ORIGINAL RESEARCH PAPER*

Extending Classroom Learning Borders: Caregiver Training Workshop for Chronic Disease Family Caregivers

Adriana C. Salvia[a], Nazlin Z. Hirji[b], Het Daxeshbhai Shah[a], Sandra Devlin Cop[a], Sue D. L'Europa[a]
[a]*Humber College Institute of Technology & Advanced Learning,* [b]*Insurance Institute of Canada*

Keywords
caregiver burden, educational interventions, chronic disease, reframing experiences, coping strategies, social support, program evaluation, program impact

Article History
Received 23 Sept 2022
Received in revised 22 Aug 2023
Accepted 15 May 2023
Available online 19 Dec 2023

***Original Research Articles** are papers that report on original empirical research with a focus on teaching and learning. Papers may be qualitative or quantitative and include an Abstract, Introduction, Method, Results, Discussion, and Reference section, as well as any tables and/or figures.

Abstract

Through the provision of education and training, the Caregiver Training Workshop (CTW) pilot study aimed to advance knowledge about in-person educational interventions for primary family caregivers aiding ill adults (18 years of age and over) at home. The target population was community-dwelling chronic disease caregivers, 14 of whom participated in the workshop/pilot study in September and October 2019. The sessions were offered once a week, over five weeks—each session lasting two hours. The goal of the CTW pilot study was to measure any relationship between caregiver burden levels and the study's multi-component curriculum and course design, and to obtain participant feedback about the content and structure. Curricular topics were chosen based on a review of the literature. The methodology selected was mixed-methods and convergent pretest–posttest design. Data was collected at three points in time. The pre-workshop data collection instruments consisted of the Burden Scale for Family Caregivers (BSFC) in long form and a mixed demographics form. Post-workshop instruments consisted of the BSFC (second time) and open-ended questions evaluating the program. Three-months post workshop conclusion, the instruments consisted of the BSFC (final time) and a mixed questionnaire regarding the program's impact. The reduction in caregiver burden was not statistically significant; however, burden scores from three of the 14 caregivers improved over the study period. Analyzing the qualitative data, as well as viewing caregiver burden through self-efficacy theory, offer insights as to why. Many caregivers expressed interest in maintaining contact with each other post workshop completion. This supports research indicating that some caregivers are interested in maintaining social connections throughout their care recipients' illness trajectories.

Funding

This research study received funding from Humber College's Teaching Innovation Fund in 2019/2020, since renamed the Seed Research & Innovation Fund, enabled by the Scholarship of Teaching and Learning (SoTL).

Introduction

A long-standing explanation for why family caregivers have assumed and/or are expected to assume the bulk of care for their care recipients (recipients) is that efficiencies in the health care system have resulted in earlier discharges from hospital (Houts et al., 1996). This has placed heightened pressure on caregivers to coordinate care for family and obtain the knowledge needed to provide care on a long-term basis—responsibilities previously handled by health care workers (Houts et al., 1996). The health care system has become reliant on caregivers (The Change Foundation, 2016). The need for caregivers is expected to rise in the coming years as persons aged 65 years and older will become a larger proportion of the population; they are projected to live longer and with more complex illnesses (Battams, 2016; Plöthner et al., 2019).

The Caregiver Training Workshop (CTW) pilot study endeavoured to build on the findings of previous research-based, in-person educational interventions targeting primary family caregivers (caregivers) of adult recipients (18+) living at home with long-term, chronic illnesses. The CTW pilot study was constructed as five, weekly, two-hour sessions delivered by a multidisciplinary team of faculty members at a large polytechnic institute in an urban centre in Ontario, Canada. The goal was to determine whether there was a relationship between caregiver burden levels and the multi-component curriculum and course design. The study also obtained feedback from participating caregivers about the course design (content and workshop structure) to explore teaching and learning with a community-based population that extends the borders of established classroom learning.

Literature Review

The evidence suggests that there is often little advance preparation time to become a caregiver; they are frequently thrust into their new roles with insufficient supports (The Change Foundation & Ontario Caregiver Organization, 2019; MacDonald et al., 2010; MacIsaac et al., 2010). Caregivers can more effectively manage their burden and build task mastery through formalized training and also through supportive interventions, e.g., receiving a socially supportive phone call from a health care practitioner (MacDonald et al., 2010; Reinhard et al., 2008). Caregiver training needs should be assessed by health care providers and classified within the three domains of adult learning: cognitive, affective, and psychomotor (Given et al., 2008). Training should be provided by health care professionals to enhance caregiver competencies and confidence (Given et al., 2008; Houts et al., 1996; Reinhard et al., 2008). Given et al. (2008) propose that “program planners, providers, and policymakers” (p. 33) collaborate to construct evidence-based educational interventions that consider the multifaceted needs of caregivers. Involving other family members and/or offering on-site respite/concurrent activities for recipients is an accommodation that facilitates caregiver participation (Ostwald et al., 1999).

Research-driven educational interventions for caregivers have typically focused on recipients with a single affliction (Reinhard et al., 2008). Chronic disease caregivers may take on greater care responsibilities, particularly in advanced stages of illness, as they often try to manage more than one condition. Mardanian Dehkordi et al. (2016) refer to this as walking an “unpredictable path” (p. 128). Depending on the chronic condition(s), as the recipients’ health needs change and care demands increase, caregivers must continually learn new skills and/or perform increasingly complex tasks, without adequate training—which can result in higher stress levels and the institutionalization of recipients before their actual need (MacDonald et al., 2010; Reinhard et al., 2008). As it is, more than half of caregivers worry that they might make a mistake when administering care (White et al., 2022). Ultimately, caregivers shoulder “significant demand and burden to their own endurance and coping mechanisms” (Burleson Sullivan & Miller, 2015, p. 7).

