SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS
ANNUAL EVALUATION - 2021
SUBMITTED TO SOUTH EAST LHIN

StrokeUnderstood

ANNUAL EVALUATION FISCAL 2020/21
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Background

Since 2014, the SE LHIN Regional Stroke Support Groups have submitted an annual evaluation report detailing the demographics of participants, sustained and new programs, participant outcomes and participant satisfaction with the groups. As a key component of this evaluation, participants (stroke survivors and caregivers) are surveyed. Many participants may need in-person assistance with the completion of these surveys due to cognitive, communicative and/or fine motor skill impairment. With the onset of the pandemic and the associated restrictions placed on in-person meetings, this was not feasible. As a result, this annual report will focus on available data outside of the surveys as well as the innovative responses initiated by the Stroke Support Group Faciliators (SSGF) to ensure that participants continued to receive critical supports during the in-person meeting restrictions.

COVID Response

COVID has continued to significantly impact the service models adopted by the Stroke Support Group Facilitators (SSGF) for this reporting period. Virtual meetings have continued however this model does not meet the needs of all individuals and is not always the preferred approach for the majority of stroke survivors and caregivers. Various post-stroke impacts can impact an individual's ability to participate in virtual meetings including aphasia, visual and hearing impairments, cognitive challenges and fine motor movement restrictions. Additionally, there are many practical barriers to virtual participation particularly for those living in rural areas such as lack of adequate connectivity (or the financial means to afford internet services), lack of an appropriate device (e.g. laptop, tablet, smart phone), lack of comfort with this medium and/or lack of a support person in the home to assist them with the logistics needed to join a meeting. In some cases, the lack of a private space within a home setting may also prove to be a barrier.

For Adults with Aphasia (AWA), virtual groups pose very specific challenges as they often need supportive communication strategies to enable their participation. While virtual Aphasia Supportive Conversation Groups (ASCG) can be of benefit to those with milder aphasia, the lack of in-person supports tends to exclude those with more moderate or significant communication challenges. These individuals already tend to be quite isolated so this service gap adds to that isolation and reduces opportunities to practice communication in a safe environment. In hosting virtual groups, SSGF and the Speech-Language Pathologists (SLP) introduced different strategies to support communicaton including the use of virtual and non-virtual white boards to visually display words and leveraging the shared screen function.

For virtual stroke-specific exercise programs, one of the primary concerns is safety. To ensure adequate surpervision, the ratio of exercise leaders to participants must be adjusted (i.e. a lower ratio). Other safety considerations need to be in place including screening processes to ensure that participants can safely exercise in their own environment without in-person supervison, remote-based emergency processes and a learning curve for the exercise leaders and the participants as they adapt to this new model.

In summary, while virtual models can function as interim approaches for many stroke survivors and caregivers it unfortunately excludes others due to individual abilities and technology requirements. Often it can be those most significantly impacted by stroke and in need of complex supports who are excluded. Anecdotally, stroke survivors and caregivers have indicated a strong preference for in-person groups although many are also open to the concept of hybrid models. Including the virtual option in a hybrid model recognizes barriers that travel can often impose on participation (e.g. inclement weather, travel distance, inability to drive, lack of access to accessible transportation, cost of travel). Work is currently being done by the SSGF to assess what will work best for their respective clientele.

The initiation of COVID restrictions resulted in other changes to the pre-COVID stroke support services model. In LLG, the SSGF initiated 'porch pal' visits where the stroke survivor and/or caregiver received an in-person visit which respected the relevant infection control practices while providing an opportunity to communicate their needs and experience social interaction. This approach reached individuals who were unable to join virtual groups or did not feel that the virtual model would meet their needs. All SSGF conducted telephone check-ins and the frequency of these check-ins were adjusted to meet individual needs. Belleville offered virtual bingo games via teleconference which have had sustained popularity as they contributed to the need for social interaction and, simply, a fun diversion from the stress of COVID. All SSGF conducted virtual groups and ensured that supportive communication strategies were in place to help enable the participation of AWA. As well, all SSGF have found that individual case management needs have continued to increase as COVID persists. This may be in response to the growing complexity of clients referred to the program (e.g. decreased hospital length of stay), the decrease or absence of some services due to COVID and/or the prolonged social isolation.

The impacts of COVID leading to the introduction of virtual groups and enhanced case management activities have stretched the already limited SSGF resources. It is imperative that all three areas (LLG, KFLA and HPE) be funded for full time SSGF positions. As the pandemic (hopefully) winds down, significant work will now need to be done to transition back to in-person groups and to explore alternate models of support (e.g. hybrid model).

