

AN EVALUATION OF THE EFFECTIVENESS OF THE *CAREGIVING*
ESSENTIALS COURSE FOR INFORMAL CAREGIVERS OF OLDER
ADULTS IN ONTARIO AND ITS ONLINE DELIVERY

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ESSENTIALS* COURSE FOR INFORMAL CAREGIVERS OF OLDER
ADULTS IN ONTARIO AND ITS ONLINE DELIVERY

By

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Abstract

Informal caregiving is a growing phenomenon, but many family members and friends fall into the role unequipped with the necessary knowledge and skills. Informal caregivers often experience high levels of burden and are vulnerable to developing negative health outcomes. Effective and easily accessible interventions are needed for this group. This research evaluates the effectiveness of the *Caregiving Essentials* pilot course offerings and their online delivery. The objectives of the course are to increase the following in terms of the caregiver experience: 1) Knowledge, ability, skills, confidence, and self-efficacy in caregiving, 2) Self-reported sense of personal health and well-being, 3) Perceptions of health and well-being of older adults in their care, and 4) Understanding and access of the health and social service system. The evaluation study determines whether these four objectives were met, and to what extent. Additionally, the research explores the ways in which the online delivery of the course contributes to its overall effectiveness, and specifically, whether aspects of the web-based modality enhance or hinder participants' learning experience. The methodology includes pre/post-course surveys (n=111/n=39), participant interviews (n=26), stakeholder interviews (n=6), and a focus group (n=5). *Caregiving Essentials* met many of the proposed research objectives. Increasing knowledge, understanding, and confidence was a stronger outcome than increasing the health and well-being of the caregivers and their care recipients. Overall, most of the participants reported positive experiences with the course, including a perceived positive future impact. Furthermore, the online delivery of the course enabled greater accessibility for participants and the discussion boards provided the opportunity for social interaction and a sense of community. The findings from this evaluation have been applied to future course offerings and may also inform other interventions for informal caregivers with similar objectives. In addition, this work provides contributions to policy decisions surrounding informal caregiving in Ontario, Canada.

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Preface

This Master's thesis is comprised of two research papers which have been prepared for academic journal submissions.

Chapter Two:

Rottenberg, S. & Williams, A. Evaluation of the *Caregiving Essentials* Course for Informal Caregivers of Older Adults in Ontario. Submitted to *Health and Social Care in the community*.

Chapter Three:

Rottenberg, S. & Williams, A. Evaluation of the Online Delivery of the *Caregiving Essentials* Course for Informal Caregivers of Older Adults in Ontario. Submitted to *Journal of Medical Internet Research Aging*.

Both papers are co-authored with Dr. Allison Williams (Master's supervisor). As co-investigator of the *Caregiving Essentials* evaluation research project, Dr. Allison Williams provided guidance on the direction of this research. The purpose of this research was informed by the creation of a project funded by the Ministry of Seniors Affairs titled, "Building Caregiver Knowledge and Skills to Support Older Adults: A Scalable, Technology-Enabled Learning Model." The larger project was created by team members from the McMaster Centre for Continuing Education, the McMaster Institute for Research on Aging, and the THRIVE Group. It should be noted that both authors collaborated on identifying the need for the research and the suitable methodologies required to conduct the evaluation for both papers. The first author, Shelley Rottenberg, was solely responsible for the remaining research data collection, data analysis, and interpretation of findings, literature review and writing the papers. The second author, Dr. Allison Williams, provided critical review and editorial advice for both papers in preparation for submission.

Chapter One: Introduction

1.1 Research Context

Canada's population is aging as more people are living longer, which means there is an increase in the number of older adults requiring care due to age-related needs. Partially due to this demographic trend, home care has become one of the fastest growing sectors of health care in the country (Kitchen, 2011). Another factor that has led to the growth of home care is the deinstitutionalization of health care in Canada, which has left many family members, friends, and communities with the responsibility of providing care (The Vanier Institute, 2013). Informal caregiving can be defined as unpaid care work provided by family members, friends, neighbours and other individuals (Yantzi & Skinner, 2009). Most caregivers are adult children; however, caregivers also include spouses, siblings, and grandchildren (Sinha, 2013). The nature of informal care work can be complex because of the variety of responsibilities it entails. Caregiving usually involves a combination of the following types of support: emotional, physical, psychological, social and financial (Hudson, 2004). Providing transportation, household work, and household maintenance were identified as the most common caregiving tasks (Sinha, 2013). However, informal care duties depend on the circumstances surrounding the care recipient and their health diagnosis.

The burden associated with informal caregiving of older adults can be overwhelming and stressful. Family caregivers are sometimes called the backbone of the health care system because while their work is important, they are often invisible to

society (Health Council of Canada, 2012). Becoming a family caregiver can happen suddenly if unexpected health crises arise, and it is not uncommon for this level of unpredictability to continue throughout the caregiving journey. Unlike paid caregivers, many informal caregivers take on the role not by choice, but due to family obligations (Marziali & Garcia, 2011). Thus, most informal caregivers are not equipped with the necessary knowledge, skills, and training when they begin their caregiving role (Given, Given, & Sherwood, 2008). Another aspect that makes this work challenging is the time required for informal caregiving. Some informal caregivers of older adults spend 30 hours per week or more on caregiving tasks, which is equivalent to the hours of a full-time job (Turcotte, 2013). Additionally, unlike normal childcare, there is often not a clear ‘end’ in sight when providing care for a senior, and care responsibilities may intensify as the care recipient grows older.

Caregivers reported feeling anxious or worried, often due to their caregiving duties, with approximately 1 in 5 caregivers reporting that their physical and emotional health suffered as a result of their caregiving responsibilities (Sinha, 2013). Family caregiving can be especially challenging due to the personal nature of the relationship between caregiver and care recipient. According to the 2008/2009 Canadian Community Health Survey— Healthy Aging, more than half of informal caregivers reported that they have encountered difficulties and challenges, one of them being the emotionally demanding nature of the work (Turner & Findlay, 2012). Based on data collected from The General Social Survey, spousal caregivers were more likely to experience psychological distress than other types of caregivers of older adults (Turcotte, 2013). This

may be because spousal caregivers oftentimes live with their care recipients and are usually spending more hours per week providing care. The intensity of caregiving also plays a role in the level of burden felt by informal caregivers. For example, based on the assessment of RAI-HC (Resident Assessment Instrument – Home Care) data, it was seen that caregivers of older adults who had higher MAPLe (Method for Assigning Priority Levels) scores were more likely to experience caregiver burnout (Health Council of Canada, 2012). It is essential for informal caregivers to prioritize their own health and well-being because they cannot properly provide quality care to their loved ones if they are in distress.

There are many other factors that can differentially influence the level of burden experienced by informal caregivers. For example, gender shapes the caregiving experience in many ways, and this stems from traditional gender norms regarding who participated in paid labour and unpaid work in the home (Williams & Crooks, 2008). Therefore, women are more likely to feel a greater family obligation to provide care for their parents or in-laws as they age. In Canada, women are: more likely to provide care than men; more likely to put in more hours of care per week, and; more likely to engage in a greater variety of tasks and responsibilities (Sinha, 2013). For instance, women are more likely to provide emotional labour while men are more likely to provide financial assistance. Thus, due to the increased amount of time and energy spent on caregiving tasks, women are more vulnerable to experiencing negative health outcomes.

Age is another individual characteristic that can create greater burden in some caregivers over others. The average caregiver is between the ages of 45 and 64 (Sinha,

2013), which overlaps with the age range of the labour force who are often in their prime earning years. More than one-third of the Canadian workforce are care employees, balancing unpaid care work with paid employment (Government of Canada, 2015). Juggling the responsibilities of both leaves less time for social/leisure activities and self care, which can cause heightened stress levels and negatively impact caregiver health and wellbeing (Duxbury & Dole, 2015). Moreover, informal caregivers between the ages of 35 and 44 represent those most likely to be sandwiched between childcare and eldercare duties (Sinha, 2013). This means that caregivers who have this double care responsibility are faced with role overload because they have more demands than those carers who do not have dependent children to take care of (Duxbury & Dole, 2015). Another challenge is caregivers who are older adults themselves, as they may be dealing with their own health issues associating with aging (Sinha, 2013). In this situation, it is even more crucial for them as caregivers to not neglect their own health needs.

In addition, since the availability and accessibility of care resources are unequally distributed across geographic regions, informal caregivers residing in remote areas face more barriers in using formal care services and seeking help from healthcare professionals (Yantzi & Skinner, 2009). The spatial distance between where informal care is provided and where care support services are offered is one of the biggest accessibility problems. Also, the lack of adequate transportation services for care recipients and their caregivers is another common issue for those living in rural communities. These barriers are especially challenging in the event of a health emergency. With caregiving resources for older adults being sparser and unobtainable (Williams & Cutchin, 2002), the burden

of care for family caregivers becomes that much more demanding. Without being able to rely on external support, informal caregivers living in more remote locations are doing more with less compared to caregivers that reside in more urban city centres.

Due to the high level of burden that many informal caregivers of older adults experience at some point in their caregiving journey, there is a great need amongst this population for more support resources. Many family caregivers report that they do not receive enough guidance from providers, they lack confidence in their role, and that they do not know how to access and utilize resources (Given, Given, & Sherwood, 2008). Furthermore, informal caregivers have also expressed not feeling entitled to ask questions or not knowing the appropriate questions to ask (Health Council of Canada, 2012). There is a lack of easily accessible information and training to prepare family members and friends for the wide range of tasks and responsibilities that come with being a caregiver. Informal caregivers who find themselves unable to cope are at risk of becoming care recipients themselves, which increases the likelihood of their care recipient transitioning into institutional care. Therefore, it is incredibly important that the needs of informal caregivers of older adults do not go unmet and that they are provided with the necessary knowledge and tools to help them effectively care for their loved one.

1.2 Research Purpose & Objectives

For information regarding the *Caregiving Essentials* module content, please see Appendix A. The purpose of this research is to evaluate the overall effectiveness of the

Caregiving Essentials course. The objectives of the project are to improve the following in terms of the caregiver experience:

- 1) Knowledge, ability, skills, confidence, and self-efficacy in caregiving;
- 2) Self-reported sense of personal health and well-being;
- 3) Perceptions of health and well-being of older adults in their care, and;
- 4) Understanding and access of the health and social service system.

This research evaluates whether the four main objectives were met after participants completed the *Caregiving Essentials* course (the knowledge intervention), and to what extent. Additionally, it explores the ways in which the online delivery of the *Caregiving Essentials* course contributed to the overall effectiveness, and specifically, whether aspects of the web-based modality enhanced or hindered participants' learning experience.

1.3 Thesis Outline

This thesis has been organized into four chapters. The first, this introduction, provides an overview of contextual information on informal caregiving in Canada. Specifically, the challenges associated with informal caregiving are highlighted to show the varying levels of burden that many informal caregivers may experience. This summary of the existing literature aims to establish a foundation of knowledge that is important for understanding the purpose of the *Caregiving Essentials* course, as well as its evaluation. In addition, the aim of this thesis has been identified by outlining the

overall research purpose and objectives, as noted above. Chapter 2 and 3 are presented in what follows as independent papers that have been submitted to scholarly journals for publication. Chapter 2 is an evaluation of whether *Caregiving Essentials* met the project's four objectives in terms of the caregiver experience. Participant feedback via post-course surveys and telephone interviews revealed that the most beneficial takeaways from the course were: increased knowledge and confidence (Objective 1), and increased access to and understanding of various resources that are available to support them in their caregiving role (Objective 4). An increase in their own health and well-being (Objective 2), and their perceptions of the health and well-being of their care recipient(s) (Objective 3) were more difficult to fully assess due to the influence of external factors unrelated to the course. However, the course was deemed effective overall due to the positive results and the perceived future impact that caregivers expected it will have on their role moving forward.

Chapter 3 is an evaluation of the effectiveness of the online delivery of the *Caregiving Essentials* course and explores the ways in which it enhanced or hindered participants' learning experiences. Stakeholders, nursing students, and informal caregivers of older adults provided feedback through telephone interviews or a focus group. The qualitative data revealed that the online delivery increased users' ability to access the course and enhanced the way in which they engaged with the module content. The online discussion boards also enabled social interaction among participants which was identified as a major strength. One barrier that inhibited full participation was the lack of comfort with using and contributing to online platforms. A couple of

recommendations that were suggested include adding more interactive methods of virtual communication and the reorganization of the module content for easier viewing.

Chapter 4, the thesis conclusion, summarizes the significant findings of the research. It also identifies possible limitations in the study before discussing the potential contributions that the thesis work can make for both policy and research. Finally, it offers some direction for future research both within the field of human/health geography and beyond.