Caregivers with high self-efficacy appear to be better able to manage complex care, while those with low self-efficacy appear to experience higher levels of burden; self-efficacy is described as having the belief in one’s self to confidently execute certain tasks (White et al., 2022). Seemingly, self-efficacy is not intrinsic to some caregivers and extrinsic to others; it can be learned. To illustrate, it has been suggested that for dementia caregiving, levels of caregiver self-efficacy are modifiable through psychoeducational interventions (De Maria et al., 2021; White et al., 2022); and, in a hospital-based, nurse-led educational intervention designed for cancer caregivers, levels of self-efficacy increased for caregivers with respect to both recipient care and caregiver stress (Hendrix et al., 2015).

Regarding their own health needs, caregivers often neglect booking routine health care visits for themselves. One reason cited is that in taking recipients to so many appointments, caregivers experience “medical visit fatigue”

(Burleson Sullivan & Miller, 2015, p. 8). They also face higher risks of acquiring or exacerbating their own "age-related diseases" (Barrett & Blackburn, 2010, p. 203) based on the demands of care, e.g., providing care for Alzheimer's disease may lead to a more rapid deterioration of a caregiver's immune system (Barrett & Blackburn, 2010).

Research Purpose Statement and Guiding Questions

There appears to be a significant gap in family caregiver training programming, i.e., multi-component educational interventions have not been made widely available to caregivers, specifically those aiding chronically ill adult recipients at home. There was, and remains, a lack of longitudinal studies examining whether the interventions that have been offered are meeting the ongoing needs of chronic disease caregivers.

The purpose of this research study then was to determine whether and to what extent offering a multi-component curriculum and course design to primary family caregivers improved their burden levels, using a pretest–posttest design. The following questions about caregivers guided the research:

- Are burden levels impacted by participating in this educational intervention?
- Could burden be reduced for only some caregivers and not all? If so, why not all?
- Is there a relationship between caregiver burden levels and the topics/curriculum covered?
- Is there a relationship between caregiver burden levels and the workshop structure?
- What knowledge/learning will caregivers demonstrate immediately post-workshop vs. three months post?

The researchers hypothesized that using a multi-component curriculum and course design would improve caregiver burden levels in both the short- and longer-term.

Recruitment Approach, Sample, Site, and Session Topics

Participants were recruited through flyers posted in public areas throughout the community of a large urban area in Ontario, Canada. Flyers were also distributed electronically to interested health care practitioners and adult day program administrators.

To enroll in the workshop, an interested caregiver contacted the principal investigator (PI) by email or telephone. Herein, they discussed eligibility (i.e., a primary family caregiver of an adult recipient living at home with a chronic disease; caregiver and recipient did not have to live in the same dwelling). To confirm eligibility, chronic disease was based on the list of conditions outlined by the Public Health Agency of Canada (current as of 2019). The PI and caregiver also discussed the at-home care situation, workshop logistics, and the availability of on-site respite and/or concurrent activities for recipients. These activities, e.g., group conversation and indoor walking, were conducted with students from a Practical Nursing (PN) diploma program with faculty oversight.

After caregivers were confirmed as meeting the eligibility criteria, they were asked whether they wanted to learn more about the research study (eligible caregivers could take the workshop whether or not they elected to participate in the research). Interested caregivers were contacted by a research assistant and apprised of study details, i.e., informed consent document, timeline for completion of the evaluations, and incentive for participation.

At the conclusion of the recruitment process, 17 primary caregivers were both eligible and expressed interest in taking the workshop. Prior to the start of session one, three caregivers elected to step away from workshop participation. Of the remaining 14 caregivers enrolled in the workshop, all agreed to voluntarily participate in the study. Two of the caregivers and their recipients accepted the offer of on-site respite.

The workshop/study took place over five Saturdays in September and October 2019, from 10:00 AM to 12:00 PM. Curricular topics included: Staying at Home Versus Long-Term Care; Symptom Management; Medication Management; Maximizing Nutrition; Funeral Planning; Safety at Home; Emergency Preparedness; and, Coping with Caregiving. Time was also devoted to survey completion in sessions one and five.

Method

The researchers opted for mixed methods research, specifically a convergent design, which involves concurrent collection of quantitative and qualitative data to compare and identify any inconsistencies in the results (Creswell & Guetterman, 2019).

Data Collection Instruments

The researchers used the Burden Scale for Family Caregivers

(BSFC) as the quantitative measure for burden levels. It is designed for chronic disease caregivers who are providing at-home care. The BSFC in long form (28 questions, four-point Likert scale), offers a subjective measure of a caregiver's emotional and physical health. The lower the score on the scale, the lower the caregiver's perceived burden, with a range of scores from 0–84 (Burden Scale for Family Caregivers, n.d.; Gräsel et al., 2003).

A mixed demographics form was created by the researchers and administered prior to the start of session one. In addition to general demographic information, this document asked caregivers to identify who they provide care for, care tasks they perform, how many hours a week they devote to caregiving, length of time caregiving, their employment status (pre and during caregiving), their own health concerns, which features they would like to see in an in-person caregiver training workshop, and whether they had previously used any services to help with burden management.

In addition to administering the scale for burden measurement, the researchers collected feedback on the curriculum and course design, specifically, an open-ended program evaluation questionnaire at the end of the workshop (after completion of session five), and a mixed questionnaire assessing program impact at three-months post workshop completion.

Data Collection Process

Prior to the start of session one, the following documents were administered and collected in person by a project research assistant; the project investigators and logistics team exited the classroom during collection of the following:

- informed consent
- BSFC (first time)
- mixed demographics form

At the conclusion of session five, the following documents were administered and collected in person by a project research assistant; the project investigators and logistics team exited the classroom during collection of the following:

- BSFC (second time)
- open-ended questions regarding program evaluation

At three-months post workshop, the following documents were administered and collected by mail by a senior representative of the institution's research office.

- BSFC (third and final time)
- mixed questionnaire regarding program impact

Any participant who completed all forms over the study period received an incentive of a $25 CAD gift card.

