course before, just being in the room with other people who were going through the same thing was such a relief.

| -2 | -1 | 0 | 1 | 2 |
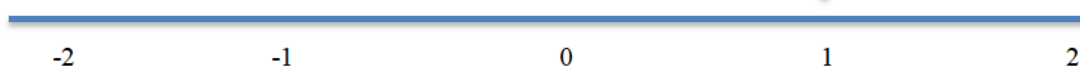
Description of "Much Better"
I wouldn't have to consider him going in a home because I could manage this problem.
Which would be a huge relief to me.

```
   -2            -1            0            1            2
```
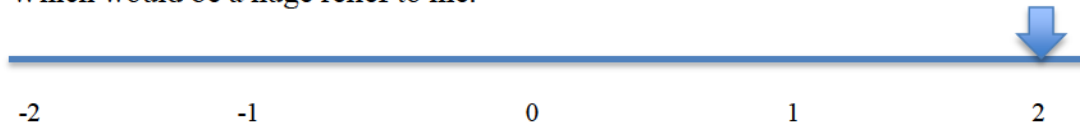
Goal 2: Social Support

Current Status
I really feel at this point like I'm taxing my friends, I don't have very many friends
because I moved home here after 25 years, I mean no body I knew, I mean we're all just
in different worlds. But I do have my very best friend in the whole world here, and she
has been such a huge support but there comes a time when you listen to yourself so much
that you think oh my God, I can't say that again to somebody else. I feel like I'm just a
broken record.

```
   -2            -1            0            1            2
```
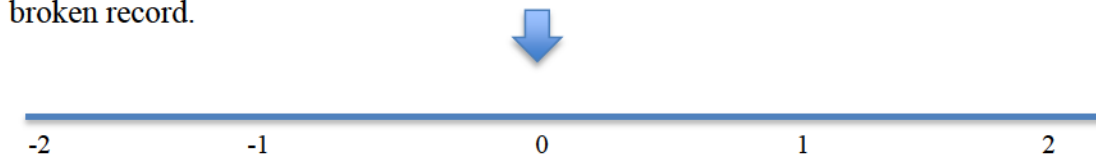
Description of "Much Worse"
My friends would not want to be around me as much because I would only talk about my
problems with Dad and I would not be able to be a good friend to them.

```
   -2            -1            0            1            2
```

Description of "Worse"
You want to be able to express your feelings but you find that you almost feel like you're
being repetitive to your friend and then it makes you feel like you're not being as good a
friend.

```
   -2            -1            0            1            2
```

164

**Description of "Better"**

If I had other social support it might improve some of my other relationships because I would feel like I wouldn't need to rely on them [my friends] so much to talk about the problems with my Dad.

| -2 | -1 | 0 | 1 | 2 |
|---|---|---|---|---|
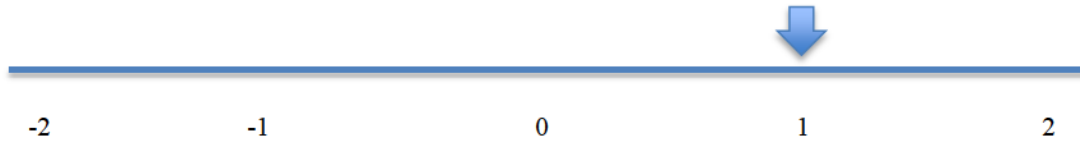
**Description of "Much Better"**

Other people who are in the same situation, they do different things, they have different ideas. Maybe somebody out there has been through this and found a switch that worked. I mean somebody could say, oh my God, I had that problem and this is what I did and it worked! You know amazingly enough it worked. Or you know half the time it worked, or most of the time, a quarter of the time...

| -2 | -1 | 0 | 1 | 2 |
|---|---|---|---|---|
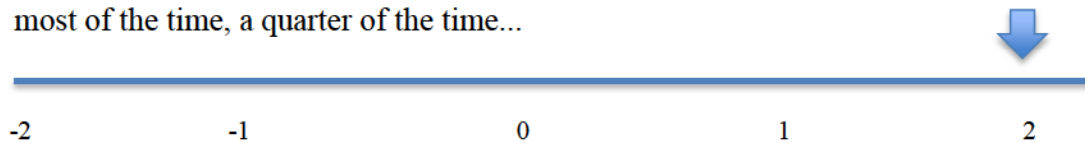
**Goal 3: Getting Information on Placement in Long Term Care**
**Current Status:**

I'm very hesitant to put him in a home. I don't feel comfortable with it. And I would like to listen to anything anybody has to say concerning those kinds of issues and when is the time and what do you do. I just don't know when is the time, and I'm not sure if there is a time, when is it?

| -2 | -1 | 0 | 1 | 2 |
|---|---|---|---|---|
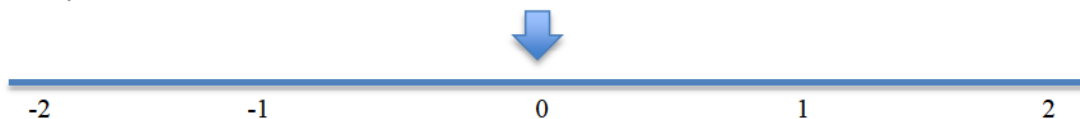
**Description of "Much Worse"**

I will be forced to make a decision about putting him in a home before I'm ready. If they come to me and tell me it's his turn on the waiting list and I turn it down, then I may have to put him on the wait list again and potentially be waiting in crisis before it's his turn again.
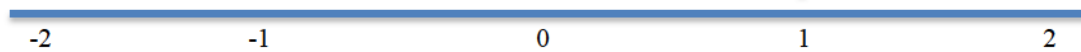
| -2 | -1 | 0 | 1 | 2 |
|---|---|---|---|---|

