

# Evaluation of an Online Home Caregiver Support Program for Non-Professional Caregivers of Patients With Palliative Care Needs

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## Abstract

**Background:** Caring for loved ones with palliative needs can be very stressful for carers'. To address this growing issue, an online Home Caregiver Support Program course was created to provide information to non-professional home caregivers about end-of-life care. **Objectives:** To measure non-professional caregivers' perceived level of competence in addressing physical, psychological, social, and spiritual needs before and after completing online training modules. **Methods:** Learners rated their competence before and after completing online modules addressing 4 key dimensions relevant to palliative caregivers. Self-ratings of competence were assessed through surveys, completed before and after the online modules. Scores from before and after each module were compared to determine if the online course had increased participant competence. The Wilcoxon signed rank test was used to analyze participant responses to the pre- and post-survey questions. **Results:** A total of 176 participants who completed one or more of the online modules between July 2017-December 2018, 70 (40%) of the participants completed at least one pre- and post-module survey and did not declare themselves as a professional caregiver. Participating in the online Home Caregiver Support Program increased participants' ratings of perceived competence in all domains ( $p < .01$ ). This significance was maintained when professional caregivers were added to our analysis. **Conclusion:** After the completing the modules, participants' self-ratings of perceived competence increased suggesting that participants completing the online program had improved knowledge in addressing the physical, psychological, social, and spiritual challenges faced by non-professional caregivers.

## Keywords

caregivers, palliative care, surveys, training, family medicine, end-of-life care

## Introduction

It has been well-documented that most people with a life-limiting disease would prefer to remain at home as long as possible.<sup>1,2</sup> However, remaining at home is difficult for many individuals and relies heavily upon the availability and commitment of family members for care. This can be very stressful for carers', and its overall physical and psychosocial impact on carers' is well recognized.<sup>3-6</sup> To address this growing issue, St. John Ambulance, Council for Ontario, in association with the Order of St. Lazarus of Jerusalem in Canada, produced a complete 9 hour in-person pilot course, entitled Home Caregiver Support Program (HCSP), to provide information to non-professional home caregivers about end-of-life care. The HCSP was designed to provide much needed information and assistance to caregivers who provide care for family members or friends suffering from chronic or terminal illnesses (caregivers can include other family members, partners, parents, children, and close friends). The program consisted of a series of presentations offered at an easily accessible location with no

single presentation exceeding 3 hours in length. Participants were advised that they could attend only those topics that were of interest to them, as their needs dictated. It was hoped that by attending in person, there would also be an opportunity for sharing of experiences and peer-mentoring.

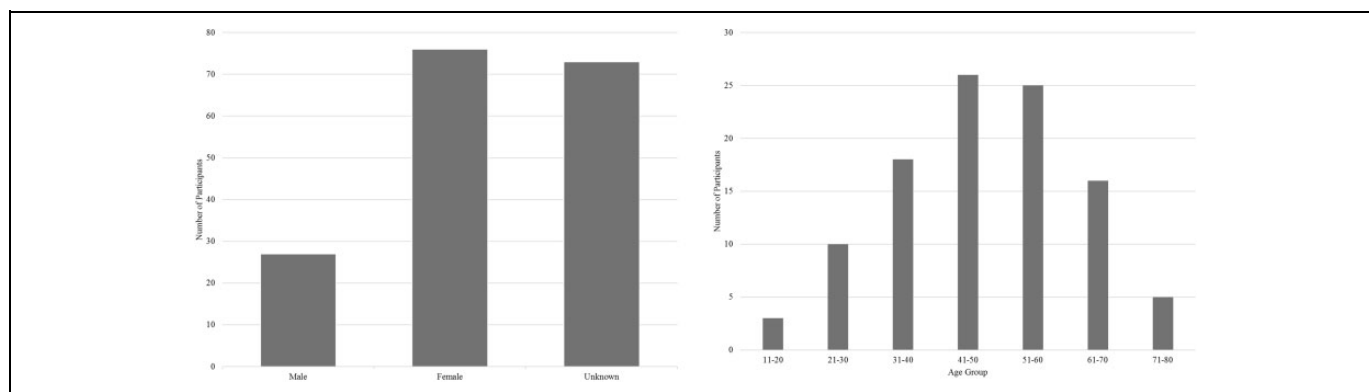
Despite excellent reviews from participants, it was difficult to recruit home caregivers to attend the in-person sessions. Access to in-person sessions can be problematic, particularly for rural caregivers or members of ethnic minorities.<sup>7,8</sup> The burden of caring for a loved one with a serious illness is another barrier, as many caregivers have difficulty leaving their family member to attend in-person sessions. As a result, an online version of