Data Analysis

In addition to scoring the BSFC per specifications, measures of central tendency were performed. The mean burden score declined from the pre-workshop stage to post-workshop, and increased again at three-months post. Pre-workshop, mean burden was found to be 48.57 which fell to 46.09 post-workshop and then rose to 48.88 after three months. Due to the small sample size, parametric tests, e.g., a paired t-test, could not be performed to better understand the findings. This mean pattern persisted when isolating the participants who completed evaluations at all points across three time periods, which entailed six participants. Next, a non-parametric test was chosen, specifically the Wilcoxon signed-rank test, to search for differences among the three sets using the Statistical Package for the Social Sciences (SPSS software). According to Scheff (2016), the Wilcoxon signed-rank test is more powerful than the Sign test as it uses the magnitude of the difference and is highly sensitive. The results of this test were not statistically significant (see Table 1). The Friedman test was also run to interpret the means and confirmed the Wilcoxon test results. As a result, the hypothesis could not be supported.

It is possible that the decline in mean burden from pre- to post-workshop is related to workshop participation and the offer of respite as having been a crucial support to the caregivers. It is further possible that the rise in mean burden from post-workshop to three-months subsequent is related to the absence of that support and the empowerment caregivers had derived from the group setting. It is therefore feasible that support should be offered to caregivers on an ongoing basis, meeting their needs based on where they reside on the caregiving trajectory and what they are enduring at a specific point in time. Subsequently, the researchers isolated the burden scores of three individuals who experienced the largest changes in perceived burden over the three data collection periods for further analysis. Finally, to inform proposed changes to the curricular topics and workshop structure (within the course design), thematic analysis of all participant feedback was conducted.

Table 1 Burden Scale for Family Caregivers: Wilcoxon signed-rank test

	Pre- and Post-Workshop	Post-Workshop and after three months	Pre-Workshop and after three months
Number of Matching Pairs	11	6	8
p:	0.238	0.553	0.465

Note: For each of the three pairs, the Null Hypothesis–that the difference in the median is 0–was accepted. Therefore, it could not be concluded that the difference among the three sets of measures was statistically significant.

Results

Workshop Participants / Demographics

Of the 14 primary caregivers enrolled in both the workshop and the research study at the outset, 11 identified as female, and three as male. Sixty-four percent were between the ages of 35–54. The remaining 36% were between 55–75 years old. These age ranges align with the national average; nearly two-thirds of Canadians who identify as caregivers—which is 1 in 4 Canadians—are 45 years or older (Statistics Canada, 2018). Of the 14 participants, 57% had been caregiving between one to five years, and 36% for more than five years. Only seven percent said they had been caregiving for less than six months (see Figure 1).

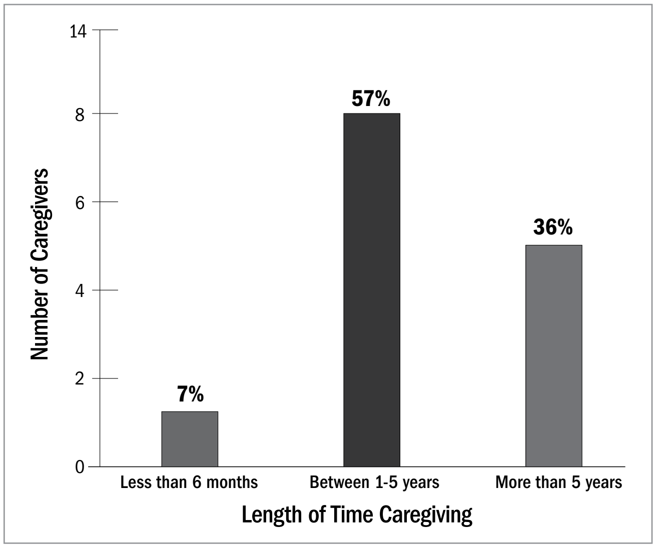

Figure 1. Length of Time Primary Family Caregivers Have Been Providing Care at Home

Caregivers were asked in the mixed demographics form about the duties they perform. Responses included: providing personal care, administering medications, preparing meals, maintaining the household, managing finances, coordinating the recipient's health care schedule, and driving them to appointments. These responses are largely echoed in the research (Committee on Family Caregiving for Older Adults et al., 2016). While there was no attrition in workshop attendance throughout the five weeks, research study participation, which began at 14, fell to 11 at the end of session five and reduced further still to eight at three-months post.

A ninth survey was received three months after the allotted submission time frame. The researchers decided not to include the submission in the analysis and findings.

Burden Scale for Family Caregivers

The sum score of the long-form BSFC is calculated based on providing either of two types of care at home: a) dementia; and, b) other chronic diseases. The BSFC correlates subjective burden to risk of psychosomatic conditions in three categories: none to mild, moderate, and severe to very severe (Burden Scale for Family Caregivers, n.d.; Gräsel et al., 2003). In their manual describing the development, validation, and instructions for administering the BSFC, Gräsel et al. (2003) do not explicitly indicate why they differentiated scoring for dementia versus non-dementia caregivers. However, dementia caregivers have reported experiencing higher levels of physical and psychological burden compared to other types of caregivers (Kasper et al., 2015; Liu et al., 2022; Schulz & Sherwood, 2008; Sörensen et al., 2002).

The BSFC was completed by all 14 participants prior to the first session, 11 participants at workshop end (session five), and eight participants at three-months post. Due to the small sample size and fewer evaluations submitted over the study period, it could not be concluded whether the workshop had an impact on overall burden levels (see Table 2). That being said, participants CTWCDM005 and CTWCDM013, who had been caregiving for five or more years, and participant CTWCDM006, who had been caregiving in the one-to-five-year range, had declines in their burden levels (see Figure 2).

In those three cases, the recipients were listed as a parent and each recipient was living with one or more chronic diseases. Participant CTWCDM005 identified as a "dementia caregiver" and classified as FT/lived with recipient. CTWCDM013 identified as an "other chronic disease caregiver" and classified as FT/lived with recipient. CTWCDM006 identified as an "other chronic disease caregiver," did not live with the recipient, and provided care for 10–20 hours a week; however, CTWCDM006 specifically indicated feeling preoccupied with providing care.