165

**Description of "Worse"**
None given.

```
 -2          -1           0           1           2
```

Description of "Better"
None given.

```
 -2          -1           0           1           2
```

Description of "Much Better"
I would not feel rushed into making a decision. I would be able to go through a process of feeling like I can say to myself, "okay I've done everything I could for my Dad and this is what's best for him now", and have information to help me make that decision.

```
 -2          -1           0           1           2
```

Mary's Goals

Goal 1: Staff Interactions with my Mom (sensitivity/kindness)

Current Status
With the nurses, I have to exercise a lot of caution. I use humor to try to take their feelings into account. The nurse coordinator has helped to problem solve, but her [my Mom's] needs are still not being met. Sometimes I feel worried if I am too assertive with the nurses, will it come back on my Mom in a negative way.

```
 -2          -1           0           1           2
```

166

**Description of "Much Worse"**
Staff would stop helping her to use the commode/changing her regularly, giving her books and would push for increasing medications. There would be a total breakdown in communication and I would feel very angry at the staff.

| -2 | -1 | 0 | 1 | 2 |
|----|----|----|----|----|
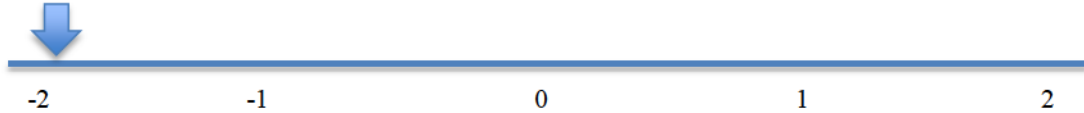
**Description of "Worse"**
I would become angrier with the staff and there would be a breakdown in communication.

| -2 | -1 | 0 | 1 | 2 |
|----|----|----|----|----|
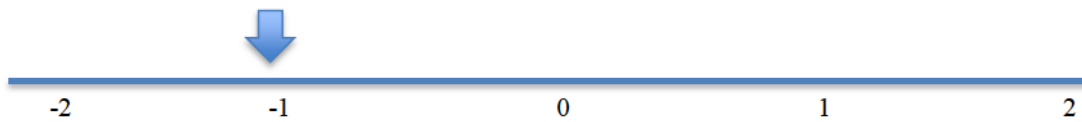
**Description of "Better"**
I would only occasionally need to remind them of Mom's needs and only tell new staff. I would only occasionally need to remind them to be kind to Mom and to treat her respectfully.

| -2 | -1 | 0 | 1 | 2 |
|----|----|----|----|----|
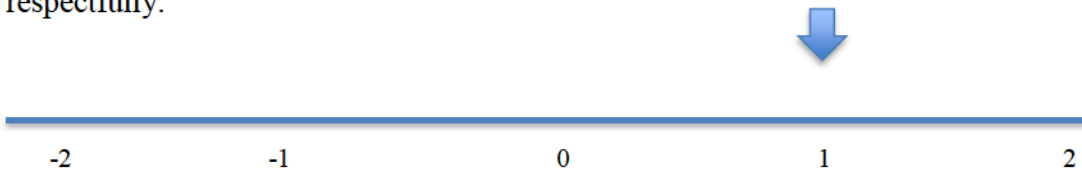
**Description of "Much Better"**
I'd only have to request things a small number of times, that request would be relayed to all staff and would result in respectful treatment of my Mom and her needs being met.

| -2 | -1 | 0 | 1 | 2 |
|----|----|----|----|----|
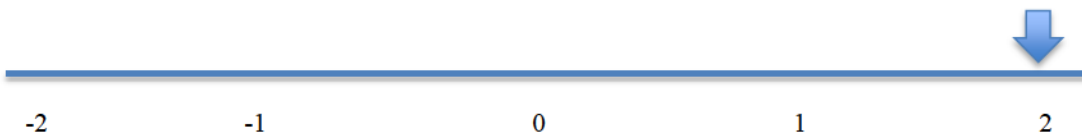
**Goal 2: Communicating with my Mom (What to do when she is confused)**

**Current Status**
I am dubious about what to do in situations when she gets confused about make-believe and reality (e.g. the baby doll) and when she asks for my Dad I don't know what to say. I just say he's busy or something like that.

| -2 | -1 | 0 | 1 | 2 |
|----|----|---|---|---|
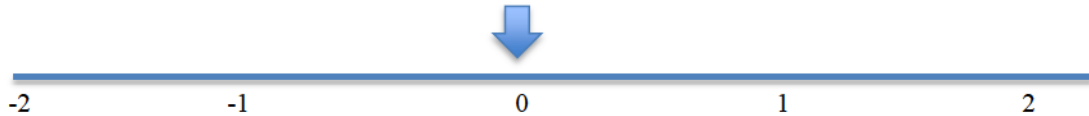
**Description of "Much Worse"**
If I didn't know how to help her I'd be afraid she might become uncooperative with the staff, refuse to eat or take medications. There could be a total breakdown in communication between us and I wouldn't be able to go back to the home. I couldn't handle it.

| -2 | -1 | 0 | 1 | 2 |
|----|----|---|---|---|
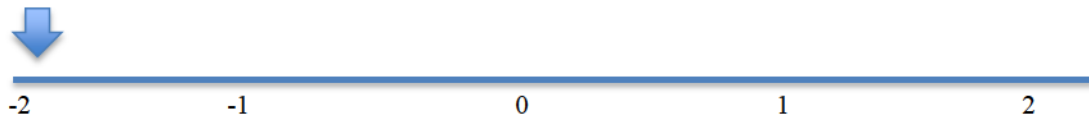
**Description of "Worse"**
I wouldn't be able to visit as often because it would be too taxing and it would translate to less quality in her care for her (e.g. I couldn't help her with the commode). She would also get less social interaction.