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**Figure 1.** Self-declared participant data. HCSP participants between July 2017-December 2018 organized by age group (right) and gender (left).

the program was created and offered nationally, in both official languages of English (<http://stlazarus.sjatrainng.ca>) and French (<http://stlazarusfr.sjatrainng.ca>). The online version was made available to the public on July 1, 2017. The program is based on *A Caregiver's Guide—A Handbook About End-Of-Life Care*, published by the Canadian Hospice Palliative Care Association and The Order of Saint Lazarus of Jerusalem in Canada.<sup>9</sup> The HCSP online course is designed for caregivers to do on their own time in the comfort of their own homes. In keeping with hospice palliative care philosophy, like the full in-person program, the online version addresses the physical, psychological, social, spiritual and practical issues faced by caregivers while looking after their loved ones at home. Each module was designed to be completed in approximately 1 hour. Caregivers were free to complete any or all modules as their needs dictated and they could return to any module at any time. The main purpose of this study was to determine if the online HCSP is effective in improving caregivers' perceived competence in addressing challenges faced by those caring for chronically or terminally-ill individuals. Pre- and post-surveys were built into the online course to gauge effectiveness by comparing the responses before and after completing any of the online modules.

## Methods

### Participants

All participants who completed one or more of the online modules between July 2017-December 2018, inclusive were included in the study. Participants who self-declared as professional caregivers were excluded from the primary analysis.

### Study Context

The online Home Caregiver Support Program (HCSP) comprised 7 modules. These included an Introductory module, 2 modules addressing Physical Needs, 2 modules addressing Emotional and Psychological Needs, one module addressing Social and Information Needs, and one module addressing Spirituals

Needs. These modules were based on *A Caregiver's Guide—A Handbook About End-Of-Life Care*, published by the Canadian Hospice Palliative Care Association and The Order of Saint Lazarus of Jerusalem in Canada.

### Procedure

All participants who completed any of the online modules were prompted to complete the pre- and post-module surveys. Participation was completely voluntary, and no penalty was incurred for non-participation. All data was rendered anonymous before analysis.

### Tools

*Pre-module competency survey:* Participants were asked to rate their perceived competence on a 5-point Likert scale. There were 5 questions on each pre-module survey, evaluating key competencies and objectives of each HCSP module (e.g., how prepared are you to provide care to a person with a terminal illness?)