Table 2 Burden Scale for Family Caregivers: BSFC–Combined (Both Diagnoses) Subjective Burden Category

Subjective Burden Category	Session One Sample Fraction	Post-Session Five Sample Fraction	Three-Months Post Sample Fraction
None to Mild	4/14	5/11	2/8
Moderate	3/14	0/11	2/8
Severe to Very Severe	7/14	6/11	4/8

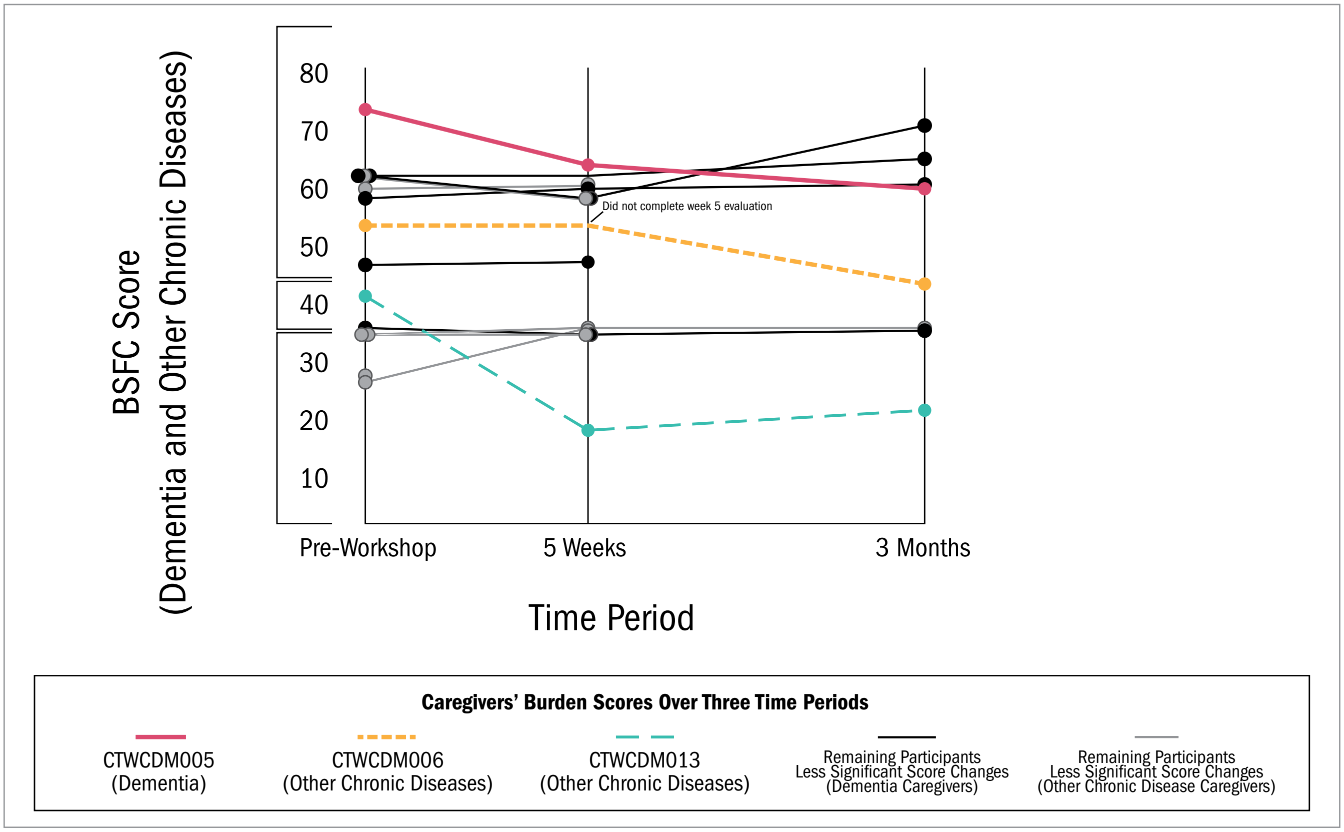

Figure 2. BSFC Throughout *the Study: Three Caregiver Participant Scores Isolated*

Qualitative Instruments

Improvement in BSFC scores largely reflected subtle changes among the three participants over the study period, i.e., feeling they could "switch off" away from the caregiving situation, and experiencing heightened life satisfaction. Given these subtleties within the quantitative measures, the researchers turned to the qualitative data to learn more about why their burden may have decreased. Sorrell (2014) supports using qualitative instruments to better understand what family caregivers endure on a case-by-case basis. Specifically, responses to the three-months post mixed questionnaire were used to identify how these three cases differed from the other workshop participants. The three cases stated that the curriculum and workshop structure better enabled them to increase their acceptance of the care situation (CTWCDM013) and/or not feel as guilty about taking time for themselves when required (CTWCDM005 and CTWCDM006). Responses to the open-ended questions from all the caregivers participating in the workshop provided greater context for the types of curricular and structural changes that should be considered to better meet their needs in the future.

Linking the Decline in the Three Burden Scores to Self-Efficacy Theory

In addition to analyzing the qualitative data, another possible explanation for the decreased burden scores among the three caregivers surfaces when viewed through self-efficacy theory. Social Cognitive Theory (SCT), a theory developed by psychologist Albert Bandura in the 1960s, emphasizes the social context of learning (LaMorte, 2022). SCT specifies that an individual can misconstrue their level of self-efficacy when performance under normal conditions changes to performance "under taxing conditions" (Bandura, 2012, p. 10). Self-efficacy theory, a subset of SCT, branches into two outcome behaviours: recognizing self-efficacy and the expectations associated with performance (Sutton, 2010). In applying self-efficacy theory to the dementia caregiving context, Stefen et al. (2018) concur with Bandura that "self-efficacy beliefs have been demonstrated to influence the initiation of coping, expenditure of effort, and the degree that behaviors are sustained in challenging situations" (p. 2). Additionally, higher levels of self-efficacy, reframing, and feeling in control during stressful situations have been associated with improved psychological fitness (Teahan et al., 2018). At three-months post, the three cases stated that their confidence improved when asking for help and accessing health-related services.