| -2 | -1 | 0 | 1 | 2 |
|----|----|---|---|---|
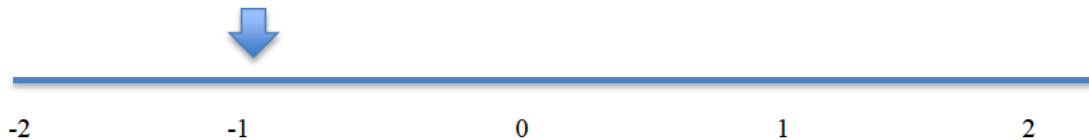
**Description of "Better"**
I would feel slightly more relaxed around her and I would only occasionally wonder if I was doing the right thing.

| -2 | -1 | 0 | 1 | 2 |
|----|----|---|---|---|
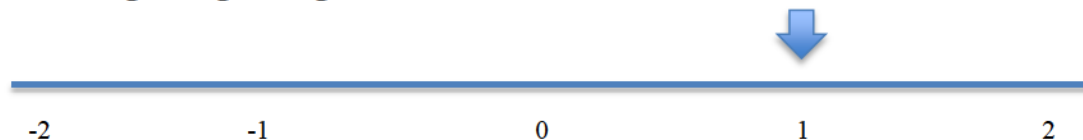
**Description of "Much Better"**

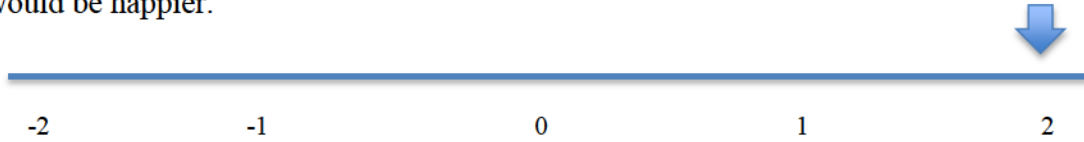There would be less tension and I would feel more relaxed. I wouldn't have anxiety to know if I was doing the right thing, and it would translate to better care for Mom and she would be happier.

| -2 | -1 | 0 | 1 | 2 |

**Goal 3: Understanding Mom's Medications**
**Current Status:**

My mom's drug regime seems to be good. She seems to have leveled out at the moment but because it's been such an ongoing issue I feel that I should know a little more about drugs and if anything new came on the market, then it would be nice to know about that.

| -2 | -1 | 0 | 1 | 2 |
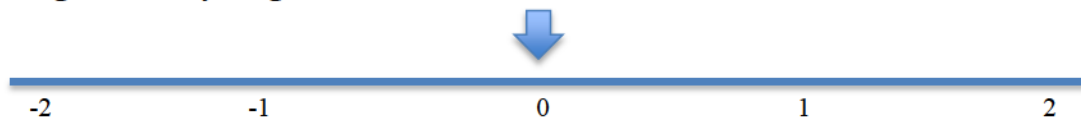
**Description of "Much Worse"**

I'd be in the dark about what was happening and why. And Mom would be totally drugged.

| -2 | -1 | 0 | 1 | 2 |
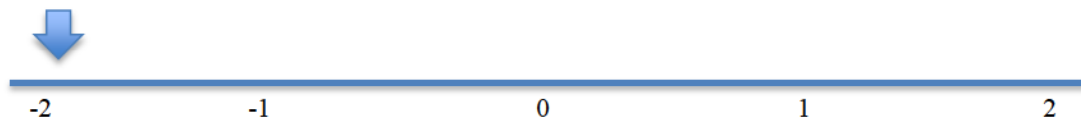
**Description of "Worse"**

I would occasionally be informed of changes to medications and have limited understanding of the medications Mom is on.

| -2 | -1 | 0 | 1 | 2 |
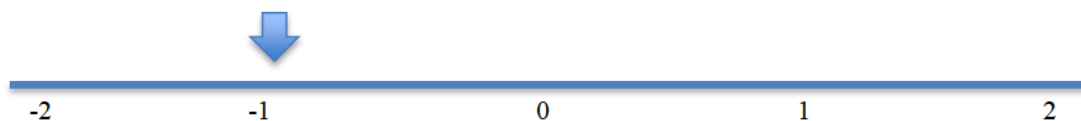
**Description of "Better"**

I would have a slight increase in knowledge and insight about the medications Mom is on.

```
-2            -1             0             1             2
```
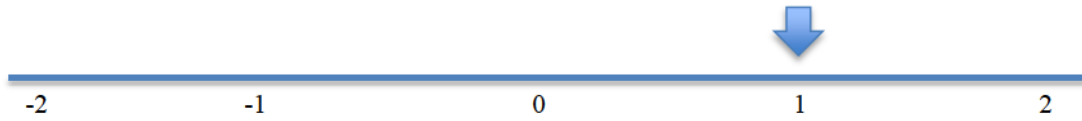
Description of "Much Better"

I would always be informed about changes in medications and I'd have an increased knowledge of future possibilities and increase knowledge of the effects of her current medications.

```
-2            -1             0             1             2
```

D
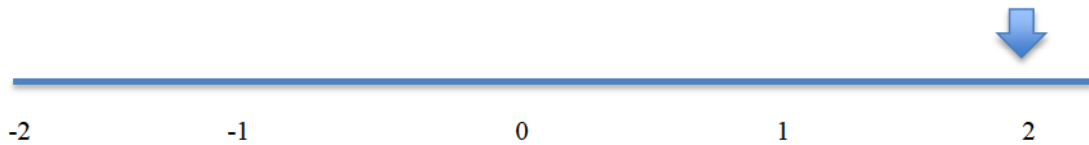
Key Informant Interviews with Service Providers

This interview seeks to explore the experiences of dementia caregiver service providers' use of the Internet, and the provider's perceptions surrounding the need for service delivery via the Internet and the impact of their clients.