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Chapter Two: Evaluation of the Effectiveness of the *Caregiving Essentials* Course for Informal Caregivers of Older Adults in Ontario

2.1 Abstract

Informal caregiving is a growing phenomenon, but many family members and friends fall into the role without any prior experience or training. Therefore, many individuals are unequipped with the necessary knowledge and skills needed to manage the demands of caregiving. The *Caregiving Essentials* course was created to meet this growing need for information and resources among informal caregivers of older adults in Ontario. The evaluation determined whether the online knowledge intervention was effective in meeting the following four objectives: 1) Increase knowledge, confidence, skills, abilities and self-efficacy; 2) Increase self-reported sense of personal health and well-being; 3) Increase perceptions of health and well-being of the care recipient; and 4) Increase understanding and access to the health and social service system. A mixed methodology was employed by collecting data through pre/post-course surveys and telephone interviews. A total of 26 semi-structured interviews were conducted with participants who completed most of the course content. Thematic coding was completed using NVivo software. Findings revealed that of the initial four objectives, the ones involving health and well-being were harder to achieve because of external contributing factors. However, due to the strong positive feedback on the increased level of knowledge, confidence, and access to resources, *Caregiving Essentials* was deemed effective overall.

2.2 What Is Known About This Topic?

- Informal caregivers of older adults are likely to experience burden and burnout due to the stressful nature of their role
- Acquiring knowledge and skills is the foundation that allows informal caregivers to then develop confidence and self-efficacy
- Multicomponent, psychoeducational interventions that involve active participation and personalization are the most effective

2.3 What This Paper Adds:

- Most caregivers reported an increase in knowledge, especially about information pertaining to available resources and supports
- Self-reported sense of health and well-being were more significantly influenced by external factors outside of the course
- Participants' perceptions of the health and well-being of their care recipients did not increase as a result of taking the course

Keywords: Evaluation, health, knowledge, intervention, informal caregiving, older adults

2.4 Introduction

2.4.1 Background

Due to Canada's increasingly aging population and the deinstitutionalization of the healthcare system, a growing number of Canadians are engaging in unpaid, informal care responsibilities (The Vanier Institute of the Family, 2013). 8.1 million Canadians report having provided care to a family member or friend with a long-term health

condition, disability or aging need in the past year (Statistics Canada, 2013), and the number of Canadians who will require caregiving is forecasted to double over the next thirty years (The Vanier Institute of the Family, 2017). Age related needs were identified as the single most common problem requiring help from caregivers (Statistics Canada, 2013).

Caregiving can be overwhelming and stressful because of the many responsibilities in which the role entails. Informal caregiving often requires a combination of emotional, physical, psychological, social and financial support (Hudson, 2004). Therefore, care can be anything from supervising the care recipient, to driving them to doctor appointments, to handling their personal hygiene needs. The role also calls for a certain level of knowledge and skills in which many family members and friends report not being equipped with (Given, Given, & Sherwood, 2008). In many cases, informal family caregivers learn as they go or must seek out relevant information for themselves which add to the burden of caregiving.

In addition, the availability and accessibility of care resources are unequally distributed across various demographic groups and geographic regions (Yantzi & Skinner, 2009). Rural locations, such as areas in Northern Canada, experience a lack of services and facilities when it comes to care supports. For the resources that do exist in these remote regions, they are often less accessible to those in need due to spatial and financial barriers. Geographic distance paired with poor transportation infrastructure makes it particularly difficult for informal caregivers. Therefore, this disparity in the utilization of health services between urban and rural areas is causing a difference in

health status among care recipients (Kitchen et al., 2011). There is a great need amongst informal caregivers, especially those of older adults, for more information that is both easily accessible and in a centralized location.

2.4.2 Literature Review

Many interventions have been developed over the years to help caregivers. They differ in terms of inclusion criteria, population sample sizes, intervention types, study objectives, and study designs. These various factors influence intervention outcomes and therefore their level of effectiveness. Despite the differences, there are still overarching similarities and patterns amongst past studies in terms of which interventions were shown to be effective, in what capacity, and why. In Hudson's (2004) critical review of caregiver interventions, it was concluded that psychoeducational interventions on an individual basis were the most valuable, which correlates with the positive outcomes of the "Learning to Become a Family Caregiver" program (Ducharme et al, 2011). Hudson's review (2004) advocates for interventions with information-focused strategies that aid caregivers in reducing burden and planning for future needs. Pinguart & Sörensen (2006) echo this finding in their meta-analysis of 127 interventions, which revealed that structured psychoeducational interventions have the broadest effects on burden, depression, wellbeing and knowledge. However, this finding was conditional on the implementation of active participation into the intervention design (Given et al., 2008).

Peacock & Forbes (2003) proposed that education interventions with specific training on how to cope with difficult situations were of the most effective. Rabinowitz et

al (2006) noted that skill-based psychoeducational interventions were more appropriate for caregivers who had a lower self-perceived sense of agency regarding their caregiver responsibilities. The authors emphasized the importance of analyzing caregiver self-efficacy because it can affect caregivers' reactions to interventions (Rabinowitz et al., 2006). In the Liddle et al (2012) paper about a DVD-based training program for informal caregivers, evidence revealed that the training group experienced improvement in knowledge of coping strategies and positive perceptions of caregiving. However, findings on burden reduction was not statistically significant. Comparable outcomes were seen on a slightly larger scale in McMillian's (2005) review of a dozen descriptive studies of various intervention types. It was determined that educational interventions tended to enhance caregivers' perceived wellbeing, but had no impact on decreasing burden or depression. Findings from the systematic review by Peacock and Forbes (2003) also suggested that education interventions are ineffective at improving psychological wellbeing of caregivers.

Conversely, multi-component interventions appeared to be more successful in reducing burden and increasing ability, knowledge and wellbeing (McMillian, 2005; Sörensen, Pinquart & Duberstein, 2002). The strength of multi-component interventions was also highlighted in the Pleasant et al (2017) evaluation of an online program for caregivers of people with dementia. It was suggested that online interventions were more likely to be successful if they were personalized and mixed with other interactive methods. The paper also noted that as online education becomes more popular, more engaging methods of assessment are being incorporated into interventions.

Evaluating effectiveness based on the type of caregiver is also crucial to maximize positive outcomes for a diverse group of participants. For some studies, there was a greater increase in ability/knowledge for female caregivers (Pinquart & Sörensen, 2006), and this may be due to the gender differences of experiencing burden. One analysis found that women were more likely to be depressed in their caregiving role than their male counterparts (Pinquart & Sörensen, 2006). Caregivers who were adult children of their care recipients and those engaged in paid employment were also more likely to be depressed (McMillan, 2005). Therefore, the ability to customize interventions to meet the needs of a diverse group of caregivers is needed to achieve inclusivity. McMillan (2005) also addresses the issue of making interventions more culturally sensitive to caregivers who are ethnic minorities.

2.4.3 Theory

Intersectionality is a theoretical perspective used across a multitude of disciplines within academia. It has been theorized as the lived experience of a person (Valentine, 2007). It is also described as a person's sense of self, comprised of the intersection of multitude identities which change across space and time (Valentine, 2007). This theoretical framework can be applied to caregiving because it can help assess how different factors intersect with the role of a caregiver to produce varying levels of burden. Female caregivers are more likely to put in more hours of care per week than male caregivers (Statistics Canada, 2013). The type of care in which female caregivers provide tends to be more personal (Statistics Canada, 2013) which could have greater

ramifications on their mental health. Additionally, caregivers living in more remote areas, or those belonging to a lower socioeconomic class, are further burdened due to their limited access to available care resources. It is important to recognize the heterogeneity of informal caregivers' experiences. Accumulative disadvantage arises when a caregiver's positionality affords them less privileges due to their intersecting identities or circumstances. It is estimated that participants who experience the highest burden in their caregiving role prior to taking the course will find the intervention the most effective.

2.4.4 Research Purpose

The aim of the research is to evaluate the effectiveness of the online knowledge intervention course, *Caregiving Essentials*, in meeting its objectives. The objectives in terms of the caregiver experience are the following: 1) Increase knowledge, ability, skills, confidence, and self-efficacy in caregiving, 2) Increase self-reported sense of personal health and well-being, 3) Increase perceptions of health and well-being of older adults in their care, and 4) Increase understanding and access of the health and social service system. The goal is to see improvement from baseline in some, or all, of these areas after participants complete the online course. This feedback will help enhance future course offerings.

2.5 Methods

2.5.1 Study Design and Recruitment

The *Caregiving Essentials* Course is an eight-week, online knowledge intervention hosted on Desire2Learn. It was created by members from the McMaster Centre for Continuing Education, the McMaster Institute for Research on Aging, and THRIVE Group. The course was launched with two pilot offerings: Fall 2018 and Winter 2019. Participants were the primary caregiver to a family member or friend who was 65 years or older and still residing at home. They were recruited from either Hamilton, Sudbury or Timmins for the first offering, and anywhere in Ontario for the second offering. Participants were recruited through community partner networks using letters, flyers, email listings, and verbal communication. For the evaluation component, participants who had completed most of the online course were asked to provide their feedback via surveys and interviews.

2.5.2 Data Collection

A mixed methods approach was used to gather participant data. Before the course, participants were asked to complete an online survey containing questions about their caregiver experience, their level of self-efficacy, their access to and use of technology, and demographic information for themselves and their care recipient. Upon completion of *Caregiving Essentials*, participants were prompted to complete another online survey which was the same as the pre-course survey except for an additional section which asked respondents about their experience participating in the course. Additionally, 26 individual

telephone interviews were conducted to gather more in-depth feedback on participants' perceptions of the effectiveness of the course. Sample size information is outlined in Table 1.

2.5.3 Data Analysis

Due to the large gap in the number of participants who completed the pre-course survey versus the post-course survey, the quantitative data before and after the course were not able to be compared. However, the post-course survey responses were analyzed and supported the major findings of the 26 interviews from both course offerings. Interviews were recorded with participants' consent and transcribed. The transcripts from the interviews were analyzed using thematic coding in NVivo 12 Pro. A total of 45 nodes and subfolders were created, which eventually led to the formation of 11 distinct categories relating to the four main course objectives.

2.5.4 Ethics

A completed ethics application was submitted to the McMaster Research Ethics Board by the individual conducting the evaluation of the project. A research ethics officer informed the research team that the study fell under TCPS 2 Article 2.5 and was therefore exempt from REB review. However, all team members who interacted with participants and/or their data still made a conscious effort to follow the research ethics guidelines throughout every stage of the project to the best of their abilities. Electronic and verbal consent was obtained from all participants who provided data. In addition, confidentiality

was maintained, and participants' real names and other identifiable information was kept private.

2.5.5 Rigour

To ensure rigour throughout the evaluation, various practices aimed to meet the criteria were incorporated into the design. For credibility, open-ended interview questions were used to gain honest answers based on the participants' true experiences. The mixed methodology also allowed for data triangulation which helped to ensure the validity of the evaluation results. To ensure transferability, the evaluation tools were easily accessible regardless of the participants' geographic location. Thus, the methodology can be applied if the course were to expand to other areas or scale up to the national level. To guarantee dependability, interviews were recorded so the interviewer could simultaneously take field notes, which provided more context and additional observations. Most of the interviews were transcribed by the researcher who collected the interview data. This consistency in roles reduced the chances of the data losing its meaning through misinterpretation by multiple researchers. To ensure confirmability, the researcher conducting the evaluation of the project was not involved in the project in any other way. Therefore, the researcher had no bias towards more positive feedback and no motivation to seek out certain results.

2.6 Findings

2.6.1 Participants

The participants involved in the evaluation were informal caregivers of older adults who had completed most of the modules by the course end date. Involvement in the evaluation was not tied to their participation in the course. Therefore, data was only collected from individuals willing to provide feedback. Demographic information was not asked during the interviews for confidentiality purposes but was gathered from participants who completed the anonymous post-course survey. Based on the post-course survey responses, over half of the respondents were between 45 to 64 years of age and more than 80% of them identified as female. With respect to other life obligations, a little over half of the respondents engaged in either part-time or full-time employment, and less than 20% of them had dependents under the age of 18. In terms of their experience as a caregiver, just over half of the respondents were taking care of a parent, and more than 70% had been a caregiver for 1 to 3 years.

2.6.2 Overview of the Findings

The post-course survey findings appear in Table 2. The interview findings have been organized to correspond with each of the four project objectives. The effectiveness of the *Caregiving Essentials* course was measured using the following objectives: 1) Increase knowledge, ability, skills, confidence, and self-efficacy in caregiving; 2) Increase self-reported sense of personal health and well-being; 3) Increase perceptions of health and well-being of older adults in their care; and 4) Increase understanding and

access to the health and social service system. All objectives were met by at least some of the participants. Objectives 1 and 4 were met by many of the participants involved in the evaluation, whereas objectives 2 and 3 had more mixed feedback. While some participants were not able to completely report an increase in all areas of an objective, if they indicated a partial increase, or a perceived increase in the future, their response was still considered positive. Interviewees were categorized based on which course offering they participated in. Therefore, the identifier F8 refers to a participant from the fall offering and the identifier W13 refers to a participant from the winter offering.

