

SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS

JUNE 2017 EVALUATION

SUBMITTED TO SOUTH EAST LHIN



CANADA

STROKE NETWORK
of Southeastern Ontario



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Background

In January of 2014, LHIN base funding was secured for the regional Stroke Survivor and Caregiver Support Groups:

- Community & Primary Health Care (CPHC) in Perth/Smiths Falls and Brockville (for LL&G Counties)
- Community Care for South Hastings (CCSH) (for H&PE Counties)
- VON Canada – Kingston, Frontenac, Lennox & Addington (for Kingston region)

Subsequent to the June 2016 Evaluation Report:

- New Facilitators were retained for the Perth/Brockville and Belleville sites
- The Facilitators in Belleville and Perth/Brockville received Living with Stroke[®] (LWS) Facilitator training and attended The Aphasia Institute for training in supportive conversation (SCA[™])
- The collaborative regional model which includes the three Facilitators as well as representation from the Stroke Network of SEO continues to support the sharing of best practices and strategies through regular teleconferences. Facilitators also participate in the quarterly meetings of the Community Reintegration Leadership Team (CRLT), a committee of the Regional Stroke Network
- Shell-Lee Wert (Executive Director, Community Care for South Hastings) and Patti Lennox (Manager, Caregiver Support and Community Programs, CPHC) continue to participate in the Regional Stroke Steering Committee as representatives of the CSS sector.
- In Kingston, the peer-led Social-Recreational Group has been sustained. This group is intended to further support community reintegration for members of the support groups who are at a stage in their recovery that supports a more independent experience. This concept is also being explored by Belleville and Brockville/Perth.
- Four Stroke Specific Community Exercise Programs have been sustained. Belleville, Trenton and Kingston are coordinated through VON and Perth through CPHC. The Brockville program coordinated by CPHC is currently on hiatus as a new venue is confirmed. The Exercise Providers have been linked with the Facilitators of the support groups to promote the programs.
- Peer Visiting Volunteer Programs are in place in Kingston (SMOL & community) and Perth (PSFDH). Brockville General Hospital has also initiated the program with the completion of volunteer training and the concept of peer visiting has been endorsed by the KGH stroke team. The Belleville Facilitator has been in discussions with the QHC stroke team re linking with inpatients to facilitate connections to the community support groups.
- The Belleville Stroke Support Group Facilitator and Community Care for South Hastings (CCSH) partnership with Quinte District Rehab (QDR) has continued to support Aphasia Supportive Conversation Groups. As this program cannot be sustained without dedicated funding, a regional working group has been convened to submit a funding proposal to the LHIN to



maintain the Belleville group and to expand the program to Kingston, Brockville and Perth/Smiths Falls to support equity of service in the southeast. It is important to note that a number of new referrals to support groups would have benefited from an aphasia group in their community. As an example, in Kingston there were 5 individuals/caregivers who requested or required an aphasia group. These individuals either declined to participate in the Survivor or Couples Support Group or were deemed inappropriate due to the severity of their aphasia.

- Two Living with Stroke[®] (LWS) programs were delivered in this reporting period. One LWS & Aphasia Program in Belleville was completed last spring.
- The pilot outreach initiative in collaboration with regional Ontario Telemedicine Network (OTN) nurses which was initiated in Belleville in 2015 has been sustained and expansion is currently being explored. The concept of outreach is also being explored by Brockville/Perth.
- OT students completing a placement with the Kingston Facilitator developed community resource booklets for the Kingston/Frontenac and Lennox/Addington areas. As well, OT students prepared a presentation on driving assessment following stroke which is a topic of continued interest among stroke survivors and caregivers.
- The Kingston Facilitator has connected with the Clinical Education Centre at Queen's and eight stroke survivors have volunteered to participate in classes and labs (medicine, nursing, OT and PT).
- The Perth/Brockville Facilitator has participated in media interviews to enhance awareness of the stroke groups in partnership with a stroke survivor.

S.U.P.P.O.R.T.