1. **Brief background about the study will be given at the time of the interview.**

2. **Explanation of why we are seeking input from service providers. (small sample size)**

3. **Demographic/Descriptive Information to be collected:**

3.1 Age

3.2 Position title

3.3 Length of time in position

3.4 Description of service population (location, size, other characteristics)

4 **General Interview questions:**

4.1 Do you use technology and the Internet to support your clients?

4.2 Can you tell me about your experiences using technology and the Internet to support people?

4.3 Have your clients requested that services be available over the Internet?

4.4 What have you heard from your clients about accessing services and the Internet?

4.5 Which services have they requested be available?

4.6 Would you like more services to become available over the Internet? (Would it help your role?)

4.7 Which services?

4.8 Why?

4.9 Have you experienced barriers to using the Internet to support your clients?

4.10 Have you experienced successes using the Internet to support your clients?

4.11 Is there anything else you'd like to tell me about your experiences using the Internet to support your clients?

E

Protocol for Qualitative Follow up Interview

1.0 Exploring practical aspects of using Skype
Was the use of Skype, YouTube or the Internet problematic for you in any way?
Probes:
- Did Internet speed effect your ability to participate?
- Was there a problem with the picture quality
- Did you have any problems using the web-cam, microphone and computer?

1.1 Social aspects of the program
Where there any other experiences you had while participating in the sessions that you would like to tell me about?
Probes:
- What were your feelings about the other participants?
- What were you feelings about the presenters?
  Did you feel that you had an opportunity to raise the questions that you had in the sessions?

1.2 Participating online
Why did you choose to participate online?
Probes:
- Can you tell me more about that?
- Understand if participants viewed this option as favorable over traveling for support

1.3 Experiences of being in the home during the sessions
Was the fact that the session where at home problematic in anyway?
Probe:
- The extent to which they were able to participate in the sessions while caring for the individual with dementia.

1.4 Other thoughts from participants
Is there anything else you would like to add about your experiences using Skype and/or YouTube to access the First Link Education Series?
Probes:
- Would you continue to use this method to access support?
- Would you participate in other ASNL activities online?
Would you be interested in other educational opportunities about Alzheimer's disease available?

F

First Link® Learning Series - Spring/Summer 2013

Report is divided into the following sections:

❶ First Link® Program of the Alzheimer Society of Newfoundland & Labrador

First Link®… Your first step to living well with dementia

The Alzheimer Society of NL launched the First Link® referral program in

September of 2012 for World Alzheimer's Month.

First Link connects individuals with Alzheimer's disease and related dementias, their families, friends, and caregivers, to health services and information in their community, from the time of diagnosis throughout the progression of the disease. First Link is about helping individuals and their families make informed choices so they can live better with dementia at every stage of the disease.

First Link® is easy to access

Once permission is given to the referring health care provider (social worker, nurse, doctor) they are able to share the individual's information with the First Link Coordinator as a *formal referral*. The First Link Coordinator will then contact the designated contact person directly. Individuals can also contact the First Link Coordinator as a *self-referral*.

Individuals, their families, and caregivers will be linked to local health services and resources, which best suit their situation. They will have access to Alzheimer Society programs and services to help them learn about dementia, talk about their concerns and live will with the disease.

Connecting with First Link means you can:

- Receive one-on-one or group support

- Be referred to local healthcare providers and community services

- Meet other people in similar circumstances and exchange experiences

- Get help to plan your future

You are always connected

The progression of dementia brings with it new challenges. First Link provides support and connects individuals, their families; friends and caregivers to informative workshops to help them better understand and respond to each phase of the disease with practical tips and strategies.

With over 7,681 individuals affected by Alzheimer's disease in NL the demand for connection to information, support and services is drastically increasing. The provinces first baby boomer turned 65-years-old in the year 2011 so now is the time to act and make a difference. The Alzheimer Society of NL is a mission driven organization so we plan to respond to the growing demand for service in an effective way with the use of the First Link® program. As the number of people with dementia rises, the Alzheimer Society will be faced with capacity issues related to availability of human resources and funding realities. First Link, while increasing the number of clients connected to the Alzheimer Society, utilizes a collaborative model encouraging dementia care organizations to work together to meet client needs. With clients accessing our services early in the disease process, education and support will help them navigate the health-care system more effectively, and encourage development of self-competency and resiliency in facing their journey.

Goals

❖ To ensure individuals newly diagnosed with dementia and their families have early access to learning, services and support.

❖ To increase effective and efficient utilization of community resources, including those of the Alzheimer Society.

❖ To reduce overall incidence and intensity of caregiving crisis situations.

❖ To strengthen the link between diagnosing family physicians, the Alzheimer Society and community service providers.

❖ To raise community education and awareness about Alzheimer disease and related dementias.

❷ Overview of Learning Series

The First Link® program of the Alzheimer Society of NL offers a Learning Series for people with dementia, their families and caregivers. The courses in the Learning Series are progressive. Each course builds upon the other to provide participants with a comprehensive overview

of dementia, coping strategies, resources and support systems. Participants have the opportunity to learn and share with others who are affected by dementia. The Learning Series helps people with dementia, their families and friends to live as well as possible with the disease.