2.6.3 Objective 1: Knowledge, ability, skills, confidence, and self-efficacy in caregiving

The first objective encompasses several variables that were anticipated to increase after participants completed *Caregiving Essentials*. Since this project was mainly a knowledge intervention, the online modules were information heavy. Most participants offered positive feedback on at least some of the information they received from the course. The type of positive feedback differed depending on participants' individual circumstances with their care recipient. Some participants had entered the course looking for specific information, or with certain expectations of what they would get from the course.

While some participants would have liked to receive more in-depth information on various topics, most agreed they still learned something new. For example, one participant shared, “[The course] covered things I never thought about... It's a real eye-

opener” (W7). Similarly, another respondent said, “I did learn something from every single module” (W5).

Caregivers who were newer to the role found that the information allowed them to be proactive. For instance, one participant said, “It was an eye-opener... things to start to prepare for... It met my needs perfectly at that point” (F7). Even caregivers that were more experienced in their role were able to leave the course with increased knowledge. This was seen when one participant mentioned, “Even with my exposure, I did learn new information through this course” (F2).

Some participants who already knew a wealth of the information still felt their confidence had increased because the course assured them of prior knowledge. One participant stated, “It was really refreshing to read... and know that I'm on the right track” (F13). Another responded with, “It was just nice to see that stuff was confirmed... that I hadn't missed anything. It was reassuring” (F4). Additionally, coming across information that was relevant to their caregiver experiences further validated them in their role: “I was able to quantify my experience into words by doing the course” (F3). The ability to understand and communicate their own experiences allows caregivers to have more confidence when they are sharing their story with others.

Some participants did express an increase in self-efficacy when navigating the healthcare system and social services. A couple specifically shared that they were more able to advocate for their care recipient and play a more active role in their health. For example, one caregiver shared the course's impact as “not being afraid to advocate to help where you can... I think that impacts [my care recipient's] health” (F10). Likewise,

another individual said, “I’ve gained confidence in navigating it and I feel I’m a pretty strong advocate for them” (F4).

Skills and abilities were two of the variables from this objective that did not see as much of an increase because the course information was purposefully general so the modules could apply to most caregivers. Learning new skills or allowing for participants to enhance their abilities was somewhat achieved in relation to their increased knowledge and confidence. Also, skills and abilities are developed over time and become stronger the more they are practiced. The information from the modules could have led to an increase in skills and abilities, but this outcome may not have been apparent soon after the course end date, meaning participants would not be aware of them or able to speak on them.

2.6.4 Objective 2: Self-reported sense of personal health and well-being

Many of the participants described experiences of caregiver burden. Some talked about stress, anxiety, and feeling overwhelmed: “It can be very overwhelming, and you don’t really know where to turn to for resources” (W2). Many shared about the busyness of their role: “I’m providing full-time care to both my parents, so I’m here basically from 7 in the morning to 7 in the evening” (F4). A number of caregivers spoke of balancing their caregiver responsibilities with other duties, such as work: “It’s a lot on me because I work and I’m self-employed” (F1), or other forms of care: “I’m a before and after school grandma” (F8). Others reported a lack of self care practices which further exacerbated their level of burden: “I was making excuses when it came to taking care of myself” (F1).

Some burden was caused by issues surrounding the health of their care recipient, some related to difficulties with navigating the healthcare system, and some stemmed from a lack of supports available or accessible to them.

Some of the causes of burden were reduced through the information and resources provided in the course. A couple participants explained how their increased confidence after taking the course had a positive impact on their health: “I’m calmer. I now have another box to open when I’m researching something for action or to help resolve something” (F5). Comparatively, another interviewee said, “It gave me the confidence and helped me to calm down about the situation and not panic and just take it one day at a time” (F8). Some participants also reported that their wellbeing was influenced by knowing they were not alone “It was very eye-opening and refreshing to see that you're not alone.” (W3). Additionally, another caregiver mentioned that “[It’s] nice to know that someone else is experiencing what you're experiencing. [It's] validating almost” (W4).

Alternatively, several participants claimed the course had no effect on their personal health and wellbeing. While they found the course useful, and may have learned new information, there were participants that said it wasn’t enough to improve their health in any material way. This was especially true for caregivers that were experienced and had the knowledge and access to support services, but experienced burden from more concrete factors such as the health of their care recipient:

“It did not impact my health and wellbeing in any way. I continue to do my regular thing as a caregiver. It didn't necessarily relieve my stress... make my caregiving experience better” (F3).

When asked if their participation had an impact on their own health or wellbeing, one person said, “I can't say that it did. I don't know that things are any better” (F4).

2.6.5 Objective 3: Perceptions of health and well-being of older adults in their care

None of the participants reported a positive change in their perceptions of their care recipient's health and wellbeing as a result of taking the course. Most participants perceived the health and wellbeing of their loved one accurately and based on their care recipient's health status. Those that had positive perceptions of their care recipient's health already had those insights prior to their participation in the course. One participant explained that their loved one was already being well cared for and the course did not play a role in that: “They are well cared for and they know they are... I don't know that the course impacted that in any way. A lot of that was already in place before I signed up for the course” (F4). Another participant had similar remarks in saying that this objective was not an expectation of hers going into the course:

“My mother is getting what she needs here... we've done a lot of things over the course of time to make it as comfortable as possible for everybody, including my mother. I wasn't really anticipating any... revelations on that front” (F11).

Likewise, another participant said they didn't see how the course content could correlate to improved perceptions in their care recipient's health and wellbeing.

Four of the participants had their care recipient's health decline either during the course or afterwards because of external factors. One of those participants unfortunately had their loved one pass away near the start of the course. Therefore, their perceptions

surrounding the health of their care recipient would have gotten worse despite any increases in their knowledge, abilities, skills, confidence, and/or self-efficacy as a result of taking the course:

“After the caregiving course was over, my dad, he became really ill... I had to take him to the intensive care unit. His health has gone down, but his health has nothing to do with the course. It has everything to do with himself” (F3).

“I think the course had not even started or it was maybe in the first week, I contacted [the project coordinator] I think to let her know that my mother had died.” (F12).

Some participants did talk about more positive perceptions in relation to the care they provide to their loved one moving forward. Some participants described feeling better equipped for some of their caregiving responsibilities and how that could lead to an indirect positive change in their care recipients' health and wellbeing over time. For instance, one participant shared, “I don't think I'm at that point yet where I'm going to need all of it. I think [the information] will be helpful for me in the coming future” (F7). “[I] think it did help. Just about getting financial things in place, responsibilities of family down the road, and end of life things should be in place just in case” (F10).

Therefore, since the course content was created for the caregiver, the participants' positive perceptions were more self-centred. Participants who estimated their care recipient's health and wellbeing would improve in the future were optimistic because they believed the course enhanced the way they delivered care. Thus, the perceptions regarding their own level of control over their caregiving circumstances was influenced. In several instances, participants were trying to be proactive so that they could maintain

their care recipient's good health within the coming years. "I think because my mom is not really dependent on me so much right at the moment, I'm more anticipating what they're going to be needing after" (F14).

2.6.6 Objective 4: Understanding and access to the health and social service system

Many participants were already connected to some social services or had experiences with navigating the healthcare system. Many referenced support resources they had accessed in the past or were currently utilizing. Respondents also mentioned doctor appointments, hospital visits, and interactions with various healthcare professionals. Some shared about the gaps in the current system, explaining that there is a lack of resources and services, or at least a lack of knowledge on how to find ones that are both applicable and accessible to them: "There's just so many things in the community that is so difficult to find out what's available, but I'm just not sure how you do that." (F12). This was especially true for one participant living in a more remote region: "In a smaller community, some of the services are really poor and were lacking." (F10).

One participant described a couple of negative experiences they have gone through at the hospital and the need to advocate for their care recipient (F1). Whether navigating the internet for resources or physical spaces within the care landscape, participants commonly expressed feeling overwhelmed at times. There seemed to be a need for greater understanding on how to navigate and access different health systems.

In terms of social services, many participants did discover new resources and areas of support that they were either not aware of or did not have a strong understanding

on how to access them. One respondent noted, “The section I found most useful was the section on the resources and having those all in one place” (F4). A different caregiver shared, “Having that information and knowing there's places to go to help you navigate this is just amazing as far as I'm concerned” (F8). The last module of the course contained external resources to further help caregivers beyond the scope of the course. Many participants cited this specific module and the comprehensive list of resources as being one of the major strengths (W1, F12, F7).

2.7 Discussion

2.7.1 Data Analysis

The post-course survey results show higher participant agreement with statements relating to the acquisition of new information and the ability to use the information in their caregiver role. These statements loosely correlate with Objective 1 and Objective 4. Statements regarding an improvement in caregiver confidence, care recipient impact, and attitude towards their caregiver role all experienced less agreement from respondents. These statements loosely correlate with the Objective 1 and Objective 3. The post-course survey results reflect participant interview responses as most caregivers were able to report gaining knowledge from the course, with many specifically referring to learning about resources and supports that are available to them. Not as many respondents were able to provide feedback that indicated Objective 3 had been met. Participants either reported no change in their perceptions of the health and well-being of their care recipients after completion of the course, or some even reported a decline due to

worsened health outcomes. Therefore, it was determined that the health and well-being of both the caregivers and the care recipients was more strongly influenced by external factors not relating to the course.

In addition, some participants who were interviewed expressed being advocates for their care recipients and felt that the course material supported them in that role. This relates to Objective 1 because it represents confidence and self-efficacy. It also connects to Objective 4 because their knowledge and confidence allows them to better understand and navigate the healthcare system and social services. Acting as an advocate for their care recipient may only become useful when the opportunity arises, therefore it is harder to measure immediately after the course end date. However, this ability has the potential to indirectly improve the health and well-being of the care recipient, which was an objective that participants were only able to report as potentially having a positive impact later in their caregiving journey.

Another noteworthy observation of the interview responses was that the participants who had shared experiences of greater caregiver burden prior to taking *Caregiving Essentials* were more likely to report a higher level of effectiveness afterwards. Caregivers who were having more difficulty in their role faced the greatest need and thus, these participants were more satisfied with their experience taking the course. Whether the burden was associated with the circumstances relating to their care recipient or a lack of knowledge on their end, these respondents seemed more likely to describe the course as valuable and helpful. Although interviewees were not directly asked personal or identifying information, based on the survey data, these participants

were more likely to be newer caregivers, those living in more rural areas, and/or those who were balancing their caregiving with other obligations such as childcare or paid employment.

Using the theoretical framework of intersectionality, the level of burden experienced by informal caregivers of older adults is more likely to be greater for individuals who face cumulative disadvantage. As the literature suggested, spousal caregivers that are older themselves may experience more difficulty because they are more likely to live with their care recipient and may have health issues themselves. Additionally, due to traditional gender norms and family obligations, women are more likely to be tasked with the responsibility of providing care. Therefore, the intersection of gender and age creates the opportunity for even more burden, which can grow once other factors are considered such as socio-economic status, sexuality, race etc. The ways in which the lived experience of an individual influences their caregiver role and their level of burden must be acknowledged to understand the heterogeneity of needs. The variation in needs amongst informal caregivers of older adults can then be addressed with more tailored and targeted interventions to increase the effectiveness for each end user.

2.7.2 Limitations

A limitation of the evaluation was the recruitment constraint. Only participants who had completed most of the course content were asked to provide feedback for the evaluation. This was decided because in order to comment on the effectiveness of the project, participants needed to discuss all four objectives. They would not be able to fully

evaluate the course if they did not go through at least three of the five modules. Thus, the interview results do not capture the experiences of those who stopped partway through the course. It is possible that the participants who qualified to be involved in the evaluation were more likely to give a certain type of feedback. Therefore, the interview responses may not accurately represent all participants who took the course.

Furthermore, participation in the evaluation of the course effectiveness was voluntary, and not everyone who finished the course were willing to offer their feedback. Participant attrition occurred over the duration of the evaluation period. The number of people that filled out the post-course survey was less than the number of people who filled out the pre-course survey. Therefore, the before and after responses could not be compared because of the difference in the number of completed surveys. An even smaller amount of people agreed to a telephone interview due to a lack of time, disinterest, and other reasons. The drop in participants partially speaks to the busy nature of caregiving and thus attrition is to be expected when working with these types of sample populations.

2.7.3 Conclusion

In conclusion, *Caregiving Essentials* appeared to meet some of the proposed research objectives. Increasing knowledge, understanding, and confidence seemed to be areas that were more inclined to improvement. On the other hand, the health and well-being of the caregivers and their recipients were more difficult to have a positive effect on. However, overall, the participants did report positive feedback in terms of the effectiveness of the course, both through survey response and interview answers. This

project confirmed that there is a gap in easily accessible resources and information for informal caregivers of older adults. Therefore, more research should be conducted on this topic to further develop the supports available to this under-served demographic.