Stroke Understood: a Peer Program Optimizing Recovery Together

SERVICES PROVIDED

- Planning, delivery, and evaluation of 8 support groups (Perth/Smiths Falls Stroke Survivors & Caregivers Support Group, Brockville Stroke Survivors & Caregivers Support Group, Belleville Stroke Survivors Group, Belleville Couples Group, Belleville Caregivers Group, Kingston Caregivers Group, Kingston Couples Group and Kingston Stroke Survivors Group). Support for Kingston Social/Recreational Group.
- Identification of educational needs of stroke survivors and caregivers with subsequent provision of educational information to the groups verbally, written, and/or via guest speakers.
- Therapeutic group discussions with respect to psychosocial concerns and issues which may be prompted by 'stimulus' questions brought forward by the Facilitators
- Management of referrals for potential group participants (which may include home visits)
- Data gathering through the administration of evaluation tools for LHIN Evaluation Reports
- Outreach to and networking with community based partners, healthcare professionals, and health/wellness fair presentations
- Transportation arrangements for stroke survivors and/or caregivers if required
- Referral to community resources, as required, (with consent)



- Monitoring of individual participants as required through phone calls and email.
- System navigation including the identification of appropriate community resources, how to access local supports and services and initiation of referrals
- Case management when social and community resources are either non-existent or limited and the participant requires assistance, information and/or advocacy to meet their needs
- Maintaining administrative records for groups including attendance and case notes
- Responding to general/public requests for information about stroke and community resources and liaising with media
- Participating in regional Facilitator teleconferences to support sharing of successes and challenges and to support regional consistency
- Attending regional CRLT meetings on a quarterly basis
- Participating in Belleville pilot of community-based Aphasia Supportive Conversation Groups and subsequent drafting of proposal to LHIN in support of sustained funding for Belleville and expansion to Kingston, Brockville and Perth
- Distribution of an e-mail newsletter to group participants in Kingston which includes community events, health promotion information and volunteer opportunities

METHOD OF DATA COLLECTION

Perceived Recovery & Caregiver Burden (Montgomery-Borgatta) Scores

To enhance validity of the perceived recovery and caregiver burden scores, a minimum of 6 months is required between the pre and post scores.

Stroke Services Evaluation Tool

Administered to stroke survivors and caregivers to evaluate their satisfaction with the support groups as well as how they perceived the impact of the support groups on various health and lifestyle domains. This evaluation continues to include three additional questions intended to provide a better understanding of how stroke survivors and caregivers are supported when navigating the health and social support systems.

Note that quotes included in this report are derived from responses to the Stroke Services Evaluation Tool. All quotes are italicized.

SERVICES PROVIDED

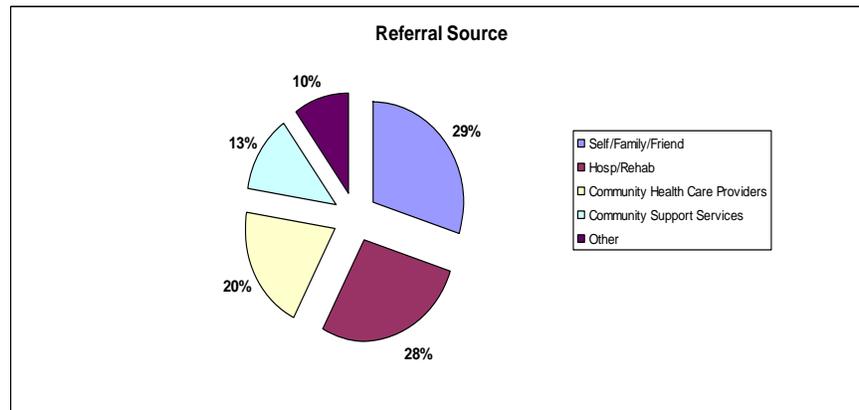
- 8 facilitated stroke groups (groups meet monthly)
- 2 Heart and Stroke Foundation Living with Stroke[®] series
- 3 Peer Visiting Programs (Kingston, Perth & Brockville). Kingston & Belleville in planning and pre-planning phase.
- 1 Social/Recreational Group (Kingston)
- 1 Outreach Initiative (Belleville)
- 1 Aphasia Supportive Conversation Group (Belleville)