First Steps for people with dementia and caregivers

This series is to help individuals newly diagnosed with a dementia and their caregivers understand their diagnosis and the changes they experience.

This series will also offer participants an opportunity to share and connect with others embarking on a similar journey.

- What is dementia
- Memory loss, changes to the brain and their effect on behaviours
- Coping strategies
- Drugs, treatment and research
- Future planning – legal and financial matters
- Community resources and support

Care Essentials

This series will offer family members and friends caring for people with Alzheimer's disease and other dementias problem solving strategies, approaches for communication and available avenues for support, all of which can strengthen their ability to provide care. Topics discussed at this series will include:

- The progression of the disease
- Understanding behaviour
- Day-to-day care
- Community resources

Options for Care

This series is to help family members and friends caring for people with Alzheimer's disease or other dementias evaluate their current care giving needs and explore other possible care options available, including long term care. The following topics will be discussed in this series:

- Where to turn when care needs are increasing

- Long Term Care – how the system works

- Coping with changes

Care in the Later Stages

This series is to help family members and friends caring for people with Alzheimer's disease or other dementias understand what to expect in the later stages of dementia. The following topics will be discussed in this series:

- Understanding the experiences of grief and loss

- Learning about the later stages

- Recognizing pain and distress

- Providing care that promotes dignity, comfort and quality of life

❸ Spring/Summer 2013 Learning Series

During the Spring and Summer of 2013 the Alzheimer Society launched the Learning Series component of the First Link® program. The Learning Series has a total of 16 information sessions for families, friends and caregivers of individuals affected by Alzheimer's disease and related dementias.

On May 1, 2013 the Alzheimer Society launched the First Link® Learning Series with the First Steps information session on Memory Loss and the Brain. The Learning Series is designed to educate participants on the disease from beginning to end, explaining what exactly Alzheimer's disease is in the beginning of the First Steps Learning Series to talking about understanding grief at the end of the Care in the Later Stages Learning Series.

When we first began the Learning Series in the Spring of 2013 there were some things that we did not think of right away. We had moved in to a new office the end of March – beginning of April and then decided to launch the Learning Series at our office on May 1, 2013. Before we had relocated we were going to have to facilitate the Learning Series at an outside location by working with one of our community partners. We were very lucky to have the new space to work with so we went through some trial and error in the office for the first few sessions while experimenting with which would be the best spot to hold the session in our office space. After trying the session in one half of our main office area we decided to move the session in to a long room, which we set up theatre style so participants could easily view the presentation.

At that time we were also extremely focused on making the Learning Series available to all interested individuals in NL by any means possible. To make this possible we explored options such as conference calling interested parties into the Learning Series, Internet video calling individuals into

the Learning Series using a program called Skype with the assistance of Elizabeth Wallack, a master's student with Memorial University's Faculty of Medicine, Division of Community Health and Humanities. We also video recorded all 16 of the sessions so we were able to launch a YouTube channel after the series with these videos and we are now able to distribute these videos on DVD to interested parties.

<u>First Steps</u>

During the First Steps Learning Series we had approximately 20 – 25 participants per session. Unfortunately during this series we did not circulate a sign in sheet. This was a resource, which was introduced during the Care Essentials Learning Series.

During the First Steps Learning Series the Eastern College Personal Care Attendant (PCA) instructor and class of 16 students attended sessions held on May 8, May 15, May 22, and May 29.

For the First Steps Learning Series there were a total of 15 other registration forms for interested individuals outside of the Eastern College PCA students who attended four of the five First Steps sessions. The 15 registrants can be categorized as follows:

- First Link® Community Partner with provincial medical service business, female, Avalon Peninsula: Attended May 1, 2013

- Middle-aged male caring for his Father on the Avalon Peninsula (First Link® client – self-referral): Attended May 1, 2013

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered (for no specific session) but did not attend

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend May 1, 2013 (Unable to confirm if this registrant did attend or not)

- Female, Registered Nurse with Eastern Health Long Term Care Homes: Attended May 8, 2013

- Female from the Avalon Peninsula, caring for her husband who now resides in a long term care home, regular Family Support Group attendee at the Alzheimer Society of NL (ASNL): Attended May 1, 2013

- Male from the Avalon Peninsula, client of the ASNL Executive Director (one-on-one family support meetings): Attended May 8, 2013

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend May 8, 15, 22, 29 sessions of 2013. (Unable to confirm if this registrant did attend or not)

  - Female caring for her Mother in Central NL, First Link® self-referral via online registration, Memorial University of Newfoundland research project participant for Using Skype and YouTube to Facilitate Alzheimer Society First Link Education Sessions for Informal Caregivers of People with Dementia in NL: Attended May 22, 2013 via Skype Internet video calling under the assistance of the MUN research project principal investigator, Master's student Liz Wallack

- Four Western Health Social Workers (1 male, 3 female) joined the five First Steps Learning Series sessions by conference call

- Female, Registered Nurse with Eastern Health, First Link® Referring Partner: Attended via conference call May 8, May 15, May 22 and May 29

- Female, Health professional working in Mental Health and Addictions with Eastern Health: Attended May 29, 2013 via conference call

First Steps – Spring 2013:

- ❖ May 1, 2013 1:00pm – 2:30pm – **Memory Loss and the Brain**

    Speaker: **Dr. Isabel Martins (B. Med. Sc., M.D. Memorial, FRCPC, 1ˢᵗ referring partner for the**