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2.9 Tables

Table 1: Participant Engagement Numbers

Pilot Course Offering	Number of Recruitment Inquiries	Number of Course Registrants	Number of Completed Pre-Course Surveys	Number of Completed Post-Course Surveys	Number of Conducted Telephone Interviews
Fall 2018	150	70	52	20	14
Winter 2019	165	70	59	19	12
Total	315	140	111	39	26

Table 2: Post-Course Survey Results (Paper 1)

Survey Statement	Respondents who Agreed
I would recommend this course to a friend.	97%
I learned new information in this course.	91%
I am able to use this information in my role as a caregiver.	91%
I am confident in my knowledge, skills, and abilities to care for my loved one.	70%
I feel my care recipient has benefitted from my participation in this course.	71%
I have recognized that I have a more positive attitude towards my caregiver role after completing this course.	69%

Chapter Three: Evaluation of the Online Delivery of the *Caregiving Essentials* Course for Informal Caregivers of Older Adults in Ontario

3.1 Abstract

Background: Many informal caregivers of older adults have limited time due to the number of responsibilities their caregiving role entails. This population often also experiences high levels of burden due to the stressful nature of their work and are vulnerable to developing negative psychological health outcomes. Easily accessible and flexible knowledge interventions are needed to alleviate the burden and stress felt by this group.

Objective: The aim of this paper is to evaluate the online delivery of the *Caregiving Essentials* course for informal caregivers of older adults, as well as evaluate its effectiveness. Both strengths and limitations of using an online platform to provide information and resources were explored to see whether the method of delivery enhanced or hindered the overall learning experience for participants.

Methods: A mixed methodology of online pre/post-course surveys (n= 111/39) and telephone interviews (n=26) were used to collect both qualitative and quantitative data from participants. Individual interviews were also conducted with key stakeholders (n=6) and a focus group was conducted with nursing students (n=5) who were involved in the project.

Results: The online delivery of the course enabled greater accessibility for participants because it allowed them to independently work through the modules at their own pace,

wherever and whenever. The discussion boards were also identified as a major strength because of the opportunity for social interaction and the sense of community that many felt through sharing their experiences. Some barriers to participation included age-related factors, issues with navigating aspects of the course, and concern for privacy and anonymity. Some key suggested improvements include more engaging methods of virtual communication and the reorganization of the module content to reduce text and streamline information.

Conclusions: The online delivery of the *Caregiving Essentials* course appeared to enhance the overall learning experience by increasing accessibility and allowing for interaction among caregivers. The findings from this study has shown that internet-based interventions can be effective in providing informal caregivers of older adults with knowledge, resources, and support.

Keywords: Informal caregivers; family caregivers, older adults, elder care, web-based intervention; online intervention, online course, health education, eHealth, evaluation

3.2 Introduction

3.2.1 Background

There is a growing number of Canadians engaging in unpaid, informal care work [1]. This is largely caused by Canada's aging population which is an increasing demographic trend. Another contributing factor includes the shift in the responsibility of

care from institutions to communities and families. Approximately 8.1 million Canadians reported having provided care to a family member or friend with a long-term health condition, disability or aging need almost a decade ago [2]. This statistic is likely much greater today, and the number of Canadians who will need to be cared for is expected to double over the next thirty years [3]. Caregivers identified age related needs as the single most common problem for which they required help [2].

Informal caregiving of an older adult is oftentimes overwhelming and stressful because of the diversity of responsibilities and unpredictable nature of the work. It usually calls for a mixture of emotional, physical, psychological, social and financial support from the caregiver on a regular basis [4]. In addition, the role requires a knowledge base and skillset which many family members and friends are unequipped with at the onset of their caregiving journey [5]. In many cases, family caregivers must learn information and seek out resources along the way, which only further adds to the burden they experience. Sometimes, people may be unexpectedly thrown into the role of caregiving when health complications arise suddenly in a friend or family member. In some cases, informal caregivers assume the role because it is seen as a family obligation [6]. Consequently, it is crucial that caregivers have access to proper support and resources to help alleviate stress and potential negative health outcomes.

However, the availability and accessibility of formal care services are not equally distributed across space [7]. Rural and remote locations have little to no services to support a family member providing care for an older adult. Even for the resources that do exist in rural areas, limitations such as distance and money may prevent caregivers from

accessing them. When informal caregivers are isolated from the healthcare system and from trained professionals, they experience more unmet tangible needs and thus more burden. This accessibility gap between urban and rural caregivers can result in differential health status among the care recipients [8]. Consequently, there is a significant need for more easily accessible information to be available for informal caregivers of older adults, irrespective of where they live.

3.2.2 Prior Work

Many interventions have been implemented over the years to meet the needs of informal caregivers of older adults. The literature shows that interventions which are individually tailored and have multiple components are the most effective types for this population [9], [10]. Research indicates that interventions with multiple components have led to stronger physical and mental health benefits for participants when compared to single component programs [6]. Psycho-educational interventions that can be personalized allow for more significant effects because of the targeted intervention delivery [11].

Although traditional face-to-face interventions are more common, E-health interventions are growing in popularity. The number of people who are seeking support online is increasing [12], as is the number of internet users who are older adults [13]. Therefore, web-based interventions fit with the contemporary behaviour of many informal caregivers today. Additionally, they easily allow for both individualization and the use of multiple components, increasing their effectiveness. The four major

components of internet-based interventions are: (1) content, (2) multimedia, (3) interactive online activities, and (4) guidance and supportive feedback [14].

Several online interventions have been conducted for different types of informal caregivers, showcasing the feasibility of using this mode of delivery. In a systematic review, results indicated that internet interventions can improve various aspects of caregiver well-being [13]. Similarly, in another systematic review, the impact of online interventions for caregivers was deemed to be clearly positive, with improvements in self-efficacy, anxiety and depression observed [15]. Other promising online intervention outcomes have been seen, such as a reduction in caregiver burden [16], an increase in social support and role awareness [17], and a greater intention to access help from others [9].

In terms of the effectiveness of online delivery, caregivers have responded positively to initiatives involving online education and internet support groups [18]. For example, in one pilot study on a videoconferencing intervention, 95% of the family caregiver participants reported that using computers for the group meetings was either very positive or moderately positive [19]. Moreover, it has been shown that internet-based interventions for informal caregivers are acceptable and just as effective as the conventional face-to-face interventions [15].

Due to service-access limitations, informal caregivers may not want or be able to use formal care services and other resources. Therefore, internet interventions can provide education and support to informal caregivers facing participation barriers [19]. Furthermore, since online interventions are generally more cost-effective and accessible

to informal caregivers than in-person interventions, they present promising opportunities for scalability [20].

Accessibility and asynchronism, which is the lack of simultaneous occurrence, were two advantages identified by participants regarding the online modality of a training program [11]. Participants in that intervention also emphasized the importance of interacting with other caregivers because it reduced social isolation [11]. In another study on internet-based support, findings revealed that anonymity, asynchronism, and connectivity were main advantages of computer-mediated communication [12]. In terms of connecting with other caregivers, participants have been more engaged and experienced more benefits when the intervention type was more interactive [6]. One systematic review observed that interactive online activities paired with the provision of human support were effective in enhancing psychological well-being of caregivers [14].

Despite the many positive outcomes of internet-based interventions and the several strengths of the online delivery, there is a lack of randomized controlled trials [20]. The heterogeneity in intervention design, methodologies, outcomes, participant characteristics etc. makes cross comparison unattainable. More rigorous study designs and stronger methods would allow for more robust conclusions on the efficacy of such interventions for informal caregivers of older adults [18]. Also, more research should be done to determine which types of online interventions work best for which types of caregivers [21].

3.3.3 Context and Goal of the Study

The *Caregiving Essentials* course is an open-access knowledge intervention hosted on Desire2Learn. The eight-week course was created by team members from the McMaster Centre for Continuing Education, the McMaster Institute for Research on Aging, and THRIVE Group. The online course was launched with two pilot offerings, one in the Fall of 2018 and the other in the Winter of 2019. The course aimed to enhance caregivers' knowledge and confidence regarding health care issues pertaining to older adults, improve caregivers' understanding and access to health and community care systems, and increase caregivers' personal health and well-being. *Caregiving Essentials* is comprised of five modules (see Figure 1 below), discussion boards, and interactive activities. The goal of the research is to evaluate the online delivery of the *Caregiving Essentials* course for informal caregivers of older adults. To determine whether the online delivery had a positive or negative impact on the overall effectiveness of the course, those involved in the project were asked to identify strengths, limitations, and areas of improvement regarding the online learning experience.

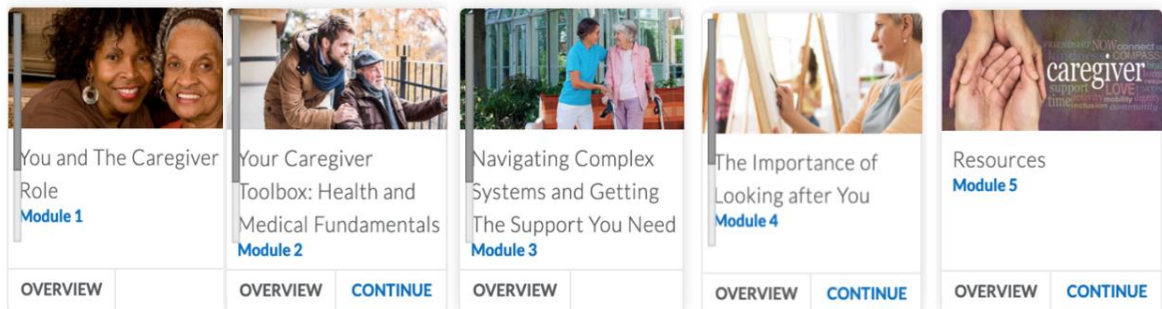


Figure 1: Modules from the *Caregiving Essentials* Course

3.3 Methods

3.3.1 Recruitment

The inclusion criteria for the *Caregiving Essentials* course specified that participants must be the primary caregiver to an older adult (65 years or older) who is still living at home. Recruitment strategies targeted people residing in Hamilton, Sudbury or Timmins for the fall course offering, and then efforts were expanded to anywhere in Ontario for the winter course offering. Participants were recruited using various community partner networks such as long-term care homes, respite relief services, senior community centres and academic institutions. The participants involved in the evaluation of the project were informal caregivers of older adults who had finished most of the module material by the official course end date. Participation in the course evaluation was not compulsory, therefore data was only collected from those who were willing to offer their feedback (see Table 3 below).

Table 3: Participant Engagement Numbers

Pilot Course Offering	Number of Recruitment Inquiries	Number of Course Registrants	Number of Completed Pre-Course Surveys	Number of Completed Post-Course Surveys	Number of Conducted Telephone Interviews
Fall 2018	150	70	52	20	14
Winter 2019	165	70	59	19	12
Total	315	140	111	39	26

Recruitment for the study was done via email communication, and both electronic and verbal consent was obtained. Six key stakeholders were also recruited to participate in the evaluation, as well as a group of nursing students who moderated the course discussion boards and offered support to participants through email.

3.3.2 Data Collection

A mixed methodology was used for the evaluation of the online delivery of the course. Participants were asked to complete an online pre-course survey which contained questions about their experience as a caregiver, their access to and use of technology, and demographic information for both themselves and their care recipient. Participants were then asked to complete a post-course survey which contained a variety of questions about their experience taking the course. For both online surveys, participants' confidentiality was maintained, as answers could not be linked to individual participants. Caregivers who

finished most of the module content were invited to participate in one-on-one telephone interviews to provide more in-depth feedback. A total of 26 participant interviews were conducted. Telephone interviews were also conducted with six key stakeholders. A virtual focus group was also conducted with five nursing students who had an active role in the course.

3.3.3 Data Analysis

The survey data collected from participants before and after the course could not be compared because there was a significant difference in the number of people who completed the pre-course survey versus the post-course survey (see Table 1). However, the post-course survey responses were compared with the qualitative feedback and supported the major findings. The audio recorded interviews and focus group were transcribed and analyzed using thematic coding in NVivo 12 Pro. The data from the stakeholders, nursing students, and participants were triangulated which assisted in insuring the validity of the results.