Course Feedback: Structure

The five sessions were scheduled from 10:00 AM to 12:00 PM on Saturday mornings. Two topics were scheduled per session, e.g., *Symptom Management and Medication Management*. Each of the sessions ran longer than the prescribed two-hour time frame due to often lengthy content discussions, as well as logistics, e.g., survey completion designated during session time. When asked about this at the end of session five (open-ended questionnaire), of 11 responses logged, 82% said the sessions needed to be extended; others suggested increasing the number of sessions in the workshop. Examples of feedback included: "Make it 3 hours... will ensure the topics don't run overtime and will allow Q&As," and "It could have been longer. Maybe 8 weeks." When asked about the timing of the workshop, of 10 caregivers who responded to the question, 80% affirmed a Saturday morning preference; 20% suggested an early weekday morning, e.g., 7:00 AM on Mondays.

On-Site Respite

Two caregivers brought their recipients for on-site respite/concurrent activities. When asked about this at the end of session five, 11 caregivers responded and 100% said they were pleased that respite had been made available. Not all caregivers elaborated on this question, but for those who did, their reasoning for not using the respite included having planned for recipient care while they pursued the training.

Course Feedback: Evaluation

When asked at the end of session five what they liked most about the workshop, course content was dominant among 11 respondents, with 73% identifying the following topics: *Coping with Caregiving, Safety at Home*, and *Maximizing Nutrition for Chronic Disease*; 28% stated they wanted more hands-on skills per session. When asked for other topic suggestions, 55% proposed wellness and wellbeing, family dynamics, patient lifting techniques, taxes and estate planning, and the role of provincial government supports, e.g., Home and Community Support Services (formerly called the Local Health Integrated Networks - LHINs) in Ontario, and their clinic systems (see Table 3).

When probed about what they liked least about the workshop, 28% of respondents specified that due to time constraints in each session, they felt they lacked opportunities to share their own care stories, or listen to others', either in larger or smaller group settings. This comment was also reiterated when respondents were asked for their advice about what researchers should include if/when offering subsequent intakes of the workshop: "I wish there was more time to share my personal stories," and, "Maybe incorporate a group chat for those that need an avenue to express themselves."

Course Feedback: Impact

When asked in the three-months post mixed questionnaire what they learned at the workshop, of eight respondents, 100% referred to course content and discussion topics, which included: Coping with Caregiving, Emergency Planning, Maximizing Nutrition for Chronic Disease, and referenced using the resources provided to increase communication and advocacy for their recipients. Thirty-eight percent felt the workshop validated that others shared their caregiving experiences: "Learnt that I am not alone

Table 3 Feedback to Improve Delivery of the Caregiver Training Workshop: Course Evaluation

Description of Feedback	Percentage of Caregivers	Number of Caregivers
Coping with Caregiving, Safety at Home, Maximizing Nutrition for Chronic Disease	73%	8/11
Wellness and Well-being, Family Dynamics, Patient Lifting Techniques, Taxes and Estate Planning, Role of Home and Community Support Services (formerly called the LHINs)	55%	6/11
Want more hands-on skills	28%	3/11

Note: Respondents to this evaluation were encouraged to provide multiple responses.

in the caregiving situation and many of us facing similar situations."

When asked if they would recommend the workshop to other caregivers, 50% said they would do so, believing the workshop was an important asset. Twenty-five percent stated 'maybe' to recommending the workshop. One 'maybe' response said they would do so if structural changes were applied (e.g., session length). Regarding the other 'maybe', the respondent said: "Seemed as if most people there were searching for support or help. Most seemed exhausted." The other 25% did not respond to the question.

To learn more about caregivers' motivation to attend the workshop—outside of the initial telephone assessment—the researchers revisited the mixed demographics form (administered pre-workshop). Caregivers had been asked if they used any services to manage the stress or burden of caregiving. Only four of the 14 caregivers said that they had done so.

According to Knowles et al. (2016), caregivers may be hindered from accessing support due to their reluctance to identify as caregivers. In their study, caregivers indicated feeling reticent about having their other labels minimized, e.g., partner or child. As well, caregivers offered that the identity of 'caregiver' could be upsetting to their recipients, as it implies that they are in need of care. Caregivers might also not be aware of various services offered or have time to use (access) them. Further, they may simply prefer to call on family and friends first when in need. To exemplify, 12 of the 14 participants replied that they rely on either family members or friends for informal support. This finding aligns with research stating that caregivers receive the bulk of their social support from a spouse or partner, children, and extended family (Hango, 2020). Caregivers might also have attended the workshop appreciating that the subject matter taught could optimize their care provision at home, but what they might actually have been seeking was support from peers who shared their lived experiences. Informal social support has been deemed important to some chronic disease caregivers along the entire caregiving trajectory, i.e., caregivers want support from peers from the early stages of a recipient's illness, and continue to want it should their caregiving role continue longer-term (Cameron et al, 2013; Walshe et al., 2017).

Discussion

The researchers endeavoured to answer five separate research questions.

Q.1. Are burden levels impacted by participating in this educational intervention?

The research indicates that multi-component interventions, which include respite, education, and support from peers (Sörensen, 2002), have the most significant effect on burden when compared to singular interventions, e.g., support groups alone (Reinhard, 2008; Sörensen, 2002). However, according to Sorrell (2014), researchers should focus less on measuring burden (i.e., with a goal to decrease it), and focus more on constructing interventions that can address the types of burden caregivers experience, i.e., psychological, social, and financial.

Q.2. Could burden be reduced for only some caregivers and not all? If so, why not all?