    First Link® program, Director with the Alzheimer Society of NL Board of Directors)

- ❖ May 8, 2013 1:00pm – 2:30pm – **Communication and Coping Strategies**

    Speaker: **Megan Harris-Edwards, First Link Coordinator**

- ❖ May 15, 2013 1:00pm – 2:30pm – **Navigating the System**

    Speaker: **Megan Harris-Edwards, First Link Coordinator**

- ❖ May 22, 2013 1:00pm – 2:30pm – **Legal and Financial Matters**

    Speaker: **Brad Wicks, Q.C., Managing Partner, Roebothan McKay Marshall Law Firm**

- ❖ May 29, 2013 1:00pm – 2:30pm – **Resources and Support**

    Speaker: **Megan Harris-Edwards, First Link Coordinator**

Care Essentials

The Care Essentials Learning Series took place during June and July of 2013. At each Learning Series

session the participants had the opportunity to browse the educational materials that are on display at

the Alzheimer Society office while enjoying a coffee with other participants at the series. The Learning

Series has proven to provide an excellent learning and sharing opportunity for family members and

friends of individuals with Alzheimer's disease or dementia. Participants have an opportunity to socialize

with others who are on the same journey so they can share tips and tricks to their caregiving methods. It

creates another support system for these individuals.

Participant numbers remained consistent with the First Steps sessions. Participants seemed to be thoroughly enjoying the free education sessions and all of the information and educational materials, which they were taking home with them after each session.

During the Care Essentials Learning Series we had approximately 15 – 20 participants per session. We began circulating a sign in sheet during the second session of this series to record the number of participants present and to obtain some contact information for follow up and further promotion of the Learning Series and First Link® program.

During the Care Essentials Learning Series the Eastern College Personal Care Attendant (PCA) instructor and class of 16 students attended sessions held on June 12, June 19, and July 3. Instructor is female with a class of 15 females and 1 male.

For the Care Essentials Learning Series there were a total of 20 other registration forms for interested individuals outside of the Eastern College PCA students who attended three of the five Care Essentials sessions. The 20 registrants can be categorized as follows:

- Female caring for her Mother in Central NL, First Link® self-referral via online registration, Memorial University of Newfoundland research project participant for Using Skype and YouTube to Facilitate Alzheimer Society First Link Education Sessions for Informal Caregivers of People with Dementia in NL: Registered to attend June 5 session via Skype Internet video calling (under the assistance of the MUN research project principal investigator, Master's student Liz Wallack) but did not attend session due to technical difficulties.

- Middle-aged female from the Avalon Peninsula, Mother has Alzheimer's disease but she is not the primary caregiver: Attended June 5, June 12, June 19, June 26, and July 3.

- Middle-aged male from the Avalon Peninsula, Mother has Alzheimer's disease but he is not the primary caregiver: Attended June 5, June 12, June 19, June 26, and July 3.

- Young woman, MUN Medical student: Registered to attend but did not attend any Care Essentials Learning Series sessions.

- Middle-aged male caring for his wife with early onset Alzheimer's disease, client of the ASNL Executive Director (one-on-one family support meetings): Attended June 19, June 26 and July 3.

- Middle-aged female with early onset Alzheimer's disease, client of the ASNL Executive Director (one-on-one family support meetings): Attended June 19, June 26 and July 3.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend Care Essentials (no specific sessions) but did not attend

- Male, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend Care Essentials (no specific sessions) but did not attend.

- Middle-aged female caring for her husband with Alzheimer's disease, client of the ASNL Executive Director (one-on-one family support meetings): Attended June 5 and June 19.

- Middle-aged male with Alzheimer's disease, client of the ASNL Executive Director (one-on-one family support meetings): Attended June 5 and June 19.

- Female health professional with Eastern Health working in a long term care facility: Registered to attend Spring/Summer 2013 Care Essentials Learning Series but ended up attending Fall/Winter 2013-14 Learning Series by conference call.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Attend Care Essentials sessions on June 12, June 19, and July 3. Registered for the session on June 26 but did not attend.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend Care Essentials sessions on July 3 but did not attend.

- First Link® Community Partner, female, Central: Attended June 5, 2013 by conference call.

- Female, Avalon Peninsula, health professional (LPN), family member with Alzheimer's disease or a related dementia (Mother): Registered to attend session on June 19 but did not attend.

- Middle-aged female, Avalon Peninsula, caring for her husband with Alzheimer's disease, client of the First Link® program (self-referral): Registered to attend session on July 3 but did not attend. Now attending the Fall/Winter 2013-14 Learning Series.

- Male, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend session on July 3 but did not attend.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend session on July 3 but did not attend.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend session on July 3 but did not attend.

- First Link® Referring Partner, female, Central Health: Attended sessions on June 5, 12, 19, 26 and July 3 by conference call.

- Female, health professional with Central Health: Attended sessions on June 5, 12, 19, 26 and July 3 by conference call.

Care Essentials – Spring/Summer 2013:

- ❖ June 5, 2013 1:00pm – 2:30pm – **What to Expect**

  Speaker: **Dr. Roger Butler (Referring partner for the First Link® program)**

- ❖ June 12, 2013 1:00pm – 2:30pm – **Community Resources**

  Speaker: **Megan Harris-Edwards, First Link Coordinator**

- ❖ June 19, 2013 1:00pm – 2:30pm – **Understanding Behaviour**

  Speaker: **Dr. Roger Butler**

- ❖ June 26, 2013 1:00pm – 2:30pm – **Day-to-Day Care**

  Speaker: **Dorothy Bragg (Former Vice President of the Alzheimer Society of Newfoundland and Labrador Board of Directors)**

- ❖ July 3, 2013 1:00pm – 2:30pm – **The Caregiver Journey**

  Speaker: **Roseanne Leonard (Current Vice President of the Alzheimer Society of NL Board of Directors)**

<u>Options for Care</u>

The First Steps and Care Essentials Learning Series both have five sessions per series. The Options for Care and Care in the Later Stages Learning Series both have three sessions per series.