It should be noted that individuals not attending a support group may still receive Facilitator support. The reasons for not attending a group may include a decline in health, work or caregiving responsibilities, or bereavement. In cases of health decline, the Facilitator may make periodic phone calls to reassess, provide support and a continued connection to the group as well as referral to community resources. If it becomes evident that a return to the group is not feasible in the near future, services are discharged, with the invitation extended to the client to call if they wish to return in future and connections to other supports are facilitated. In a situation of bereavement, follow up may be done with referral to bereavement support in the community prior to discharge.

Clients receiving individual support may include new referrals which are followed for a period of time before they are able to attend a group or decide not to follow through with attending a group. Clients referred for stroke support soon after discharge from hospital often have many appointments which will interfere with their ability to participate in groups. Prior to discharge from the support group or individual support, the Facilitator ensures that clients are receiving adequate community support to deal with their circumstances. This approach respects client preferences, avoids premature discharge from service and also helps to manage a growing caseload.

REFERRAL SOURCES

Fig. 1 Source of New Referrals



SOURCE: STROKE SERVICES EVALUATION TOOL

A total of 41 new referrals have been received subsequent to the last report. Self-referrals (survivor or family member) as well as hospital and community settings continue to be significant referral sources.

STROKE SUPPORT GROUP MEMBERSHIP

- 97 survivors and 49 caregivers are attending support groups

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH - CAREGIVER BURDEN

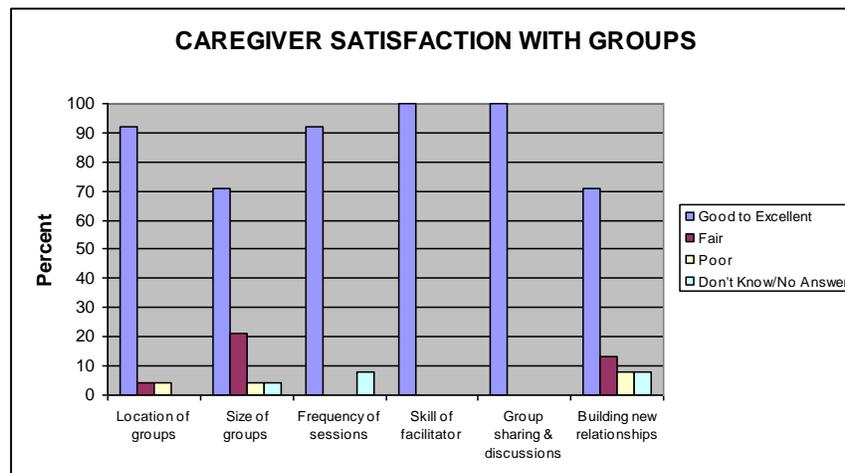
Caregiver Support Groups

As stated in previous Evaluation Reports, the needs of the caregivers are recognized and addressed by the Facilitators and through the support of their peers. Groups include:

- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g., cardiac and diabetes)
- Information on identifying stressors and implementation of coping strategies
- Referral/facilitating connections to community supports and, when identified as a need, to additional counselling
- Peer support and providing the opportunity to engage with others who are on a similar life journey/facing common issues and concerns

DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS

Fig.2 Caregiver Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

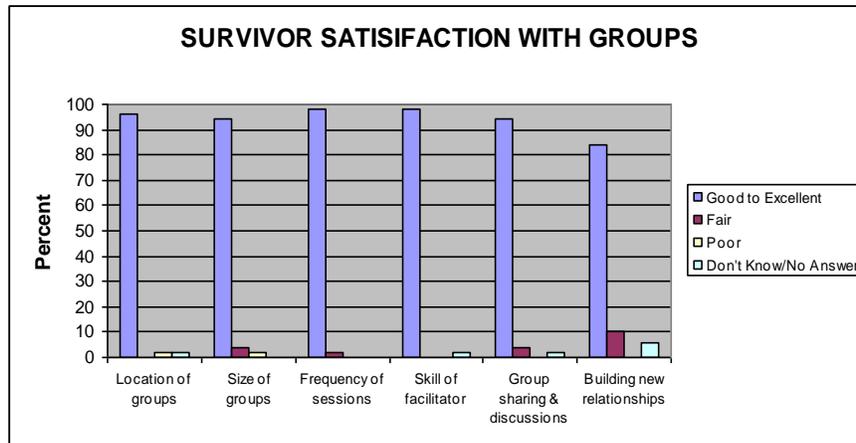
“The stroke groups are essential for the stroke victim and their caregiver. The continued support as time passes is necessary, builds confidence, lessens stress, and makes for a better quality of life.” ~ Caregiver

“The support is great. It helps to increase my understanding and improve my coping skills.” ~ Caregiver

“Would like if the group was able to meet more, personally I think it is great and think it's great we are able to help a lot of people.” ~ Caregiver

“Our Facilitator is very skilled and compassionate and intuitive.” ~ Caregiver

Fig. 3 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Stroke survivor groups helps understand how others are coping with the change in their lives.” ~ Stroke Survivor

“Always looking forward to reconnect with my fellow stroke survivors. We are learning from each other how to cope with our disabilities in various environments.” ~ Stroke Survivor

“Sharing situations is extremely important and useful to the stroke survivor.” ~ Stroke Survivor

Figures 2 and 3 indicate a continued high level of satisfaction with groups for both stroke survivors and caregivers. The excellent ratings are consistent with previous reports and clearly demonstrate a very high confidence in the skills of the Facilitators. The Facilitator continues to play a key role in:

- Liaising with health and social services partners to enhance referrals
- Conducting intake assessments to ensure an effective transition into the appropriate group and to gain an understanding of the needs of each individual participant
- Coordinating the groups including responding to education and information needs by arranging speakers with the relevant expertise
- Ensuring that all voices are heard in the group setting and that there is a therapeutic balance between an acknowledgement of this significant life event and the fostering of hope
- Providing system navigation support to make certain that survivors and caregivers are linked to community resources and managing referrals where appropriate



As noted earlier, three additional questions have been included in the SSE tool. Respondents indicated 97% agreement when asked if they were satisfied with the individual information and/or the referral information that they received from the group Facilitator. In response to the question, “Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group Facilitator?” 86% indicated that they were satisfied. When respondents were also asked to provide the name(s) or organization(s) that had provided the information, the following were cited (categories inserted for report purposes):

Comments on Navigation Support by Group Facilitators

- [Facilitator] was a major help in trying to find placement for my husband. Much better than CCAC were.
- [Facilitator] is very good with all the information and help.

Organizations/Individuals Identified as Providing Navigation Support

Numbers indicate how many times the organization or individual was cited by a survey respondent.

- CSS Agencies X 4
- CCAC X 3
- VON X 2
- Regional Brain Injury Services X 2
- Physician X 2
- Physiotherapy X 1
- OT X 1
- Nutritionist/Fitness X 1
- Heart & Stroke X 1

One respondent indicated that s/he had received no assistance other than from the support groups

Additional Comments

“Feel very let down by healthcare.” ~Caregiver

“It’s been a nightmare.” ~ Stroke Survivor

“No contact, no information made by other agency than CCSH.” ~ Stroke Survivor

“I still believe there is a general lack of coordination between hospitals and community services over different regions/areas.” ~Caregiver

These survey responses continue to highlight a rather fragmented and random navigation system (consistent with results from previous surveys) as well as confirming the benefit of having the Facilitators fulfill a knowledgeable and consistent access point for system navigation that is responsive to the needs of each individual.