3.4 Results

3.4.1 Survey Data

As noted in Table 4, the high number of participants that agreed with survey statements #1 and #6 suggests that the online delivery of *Caregiving Essentials* did not detract from the overall effectiveness and likeability of the course, and it may have even enhanced it. However, the online platform did seem to pose as a barrier for some of the

participants. The most challenging aspect of the online delivery appears to be in relation to the usability and navigation of the discussion board section of the course. Survey statement #2 and #3 have the lowest participant agreement, and both statements address participants' comfort and confidence levels regarding posting their ideas online. Most participants agreed to survey statement #5, which may indicate that the difficulty in using the discussion boards may have only been at the beginning of the course and did not completely prevent participants from interacting with each other online. Therefore, the delivery of information was not hindered, but the opportunity for social engagement may have been. The responses to survey statement #4 assessed participants' ability to determine the credibility of online resources. The lower agreement outcome for this statement may highlight the need for an intervention such as *Caregiving Essentials*.

Table 4: Post-Course Survey Results (Paper 2)

#	Survey Statement	Respondents who Agreed
1	I would recommend this course to a friend.	97%
2	I am comfortable sharing my ideas in written format online.	42%
3	I am confident using and contributing to an online discussion group when I need help or information.	47%
4	I feel comfortable assessing the information I discover online for their integrity and truthfulness.	53%
5	I am satisfied with the level of interaction in this course.	76%
6	In the future, I would be willing to take an online course again.	86%

3.4.2 Stakeholder Interviews

Stakeholders emphasized the importance of the online delivery for the effectiveness of the *Caregiving Essentials* course: “People don’t want to come out or maybe they can’t get out because of that person that they have at home and it’s not easy to find some relief [...] The online was just vital” (S2).

The online delivery made the course more flexible, which was noted as a strength by one stakeholder: “It was presented in a manner that would be palatable to older adults who are quite busy – in short packages” (S5). Since many informal caregivers are already overwhelmed, they may not have the time to search the web for help. This problem was addressed by one of the respondents: “The other thing that I think was really good about this project was that it brought a whole lot of different resources together in one place” (S6).

The online delivery also made it easier to reduce potential participation barriers. Accessibility was considered throughout the whole design process: “A distinct strength was that this was a ‘no cost,’ open opportunity for caregivers. We worked hard to ensure there would be as few hurdles to access as many online materials as possible” (S4). Besides reducing financial barriers, the online aspect of *Caregiving Essentials* also helped to tackle geographical limitations: “Technology [...] can facilitate crossing a barrier, including the barrier of geography [...] Again, it ties into access” (S4).

As one stakeholder stated, “It’s an online course and we very specifically reached out to people who were living in Northern Ontario” (S6). One interviewee spoke on the lack of accessibility of care resources in the North from personal experience: “... because

of my northern roots and because I'm working up in education in the north, I knew that there's a tremendous need for this kind of education" (S4). The online delivery ensured that even caregivers in remote locations had equal access to the course.

Another strength identified by the stakeholders was the discussion boards: "The idea that people could talk to each other, get to know each other, share stories with each other" (S6). Another interviewee made the following observation about the discussion board activity: "People were using it to either commiserate or to justify some of the decisions they are making as caregivers themselves" (S3).

A couple of suggested improvements to enhance the discussion boards were using caregivers as moderators to offer more of a "peer-to-peer experience" (S1), and creating smaller discussion groups to "connect [those] who were living in the same areas" (S6). Other ideas to enhance participant interaction was using additional communication methods, such as a web-conference (S1) or audio-video chats (S4). One interviewee remarked that when "you can see someone's face, and who they are, it makes a big difference" (S2).

Moreover, the online delivery enables the course to be scaled up to the national level since geographical barriers are reduced. "In terms of how the course is actually designed, it certainly could handle a larger audience" (S6). Two identified challenges involved with expanding the project would be ensuring that the information and resources in the modules are kept updated (S3, S6) and remain region-specific (S2, S6).

3.4.3 Student Focus Group

The nursing students involved in *Caregiving Essentials* also identified accessibility as one of the key strengths of the intervention. One student shared, “I also liked [how] the course is very easy to navigate... it was really well organized” (NS4). Another member of the focus group added, “Having it on their own terms... knowing they have it right in their own home, was valuable to them” (NS5). Therefore, it seems that both access to the online course itself, as well as ease of accessing information were two highlights of the user experience from the students’ perspective.

One limitation that was addressed was the accessibility of the online course to participants that were older adults. One student mentioned, “I think maybe in weaknesses that might occur – depending on how old the caregiver is, they may not be ‘technology acceptable,’ or able in a way” (NS5). One of the students even said themselves that they found “the site isn’t the most intuitive” (NS4) which could make accessibility more of a challenge for certain participants, especially older ones.

Another recognized strength by the nursing students was the discussion boards, described as being “really important for the caregivers to feel that they were supported in their role, and kind of feeling that they weren’t alone” (NS3). Another focus group member said they were “essential to the course in order to relate with other caregivers” (NS2). Likewise, one student described the sharing of experiences as creating “a sense of comradery” (NS4) while another referred to it as a “community” with “peer support” (NS5). Additionally, one student noted, “The discussion board gets interaction going... different caregivers answer back... help each other out” (NS1).

Furthermore, the engagement level within the modules was deemed another advantage of the online delivery. Regarding the self-check quizzes after each module, one student expressed: “I really liked that it tested your knowledge” (NS2). Another student also commented on them: “I think that the modules are already quite interactive when testing your knowledge” (NS4). Participants being able to reach out to the nursing students appeared to be an additional strength: “I know the email was good too. They could directly contact us if they were having issues with IT, or if they had [...] more sensitive issues that they wanted to discuss” (NS2). Thus, the more interactive elements of the course seemed to enhance participants’ learning experience.

3.4.4 Participant Interviews

Most of the caregivers who participated in the evaluation component of the project felt that the online delivery enhanced the course. Many of them stated that they preferred it over an in-person intervention. One participant shared, “If I had to show up at a place, I probably would not have participated as much as being able to do it online” (W2). Similarly, another interviewee said, “The reason why I enrolled in this online course is because I’m extremely busy and I couldn’t always make it in person” (W8).

More specifically, several participants praised the flexibility of the course and their ability to participate wherever and whenever. One respondent noted, “The material [...] lent itself well to doing things independent and online— which is what I was looking for” (F11). Quite a few caregivers mentioned how the ability to “[do] it on my time” (W9) and “hop online anytime that works” (W4) as being extremely valuable. One

participant described how the flexibility benefitted their level of access: “I could participate in the course at home, when I'm at school; it didn't prevent getting access to the information in any way [...] doing it online was the best option” (F3). While some liked the fact that “It's in the comfort of your own house” (W7), others enjoyed the ability to log into the course from work, “on and off throughout the day, and during my lunch breaks” (W3). As one respondent put it, “It was a good way because... for all the caregivers, we all have different times of when we're available” (W10).

Flexibility of information intake was highlighted as another important feature: “I liked how you could stop and play at your own pace” (W8). Another caregiver stated, “It was a good thing because you could go back if you forgot anything” (W12). Other participants talked about repetition in viewing module content, such as “I've gone through it a couple of times” (F5) and “I could go back and look at some of the modules I had already finished, just to kind of review” (W5). Others chose to only read through the information that was most relevant to them: “I kind of just scanned over and kept going, and really focused on the things that I needed” (F8). The control over choosing how much time to invest into the course and into each section of the modules seemed beneficial: “Then you can just spend as much time or as little time on those modules as you like” (W2).

An additional element of accessibility was the user-friendliness of the course. One participant commented, “I was very impressed about how the course was set up, how easy it was to access, and how easy it was to maneuver through all the areas” (W1). Another remarked, “The navigation through the learning or training was straight forward, well

labeled, the links all worked, everything was functional and very easy to use” (W12). Although, there were others who had trouble: “It’s just when I was going into a video or something, it would go into the video and then it was hard for me to go back” (W10). A different participant described a similar situation: “I did find [...] certain links take you to other places and navigating to get back to the original place [...] was a little bit challenging” (W4). Another caregiver explained that the navigation became easier over time: “It took me a bit the first module to find out how to get to the next, but once I did that, it was okay” (W5).

In terms of barriers to participation, some caregivers expressed appreciation for the affordability of the course (F3, F8, W3, W11). However, not having access to a computer acts as a potential financial barrier and may be more pertinent to participants of an older demographic. One interviewee commented that “I have a computer, [but] a lot of people do not in my age bracket” (F4). Age and a lack of comfort with using the internet or technology was also identified as a limiting factor: “I am 75 [...] Not everybody this age is limited in their computer experience, but unfortunately, I am one of them that is” (F5). Comparably, another person declared, “I’m 70, so I’m not as computer literate... so things are a little more difficult for me” (W5). The same respondent explained that due to their lack of computer experience, they found the online delivery somewhat hindered their overall learning experience.

Furthermore, offering the course online made it more accessible to informal caregivers living in more remote regions of the province. One participant praised the project leadership for targeting recruitment efforts to Northern communities in Ontario: “I

thought that was excellent because you're reaching the people that are– there's a whole bunch of need obviously [...] They're really isolated it feels” (F10). However, people living in these Northern areas face their own barriers to accessibility, as noted by one participant: “It's unfortunate being online, there's so many people in the community who don't have internet or don't have access to internet [...] in Northern Ontario” (F13).

Another strength of the online delivery reported by numerous participants was the discussion boards. Many believed that the opportunity to connect with other participants was an important part of the course: “The really nice thing was there was a common camaraderie [...] It was nice [...] that you do have that option to connect” (W4). One caregiver described discussing shared experiences as “really comforting in a lot of ways” (F12). For the less experienced caregivers who did not contribute to the discussion boards, some still found the posts to be “kind of refreshing to get the perspective that there's lots of people out there dealing with this” (F11). Newer caregivers were able to read posts from more experienced caregivers and consequently felt more prepared: “For me, it's more hearing what other people have to say and seeing what I have to look forward to... or not look forward to” (W5).

Even amongst the ones who did not use the discussion boards, some still saw value in incorporating social interaction for others: “I never get involved with that kind of thing, but I think that's great [...] You don't want to feel like, 'Am I the only one going through this?'” (W7). Part of the reason for lower participation in the discussion boards was simply personal preference, or due to prioritizing learning over making connections.

However, there were a few participants that experienced challenges with accessing the online posts: “I had difficulty navigating out of the discussion board [...] I would always end back at the home screen and then have to go back into the module” (F2). One of the older caregiver participants remarked, “I didn't try because I couldn't figure out how to make it work” (F5). Someone else mentioned, “I'm pretty savvy with computers so it wasn't so much that I didn't know how to access it. I just found it a little bit clumsy with the windows and having to scroll down” (F4).

Some individuals felt the discussion boards were lacking interaction between caregivers: “There weren't many people at all engaged in sharing information, which is a shame because I think we're all on the same journey” (W9). Someone else expressed the desire for lengthier conversations: “I would've liked to see a back and forth more with what people were saying [...] I would've liked to have had more discussion on what other people's opinions were” (W10)

Unfortunately, while several participants did experience a sense of community, others felt that opportunity was not there for them:

“I thought one of the reasons I'd join the course was to perhaps be part of the community, be part of the tribe, dealing with the same issues. I just didn't find that. People that perhaps did log in weren't consistent in logging in. Or people that had very similar issues to what I was going through, I couldn't find them again on various chat boards” (W11).

Another caregiver cited the self-paced nature of the course as being problematic in this way as well: “I went through it faster than what was recommended... so because of that, there was nothing in the online chat because other people hadn't gotten there yet” (W5).

Recommendations for improving engagement between participants included: adding a discussion thread where caregivers could share resources (F3), creating small participation groups based on geographic location (W12), and using a telecommunication for live discussions (F3, F4, F7, F11, W3, W9). Some people specifically referred to integrating videoconferencing and emphasized the significance of face-to-face interactions. Conversely, there were a few individuals that voiced concerns with sharing private information online: “I wasn't ready to share on the internet... I don't do too much on the internet when it comes to personal stuff” (F5). Another respondent reiterated this worry: “I wasn't comfortable using my personal experience in an online public discussion” (W8). One potential solution to this problem was offered by the following participant: “My name was on the post. Is there a way to make it anonymous or change your identity when commenting? My concern was anonymity for myself and for my family members” (W11).

Another recommended upgrade for the online delivery was to organize the content so more information is presented broadly via modules, and then each module contains more specific information through a series of different subsections (F1, F14, W11). This structure would streamline content better and make it easier for caregivers to find what they are looking for. Some participants said there was too much text to read (F3, F5, W4, W10), and it was suggested to either add a feature that reads the text or include more

video clips into the modules (F3). Other proposed enhancements were to offer a download option for the material (W11), and to include short testimonies from informal caregivers and/or older adults (W6).

In terms of the online delivery aspects that participants liked and would keep the same, eight participants mentioned the post-module quizzes, and eight said the online support relating to course information, IT troubleshooting, and general questions. The variety of resources used to showcase information was also identified as a positive: “I hadn't encountered such a comprehensive collection of resources. Also, in terms of types of resources— so videos, documents, templates” (F12). Likewise, someone else highlighted this as a strength: “I liked the fact that there was a variety of different ways to get the information. You had the odd case study, you had a link to another website, [...] downloadable files” (W12).