The small sample size and lower responses over time prohibit the researchers from determining whether and to what degree participating in the workshop helped all caregivers. That being said, burden levels remained largely consistent for all caregiver participants (excluding the three isolated cases) over the study time period. Nonetheless, the qualitative feedback points to the caregiver cohort improving their care management at home based on the content and/or workshop structure. This reinforces Sorrell's (2014) recommendation to use qualitative instruments for long-term follow up with caregivers to learn more about their context and caregiving experiences.

Three caregivers in the workshop demonstrated decreases to their burden scores. Each of the three caregivers shared some common characteristics with all caregiver participants, e.g., providing care to a parent and the recipient having acquired one or more chronic illnesses. But the three-months post mixed questionnaire revealed specific themes among these three cases that may explain the reduction in their burden levels over time and/or increased self-efficacy: greater acceptance of the situation, feeling less guilt in taking time for themselves, and experiencing increased confidence asking for help or accessing needed services.

Q.3. & Q.4. Is there a relationship between caregiver burden levels and the topics/curriculum covered? Is there a relationship between caregiver burden levels and the workshop structure?

When probed at the end of the study, caregivers identified the following topics as most memorable: *Coping with Caregiving, Safety at Home, Emergency Planning*, and *Maximizing Nutrition for Chronic Disease*. While a statistically significant decrease in burden levels was not substantiated in this study, these topics appear to be in line with literature that suggests the following subjects as potentially effective in reducing caregiver burden right from the acute phase of a recipient's illness: *meeting informational needs*, i.e., ensuring the caregiver understands the illness and its course; *health education*, i.e., personal care skills, transferring/ assistance with activities of daily living (ADLs), first-aid and cardiopulmonary resuscitation (CPR), behaviour management, medication management, and recognizing signs of relapse or worsening condition; and, *providing emotional support*, i.e., cultivating an environment that encourages caregivers to discuss their fears and frustrations, and minimizes their loneliness (Stavrou et al., 2017).

Q.5. What knowledge/learning will caregivers demonstrate immediately post-workshop vs. three months post?

The responses from the caregivers at three-months post generally indicated that their confidence levels increased to carry out the caregiving role, but as previously stated, they did not experience a reduction in burden. Noel et al. (2022), having offered a virtual program for dementia, found similar results related to confidence and burden at three-months post. Ducharme et al.'s (2011) psychoeducational in-person program targeting caregivers of recipients with Alzheimer's disease, similarly found that after three months, caregivers had more confidence and, "perceived themselves to be better prepared to provide care" (p. 484); however, the participants also exhibited no discernible change to their stress-management, i.e., burden. Overall, based on participant feedback, it is plausible that program adjustments could result in heightened levels of self-efficacy among a greater number of caregivers, but it is unclear whether this would be impactful to burden levels.

An unexpected finding emerged at the workshop's conclusion: many of the caregivers expressed interest in maintaining contact with one another. As a result of this, two questions received research ethics board (REB) approval for addition to the three-months post mixed questionnaire, to ascertain if the caregivers did in fact remain in touch and whether this facet should be considered in the future: "Did you stay in touch with any of the caregiver participants once the workshop concluded? Yes or No?" and "If you responded yes, do you feel you benefitted from maintaining contact with the caregiver(s), and if so, how?" Of the eight caregivers who responded, 50% said they stayed in touch. They indicated that peer support, exchanging stories, and learning from others' experiences helped with stress reduction. Comments included: "The peer group was the most important thing to come out of the workshop," and "I believe sharing stories and experiences of others who are in similar circumstances lightened my load." While generally indicating that they wished they had done so, 37.5% did not maintain contact. There was one reply missing (no response).

Limitations

The main limitation of this study was the small sample size. Fourteen participants were insufficient to establish statistical significance of burden levels through the use of additional quantitative testing techniques. Rather the researchers had to interpret trends and patterns. Regarding the three-month post-workshop evaluations, a ninth participant had submitted surveys. However, this submission arrived three months past the submission deadline. This positioned receipt of the ninth submission during the first global wave of the COVID-19 pandemic. The researchers did not include this submission in the data analysis due to the time discrepancy and uncertainties about the possible confounding relationship between responses provided and the pandemic.

As well, during initial conversations with primary family caregivers, the PI identified the importance of secondary caregivers attending the workshop. A secondary caregiver could have included a spouse, a sibling, or another adult, related or unrelated, to the recipient. The secondary caregivers who attended wanted to assist as much as possible and/or they wanted to learn more about the recipients' conditions. While secondary caregivers were invited to the workshop sessions (two attended), they were not included in the research study, and therefore their feedback was not collected. It is possible that their burden scores as well as feedback regarding the course design could have differed from the primary caregivers and may have provided further insights.

Future Directions

An important lesson to emerge from the study is that caregivers want increased opportunities to share their stories and learn from the care situations of their peers. This need for social support should be prioritized in the future. While there are disease-specific support groups offered by various established organizations, the cohort in this study included an amalgamation of chronic disease caregivers. The researchers combined this group to enhance understanding about their common experiences, regardless of the recipient's specific condition. Few research reviews have focused on educational interventions for chronic disease caregivers (Farquhar et al., 2016). In conjunction with the identified needs of the small cohort of caregivers in this workshop/pilot study, additional research projects could deliver similar educational interventions to caregivers who are managing chronic care situations at home. This could be advanced in other post-secondary college environments, and the results shared. Findings from these interventions could better inform policymakers and other stakeholders about the educational and holistic needs of a wider range of chronic disease caregivers, ways to make the learning accessible, and how to optimize delivery modes (e.g., in-person and/or online).

Conclusion

As the current study and literature suggest, design of effective educational interventions for chronic disease family caregivers would benefit from and require addressing the known types of burden they experience. Some greater context for why burden decreased for three caregivers over the study duration was obtained through qualitative data collection and applying self-efficacy theory. The three caregivers indicated how the workshop enabled them to reframe their specific care situations at home. Further, all the study participants provided feedback to inform curricular and course design changes. Importantly, caregivers revealed that they wanted additional dedicated time to discuss their caregiving stories; they also stressed the need to stay in touch with other attendees once the workshop concluded.

