Pilot evaluation of the family informal caregiver stroke self-management program

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Abstract

Background: Due to the abrupt onset of a stroke, caregivers are often unprepared for the role, have extensive needs and are at risk for negative outcomes. Interventions facilitating development of coping and problem solving skills are shown to decrease the negative effects of caregiving. The Family Informal Caregiver Stroke Self-Management (FICSS) program was developed to address the unmet needs of family caregivers of stroke survivors.

Methods: The FICSS program is a four-module education and support series of facilitated small group discussions. Topics included: balancing changing roles, managing behaviour changes, sexuality/intimacy, and community linkages. Each module was evaluated weekly and by focus group one month after the program.

Results: Eleven family caregivers of stroke survivors with three years of mean caregiving experience participated. Caregivers valued the opportunity to share experiences and learn from others who understood what they were going through. Recommendations were made to improve the program topic areas, content and flow.

Conclusions: The pilot evaluation of the program validated the content of the FICSS program and indicated recommendations for improvement.

Introduction

Stroke is an unexpected event that can have profound life-altering effects on the stroke survivor and their family members. Approximately 300,000 Canadians are living with the effects of stroke and many are left with mild to moderate disabilities that impact their ability to perform everyday activities (Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002). It is estimated that 68%-74% of stroke survivors depend on the daily care of family caregivers once they return home (Dewey et al., 2002; Dorsey & Vaca, 1998). Families of stroke survivors may have difficulty coping with the changes associated with stroke, due to the unpredictable nature of stroke recovery and the variety of impairments experienced post stroke (Clark & King, 2003; White, Poissant, Cote-Leblanc, & Wood-Dauphinee, 2006). As a result, family caregivers of stroke survivors are often unprepared for the role of caregiving and may lack the necessary skills to obtain information about stroke, provide physical and instrumental care and manage difficult behaviours and emotions of the stroke survivor (Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005; Brereton & Nolan, 2002; King et al., 2001; Teel, Duncan, & Lai, 2001). The purpose of this paper is to describe the development, implementation, and evaluation results of the Family Informal Caregiver Stroke Self-Management (FICSS) program.

Literature review

Researchers have found that family caregivers of stroke survivors are at risk for a number of negative outcomes, as a result of providing care including depressive symptoms, psychosocial impairments, declining physical health and reduced
health-related quality of life (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Bakas, Champion, Perkins, Farran, & Williams, 2006; Berg et al., 2005; Han & Haley, 1999; White, Mayo, Hanley, & Wood-Dauphinee, 2003; VON Canada; 2008). Difficulty managing caregiving tasks is a strong predictor of emotional distress for family caregivers of stroke survivors (Bakas & Bur- gener, 2002) and is considered the leading cause of long-term institutionalization of stroke survivors (Bakas, Austin, Jessup, Williams, & Oberst, 2004). Research findings emphasize the need for programs designed to minimize the negative effects associated with the caregiving experience and improve overall quality of life for both the family caregiver and stroke survivor.

The 2010 Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2010) identify that patients, families, and caregivers should be prepared for transitions between care environments and be provided with the information related to education, training, emotional support and community services necessary for effective transitions. However, the availability of ongoing professional services and programs to address these needs is limited.

Cameron and Gignac (2008) developed the “Timing it Right Framework” to identify the specific needs of family caregivers of stroke survivors for education and support across the care continuum. Five phases of education and support needs post stroke were identified as: (a) event/diagnoses, (b) stabilization, (c) preparation, (d) implementation, and (e) adaptation. The implementation and adaptation phases occur when the stroke survivor returns home. During the implementation phase, the caregivers’ information, emotional and training needs are extensive and caregivers often report not receiving enough training for their new role and responsibilities. In the adaptation phase, caregivers have a period of adjustment at home, in which outpatient rehabilitation programs are completed and improvements in the stroke survivors’ abilities have stabilized. During this phase, caregivers become more confident in their ability to support activities of daily living and begin to shift to helping stroke survivors reintegrate into the community. However, during this transition, caregivers often experience difficulty coping, accessing community services and may lose part of their support system. Therefore, family caregivers of stroke survivors are in need of advice from peers and health professionals and may require additional training to manage difficult situations, emotional support and guidance to manage competing roles.