One last minor theme that arose from the participant interviews was the opportunity for growth and expansion. A couple of individuals recommended that the course should be opened to a broader and larger audience, such as other types of caregivers, caregivers living in other provinces, and other care workers (F10, W1, W4). The online delivery of *Caregiving Essentials* would certainly enable scalability.

3.5 Discussion

3.5.1 Principle Results

Many of the strengths and areas of improvement identified by the participants aligned with the feedback from the stakeholders and nursing students. The online delivery

of the *Caregiving Essentials* course enabled greater accessibility for most of the informal caregivers who participated in the study. Stakeholders were aware of informal caregivers' busy and oftentimes unpredictable schedules, so the course was designed to be flexible, which participants valued a great deal. The self-paced, independent nature of the course was made possible by the online, stand-alone modules. Participants liked the fact that they could access the course from home, work, or school whenever they had free time. Some also found it helpful that they could pick and choose which information they wanted to focus on and could even go back to review material if they needed. This flexibility was highlighted as a benefit by the stakeholders and nursing students as well.

Only one participant that was interviewed thought the online delivery of the course hindered their learning experience and it was due to their lack of experience with computers and technology. Others also shared some experiences of having difficulty navigating through certain areas of the course. While several participants described the course as easily accessible, user-friendly, and straightforward, a few referred to sections of the course as being clumsy or sporadic. This variation in feedback may be caused by individual factors such as familiarity with online courses or generational differences in use of technology. The disparity in positive and negative responses can also be due to areas of the course that need to be improved to better suit the diverse needs of various learners.

Geography played a role throughout the project from the recruitment process to the data collection stage. Since some of the participants were specifically recruited from Sudbury and Timmins, their ability to access the course and their insights about the online

delivery were especially appreciated. Stakeholders belonging to the project leadership team were knowledgeable about the lack of care services and facilities in Northern Ontario. Therefore, the online delivery of the course reduced spatial barriers and allowed for equal participation from caregivers, no matter where they were located. This is a key factor to recognize, especially if the project were to expand to other geographic areas. However, other barriers to accessibility were still present, such as language and financial barriers.

The discussion boards were another major strength identified by the stakeholders, nursing students and participants because they made the course more engaging. The course designers created discussion board topics that coincided with the module topics to encourage participant activity. The main goal of the online communication was to increase interaction among the users, and to combat social isolation. Many participants did report a sense of community and camaraderie. The nursing students who moderated the discussion boards confirmed the positive connection building when they spoke of participants sharing stories and giving each other advice.

Unfortunately, not all participants found the discussion boards to be beneficial. The post-course survey results showed that around half of the respondents were not confident in sharing their ideas in written format online. This correlated with the participants who had privacy concerns and did not wish to share personal information online. Some participants found the discussion boards to be challenging to navigate, others prioritized exploring the module content, and a few accessed the discussion boards when there was little interaction.

Other interactive features, such as the post-module quizzes, the downloadable PDF document, and the email support, were said to enhance the overall effectiveness of *Caregiving Essentials* as well. A couple of participants were satisfied with the variety of ways in which information was presented, though numerous people suggested that even more multimedia be added to the modules to help reduce the amount of onscreen text. Increasing the level of engagement was a comment made by the stakeholders, nursing students and participants. Potential improvements that were offered included: adding web conference presentations, smaller group chats, and live video calling. Telecommunication applications like Google Hangout and Skype were brought up as many people emphasized the importance of face-to-face connections. Thus, the aspects of the online delivery that separated the *Caregiving Essentials* course from any other web-based information tool were identified as strengths by all three participant groups. Furthermore, these interactive features of the course are the areas from which respondents desired more engagement and improvement. This is in keeping with findings from the literature, which report that multiple components, interactive activities, and direct interactions as being key elements of effective online interventions.

3.5.2 Limitations

A limitation of the evaluation was the recruitment strategies for participants. Only caregivers who had finished most of the module content were contacted for an interview. Therefore, if participants stopped partway through, they were never given the opportunity to provide in-depth feedback pertaining to the online delivery of the course. The topic of

evaluation is one which participants would likely still be able to speak to if they had completed at least one module and had explored other features of the course. Thus, it is possible that participants who qualified to be involved in the evaluation (i.e. finishing most of the module content) were more likely to offer certain kinds of responses. This means that the participant interview data may not accurately represent the perspectives of everyone who took the course.

Furthermore, the voluntary aspect of the project's evaluation is another potential factor that may reduce the generalizability of the participant interview findings. Again, individuals that agreed to provide feedback may be more likely to hold extreme opinions, whether they be positive or negative. Also, since the evaluation was not mandatory, the number of participants that completed each step decreased through the duration of the project. If participation in the *Caregiving Essentials* Course was tied to their commitment to contribute evaluative feedback, then there may not have been such a loss in numbers between the pre- and post-course surveys.

3.5.3 Conclusion

In conclusion, the online delivery of the *Caregiving Essentials* course enhanced the overall learning experience for most of the informal caregiver participants. A diverse range of accessibility issues and the ways in which they enabled online learning were discussed in the stakeholder and participant interviews and the nursing student focus group. Suggestions to further develop the existing interactive features of the intervention were made, as well as recommendations to incorporate additional methods of engagement

via technological opportunities. While there were some barriers to participation due to the online delivery, most participants were able to overcome them and still benefit from the course. Therefore, using an online course to deliver information to informal caregivers of older adults proved to be an effective intervention method for this project.

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Conflicts of Interest

There are no conflicts of interests.

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Chapter Four: Conclusion

4.1 Introduction

Although the purpose of this research is to specifically evaluate the effectiveness of the *Caregiving Essentials* course and its online delivery, the study results have broad implications. The online course was created as a knowledge intervention for informal caregivers of older adults in Ontario, Canada. Participants who completed most of the module content from the pilot course offering were invited to participate in the evaluation by providing feedback via a pre-course and post-course survey and a telephone interview. In addition to the caregiver participants, feedback was also collected from key project stakeholders via telephone interviews and nursing students via a virtual focus group. The responses from these three groups were used for the evaluation of the effectiveness of the online course delivery.

Chapter 2 explores whether the main objectives of the course were met in terms of the caregiver experience. The knowledge intervention was evaluated based on the following objectives in relation to the caregiver experience: 1) Knowledge, ability, skills, confidence, and self-efficacy in caregiving; 2) Self-reported sense of personal health and well-being; 3) Perceptions of health and well-being of older adults in their care, and; 4) Understanding and access of the health and social service system. Following participants' completion of the course, their reported increase in either some or all the four main course objectives was needed in order to determine if the *Caregiving Essentials* course was effective.

Chapter 3 focuses on the online delivery and its impact on participants': overall learning experience, and the effectiveness of the course. Various aspects of the online delivery are discussed from the perspectives of the: stakeholders, nursing students, and caregiver participants. Their feedback on the initial registration, course navigation, discussion board interaction, module layout and other web-based features offered insights into the accessibility and user-friendliness of *Caregiving Essentials*. Several strengths and weaknesses were identified, which helped determine which elements of the online delivery enhanced or hindered the participants' educational experience.

The next section of this concluding chapter will provide an overview of the significant findings from Chapters 2 and 3. In addition, the limitations of the study will be briefly discussed. Next, the contributions that this research offers to: (a) policy decisions, and (b) the wider research community will be discussed. Finally, this thesis concludes with potential directions for future research.

4.2 Overview of Significant Findings

4.2.1 Prior caregiver burden linked to higher reports of effectiveness

Participants that expressed feeling burnt out, stressed or overwhelmed were more likely to report that the course had a positive impact on their health and well-being. Those who felt more unprepared and described difficulties with managing their various caregiver tasks and responsibilities were more likely to report increased knowledge, confidence, or self-efficacy. Similarly, the participants who shared frustrating stories of navigating the healthcare system or simply not knowing what resources were available to

them were the ones who were more likely to find the resources in the last module of the course useful. Therefore, a correlation was seen between informal caregivers who were experiencing a greater level of burden at the onset of the course with participants who reported higher overall effectiveness of *Caregiving Essentials*. As discussed in Chapter 2, informal caregivers who are female, employed, elderly and/or living in a remote area have higher chances of experiencing burden due to their caregiving responsibilities. Therefore, results illustrate that the participants who had the greatest need for information and resources were the ones who benefitted the most from taking the online course.

4.2.2 Health and well-being of caregivers and their care recipients

The two course objectives that focused on the health and well-being of the caregivers and their care recipients were not met by as many participants as was initially hoped for. Through the one-on-one telephone interviews, participants explained that the course had a smaller effect on health and well-being compared to other external factors in their life. If participants' burden was caused by an increase in care intensity and/or worsening health conditions for their care recipient, then the knowledge they gained from the course would not improve their caregiving circumstances, or their perceptions of it. Some participants said that if they had discovered the course earlier on in their caregiver journey, then it may have had a more positive impact on their situation. Therefore, the effectiveness of the intervention appears to vary, depending on how much control caregivers have over their individual circumstances, and what aspects of their situation have the potential to improve with increased knowledge. Informal caregivers struggling

with more demanding and intensive care work may benefit more from interventions that are specific to what they are going through, and ones that offer skills-based training and coping strategies.

4.2.3 Online delivery enabled greater accessibility

The online delivery of the *Caregiving Essentials* course increased accessibility in numerous ways. Unlike with in-person interventions, location and distance were not barriers to participation. Instead, informal caregivers from across Ontario were able to participate if they had a computer or mobile device with an internet connection. The web-based modality allowed participants to log into the course from anyplace that was most convenient for them, whether it be at home, work or school. Participants also had the flexibility of accessing the course whenever it fit into their busy schedules. All of these aspects of the online delivery were identified as strengths by some, or all participants interviewed. Participants also highlighted the self-paced nature of the course as being beneficial, as it allowed them to spend as much or as little time as they wanted on each section of the course. Some participants skimmed over parts of the modules that were less relevant to them, while others went back to review information again to solidify their understanding or take extra notes. Overall, the online delivery of the course facilitated a flexible and tailored learning experience for each participant, whilst making it easy for them to access the information and resources that could help them in their caregiver role. Several participants said that *Caregiving Essentials* being online enhanced their educational experience.

4. 2. 4 Improvements to the online delivery to enhance learning experience

The discussion boards were a strength identified by many of the participants because the social interaction provided comfort and support for some of the caregivers. Since making connections was such a valuable element of the course experience for some of the participants, several people offered ways that this could be further improved in the future. Expanding the online delivery to incorporate a live chat feature or scheduled video calls were a couple of the suggested ideas that would allow caregivers to create even more meaningful discussions. Another enhancement that was mentioned by several participants was the addition of more interactive learning activities and greater variation in the ways that information was displayed. While participants already identified the diversity in resources as a strength, many still would have liked to see more multimedia imbedded into the modules. Therefore, steps that would further distinguish the online course from just another website are what participants reported would improve their learning experience.

4.3 Study Limitations

The small sample size for the evaluation of the course limits the generalizability and internal validity of the research findings. A greater number of responses for both the post-course surveys and the telephone interviews would have resulted in data that is more representative of participants' opinions and experiences. The total number of participants decreased over time for both *Caregiving Essentials* pilot course offerings. The attrition observed throughout the duration of the study is not an uncommon phenomenon

considering the population. Informal caregivers of older adults often have busy and sporadic schedules which are subject to change at any moment. Thus, the decline in participants over the eight weeks of the course speaks to the very nature of the caregiver role.

Unfortunately, participants that did not complete most of the course content did not have the opportunity to provide their feedback in the evaluation. In these cases, possible reasons for dropping out of the course partway through are unknown, introducing potential bias in the research results. It is possible that those who finished at least three of the five modules in the course were more likely to have had a positive educational experience and consequently report a higher level of effectiveness. Similarly, since the evaluation was an optional component of the course, it is again a possibility that participants who were willing to provide their insight were more likely to highlight the strengths of the course and its online delivery. Due to the attrition of participants over time, there was a large gap between the number of participants who filled out the pre- and post-course surveys, preventing the two data sets from being rigorously compared during analysis. These limitations could have been avoided, or at least reduced, by making the evaluation a compulsory part of the pilot course offerings.

4.4. Policy Contributions

In a survey conducted for the second annual “Spotlight on Ontario Caregivers” report, 77% of caregivers stated that they wanted a ‘one-stop-shop’ that they can turn to for help and advice (The Change Foundation & The Ontario Caregiver Organization,

2019). The *Caregiving Essentials* course can fill this need, as it provides informal caregivers of older adults with a variety of easily accessible information and resources, all in one place. The knowledge intervention was shown to be effective and the online delivery of the course increased the accessibility. Therefore, more funding and resources should be allocated to support research studies and community programs that aim to provide online education to informal caregivers at no cost. This policy recommendation aligns with the sixth step in “A Roadmap to Strengthen Home and Community Care,” which is to expand caregiver supports (Ministry of Health and Long-Term Care, 2015). The implementation plan for this step recognizes the value of a web-based resource, and the ability for such a resource to streamline a wide range of essential information from different sources.