Conflict of Interest

The authors have no competing or financial interests to disclose.

Acknowledgements

The family caregivers who participated in the workshop and/or research, the multidisciplinary faculty team from Humber College who led the workshop sessions, the on-site logistics team, and leadership from the Faculty of Health Sciences & Wellness (FHS&W) and Continuous Professional Learning (CPL) division, and the Office of Research & Innovation. Additional thanks to the following from FHS&W: Craig MacCalman, Program Coordinator, Paramedic Program; Tammy Cameron, CPL Program Advisor; and Scott Williams, CPL Graphic Designer.

Authors Note

Adriana C. Salvia, MEd, Developer, Continuous Professional Learning, Faculty of Health Sciences and Wellness, Humber College, Toronto, Ontario, Canada, adriana.salvia@humber.ca. Principal Investigator of the Caregiver Training Workshop Pilot Study.

Nazlin Z. Hirji, RN, MN, MSc, Vice President, Programs, Insurance Institute of Canada, Toronto, Ontario, Canada, nhirji@insuranceinstitute.ca. Co-Investigator of the Caregiver Training Workshop Pilot Study.

Het Daxeshbhai Shah, MSc, Student Researcher, Office of Research and Innovation, Humber College, Toronto, Ontario, Canada. Data analysis researcher on project.

Sandra Devlin Cop, RN, MScN, Nursing Professor, Faculty of Health Sciences and Wellness, Humber College, Toronto, Ontario, Canada, sandra.cop@humber.ca. Co-Investigator of the Caregiver Training Workshop Pilot Study.

Sue D. L'Europa, BA, Faculty Scheduler, Longo Faculty of Business, Humber College, Toronto, Ontario, Canada, sue.leuropa@humber.ca. Co-Investigator of the Caregiver Training Workshop Pilot Study.

References

Bandura, A. (2012). On the functional properties of perceived self-efficacy revisited [Editorial]. *Journal of Management*, 38(1), 9-44. https://doi.org/10.1177/0149206311410606

Barrett, G. J., & Blackburn, M. L. (2010). The need for caregiver training is increasing as California ages. *California Agriculture, 64*(4), 201-207. https://escholarship.org/uc/item/2c411596

Battams, N. (2016, February 18). *Family caregiving in Canada: A fact of life and a human right.* The Vanier Institute of the Family. https://vanierinstitute.ca/family-caregiving-in-canada-a-fact-of-life-and-a-human-right/

Burden Scale for Family Caregivers. (n.d.). *English / original version.* https://www.psychiatrie.uk-erlangen.de/med-psychologie-soziologie/forschung/psychometrische-versorgungsforschung/burden-scale-for-family-caregivers-bsfc/

Burleson Sullivan, A., & Miller, D. (2015). Who is taking care of the caregiver? *Journal of Patient Experience, 2*(1), 7-12. https://doi.org/10.1177/237437431500200103

Cameron, J. I., Naglie, G., Silver, F. L., & Gignac, M. A. M. (2013). Stroke family caregivers' support needs change across the care continuum: A qualitative study using the timing it right framework. *Disability and Rehabilitation, 35*(4), 315-324. https://doi.org/10.3109/09638288.2012.691937

The Change Foundation. (2016, June). *A profile of family caregivers in Ontario.* https://changefoundation.ca/wp-content/uploads/2016/06/Profile-of-Family-Caregivers-report-FINAL.pdf

The Change Foundation & Ontario Caregiver Organization. (2019, November). *2nd annual spotlight on Ontario's caregivers.* https://changefoundation.ca/wp-content/uploads/2019/11/Spotlight-on-ontario-caregivers-2019_final.pdf

Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America* (R. Schulz & J. Eden, Eds.). National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK396401

Creswell, J. W., & Guetterman, T. C. (2019). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (6th ed.). Pearson Education.

De Maria, M., Iovino, P., Lorini, S., Ausili, D., Matarese, M., & Vellone, E. (2021). Development and psychometric testing of the caregiver self-efficacy in contributing to patient self-care scale. *Value in Health, 24*(10), 1407-1415. https://doi.org/10.1016/j.jval.2021.05.003

Ducharme, F. C., Lévesque, L. L., Lachance, L. M., Kergoat, M.-J., Legault, A. J., Beaudet, L. M., & Zarit, S. H. (2011). "Learning to become a family caregiver": Efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *The Gerontologist, 51*(4), 484-494. https://doi.org/10.1093/geront/gnr014

Farquhar, M., Penfold, C., Walter, F. M., Kuhn, I., & Benson, J. (2016). What are the key elements of educational interventions for lay carers of patients with advanced disease? A systematic literature search and narrative review of structural components, processes, and modes of delivery. *Journal of Pain and Symptom Management, 52*(1), 117-130. https://doi.org/10.1016/j.jpainsymman.2015.12.341

Given, B., Sherwood, P. R., & Given, C. W. (2008). What knowledge and skills do caregivers need? *American Journal of Nursing, 108*(9), 28-34. https://doi.org/10.1097/01.NAJ.0000336408.52872.d2

Gräsel, E., Chiu, T., & Oliver, R. (2003). Development and validation of the Burden Scale for Family Caregivers (BSFC). COTA Comprehensive Rehabilitation and Mental Health Services. https://www.psychiatrie.uk-erlangen.de/index.php?id=11049

Hango, D. (2020, January 8). *Support received by caregivers in Canada.* Statistics Canada (Catalogue no. 75-006-X). https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm

Hendrix, C. C., Bailey Jr., D. E., Steinhauser, K. E., Olsen, M. K., Stechuchak, K. M., Lowman, S. G., Schwartz, A. J., Riedel, R. F., Keefe, F. J., Porter, L. S., & Tulsky, J. A. (2015). Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. *Support Care Cancer, 24,* 327-336. https://doi.org/10.1007/s00520-015-2797-3