A critical review of intervention studies for family caregivers of stroke survivors found that focusing interventions and therapies specifically on caregiver needs demonstrated promising results (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). Multi-component psychological interventions tailored to the specific caregiver needs have resulted in the largest improvements including reduced caregiver burden and emotional distress, and improved psychological well-being and quality of life (Cameron & Gignac, 2008; Visser-Meily et al., 2004). Bakas and colleagues (2002) identified the necessity of providing information and counselling to deal with the stroke survivor’s emotions and behaviours, physical and instrumental care, personal responses and changes to relationships with the stroke survivor, family and friends. Although the needs of family caregivers of stroke survivors are well recognized, current stroke education programs are focused mainly on the education and support of the stroke survivor in their recovery after stroke, rather than caregiver needs. Two examples of such programs are the Heart and Stroke “Living with Stroke Program (LWS)” and Moving on after Stroke (MOST) (Heart and Stroke Foundation, 2010; Huijbregts, Myers, Streiner, & Teasell, 2008). Family caregivers of stroke survivors are invited to participate in these programs. However, the programs do not address the unique needs of the caregiver.

Currently, no stroke-specific caregiver education and support programs exist. The Victorian Order of Nurses (VON) Canada, Ontario Branch, has developed a Caregiver Education Series, “From Stress to Strength”, for caregivers providing care to individuals living with chronic conditions within the community. This four-week facilitated education and support series provides caregivers the opportunity to gain some awareness about their own needs, knowledge about community resources and skills on how to cope (Nurse & Joshi, 2002). It provides general caregiver information, tools and resources and does not focus on disease-specific caregiving information.

Development of the program

In 2007, a working group, with representatives from the Central South Regional Stroke Program, VON Canada, Ontario Branch, and March of Dimes Canada was formed to develop a program to meet the specific education and support needs of family caregivers of stroke survivors. This program was designed to support the implementation of stroke best practices in community re-integration within the Central South Ontario stroke region. The goal was to develop an education and support program for family caregivers of stroke survivors to improve their self-management skills and their ability to cope with the common struggles that caregivers of stroke survivors often face. To determine the content of the program, the specific needs of family caregivers of stroke survivors were first identified by literature review, review of existing education and support programs and a series of focus groups with caregivers of stroke survivors.

Based on the literature review, information needs of family caregivers of stroke survivors were identified including dealing with the stroke survivors’ emotions and behaviours, physical and instrumental care, changes in the relationship with the stroke survivors, and available community support services. These needs were reinforced by 18 family caregivers (mean of four years as a caregiver) who participated in three focus groups conducted in Central South Ontario in 2008. Participants identified the following unmet learning needs:

a) balancing the changing roles and responsibilities of a caregiver of a stroke survivor;
b) managing cognitive, perceptual and mood changes of the stroke survivor;
c) dealing with sexuality and intimacy; and
d) accessing community resources and linkage with allied health professionals in the community to discuss specific questions, and concerns and identify resources.
Participants reinforced their desire for a stroke-specific education and support program that met their individualized needs.

The Family Informal Caregiver Stroke Self-Management (FICSS) Program is a unique program that was developed for family caregivers of stroke survivors to participate with peers in a facilitated group without the stroke survivor present. The program was designed to provide the opportunity for caregivers to grow together, as individuals, and develop effective coping strategies to live with their new reality after the stroke event. The program is focused on self-management, recognizing that the caregiver is a key player in a therapeutic relationship and an active participant in the stroke survivor’s care management (Lorig & Holman, 2003). Individuals who are good self-managers have improved clinical outcomes and lifestyle, and use the health care system to a lesser degree (Brownson et al., 2007). The goal of self-management support is to strengthen individuals’ competence and confidence in managing their situation, making informed decisions about care, and adopting healthy behaviors (Brownson et al., 2007).

The program aims to address the seven key ingredients of self-management: (a) providing information, (b) teaching disease-specific and disease-neutral skills, (c) promoting selection of healthy behaviors, (d) developing problem-solving skills, (e) assisting with the emotional sequelae of having a chronic condition, (f) providing continued follow-up, and (g) encouraging individuals to be active participants in the management of their stroke survivor’s recovery (Bodenheimer, 2007).