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – STROKE SURVIVORS

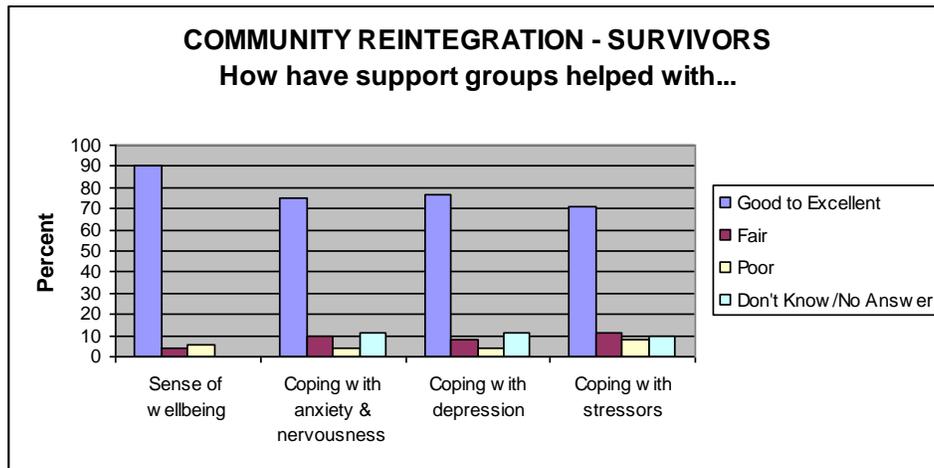
Survivor Perceived Recovery Score

The Perceived Recovery Score (PRS) asks stroke survivors to provide an overall perception of their recovery using a scale of 0 to 100 with 0 indicating no recovery and 100 indicating full recovery. Data from twenty-three stroke survivors was analysed. To be included in this analysis, stroke survivors must have completed a PRS at least six months ago in addition to the PRS for this evaluation. Results showed a stable pre/post median score of 75.

In reviewing individual data, 65% either maintained or improved their scores. A variety of factors may contribute to a lower post-score including:

- expectations for recovery/recovery goals
- co-morbidities and aging
- length of time since stroke event

Fig. 4 Survivor Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Very good to hear from other group members.” ~ Stroke Survivor

“Love this group [it] makes my month.” ~ Stroke Survivor

- The majority of stroke survivors saw the group as “good to excellent” in contributing to a sense of well-being as well as helping them cope with anxiety/nervousness, depression and stressors.
- Having an opportunity to share feelings, experiences and successes in a ‘safe’ venue supports emotional well-being and personal capacity to cope.
- Peers are often significant sources of support and experiential advice; they are also walking that recovery journey.

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – CAREGIVERS

The Montgomery Borgatta Caregiver Burden Scale consists of three domains:

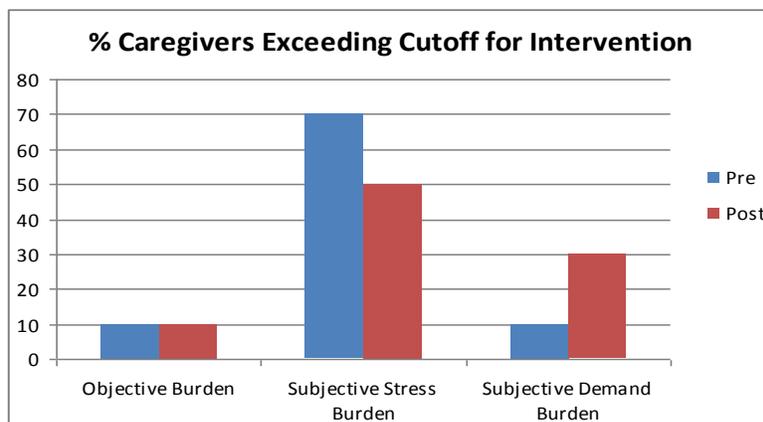
- Objective Burden which is defined as perceived infringement or disruption of tangible aspects of a caregiver's life (scores above 23 would indicate a need for intervention).
- Subjective Stress Burden which is defined as the emotional impact of caregiving responsibilities on the caregiver (scores above 13.5 indicate a need for intervention).
- Subjective Demand Burden which is defined as the extent to which the caregiver perceives care responsibilities to be overly demanding (scores above 15 signal a need for intervention)