Houts, P. S., Nezu, A. M., Maguth Nezu, C., & Bucher, J. A. (1996). The prepared family caregiver: A problem-solving approach to family caregiver education. *Patient Education and Counseling, 27*(1), 63-73. https://doi.org/10.1016/0738-3991(95)00790-3

Kasper. J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs, 34*(10), 1642-1649. https://doi.org/10.1377/hlthaff.2015.0536

Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health and Social Care in the Community, 24*(2), 203-213. https://doi.org/10.1111/hsc.12207

LaMorte, W. W. (2022, November 3). *Behavior change models: The Social Cognitive Theory.* https://sphweb.bumc.bu.edu/otlt/mph-modules/sb/behavioralchangetheories/behavioralchangetheories5.html

Liu, R., Chi, I., & Wu, S. (2022). Caregiving burden among caregivers of people with dementia through the lens of intersectionality. *The Gerontologist, 62*(5), 650-661. https://doi.org/10.1093/geront/gnab146

Macdonald, M., Lang, A., Storch, J., Stevenson, L., Donaldson, S., & LaCroix, H. (2010, December 20). *Safety in home care for unpaid caregivers: A scoping literature review.* Canadian Patient Safety Institute. https://www.patientsafetyinstitute.ca/en/toolsResources/Research/commissionedResearch/SafetyinHomeCare/Documents/MacDonald/MacDonald,%20Marilyn_Caregiver%20Safety_Final%20Report%20ENG.pdf

MacIsaac, L., Harrison, M. B., & Godfrey, C. (2010). Supportive care needs of caregivers of individuals following stroke: A synopsis of research. *Canadian Journal of Neuroscience Nursing, 32*(1), 39-46.

Mardanian Dehkordi, L., Babashahi, M., & Irajpour, A. (2016). Nonprofessional care in chronic critically ill patient: A qualitative study. *International Journal of Preventative Medicine, 7*(1), 125-129. https://doi.org/10.4103/2008-7802.195209

Noel, M. A., Lackey, E., Labi, V., & Bouldin, E. D. (2022). Efficacy of a virtual education program for family caregivers of persons living with dementia. *Journal of Alzheimer's Disease, 86*(4), 1667-1678. https://doi.org/10.3233/JAD-215359

Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. The Gerontologist, 39(3), 299-309. https://doi.org/10.1093/geront/39.3.299

Plöthner, M., Schmidt, K., de Jong, L., Zeidler, J., & Damm, K. (2019). Needs and preferences of informal caregivers regarding outpatient care for the elderly: A systematic literature review. *BMC Geriatrics, 19*(82), 1-22. https://doi.org/10.1186/s12877-019-1068-4

Public Health Agency of Canada. (2021, December 21). *Chronic diseases.* https://www.canada.ca/en/public-health/services/chronic-diseases.html

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Chapter 14. Supporting family caregivers in providing care. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (pp. 1-341-404). Agency for Healthcare Research and Quality. http://www.ncbi.nlm.nih.gov/books/NBK2665

Scheff, S. W. (2016). *Fundamental statistical principles for the neurobiologist: A survival guide.* Elsevier.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9 Suppl.), 23-27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356-372. https://doi.org/10.1093/geront/42.3.356

Sorrell, J. M. (2014). Moving beyond caregiver burden: Identifying helpful interventions for family caregivers. *Journal of Psychosocial Nursing and Mental Health Services, 52*(3), 15-18. https://doi.org/10.3928/02793695-20140128-05

Statistics Canada. (2018). *Care counts: Caregivers in Canada, 2018* [Infographic]. (Catalogue number: 11-627-M | ISBN: 978-0-660-33219-2). https://www150.statcan.gc.ca/n1/en/pub/11-627-m/11-627-m2020001-eng.pdf?st=rujefP2n

Stavrou, V., Ploumis, A., Voulgaris, S., Sgantzos, M., Malliarou, M., & Sapountzi-Krepia, D. (2017). Informal caregivers' perceived needs for health education information and emotional support: A comparison between acute and sub-acute rehabilitation settings. *International Journal of Caring Sciences, 10*(1), 243-250. https://www.internationaljournalofcaringsciences.org/docs/28_stavrou_original_10_1.pdf

Steffen, A. M., Gallagher-Thompson, D., Arenella, K. M., Au, A., Cheng, S.-T., Crespo, M., Cristancho-Lacroix, V., López, J., Losada-Baltar, A., Márquez-González, M., Nogales-González, C., & Romero-Moreno, R. (2018). Validating the revised scale for caregiving self-efficacy: A cross-national review. *The Gerontologist, 59*(4), 1-18. https://doi.org/10.1093/geront/gny004

Sutton, S. (2010). Chapter 10: Using social cognition models to develop health behaviour interventions: The theory of planned behaviour as an example. In D. Rutter and L. Quine (Eds.), *Changing health behaviour* (pp. 197-213). Open University Press. https://www.phpc.cam.ac.uk/pcu/files/2012/01/sutton-2010.pdf

Teahan, Á., Lafferty, A., McAuliffe, E., Phelan, A., O'Sullivan, L., O'Shea, D., & Fealy, G. (2018). Resilience in family caregiving for people with dementia: A systematic review. *International Journal of Geriatric Psychiatry, 33*(12), 1582-1595. https://doi.org/10.1002/gps.4972

Walshe, C., Roberts, D., Appleton, L., Calman, L., Large, P., Lloyd-Williams, M., & Grande, G. (2017). Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. *PLoS ONE, 12*(1), 1-26. https://doi.org/10.1371/journal.pone.0169071

White, C. L., Barrera, A., Turner, S., Glassner, A., Brackett, J., Rivette, S., & Meyer, K. (2022). Family caregivers' perceptions and experiences of participating in the learning skills together intervention to build self-efficacy for providing complex care. *Geriatric Nursing, 45,* 198-204. https://doi.org/10.1016/j.gerinurse.2022.04.012