Based on the information identified in the focus groups, the FICSS program was developed targeting caregivers during the implementation and adaptation phases of the “Timing it Right” framework (Cameron & Gignac, 2008). This phase occurs three to six months after the hospital discharge of stroke survivors, when caregivers have extensive needs in managing their new caregiving role. The goal of the FICSS program is to provide opportunities for caregivers to learn self-management skills and gain confidence in the responsibilities of providing care to the stroke survivor.

**Program evaluation objectives**

The objectives of the FICSS program evaluation were to: (a) validate the program content; (b) identify gaps and recommend program content revisions; (c) finalize participant and facilitator resources; (d) evaluate delivery methodology for the program; and (e) develop an understanding of the ideal time in the stroke caregivers’ journey to provide the program.

**Program evaluation approach**

**Program evaluation design**

A qualitative descriptive approach was used to evaluate the FICSS program for family caregivers of stroke survivors (Sandelowski, 2000). The evaluation was conducted in the Central South Ontario Stroke Region, which included Hamilton, Burlington, Niagara, Halimand, Brant and Waterloo-Wellington Local Health Integration Networks. Funding was received from the Central South Regional Stroke Network to develop the program and complete the pilot evaluation. The program evaluation team was composed of representatives from the Central South Regional Stroke Program, VON Canada, Ontario Branch, March of Dimes Canada, and McMaster University, School of Nursing. The program facilitators had experience in caregiver support and health promotion. Two members of the research team had experience in qualitative research.

**Program participants**

Program participants included 11 family caregivers of stroke survivors living within Central South Ontario. Participants were recruited through advertisement in existing stroke recovery support groups and associations, community support agencies, hospital outpatient rehabilitation programs, regional and district stroke centres and the local media. Family caregivers of stroke survivors were defined as family members who provide unpaid care and assistance for persons who have experienced a stroke (Canadian Caregiver Coalition, 2005; VON Canada”, 2008). Participants were included if they: (a) were 18 years or older; (b) met the definition of a family caregiver of a stroke survivor; (c) had provided care to the stroke survivor within the home for at least two months; (d) were able to communicate in English; and (e) lived within Central South Ontario Stroke Region. Participants were excluded if they: (a) were paid to provide care; (b) were friends who provide care to stroke survivors; (c) had dementia or other cognitive impairment; or (d) were providing palliative care to stroke survivors within the home.

**Program description**

The FICSS program is a four-module series that includes the following topic areas: (a) balancing the changing roles and responsibilities of family caregivers of a stroke survivor; (b) managing cognitive, perceptual and mood changes of the stroke survivor; (c) dealing with sexuality and intimacy; and (d) accessing community resources and linkage with allied health professionals in the community to discuss specific questions and concerns, and identify resources (Table 1). The modules include the principles of self-management based on the Southwest Stroke Region Self Management Toolkit (South-West Local Health Integration Network, 2010; Tomaszewski & O’Callaghan, 2009). Each module is a two-hour small group guided discussion and problem-solving session on the topic area facilitated by two experienced facilitators and guided by the particular needs of the group participants. Facilitators had backgrounds in social work and health promotion with specific expertise in the area of stroke and caregiver support.

**Qualitative data collection**

Two program evaluators who did not participate in the program development or delivery collected qualitative evaluation data using a semi-structured focus group one month after the end of the program. The evaluators took notes on the participants’ feedback. The questions were designed to assess the perceived impact of the program on the family caregivers in areas such as problem-solving abilities, behaviour management, awareness and use of community services and the perceived indirect impact of the program on the stroke survivor. Participants were asked to provide feedback on the intervention design, module
content, module topics, presentation style, flow, resource materials and the timing of the intervention. Focus group questions are listed in Table 2. The program facilitators completed an evaluation of each module at the end of each session and a summative review at the end of the program regarding feedback on the intervention design, module content, modules topics, presentation style, flow, resource materials and the timing of the intervention. Feedback from participants and facilitators were compared and reviewed to identify gaps in the program and areas requiring change.