During the Options for Care Learning Series the Eastern College Personal Care Attendant (PCA) instructor and class of 16 students registered for the sessions held on July 10 and July 24 but the instructor and students only attended the July 24 session. Instructor is female with a class of 15 females and 1 male.

During the Options for Care Learning Series we noticed a drop in participant numbers with only nine other registration forms for interested individuals outside of the Eastern College PCA students who attended one of the three Options for Care sessions. The 9 registrants can be categorized as follows:

- Female caring for her Father on the Avalon Peninsula, First Link® self-referral, Memorial University of Newfoundland research project participant for Using Skype and YouTube to Facilitate Alzheimer Society First Link Education Sessions for Informal Caregivers of People with Dementia in NL: Attended July 17, 24, and 31 via Skype (under the assistance of the MUN research project principal investigator, Master's student Liz Wallack).

- Middle-aged female, Avalon Peninsula, caring for her husband with Alzheimer's disease, client of the First Link® program (formal referral): Registered to attend session on July 17 but attended session on July 31. Now attending the Fall/Winter 2013-14 Learning Series.

- Male, Avalon Peninsula, client of the ASNL Executive Director (one-on-one family support meetings): Attend session on July 24.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Registered to attend Care Essentials sessions on July 17 but did not attend.

- Female, Avalon Peninsula (no other information on this registrant besides personal contact information): Attend Care Essentials sessions on July 17 but did not attend.

- Middle-aged female from the Avalon Peninsula, Mother has Alzheimer's disease but she is not the primary caregiver: Attended July 17 and July 31.

- Middle-aged male from the Avalon Peninsula, Mother has Alzheimer's disease but he is not the primary caregiver: Registered to attend July 17 but did not attend.

- First Link® Community Partner, female, Avalon Peninsula: Attended July 17, 2013.

- Female, Avalon Peninsula, client of the ASNL Executive Director (one-on-one family support meetings), family member with Alzheimer's disease or a related dementia (Mother): Attend session on July 17, 24 and 31.

- Female, Avalon Peninsula, client of the ASNL Executive Director (one-on-one family support meetings), family member with Alzheimer's disease or a related dementia (Mother): Attend session on July 17, 24 and 31.

Options for Care – Summer 2013:

❖ July 17, 2013 1:00pm – 2:30pm – **When Care Needs are Increasing**

Speaker: **Dr. Roger Butler (Referring partner for the First Link® program**

❖ July 24, 2013 1:00pm – 2:30pm – **How the System Works**

   Speaker: **Megan Harris-Edwards, First Link Coordinator**

❖ July 31, 2013 1:00pm – 2:30pm – **Coping with Change: The Day Placement**

   Speaker: **Dr. Roger Butler**

<u>Care in the Later Stages</u>

During the Care in the Later Stages sessions participant numbers ranged from 3 – 8 people per presentation. With a total of 6 people registered for this series. The topics discussed during this series are very personal and sensitive. Individuals seemed to really benefit from these sessions and one participant even used these sessions as a means to find comfort and support after her mother's passing. The 6 registrants can be categorized as follows:

- Female caring for her Father on the Avalon Peninsula, First Link® self-referral, Memorial University of Newfoundland research project participant for Using Skype and YouTube to Facilitate Alzheimer Society First Link Education Sessions for Informal Caregivers of People with Dementia in NL: Attended August 14 via Skype (under the assistance of the MUN research project principal investigator, Master's student Liz Wallack). Registered to attend the August 21 and 28 sessions via Skype but did not attend.

- Female from the Avalon Peninsula, caring for her husband who now resides in a long term care home, regular Family Support Group attendee at the Alzheimer Society of NL (ASNL): Attended August 14, 21, and 28.

- Middle-aged female, originally from Newfoundland but residing away now, father with Alzheimer's disease: Registered to attend August 21 but did not attend.

- Middle-aged female from the Avalon Peninsula, Mother has Alzheimer's disease but she is not the primary caregiver: Attended August 14, 21 and 28.

- Middle-aged female, Avalon Peninsula, caring for her husband with Alzheimer's disease, client of the First Link® program (formal referral): Attended sessions on August 14 and 21.

- Middle-aged female, Avalon Peninsula, family member with Alzheimer's disease or a related dementia (Mother), client of the First Link® program (formal referral): Attended session on August 21.

- Middle-aged female, Avalon Peninsula, family member with Alzheimer's disease or a related dementia (Mother), client of the First Link® program (formal referral): Attended session on August 21.

Care in the Later Stages – Summer 2013:

❖ August 14, 2013 3:30pm – 5:00pm – **What to Expect: Advanced Dementia**

Speaker: **Dr. Roger Butler (Referring partner for the First Link® program)**

❖ August 21, 2013 3:30pm – 5:00pm – **Looking for Clues: Pain and Distress**

Speaker: **Dr. Roger Butler (Referring partner for the First Link® program)** ☐

❖ August **28, 2013 3:30pm – 5:00pm – Understanding Grief**

Speaker: **Peter Barnes (Regional Bereavement Coordinator with Eastern Health)**

❹ Conclusion

The Alzheimer Society of NL is very pleased to be able to offer the First Link® Learning Series. This component of the First Link® program has proven to be instrumental in educating caregivers on Alzheimer's disease and related dementias, coping strategies, resources and support systems.