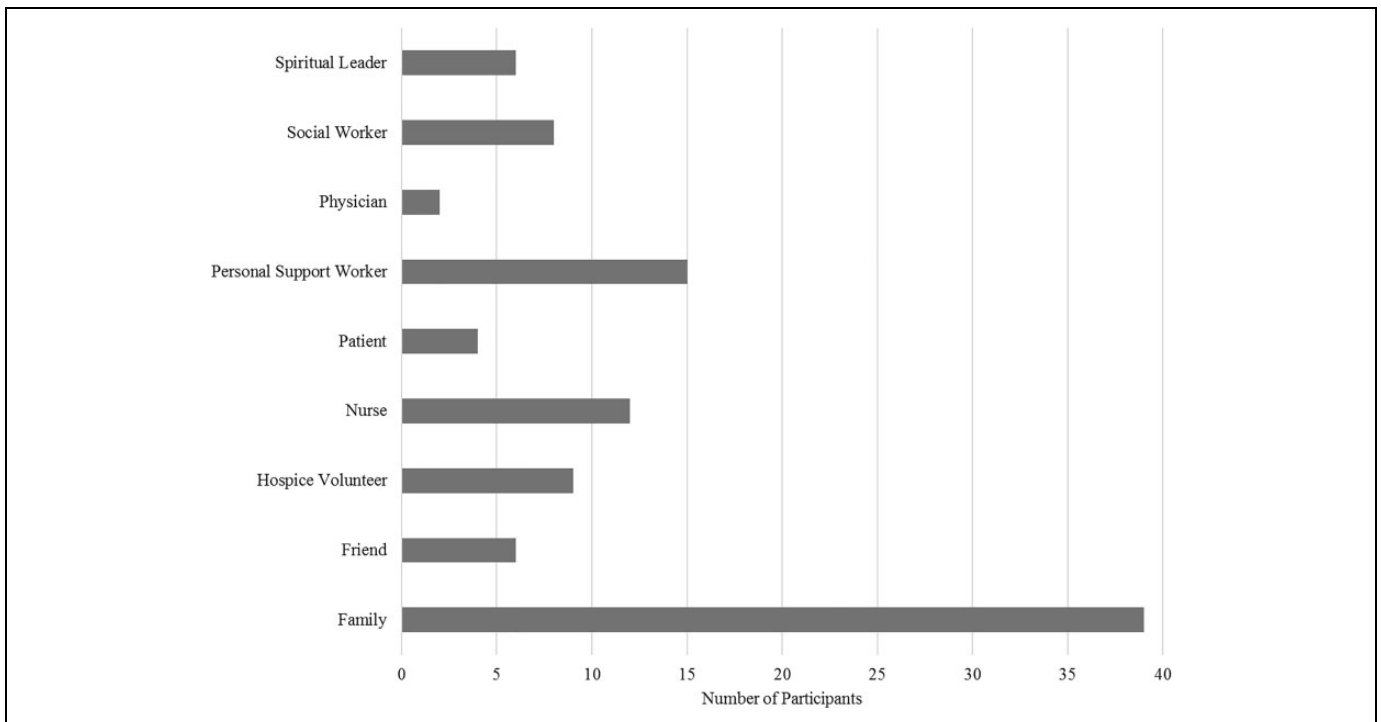
*Post-module competency survey:* Immediately following the module, participants were asked to complete the same questionnaire they completed before the module.

### Analysis

Pre-module and post-module perceived competency scores were compared using the Wilcoxon signed rank test. Individual Wilcoxon signed rank tests were conducted for each survey question for each of the 7 modules. Mean pre- and post-module survey scores for each individual question were also examined to monitor the absolute change in mean scores.

### Ethics

The Trillium Health Partners' Research Ethics Board reviewed and approved all components of this study.



**Figure 2.** Self-declared participant data. HCSP participants between July 2017-December 2018 organized by caregiver type.

## Results

### Participants

A total of 176 participants completed at least one of the online modules between July 2017-December 2018, 76 (43%) were female (15% male, 42% unknown) with most participants falling between 41-60 years of age (Figure 1). Of this population only 70 participants (40%) completed at least one pre- or post-module survey and did not declare themselves as a professional caregiver (i.e., nurse, physician, personal support worker, social worker) (Figures 2 and 3). Our primary analysis included only the results from these 70 participants to avoid bias of previous health care knowledge and focus on non-professional caregivers.

### Pre-Module and Post-Module Self-Assessments of Competence

Participants' self-rated competence increased after completion of each of the online Home Caregiver Support Program modules (Figure 4). A total of 70 participants completed the pre- and post-module survey for the Introductory module. Mean scores on each of 5 survey questions improved following the completion of the module (question 1:  $W = 68, p < .0001$ ; question 2:  $W = 52.5, p = .0001$ ; question 3:  $W = 76.5, p < .0001$ ; question 4:  $W = 34.5, p = .0044$ ; question 5:  $W = 50, p = .0028$ ) ( $W =$  Wilcoxon test statistic).