A total of 11 caregivers participated in both pre and post surveys (note that a minimum of six months between the pre and post survey completion is required). Due to the limited participants for this evaluation component, individual results can have significant impact on collated data. Figure 5 demonstrates that many caregivers joining the groups have an identified need for support, with a significant percentage in need of intervention. Note that the post-scores in the subjective demand domain may reflect the toll that continued 24/7 caregiving has on the caregiver. Results are impacted by a variety of contextual factors including:

- Severity of the stroke
- Age of the survivor and caregiver
- Health of the caregiver
- Relationship status pre-stroke
- Time frame since the stroke event
- Co-morbidities experienced by the stroke survivor
- Deficits resulting from the stroke (e.g. incontinence, aphasia, impaired mobility)

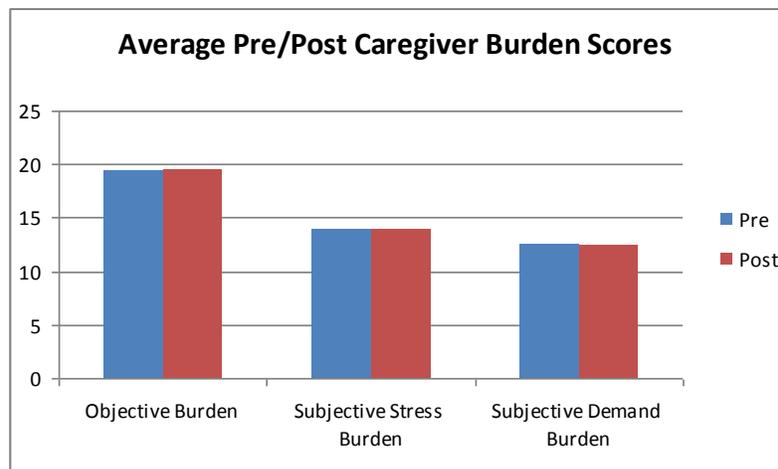
Figure 6 indicates stability in the burden experienced by caregivers.

Fig. 5 Caregivers Exceeding Cut-off for Intervention



SOURCE: MONTGOMERY-BORGATTA

Fig. 6 Average Pre/Post Caregiver Burden Scores



SOURCE: MONTGOMERY-BORGATTA

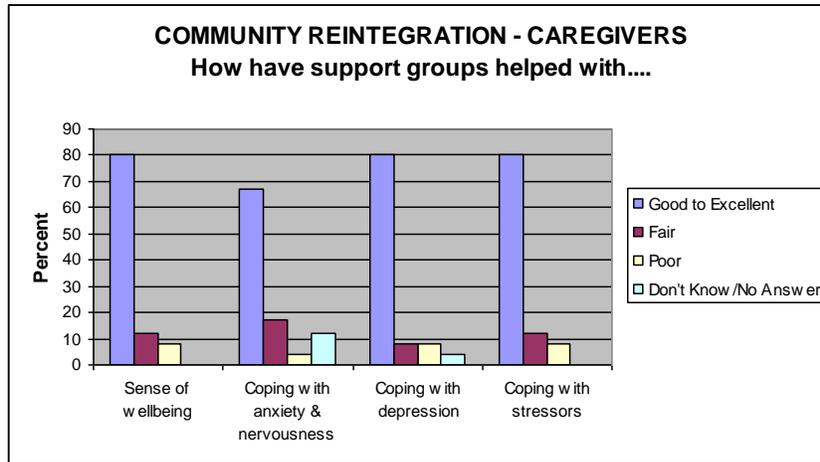
Caregiver Burden & Support Groups

The three domains of the Montgomery Borgatta Caregiver Burden scale are addressed through various strategies including:

- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g. cardiac and diabetes)
- Information on identifying stressors and implementation of coping strategies
- Referral/facilitating connections to community supports and, when identified as a need, to additional counselling
- Peer support and providing the opportunity to engage with others who are on the same life journey

Note that the 2018 Evaluation Report will see a transition to the Modified Caregiver Strain Index (MCSI). Facilitators have noted that completion of the Montgomery-Borgatta can be both stressful and confusing for the caregivers. In response, the next evaluation will report on caregiver burden using the validated MCSI.