Quantitative data collection
Baseline quantitative data included two self-administered questionnaires: The Caregiver & Stroke Survivor Baseline Questionnaire (Cameron & Gignac, 2008), and The Oberst Caregiving Burden Scale (Oberst, Thomas, Gass, & Ward, 1989). These questionnaires were used for the purposes of describing the participants and gaining an understanding of the needs of participants for future program development. The Caregiver & Stroke Survivor Baseline Questionnaire (Cameron & Gignac, 2008) is a 26-item questionnaire used to collect socio-demographic and health-related information about the stroke survivor and caregiver (e.g., age, gender, marital status, education, income, health conditions). The questionnaire was adapted from a tool developed by Dr. Cameron to include socio-demographic and health-related information on the stroke survivor. The original questionnaire has been used in Dr. Cameron's research on the “Timing it Right Framework” for family caregivers of stroke survivors (Cameron & Gignac, 2008).

The Oberst Caregiving Burden Scale (Oberst et al., 1989) is a 15-item self-report instrument using a five-point Likert scale (1 = none to 5 = a great amount) to evaluate caregiver perceptions of the time and difficulty associated with 15 tasks performed in caring for recovering family members. The instrument's 15-item time and difficulty subscales are each scored separately using the five-point Likert scale. The instrument has a minimum score of 15 and a maximum score of 75. The instrument has been validated with family caregivers of cancer and stroke survivor populations (Bakas & Burgener, 2002; Oberst et al., 1989). The questionnaire has demonstrated internal consistency reliability (0.90–0.94) and construct validity in family caregivers of stroke survivors (Bakas et al., 2004).

Data evaluation
The focus group notes were interpreted using thematic analysis.

Table 1: Overview of intervention: Modules and objectives

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<th>Module</th>
<th>Objectives</th>
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| Session 1: Balancing changing roles & responsibilities | • Identify the roles that have changed for you since the stroke  
• Choose and practice one strategy for building your relationship with your care partner |
| Session 2: Dealing with mood, thought and perception changes | • State one situation this week where you were able to step back from a challenging mood/behaviour  
• Identify two new ways to deal with that mood/behaviour |
| Session 3: Intimacy & sexuality | • Explain the difference between sex, sexuality and intimacy  
• Identify one way of expressing intimacy with your care partner that you may not have considered before |
| Session 4: Enhancing Community Linkages | • State where to call when you need extra community services such as occupational therapy, physiotherapy, speech and language pathology  
• Share one piece of information learned at these classes with one other person |

Table 2: Overview of focus group questions

**Overall Evaluation**
- What do you remember most about the project?
- What did you like best about the project?
- What did you like least about the project?
- If you were running the program, what changes would you make to it?
- What advice would you give us when we run the program again?
- Are any of the topics in the program NOT a priority to you, as a caregiver?
- Are there any topics that were not included but should be included in the program?

**Timing of the Program**
- When is the best time for you and other caregivers to attend?
- Each session was two hours in length. Was this enough time to cover the topic? Why? Why not?
- When do you think is the best time to provide a program of this type to stroke caregivers to help them the most?
- As we move forward with a program, should we offer onsite respite to make it easier for caregivers to attend the program?

**Program Impact**
- Would you recommend attending the project to other stroke caregivers? Why? Why not?
- Describe one thing you will do differently since attending the project.
- Describe the things you learned from attending the project.
- Describe the impact the project has had on your life.
- Has there been any impact of the program on the life of the stroke survivor?
- Has attending the program had any impact on your awareness of community and support services? If so, in what way?
- Has attending the program had any impact of your use of community and support services? If so, in what way?
- Is there anything else we should consider as we plan for future sessions?
- Is there anything else you wanted to tell us, but we have not asked?
Three authors and a student independently evaluated the data and met to reach agreement on the themes post analysis. Descriptive statistics were used for both the Caregiver & Stroke Survivor Baseline Questionnaire and the results of the Oberst Caregiving Burden Scale. All questionnaires were de-identified and given a coded number. Aggregate data only were reported to describe the evaluation sample.