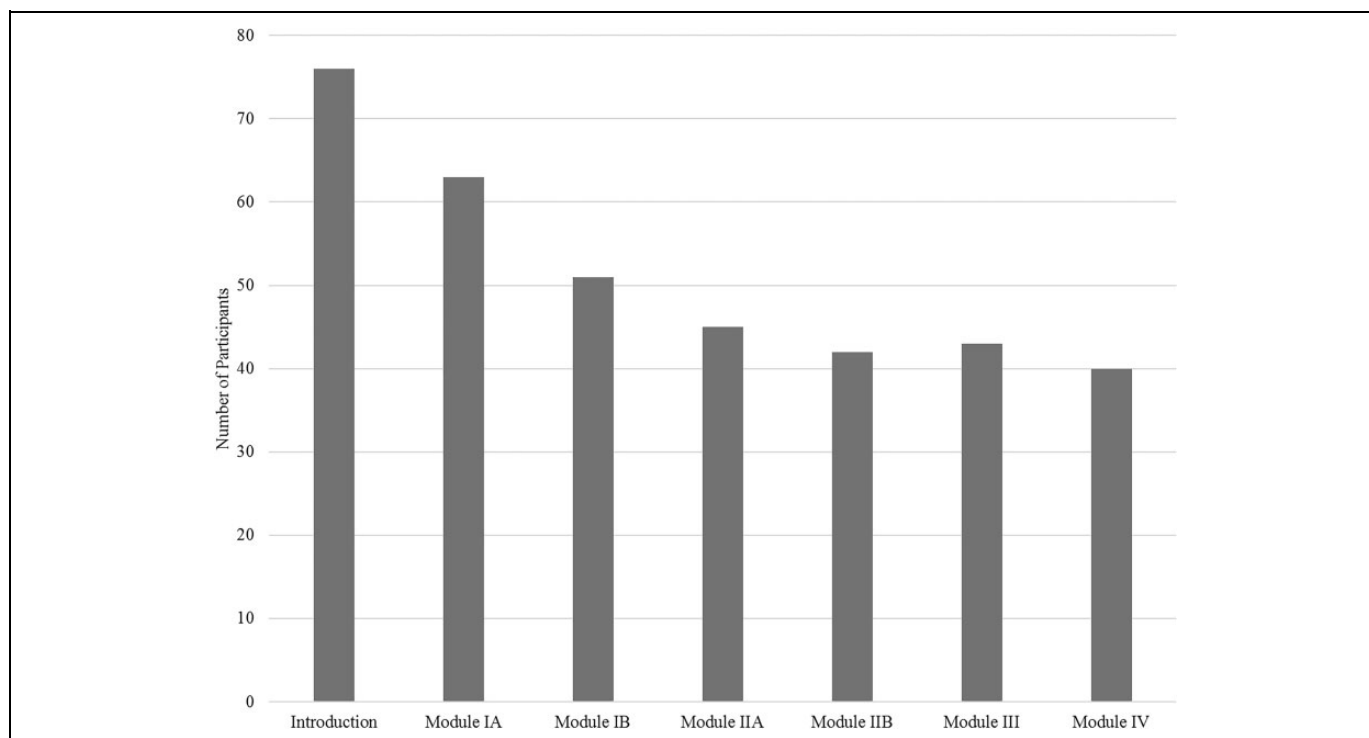
A total of 55 and 35 participants completed pre- and post-module surveys for the Physical Needs modules IA and IB, respectively. Mean scores on each of 5 survey questions

improved following the modules IA (question 1:  $W = 68, p < .0001$ ; question 2:  $W = 63, p = .0003$ ; question 3:  $W = 85.5, p < .0001$ ; question 4:  $W = 45.5, p = .0002$ ; question 5:  $W = 52.5, p = .0001$ ); and IB (question 1:  $W = 68, p < .0001$ ; question 2:  $W = 60, p < .0001$ ; question 3:  $W = 68, p < .0001$ ; question 4:  $W = 60, p < .0001$ ; question 5:  $W = 52.5, p = .0001$ ). A total of 36 and 32 participants completed pre- and post-module surveys for the Emotional and Psychological Needs modules IIA and IIB, respectively. Mean scores on each of 5 survey questions improved following the modules IIA (question 1:  $W = 76.5, p < .0001$ ; question 2:  $W = 76.5, p < .0001$ ; question 3:  $W = 68, p < .0001$ ; question 4:  $W = 33, p = .0010$ ; question 5:  $W = 60, p < .0001$ ); and IIB (question 1:  $W = 85.5, p < .0001$ ; question 2:  $W = 68, p < .0001$ ; question 3:  $W = 39, p = .0005$ ; question 4:  $W = 76.5, p < .0001$ ; question 5:  $W = 60, p < .0001$ ).

A total of 37 participants completed the pre- and post-module survey for the Social and Information Needs module III. Mean scores on each of 5 survey questions improved following completion of module III (question 1:  $W = 76.5, p < .0001$ ; question 2:  $W = 60, p < .0001$ ; question 3:  $W = 85.5, p < .0001$ ; question 4:  $W = 77.5, p = .0007$ ; question 5:  $W = 95, p < .0001$ ).