Fig. 7 Caregiver Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

"I think the groups are great and more people should know about them." ~ Caregiver

"I think this is wonderful. It's nice to get out of the house and come here and talk and enjoy each other and change your perspective; get new ideas." ~ Caregiver

"I don't get away for time on my own. [Spouse is] very angry and demanding." ~ Caregiver

"I need respite." ~ Caregiver

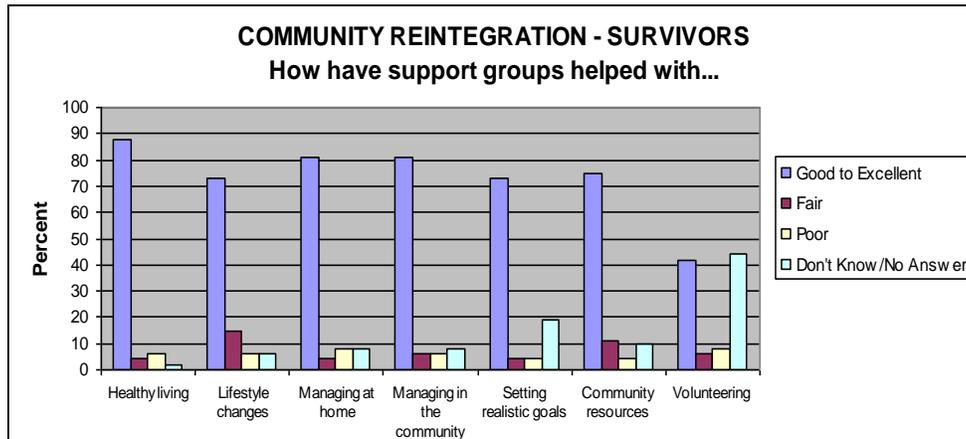
"I need respite in order to get out more." ~ Caregiver

"Wife is in LTC - very demanding on my time as she has Alzheimer's." ~ Caregiver

There is a significant 24/7 burden of care placed on informal caregivers (most typically a spouse). Note the quotes speaking to a need for respite and relief. Often, the role of caregiving is new to the individual and the stroke event has impacted on their other life roles as well (e.g., volunteering, career, social & recreational activities). As well, future plans must be altered, financial status re-evaluated, modifications made to the home environment and a myriad of other adjustments. All of this often takes a toll on the caregiver's own health. Attending a support group provides an opportunity to share challenges and successes and can also lead to new relationships and less social isolation.

PARTICIPANTS ABLE TO TRANSITION BACK TO COMMUNITY SETTING

Fig 8 Survivor Community Re-Integration Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Love this group [it] makes my month.” ~ Stroke Survivor