Participants seem to be benefiting positively from the learning and sharing environment, which the Learning Series provides. These attendees have the chance to meet others who are on the same journey and to share tips and tricks for different caregiving methods.

The First Link® Learning Series educates participants on appropriate health-care information and services available locally, such as medications, activity programs, and life planning. Families learn about, plan for and adjust to dementia.

Early access to ongoing services and support makes a huge difference to people with the disease, their families and caregivers. It increases their knowledge and understanding of dementia. It helps them better cope and plan for the future, improving quality of life.

G

Script for First Contact with Potential Participants by the First Link Coordinator

The Alzheimer Society of NL has partnered on a research project, taking place through Memorial University (MUN). Would it be okay if I tell you a little about the project? (If no then conclude conversation)

(If yes)
The principal investigator is a Master's student named Liz Wallack. She used to work here at the Alzheimer Society and also has family living with Alzheimer's. She is still volunteering here at the Society and is helping us as we get the First Link project up and running.

Her study aims to help us address the problem of reaching caregivers in rural parts of the province with our educational opportunities and support.

She is looking for people to give her feedback about their experiences while participating.

The research has two goals:
- To learn about *your* goals as a caregiver, that you hope to accomplish by participating in the First Link educational series, and
- To learn about your experiences using the Internet to access the educational series

In addition to your regular participation in the educational series, participating in Liz's research would add about two extra hours to the process. You would speak to Liz via Skype or the phone and answer her interview questions.

The information she collects may help us as we expand the First Link program to other parts of the province. You don't have to participate in the research to take part in the sessions online, and you could stop participating in the research at anytime if your situation changes or you find it to be too stressful.

Would it be okay if Liz contacted you with more information about her research? Saying yes at this time will not commit you to participating in the study, it will just give you an opportunity to speak with Liz directly and learn more about her project.

How can she contact you? _____.
Is there a time that works best for her to contact you? _____

H

The Southern Gazette > Community

The Southern Gazette

Paul Herridge
Published on March 20, 2013

First Link Coordinator at the Alzheimer of NL Megan Harris-Edwards with Elizabeth

Wallack. Photo Submitted

Alzheimer's disease is a subject that hits close to home for Elizabeth Wallack.

BY PAUL HERRIDGE

The Southern Gazette

A few years ago, she watched her grandmother pass away from the brain disorder, and more recently has seen her grandfather go through the same battle.

"I had a bit of a long distance caregiving experience because my grandparents live in Toronto. So we would travel there to kind of give respite to my aunt for weeks and months at
Society a time."

But the St. John's resident has also spent a lot of time in the rural Avalon area, and has seen the challenges people face trying to care for people with Alzheimer's outside urban centres.

Ms. Wallack is encouraging anyone who is facing difficulties to sign up for the First Link dementia education series, being offered in the coming weeks by the Alzheimer's Society of Newfoundland and Labrador.

While the series, which uses the Skype video streaming Internet service to tune in live or follow up afterwards with YouTube, has been offered in other parts of the country, it's the first time for this province. The program helps connect individuals and families affected by dementia to opportunities for learning, community services and support.

Another key feature, according to Ms. Wallack, is the courses are progressive in order to provide support throughout the advancement of Alzheimer's disease and other dementias. She called the series a great starting point to changing people's experiences.

"One reason is that having education about the disease let's you prepare for the future. A lot of people don't know what to expect and the First Link program addresses things like that.

195

"Also there will be opportunities for people to connect with other caregivers and opportunities to connect with other people so we can build a support network across the province."

Ms. Wallack, who is a masters candidate in community health at Memorial University, is also working on a study of her own, entitled 'Using Skype and YouTube to Facilitate Alzheimer Society First Link Education Sessions for Dementia Caregivers on the Rural Avalon and Burin Peninsulas: An Exploratory Study'.

She has partnered with the Alzheimer's Society and will be inviting people enrolled in the First Link series to participate.

"The aim of my project is really to address problems of providing caregivers with skill building and support in rural areas of our province." – Elizabeth Wallack

"What my research is looking at is how people in rural Newfoundland experience the learning series when using Skype and YouTube to access the program.

"The aim of my project is really to address problems of providing caregivers with skill building and support in rural areas of our province. To answer my research questions I'm going to be conducting interviews, and I'd like to ask people about their goals for supporting loved ones with Alzheimer's disease and also about their experiences when using Skype and YouTube to access the First Link education series."

When it comes to Alzheimer's disease, Ms. Wallack says numbers speak for themselves.

A provincial government 2006 study, 'Healthy Aging for All in the 21st Century', projects 24 per cent of the Burin Peninsula will be over the critical age of 65 by 2021. She pointed out, at that age, people who have a first degree relative with Alzheimer's – a father, mother, sister or brother – have one in 10 chances of also developing the disease after age 65.

If they don't, it drops to one in 20 chances.

"The thing about that is those chances continue to increase after the age of 65. So every

five years after the age of 65, those changes double, and after the age of 85, the risk of developing Alzheimer's is almost 50 per cent."

Ms. Wallack suggested people's attitudes towards technology are changing and becoming more open. Technologies are also getting better.

As well, more and more people are using applications like Skype for social communication, particularly to stay in touch with family members living across the country.

She indicated people will be able to carry over the skills they develop from participating in the First Link series to other parts of their lives.

"I think that's something that's a little unique about the program."

The Alzheimer's Society is expecting to announce the dates for the First Link series in the coming weeks.

pherridge@southerngazette.ca