A total of 33 participants completed the pre- and post-module survey for the Spiritual Needs module IV. Mean scores on each of 5 survey questions improved following module IV (question 1:  $W = 63.5, p = .0003$ ; question 2:  $W = 79.5, p < .0001$ ; question 3:  $W = 48, p = .0011$ ; question 4:  $W = 52.5, p = .0001$ ; question 5:  $W = 49.5, p = .0007$ ).

We also performed an exploratory secondary analysis where all participants were included, including health care providers.



**Figure 3.** Self-declared participant data. HCSP participants between July 2017-December 2018 organized by the number of participants who completed each module during the same period.

However, this did not significantly change any of the results and there remained a significant increase in post-module survey scores for each module when compared to pre-module survey scores (data not shown).

## Discussion

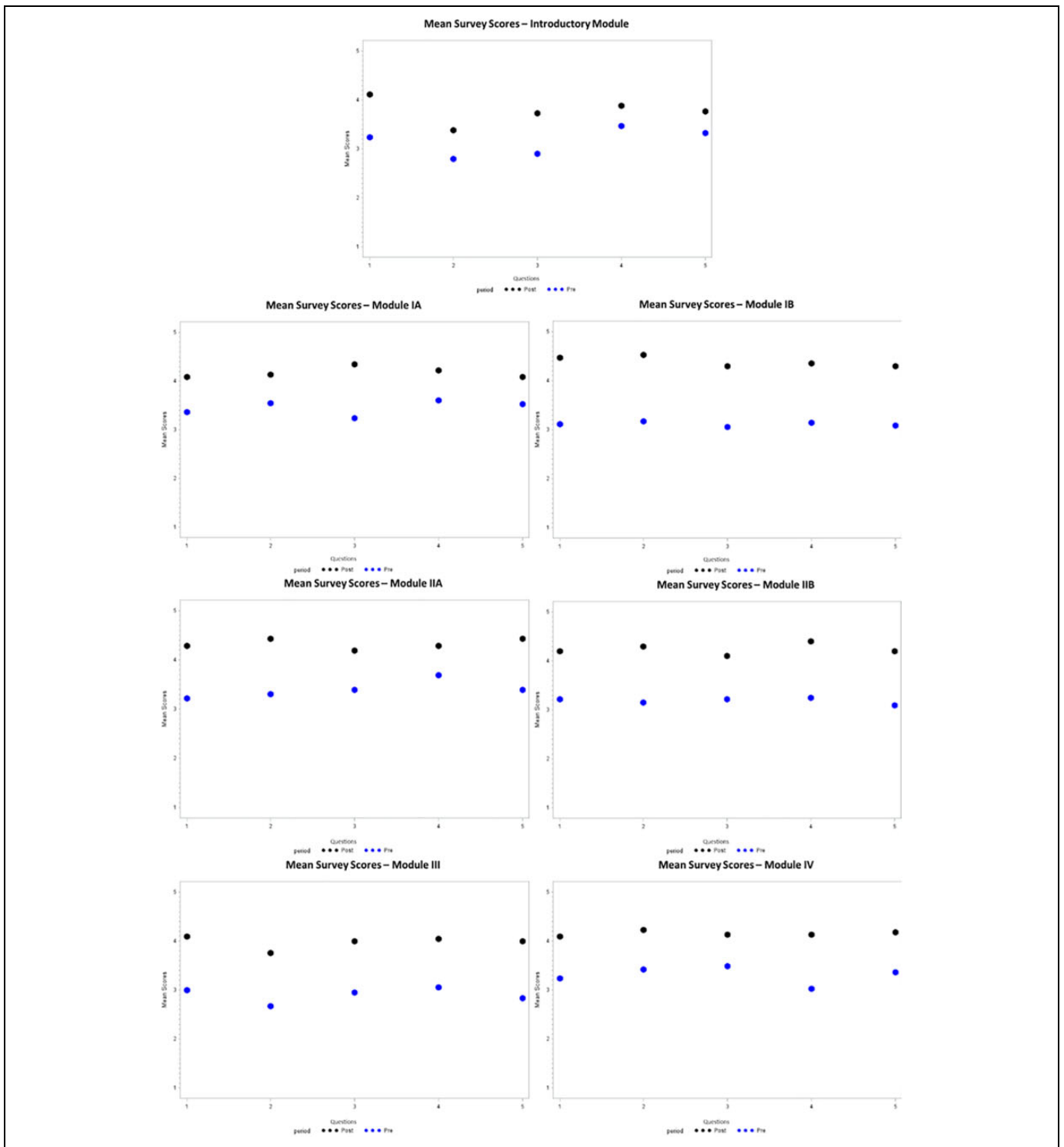
There is ample evidence in the literature that internet-based caregiver training programs can improve the experience of informal caregivers<sup>10-13</sup> Providing caregivers with the necessary knowledge needed to fulfill their role can alleviate their stress and aid them in coping with everyday demands.<sup>14</sup> Online programs may be more accessible and convenient for caregivers to participate in. This study examined the relationship between caregivers' self-rated competence before and after completing an online training program targeted toward non-professional caregivers of those with life-limiting illness. As has been noted in previous studies, we observed a majority of female caregivers.<sup>15-17</sup> Participants' self-ratings of competence increased after completion of any of the 7 online training modules, as evidenced by increased scores on post-module competency ratings when compared to pre-module scores. There was a significant increase in scores across all modules, suggesting an increase in competency across all key domains: physical needs, emotional and psychological needs, social and information needs, and spiritual needs.