“Very helpful and encouraging.” ~ Stroke Survivor

“Very helpful information. I want to start helping others.” ~ Stroke Survivor

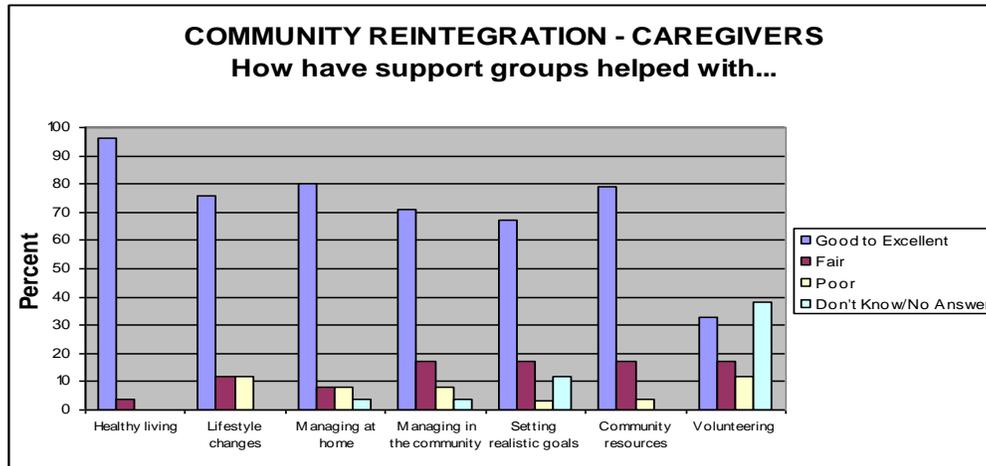
“I now attend the YMCA. [Facilitator] was the one to tell me about the VON exercise class, I like guest speakers for information, and I like the individual attention to each person.” ~ Stroke Survivor

Note the quote indicating a desire to help others demonstrating a crucial step in recovery. Results continue to illustrate the value of support group participation with respect to several domains of community reintegration.

HOSPITAL ADMISSIONS

- During this reporting period, 1 of the 49 caregivers attending support groups reported an admission to hospital for surgery.
- 7 of the 97 stroke survivors attending the support groups reported hospital admissions during the evaluation period. Reasons for hospital admission included TIA, kidney stone, pneumonia, bowel obstruction, surgery.

Fig. 9 Caregiver Community Re-Engagement Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

"[The groups provide] continued support of both victim and caregiver. The wellbeing of each is needed for the best recovery possible." ~ Caregiver

"It is very beneficial to [my partner]; therefore, to me as well." ~ Caregiver

"[Name] is an excellent Facilitator: she is very knowledgeable, has relevant topics at our meetings and shows genuine empathy! If there has ever been a time she didn't have the knowledge she promptly looked in to the matter and soon had answers. Very good group and I find the meetings very encouraging and uplifting." ~ Caregiver

"The group has helped us and now we're ready to help others." ~ Caregiver

Caregivers continue to view the support groups as helpful to daily living across many domains and the positive contributions that support groups make to the health status of the caregivers will, in turn, improve the health of the stroke survivors for whom they care. As with a previous survivor quote, note the interest expressed in now helping others as expressed by one of the caregivers.

With respect to the low scores for volunteering, it is evident that the care burden held by the family members of stroke can leave little time for volunteering.

EVALUATION SUMMARY

- Sense of well-being supported by participation in the groups rated as good to excellent for the majority of both caregivers and stroke survivors
- Individual abilities to cope with anxiety, nervousness and depression were rated as good to excellent for the majority of both caregivers and stroke survivors
- Consistent positive feedback on the skills of the Facilitators and the valuable role they play for successful and therapeutic groups as well as system navigation

RECOMMENDATIONS FOR CONTINUED SUCCESS

Consideration for:

- Future expanded base funding to support the growth of existing groups while ensuring that group size remains within recommended therapeutic numbers. Given the complexity of stroke and associated multifactorial impacts, the recommended participant number for the southeast support groups would be 15. Many resources cite smaller numbers. For example, in *Discovery Circles, The National Stroke Association's Guide to Organizing and Facilitating Stroke Support Groups*, it is suggested that 6 to 10 people is the most effective. (National Stroke Association, 1997).
- Additional funding to support the coordination/facilitation necessary to sustain and expand the Belleville OTN outreach initiative to other areas. This would enable the participation of stroke survivors and caregivers residing in rural/remote areas where distance and/or cost of transportation are significant barriers to support group participation.
- Additional funding to arrange and provide a respite component to operate in conjunction with the caregiver support group in each area in order to facilitate participation of caregivers who are unable to leave their loved one home unattended.
- Funding to sustain Belleville Aphasia Supportive Conversation Groups and to expand the program to include Kingston, Brockville and Perth/Smith Falls as per Concept Approval Worksheet and Business Plan Proposal entitled *Aphasia Conversation Groups Following Stroke: An Integrative Community Program*.