In the “Expanding Caregiver Support in Ontario” report, it was recommended that the Ministry of Health and Long-Term Care develops initiatives at the individual level, where one access point where informal caregivers can get information and connect to available services (Beed, 2018). Instead of developing this from scratch, the government should invest in existing online interventions such as the *Caregiving Essentials* course that have shown to be effective based on the feedback from participants who have taken the pilot course offerings. Increased government funding towards initiatives that have already been created to serve their intended purpose would allow programs to keep their resources up-to-date and continue to offer the information at no-cost to caregivers. Money can also be directed towards additional research to find ways to further enhance the online delivery and explore opportunities for increased technological integration. This will

ensure that initiatives evolve with the changes in Ontario's care landscapes and the needs of the growing number of informal caregivers.

4.5 Research Contributions

As online interventions for informal caregivers continue to become more popular, the need for the evaluation of these interventions is essential to ensure that the initiatives are effectively meeting their intended outcomes. The literature has shown that psychoeducational interventions that contain multiple components are more successful at reducing burden and increasing knowledge (McMillian, 2005; Sörensen, Pinquart & Duberstein, 2002). Additionally, online interventions that are interactive and allow for connections between caregivers are reported to be the most promising (Ducharme et al., 2011; Marziali & Garcia, 2011). The findings from the *Caregiving Essentials* evaluation study reinforce the existing literature in this regard. The successful implementation of the course can also support future feasibility studies in relation to online interventions for this sample population. This research also contributes to literature in the area of health geography, and specifically medically underserved areas. Since informal caregivers were specifically recruited from Hamilton and two communities in Northern Ontario – which we know have comparatively limited social and health care services (for the Chapter 2 paper), the participant sample is more representative of the wider population in terms of geographic spread. This research intentionally explores the ways in which geographic location influences varying levels of accessibility. It contributes to the existing geographic literature that focuses on the provision of informal care in rural

regions of Ontario, Canada (Kitchen et al., 2011). While other work has been done on informal care in rural areas in other parts of North America (Crouch, Probst & Bennett, 2017), the findings from this research are situated in the context of the Ontario care landscape. Therefore, this project informs future initiatives with similar objectives and comparable delivery methods being implemented in the province.

4.6 Future Research Directions and Conclusion

The evaluation of the *Caregiving Essentials* course for informal caregivers of older adults in Ontario revealed that most participants found the course effective in increasing their knowledge and understanding of available resources. The online delivery was said to enhance many participants' overall learning experience by increasing accessibility and allowing for interaction between caregivers. This research demonstrated that there is a great need amongst this population for educational interventions and other supports. Many participants described the online course as being comprehensive, valuable, relevant, and easily accessible. The identified weaknesses of the course and its online delivery were acknowledged by the project leadership team. Participant recommendations on how to best improve various aspects of the course have been applied to the future course offerings. More research should be conducted on the course to determine if the implemented changes increased the overall effectiveness in relation to the two initial pilot offerings. Furthermore, the possibility of using the online delivery to scale up the course to the national level is something that was suggested by all participant groups: the caregivers, stakeholders, and nursing students. In addition, the unique needs

of different types of informal caregivers should be ideally studied to determine new ways in which the course can be further tailored to a diversity of experiences. To conclude, the findings from this evaluation make promising contributions to both policy and research. It is the hope that the results from this evaluation will not only help informal caregivers of older adults in Ontario, but other types of caregivers too, no matter where they are located.

4.7 References

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Appendix A: Caregiving Essentials Module Information

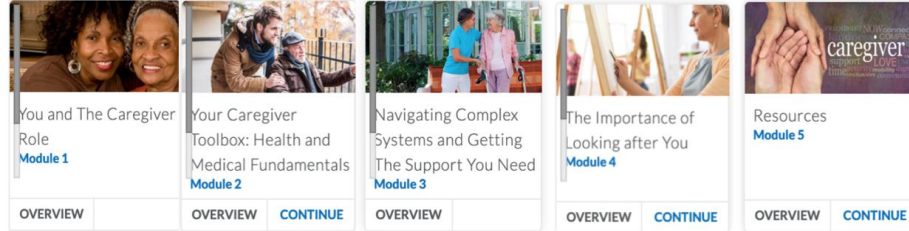


Figure 2: Modules from the Caregiving Essentials Course

You and the Caregiver Role

- Identify your roles and responsibilities as a caregiver
- Create your caregiver action plan
- Recognize basic legal and financial implications associated with your caregiver role
- Identify factors that can lead to social isolation in older adults
- List your strengths as a caregiver

Your Caregiver Toolbox: Health and Medical Fundamentals

- Select resources that can help you identify and manage common health and medical conditions and possible outcomes
- Identify signs and symptoms that indicate progression of a health condition
- Locate resources that cover a variety of skills and techniques as they relate to your well-being as a care receiver
- Recognize when a situation requires a call to telehealth, a medical appointment, or a trip to the ER
- Identify documents that are critical to bring to medical appointments or the ER

Navigating Complex Systems: Getting the Support You and Your Care Receiver Need

- Engage in difficult/courageous conversations
- Represent and advocate for your care receiver within diverse health, medical and social systems
- Locate medical and social system resources
- Identify how to secure government assistance and funding for caregivers in Canada
- Draft a financial plan to meet your, and your care receiver's, needs

The Importance of Looking After You

- Build your personal coping strategies (ex. learning how to accept help from others)
- Identify your stressors and recognize symptoms of depression, anxiety, and stress
- Set realistic expectations with loved ones and manage changing family dynamics
- Develop strategies that will make your caregiving experience positive and meaningful
- Connect with other caregivers and caregiver networks to form community and reduce the possibility of social isolation

Appendix B: Project Timeline

Table 5: Caregiving Essentials Project Timeline

Project Stage	Timeline Dates
Course design and planning	April to September 2018
Participant recruitment for Fall course	August to October 2018
Fall 2018 course offering	October to December 2018
Focus group with nursing students	December 2018
Participant recruitment for Winter course	December 2018 to February 2019
Data collection from Fall 2018 course	December 2018 to March 2019
Winter 2019 course offering	February to April 2019
Fall interview transcription	March to April 2019
Stakeholder interviews and transcription	April to May 2019
Data collection from Winter 2019 course	June to July 2019
Winter interview transcription	July to August 2019
Data analysis	August to September 2019

Appendix C: Letter of Information and Consent

LETTER OF INFORMATION / CONSENT

Caregiving Essentials Course for Informal Caregivers of Older Adults

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Research Sponsor: The Ministry of Seniors Affairs

Purpose of the Study: This project will evaluate the blended learning program created for caregivers. This project is primarily an educational development project, funded through the Ministry of Seniors Affairs, with an evaluation component.

You are invited to take part in this study on building caregiver knowledge and skills to support older adults. We hypothesize that the program will increase self-reported knowledge, ability, skills, and confidence in caregiving, self-reported sense of personal health and well-being, perceptions of health and well-being of older adult in their care, understanding and access of the health and social service system to be completed by caregivers and knowledge of online technology

Procedures involved in the Research: We will ask you qualitative questions to assess your perceptions of: the appropriateness of the curriculum, knowledge and efficacy in using new knowledge to care for older adults, ability to navigate and access the health and social services system, mental health and well-being of caregivers.

The research-based section of this project will take place in two parts – one prior to the start of the program and one at the time of program completion. You will be asked to complete an online survey containing close-ended questions about you as a caregiver and

your caregiver experiences. The pre- and post-program survey will take approximately 30 minutes of your time. They will be conducted using LimeSurvey so you can access it from any electronic device with access to the internet.

You will also be invited to participate in a one-on-one telephone interview following the completion of the program. The interview will be facilitated by the student investigator. The estimated length of the interview is 10 – 30 minutes and with your permission, will be audio recorded along with hand-written notes of the discussion.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. You may feel anxiety, anger, grief, or worry while answering the survey or interview questions depending on your unique caregiving experience. If this happens, you will be asked if you need a break from the focus group discussion and offered a list of support services if needed. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

Potential Benefits: There are many benefits to participating in this project. The participant will acquire skills and knowledge from participating in the educational program. The participant may benefit from the ability to provide feedback on the curriculum in order to improve it for the next offering. The participant will benefit from the social connections of meeting other caregivers during the program, with whom they can share experience and find support.

Compensation: You will be provided with a \$20.00 Tim Horton's gift card for the completion of both the pre and post surveys, and for participating in the interview.

Confidentiality: We will not use your real name, and we will do our best to ensure that the information you share is not identifiable to you. Only the student investigator conducting the research will know whether you were in the study unless you choose to tell them. A number will be assigned to you and will be used when referring to you or anything you say during the focus group discussion. We cannot guarantee 100% confidentiality because sometimes we are identifiable by the stories we tell. The audio recording of the focus group discussion will be kept on a password protected device and the handwritten notes and surveys will be kept in a private binder. An archive of the research data will be retained for 5 years after the completion of the project in a locked location. Afterwards, it will be securely destroyed.

b) Legally Required Disclosure:

We will protect your privacy as outlined above. If legal authorities request the information you have provided, we will defend its confidentiality.

Participation and Withdrawal: Your participation in this study is voluntary. If you decide to be part of the study, you can withdraw from the program and evaluation for

whatever reason, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results: We expect to have this study completed by approximately *March 2019*. If you would like a brief summary of the results, please let us know how you would like it sent to you.

Questions about the Study: If you have questions or need more information about the study itself, please contact: stosia@mcmaster.ca or (905) 525-9140 ext. 21518

CONSENT

- I have read the information presented in the information letter about a study being conducted by Allison Williams, Shelley Rottenberg, Lorraine Carter, and Alix Stosic of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time
- I have been given a copy of this form.
- I agree to participate in the study

Name of Participant (Printed) _____

Signature: _____

Date: _____

1. I agree that the telephone interview can be audio recorded.

Yes

No

2. I agree to have my responses from this project used in future related projects.

Yes

No

3. Yes, I would like to receive a summary of the study's results.

Please send them to me at this email address

 No, I do not want to receive a summary of the study's results.

Appendix D: Pre/Post-Course Survey

Thank you for agreeing to participate in the evaluation of the Caregiving Essentials program. Your feedback is valuable and will allow us to improve the program.

*There are **56 sections** in this survey. While we hope you'll complete each section, answering each question is optional. You will be asked about your experience as a caregiver, your experience with technology and some demographic information.*

Your information will remain anonymous and we will analyze all the feedback together, so you won't be identified (unless you choose to be)

*This survey will take approximately **30 minutes** to complete. Any questions please contact crqvr@mcmaster.ca*

PART A: Your Experience as a Caregiver

This section asks about your experience in the caregiver role. Please select the answer that best describes your situation.

1. I am aware of health and community supports available for my loved one.

Agree	Somewhat agree	Disagree
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2. Please complete the table below. In the past 12 months, have you made use of any of the following services for your primary care recipient (the person you are caring for)?

	Services	YES	NO, but I am aware of this service.	NO, I am not aware of this service	IF you selected YES was payment (out of pocket) required?	IF you selected YES, how often did you receive this service?
a.	Home nursing care (ex. RN or RPN)					Daily, multiple times/week, weekly, biweekly, monthly,

						< once/month
b.	Personal Support/Aide (ex. Bathing)					
c.	Home Support (ex. Homemaking)					
d.	Physiotherapy					
e.	Respite Care					
f.	Meals on Wheels					
g.	Transportation Services (ex. Handi-dart)					
h.	Patient Support Groups					
i.	Other, not specified above (ex. Volunteer services)					

PART B: Caregiver Self-Efficacy

1. I am confident in my knowledge, skills, and abilities to care for my loved one.

Agree	Somewhat agree	Disagree
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2. For each of the following questions, please tell us what you are feeling right now.

#	Questions	Not at all true	Hardly true	Moderately true	Exactly true
1	If I try hard enough, I can always manage to solve difficult problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2	If someone opposes me, I can find the means and ways to get what I want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3	It is easy for me to stick to my aims and accomplish my goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4	I am confident that I could deal efficiently with unexpected events.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5	Thanks to my resourcefulness, I know how to handle unforeseen situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6	I can solve most problems if I invest the necessary effort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7	I can remain calm when facing difficulties because I can rely on my coping abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8	When I am confronted with a problem, I can usually find several solutions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9	If I am in trouble, I can usually think of a solution.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10	I can usually handle whatever comes my way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Instructions for the following section:

We are interested in how confident you are that you can keep up your own activities and respond to caregiving situations. Please think about the following activities and thoughts that could come up for you as a caregiver and identify how confident you are that you could do each item. Rate your degree of confidence using the scale given below:

3. Are you confident that you can do the following activities? Please make all your ratings based on what you could do TODAY. If this is not applicable to your situation, then put N/A.