Ethics
As this was a program evaluation and not a research study, formal ethics approval was not required. When caregivers registered for the program, they were informed that the program content, design and data collection methods were being evaluated and their personal information would be kept confidential. Participants gave verbal consent to participate in the pilot evaluation of the program. They were informed that they could stop participation in the program or choose not to answer any of the questions on the questionnaires or in the focus groups. At the beginning of the focus group, all caregivers were informed that information or quotations would be de-identified and if they did not want their quotations used they could inform focus group facilitators. All hard copy questionnaires were stored in a locked cabinet in a locked office. All electronic files were stored in a password protected secure computer in a locked office.

Program evaluation findings
Eleven participants from Central South Ontario were included in the program evaluation. The average age of participants was 57 years with approximately three years of experience as a family caregiver of a stroke survivor. The majority of participants were female and caregiving for their spouse (See Table 3). Most participants (73%) had a post-secondary education and 45% had an annual income of $70,000 or more. The average Oberst Caregiver Burden Questionnaire Time subscale score was high, indicating that the caregivers were providing a significant amount of care to the stroke survivor. Only 45% of the caregivers were receiving community support services. Most participants (73%) had previously attended a stroke recovery peer support group meeting.

Three key themes were identified related to perceived impact of the program, timing of the program, and overall program evaluation. Each theme will be described in detail.

Perceived program impact
The perceived impact of the program can be represented by the following sub-themes: hope, advocacy, sharing, increased coping skills, self-management and knowledge about how to access community service resources. Participants felt more hope and patience since attending the program. They stated that they learned valuable advocacy skills from the workshops and each other.

“You need to learn to become an advocate, as I didn’t know my rights in the hospital, and you have to learn to push to get the best care for the stroke survivor so he can have the best recovery after stroke.”

Participants described the value of the program in relation to the opportunity to share their experiences, stories and advice with one another and the development of a support network and bond between the caregivers within the program.
“You felt really connected to the others and that they really cared about you ... we had one common thing we shared ... but after that it was much more—we learned from each other.”

“It was the safest place I have been in months.”

“I have much more awareness now...and I want to help other caregivers now.”

Participants explained that the program informed them of available community services but, more importantly, provided the tools and strategies to self-manage and cope with the struggles of being a caregiver. They indicated that the program provided the opportunity for them to gain an alternative perspective and helped to improve their quality of life, as well as that of the stroke survivor. Participants commented:

“I am learning to balance both the physical and emotional sides of recovery and we are working together as a partner ... I can truly say now, I am coping with my stress and frustrations by keeping my cool when overwhelmed and... when I lose it, it’s okay.”

“I liked the opportunity to share and brainstorm with other caregivers about resources and caregiving strategies.”

“I have more hope and patience since attending the program.”

Timing of the program
Three sub-themes emerged related to timing of the program in relation to the length of the session and program, time of day the program is held and the point in time in the caregiving experience that the program is offered. The participants were satisfied with the length of each session (2 to 2 ½ hours), the duration of the program (four weeks) and suggested either afternoon or evening would be appropriate. Additionally, participants commented on the need to offer the program at various times throughout the day and evening, as some caregivers still work. Participants emphasized that the program should be offered earlier on in the caregiving experience, ideally between three and six months post hospital discharge of the stroke survivor, as participants stated:

“Having this program earlier on in the care giving experience would be better, as the impact of the stroke really hit everyone when the stroke survivor came home from the hospital!”

“Timing is key ... at first we are in shock and we are not able to absorb the information so if this was made available to people by three, certainly six months it would be the best time.”

Overall program evaluation
Focus group participants shared a number of ideas on how to improve the program. They suggested: (a) removing homework as part of the program; (b) offering information on community resources earlier in the program; (c) removing the sexuality module and replacing it with topics perceived as more important (e.g., dealing with emotions such as grief and loss, changes in roles and relationships, and system navigation). Participants also suggested providing a less structured format to allow for more discussion.

“Energy went down when we were asked to do homework... but went up when we were given the opportunity to share/brainstorm, share resources.”

Overall, all participants at one month after the end of the program agreed that the program was valuable and would recommend it to future caregivers of stroke survivors.