Although the literature suggests learner self-assessment is unreliable,<sup>18,19</sup> we had postulated that comparing each

participant's pre- and post-module scores would allow for a relatively accurate evaluation of individual change in competency in each specific area. It is possible that our pre- and post-module survey questions may be too general to truly evaluate a subject-specific effect on competency. It would be interesting to see if further, more thorough assessment of participant competency with a larger pool of participant data would yield the same apparent increase in participant competency after completing the HCSP online modules.

## Limitations

This study, of course, had limitations. Our sample size was limited but was comparable to similar studies of self-assessment.<sup>20-25</sup> However, we did not fully examine whether there was a correlation between experience or pre-existing knowledge of end-of-life care and survey scores. Additionally, because participation in this training program was self-selected and completely voluntary, we were unable to control for any confounding factors influencing who chose to participate in the program. We do not know what factors were involved for caregivers choosing to complete the online training, these caregivers may have been more motivated to learn more and thus benefit more from the training. The voluntary nature of this program also meant that not all participants completed every module, this was by design and was meant to allow customization of the program to suite the needs of each caregiver. While this does limit our evaluation of the program, it may have provided a better view of how this program will be used in the real world, outside of a research setting. Further study



**Figure 4.** Mean pre- and post-module competency scores for each of 7 modules that comprise the online Home Caregiver Support Program (HCSP) from participants between July 2017-December 2018. \* $p < .01$  for all five questions of each module.

is needed to fully understand the effect of this program on the competency of a wider caregiver population, such as those with experience in the care of patients with palliative care needs. Further study will also help to further validate the effectiveness of this program in achieving its aims.

### Conclusion

This study investigated whether an online caregiver training program could improve non-professional caregiver knowledge and confidence. There is some evidence that internet-based interventions are effective in reducing stress, anxiety, and

depressive symptoms for family caregivers and in increasing self-efficacy.<sup>26,27</sup> As internet-based training programs become more widespread and accepted by the public, there is promising potential for digital interventions to support caregivers. This study describes one such web-based program which has validated the potential to improve the experience of individuals caring for terminally or chronically ill loved ones. There is still a need for high-quality research to evaluate the effectiveness of internet-based interventions for non-professional caregivers. It is hoped that with the findings of this study, there is some evidence to encourage non-professional caregivers to supplement their knowledge with online training.

### Authors' Note

All authors have seen and approved the manuscript and contributed significantly to the work. RM contributed to program development and manuscript preparation. SS and DH contributed to statistical analysis and manuscript preparation. This manuscript has not been previously published and is not being considered for publication elsewhere. Material support was received from both the St. John Ambulance and Military and Hospitaller Order of St. Lazarus. Statistical support was also provided by the University of Toronto, Department of Family & Community Medicine.

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### Declaration of Conflicting Interests

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