#	Questions	Yes	Sometimes	No	N/A
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1	Ask a friend/family member to stay with your care recipient for a day when you need to see the doctor yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2	Ask a friend/family member to stay with your care recipient for a day when you have errands to be done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3	Ask a friend or family member to do errands for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4	Ask a friend/family member to stay with your care recipient for a day when you feel the need for a break?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5	Ask a friend/family member to stay with your care recipient for a week when you need the time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6	When your care recipient forgets your daily routine and asks when lunch is right after you've eaten, can you answer him/her without raising your voice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7	When you get angry because your care recipient repeats the same question over and over, can you say things to yourself that calm you down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8	When your care recipient complains to you about how you're treating him/her, can you respond without arguing back? (e.g., reassure or distract him/her?)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9	When your care recipient asks you 4 times in the first one hour after lunch when lunch is, can	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	you answer him/her without raising your voice?				
10	When your care recipient interrupts you for the fourth time while you're making dinner, can you respond without raising your voice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you...?					
11	Think about unpleasant aspects of taking care of your care recipient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12	Think how unfair it is that you have to put up with this situation (taking care of your care recipient)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13	Think about what a good life you had before your care recipient's illness and how much you've lost?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14	Think about what you are missing or giving up because of your care recipient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15	Worrying about future problems that might come up with your care recipient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART C: Your Access to and Use of Technology

In this section, you will be asked about your experience and use of technology in your role as a caregiver. Please select the option that best fits your experience.

1. Do you have a computer with internet in your home?

- Yes
- No

2. I am comfortable sharing my ideas in written format online.

Agree	Somewhat agree	Disagree
-------	----------------	----------

3. Have you used the following online learning tools and applications?

- Online surveys and polls Yes / No
- Online videos Yes / No
- Email Yes / No
- Course-based discussion forums or boards Yes / No

4. How often do you use the computer to look for health information:

Daily	Weekly	Monthly	Less than once a month
-------	--------	---------	------------------------

5. I am confident using and contributing to an online discussion group when I need help or information.

Agree	Somewhat agree	Disagree
-------	----------------	----------

6. I am confident using the internet to navigate and find the health information I am looking for.

Agree	Somewhat agree	Disagree
-------	----------------	----------

7. I feel comfortable assessing the information I discover online for their integrity and truthfulness.

Agree	Somewhat agree	Disagree
-------	----------------	----------

PART D: About You

1. What is the closest city to where you live?

- Hamilton
- Timmins
- Sudbury

2. What is your age?

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- 75 years or older

3. What is your sex?

- Male
- Female
- Other

4. Do you have any dependents under the age of 18? YES / NO

5. In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
-----------	-----------	------	------	------

6. Are you currently employed?

- Yes - Full-time
- Yes - Part-time
- No
- Other (drop-down)

7. If yes, on average over the last 6 months, how many hours/week have you worked?

Part E: About your Care Recipient

1. What is the age of your care recipient? (the person you are providing care for):

- 65 -74 years old
- 75- 84 years old
- 85 - 94 years old
- 95 years or older

2. What is their sex?

- Male
- Female
- Other

3. What is your relationship to this person(s)?

Your care recipient is....

- your parent
- your spouse
- a family member
- a friend
- other

4. Do you live with this person? Yes / No

5. When did you start your role as a caregiver? (month, year) _____,

6. Providing care to a person can involve many tasks such as personal, emotional and social care, accompanying to appointments, providing and arranging transportation and more. Approximately how many hours per week do you provide care to this person?

1-4	5-9	10-14	15-19	20+
-----	-----	-------	-------	-----

7. In general, would you say the person's health is:

Excellent	Very Good	Good	Fair	Poor
-----------	-----------	------	------	------

8. Out of the following list, please select the top three diagnoses that your care recipient has?

- Hypertension
- Osteo- and other arthritis
- Mood disorder
- Cancer
- COPD
- Diabetes
- Other mental health disorder
- Dementia
- Renal failure
- Cardiac arrhythmia
- Asthma
- Acute myocardial infarction
- Osteoporosis
- Rheumatoid arthritis
- Crohn's disease or colitis
- Chronic coronary syndrome
- Congestive heart failure (CHF)
- Stroke
- Other - Free text

Part F: Your Experience Participating in the Course

1. I would recommend this course to a friend.

Agree	Somewhat agree	Disagree
-------	----------------	----------

2. I am satisfied with the level of interaction that happened in this course.

Agree	Somewhat agree	Disagree
-------	----------------	----------

3. I learned new information in this course.

Agree	Somewhat agree	Disagree
-------	----------------	----------

4. I am able to use this information in my role as a caregiver.

Agree	Somewhat agree	Disagree
-------	----------------	----------

5. I feel my care recipient has benefitted from my participation in this course.

Agree	Somewhat agree	Disagree
-------	----------------	----------

6. In the future, I would be willing to take an online course again.

Agree	Somewhat agree	Disagree
-------	----------------	----------

7. I have recognized that I have a more positive attitude towards my caregiver role after completing this course.

Agree	Somewhat agree	Disagree
-------	----------------	----------

End message: Thank you for your participation! We appreciate your time to provide this information. If you have any questions or concerns, please contact crgvr@mcmaster.ca

Appendix E: Participant Interview Guide (Paper 1)

1) Was the information provided in the training program useful to you?

a. Was there other information you would have liked to receive?

2) Was the information provided to you in the training program helpful to you in caring for your loved one?

3) Did the information provided to you in the training program help you understand and navigate health and social services?

4) Did participating in this training program impact your own health and well-being?

5) Did participating in this training program impact your care recipient's health and well-being?

6) What would you change about this training program?

7) Did where you live impact on your ability to participate in this training program?

Do you have any other feedback?

Appendix F: Stakeholder Interview Guide

- 1) Did the project meet its proposed objectives?
- 2) What would you identify as the strengths, as the project unfolded?
- 3) What would we do differently if we could do it again?
- 4) Did geography factor into the project? If so, how?
- 5) What will be the enablers/challenges to scaling the learning model to a larger audience?

Appendix G: Student Focus Group Script and Question Guide

Hello everyone, thank you so much for agreeing to participate in this focus group. Your involvement is greatly appreciated, and your feedback will be used to help inform changes to the *Caregiving Essentials* course in the future.

To start off, my name is Shelley Rottenberg and I will be facilitating the focus group this afternoon. I am currently studying health geography at McMaster University for my master's program. My involvement in the evaluation component of this project will be used in my thesis work. Alix Stosic, the project coordinator, is also listening in on the discussion today and she will be taking notes. I'll let her introduce herself a bit more. Can I just get everyone to go around and introduce themselves by first name?

Participant Names:

- 1.
- 2.
- 3.
- 4.
- 5.

Great, thank you. So how this is going to work is I will ask a series of questions about your experience with the course. I will start off by having everyone take turns answering the first few, and then for the rest I will open it up for more of an open discussion response. Just some ground rules before we begin:

1. Please be respectful with your responses and towards others
2. What is shared within this focus group stays here
3. One person speaks at a time
4. Let's make sure everyone who wants to speak gets an opportunity to answer

Questions:

1. What would you identify as the strengths of this project? Possible weaknesses?
2. What could we do differently if we offered the course again? (Prompt: are there other topics that could be included? Different kinds of learning activities? Management of the discussion board?)
3. Would you recommend this course to a family member or friend if they were in a caregiving role?
4. Do you think that the course content was valuable to the participants? How do you know?
5. Did you as a nursing student learn anything new in this course?
6. How would you describe the level of interaction (for example, discussion boards) in this course? Do you think participating and contributing to this course was a valuable experience as a part of your education?
7. How else could interaction be enhanced respecting that this is a self-paced independent learning situation?

That concludes the focus group questions. Thank you to each and everyone one of you for your insightful responses. Your feedback is really important to us and will help improve the course for the future. Are there any final comments, suggestions, concerns, or criticisms? ... Thanks again and happy holidays everyone!

Appendix H: Participant Interview Guide (Paper 2)

1. We are interested in learning about the on-line delivery of the *Caregiving Essentials* course. How would you describe your ability to access the course?
 - a. Prompt: Registering, logging in, navigating between modules, links and videos, use of online discussion boards etc.
2. How would you describe your ability to participate in the *Caregiving Essentials* course?
3. What aspects of the on-line course delivery would you identify as strengths?
 - a. Prompt: Modules, online discussion boards, post-module quizzes
4. What aspects of the on-line course delivery would you identify as weaknesses?
 - a. Prompt: Modules, online discussion boards, post-module quizzes
5. How would you describe the level of interaction (for example, discussion boards) in this on-line course?
 - a. How could interaction be enhanced?
6. What changes would you make regarding the online delivery of this course?
 - a. Prompt: What would you add? What would you take away?
7. Did the online delivery of the course content enhance or hinder your learning experience?
 - a. In what way(s)?
8. How user-friendly do you feel the course was?
9. Did the fact that the course was on-line deter you in any way?
10. How do you feel the on-line delivery of the course can be improved?

Appendix I: Briefing Paper for Participants



RESEARCH BRIEF

Evaluation of the Effectiveness of the Caregiving Essentials Course for Informal Caregivers of Older Adults in Ontario and its Online Delivery

What is the topic of this research?

- Informal caregiving is a growing phenomenon
- Many individuals are **unequipped with the necessary knowledge and skills** needed to manage the demands of caregiving
- Informal caregivers often have limited time due to their responsibilities, which are combined with paid work and/or parenting young dependents
- This population often experiences **high levels of burden** and are vulnerable to developing negative psychological health outcomes
- **Effective, easily accessible and flexible knowledge interventions** are needed for this group

Research Question

The goal of this study was to evaluate the effectiveness of the online *Caregiving Essentials* course, which was offered as a pilot in both the Fall of 2018 and the Winter of 2019. The objectives of the course are to increase the following in terms of the caregiver experience:

- 1) Knowledge, ability, skills, confidence, and self-efficacy in caregiving
- 2) Self-reported sense of personal well-being
- 3) Perceptions of health and well-being of older adults in their care
- 4) Understanding and access of the health and social service system

The evaluation study aimed to determine the effectiveness of the course based on whether these four main objectives were met, and to what extent. Additionally, the study explored the ways in which the online delivery of the course contributed to its overall effectiveness, and specifically, whether aspects of the web-based modality enhanced or hindered participants' learning experience.

How was the study done?

- The total number of participants who filled out the pre-course survey was 111 and the total number of people who filled out the post-course survey was 39
- A total of 26 telephone interviews were conducted with participants from both the Fall 2018 and the Winter 2019 course offerings
- Six key stakeholders of the project were also interviewed via telephone to collect data on their insights regarding the online delivery of the course
- A **virtual focus group** was also conducted with a group of five nursing students from a Northern Ontario college to gather feedback regarding their in-course experience as discussion board moderators and technical support providers

Key Research Findings

- The **objectives #1 and #4** were met by most of the participants (increased knowledge, confidence, understanding and access)

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CONTINUING
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RESEARCH BRIEF

Evaluation of the Effectiveness of the Caregiving Essentials Course for Informal Caregivers of Older Adults in Ontario and its Online Delivery

Key Research Findings Continued...

- Objectives #2 and #3 were met by fewer participants because external factors outside of the course had a stronger influence on health and well-being
 - Since most participants reported positive course feedback, *Caregiving Essentials* was determined to be effective
 - The online delivery enabled greater accessibility for participants by allowing them to work through the modules at their own pace, wherever and whenever
 - The discussion boards were identified as a major strength because of the opportunity for social interaction and the sense of community
 - Barriers to participation were noted and some improvements to the course were suggested
 - Most participants agreed that the online delivery enhanced their learning experience and contributed to the overall effectiveness of the course
- More interactive features have been added to the course, such as videos that showcase real caregivers' stories and an optional virtual book club for "The Unexpected Journey of Caregiving" by Donna Thompson and Zachary White
 - The hope is that these new changes will provide informal caregivers with a more engaging learning experience so that they can gain the information and support that they need
 - The findings from this evaluation may also inform other research interventions for informal caregivers with similar objectives
 - This work may provide contributions to policy decisions surrounding informal caregiving in Ontario, Canada

Who are the researchers?

Shelley Rottenberg, B.Sc. Masters Candidate, McMaster University

Allison Williams, Ph.D. Professor and CIHR Research Chair in Gender, Work & Health, McMaster University

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For more information about the course:

<https://www.mcmastercce.ca/caregiving-essentials>

Where do we go from here?

- Participant feedback have been extremely valuable in making enhancements to the course
- Several of the recommendations on potential ways to improve the course and its online delivery have been applied to the newer course offerings of *Caregiving Essentials*

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