The program facilitators also completed an evaluation of each module at the end of each session and a summative review at the end of the program. They recommended program changes consistent with those of the caregivers regarding the timing of the program, revisions to module topics and shifting the program to a less-structured format and more of a facilitated discussion on a topic area. Program facilitators also made recommendations regarding the program content, resources and exercises, participant and facilitator manuals and overall program facilitation. The constructive criticism from the participants and program facilitators allowed for further modifications to be made to the program in order to improve the quality of the program for future caregivers of stroke survivors.

Program evaluation limitations
There are a number of limitations associated with this program evaluation. Recruitment of caregivers in the adaptation phase—three to six months after hospital discharge of the stroke survivor—was challenging, as there is no current mechanism to identify these individuals. Thus, we recruited from a variety of settings such as stroke recovery associations and peer support groups. The average length of time as a caregiver among participants in this program evaluation was 36 months, which is greater than the targeted time of three to six months post discharge from hospital. While this length of time as a caregiver is in alignment with other studies (Bakas & Burgener, 2002; King & Semik, 2006), further evaluation of this program is needed with the specified target group of caregivers. Further, we continue to explore methods of identifying and reaching out to caregivers of stroke survivors within this timeframe of their caregiving journey.

The mean age of caregiver participants was 58 years, which was similar to the age of caregiver in studies done by King and Semik (2006) and O’Connell and Baker (2004), but slightly younger than the mean age of caregivers in other studies (range of 60.4 to 65.5 years) (Bakas & Burgener, 2002; Cameron et al., 2007; Haley et al., 2009). Furthermore, the younger age of the caregivers in this program evaluation may be reflective of the 25.5% incidence of stroke and TIA among those 46 to 65 years old in Ontario, which has increased by 3.7% from 2003 to 2010/2011 (Hall et al., 2012).

Discussion
The FICSS program evaluation provided important information on the content and format of this community-based program. The primary objectives of the program evaluation, that is, validating the content of the program and identifying gaps and recommendations for revisions of the program content,
are largely achieved in this evaluation. The constructive feedback received from both the facilitators and, more importantly, the participants will aid in the future development of the program.

Feedback from focus group participants revealed that the program offered hope, advocacy, sharing, and the sense of being more informed about various topics including: coping skills, self-management, and how to access community service resources. As a result, participants felt more confident in their caregiving abilities and more at ease since attending the program. Overall, participants perceived noteworthy benefits for themselves and developed new coping strategies. The positive results indicate the short-term benefits of the program. However, due to the short duration of the program evaluation, only the immediate perceived impact of the program was investigated. Current follow-up research will include a pre and post evaluation of the impact of the program at two weeks and six months after the program. Participants also recommended that future programs be less structured from an educational perspective and modified more towards a guided discussion on a specific topic area.

According to the participants, the length of each session and overall length of the program met their needs, whereas there was a clear indication of a need to provide the program earlier in the caregiving experience at approximately three to six months post hospital discharge of the stroke survivor. This is in accordance with the work by Cameron and Giganc (2008), where caregivers in the implementation phase (first few months after stroke survivor returns home) require information on management of ongoing activities and on the impact of providing care on the caregivers’ life and health, in addition to emotional needs including fear and anxiety of adapting to providing care in the home.

Unfortunately, caregivers have multiple demands and responsibilities in their caregiving roles and, as a result, may not feel they have the time required to participate in a caregiver education and support program. This may present an obstacle to recruitment of caregivers to such a program. We had difficulty recruiting caregivers to this program due to their perceived limited availability of time to participate. The challenge of caregiver recruitment was also experienced by White and colleagues (2007), as they found 70% of eligible caregivers refused to participate in the research, as they were either too busy or not interested in participating. It is evident that there are a large number of family caregivers of stroke survivors in the community. However, there seems to be a gap in understanding how best to reach these individuals. The program evaluation team should explore utilizing online support mechanisms or the use of video or teleconferencing technology to provide education and support for caregivers of stroke survivors, as some preliminary studies with stroke caregivers have found promising results. Huijbregts et al. (2009) found that Moving On with your Life Post Stroke (MOST) could be delivered effectively by videoconferencing and resulted in a decrease of the caregivers’ sense of isolation. Buckley et al. (2004) explored feasibility of the use of in-home telehealth as a method of rehabilitative technology and found the technology allowed health care providers to assess the needs of stroke survivors and also to provide information and emotional support to caregivers. However, they found the effectiveness of the in-home telehealth was dependent on the receptiveness of caregivers to the technology. Finally, Pierce et al. (2002) explored the use of an online caregiver support to either access educational materials, link with nurse specialists and to link with other caregivers. They found the service provided additional support and information to caregivers who found a gap in support and services due to limited time, isolation in rural and remote locations, or limited access to transportation.

While the small number of participants might be considered a limitation of the program evaluation, the education and support program is a small group learning environment and research on group work has identified six to eight people per group as ideal (MacGowan, 2008). The program evaluation team chose to increase the group size to 10–12 caregivers to obtain in-depth feedback to evaluate the program.

Future research should explore different recruitment methods to access a broader group of caregivers in the general population. The current participants were highly educated and English-speaking, similar to those in previous studies in regards to socio-demographics and level of burden of caregiving (Bakas & Burgener, 2002; Visser-Meily et al., 2005). It is possible that caregiver support and education programs, like the current program, may be more acceptable to this demographic group due to certain social and cultural norms.

The multi-component nature of the current program allows for a greater inclusion of information, education and support for the caregivers and aims to target the highly variable and specific needs of caregivers of stroke survivors. This program differs from previous programs that are typically uni-dimensional (i.e., only support, or only educational) (Larson et al., 2005; Visser-Meily et al., 2005). The current program offers support, educational tips and tools, as well as the resources needed to carry on after the program has ended. More importantly, the current program allows for the caregivers to express their needs and concerns without the stroke survivor present. This provides a sense of camaraderie among the caregivers, as well as comfort in knowing that they are not alone in their struggles. In contrast, previous stroke education programs have mainly focused on the needs of the stroke survivor, and caregivers often do not receive the information and support that is required (Heart and Stroke Foundation, 2010; Huijbregts et al., 2008).

The positive feedback received from the participants establishes the need for an education and support program specific to caregivers of stroke survivors. However, implementing the program at the ideal time during the caregiving experience and with the appropriate information during that time proves to be complex in nature. Based on caregiver and facilitator feedback, the following program changes were made: (a) focusing the first session on sharing the caregivers’ experiences, (b) moving the community connections module from the fourth
to the second session, (c) removing the sex and intimacy module as a mandatory module, and (d) adding more modules for participants to select from. These revisions led us to the format of the program that is currently being implemented and evaluated (See Table 4 for revised program). A Participant Resource Manual was also developed to provide an outline of each session, activities, stories, thoughts and resources.

Conclusions
The program evaluation of the FICSS program establishes the need for an education and support program specific to caregivers of stroke survivors. The qualitative results of the program evaluation suggest the program provides caregivers with tools, strategies and resources to better manage as caregivers. The program, with the suggested revisions, has the potential to meet the unique education and support needs of family caregivers of stroke survivors.

The value of the program is that it provides caregivers the opportunity to share and learn from each other and to develop new strategies or coping mechanisms as caregivers. Through the program, caregivers developed a strong bond, as a group, and developed a strong support network wanting to share information, so that ongoing contact would occur after the program. One unintended consequence of the program was the development of an ongoing social network of several of the caregivers and stroke survivors after the program. The development of this new social support network is critically important, as there is often a loss of the previous support network after the stroke.

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<th>Table 4: Revised education and support program for caregivers of stroke survivors</th>
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<tr>
<td><strong>Module 1</strong></td>
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<td><strong>Module 2</strong></td>
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<td><strong>Module 3 and 4 (six possible options):</strong></td>
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Many of the caregivers who participated in the program evaluation were very experienced caregivers, well beyond the three to six months targeted time for the program. The more experienced caregivers benefited from participating in the program and acted as mentors to the caregivers early in the caregiving journey. The next steps in the project will be to complete the program revisions and to evaluate the impact of the Family Informal Caregiver Stroke Self-Management Program (FICSS) on the caregiver psychosocial, emotional and health needs at two weeks and six months after the program.

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