2020/21 Summary of Stroke Support Group (SSG) Programs & Services

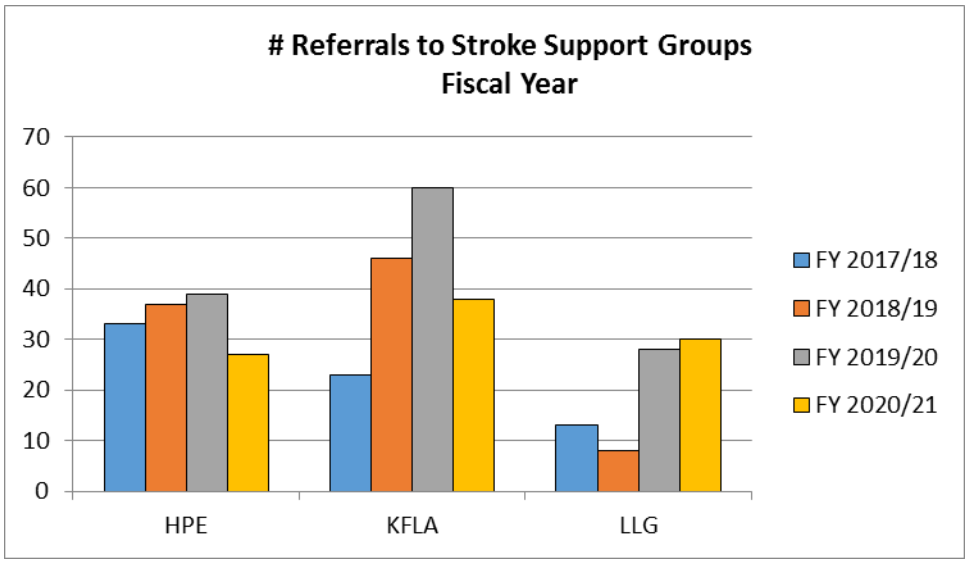
- Prior to COVID, stroke support groups had been held in Picton, Trenton, Belleville, Napanee, Sydenham, Kingston, Perth and Brockville. Fourteen supported stroke survivor or caregiver groups were in place - Perth/Smiths Falls Stroke Survivors & Caregivers Support Group, Brockville Stroke Survivors & Caregivers Support Group, Belleville Stroke Survivors Group, Belleville Caregivers Group, Belleville Introductory Stroke Survivors Support Group, Belleville Community Information Group, Belleville Young Stroke Survivors Group, Belleville Social/Recreational Group, Kingston Caregivers Group, Kingston Couples Group, Kingston Stroke Survivors Group, Kingston Young Stroke Survivors Group, Napanee Stroke Survivors & Caregivers Group, Sydenham Stroke Survivors & Caregivers Group. With the onset of COVID, a virtual group model was introduced in all areas and groups within each respective area experienced amalgamation in various forms (e.g. Perth and Brockville were combined).
- Pre-pandemic, in-person Aphasia Supportive Conversation Groups (ASCG) were in place in all three areas. These 8-week sessions were offered one to two times per year and were co-facilitated by the SSGF and an SLP. As well, in Kingston an in-person Aphasia Peer Support Group was in place.

- Four *Stroke Specific Community Exercise Programs* had been ongoing in Belleville, Trenton, Brockville and Kingston hosted by VON Greater Kingston and CPHC Senior Support Services. Both of these organizations are now offering virtual stroke-specific exercise programs. The SNSEO supported the transition to virtual classes through the facilitation of connections with colleagues from other provincial stroke networks who had already implemented the virtual model. Work is currently underway to develop a regional evaluation form and process to take effect once in-person classes resume. Implementation of this regional evaluation form is being to deferred until the resumption of in-person groups for several reasons (e.g., stroke survivors (and caregivers) often need hands-on support to complete evaluations, mail-out surveys receive very low responses rates, the virtual environment is not conducive to the survey process).
- Peer Visiting Volunteer Programs have been on hiatus since the onset of COVID restrictions. The LLG SSGF worked diligently with the Brockville Hospital Volunteer Coordinator to initiate both the in-person and, with the onset of COVID, a virtual peer visiting program leveraging the trained peer visiting volunteers. Currently, there are three stroke support group participants assuming the virtual peer visiting role. In-person peer visiting programs will resume once restrictions have been lifted. In Kingston, a trained stroke support volunteer has continued to call stroke survivors during COVID to provide support and a regular check-in.
- Virtual meetings between SSGF and inpatients (supported by hospital staff) have been intiated in Quinte Health Care (Belleville), Providence Care Hospital and Brockville General Hospital. The Kingston model also includes members of the community-based stroke support group. These meetings provide an opportunity for new stroke survivors to meet their respective SSGF prior to hospital discharge which enhances subsequent communications and linkages.
- Processes are in place across the region to obtain inpatient consents for SSGF to contact stroke survivors subequent to hospital discharge. This supports linkages to support groups and other supports and services.
- The in-person Aphasia Supportive Conversation Groups (ASCG) in Belleville, Kingston and Brockville were placed on hiatus for the duration of COVID restrictions. Kingston and Belleville have initiated virtual ASCG. Kingston has also offered a virtual support group specifically for Adults with Aphasia (AWA) and all areas support the inclusion of AWA in regular support group meetings through the introduction of supportive communication strategies for the virtual environment.
- The evaluation processes for the winter and spring sessions of the Kingston ASCG leveraged different approaches to improve response rates. The winter session used a hard copy mail-out process which resulted in low response rates. As a result, the spring session adopted an approach which provided support for survey completion. Participants could move to a virtual private room and complete the survey with support from the Stroke Support Group Facilitator (SSGF). This significantly improved the response rate.
- In Kingston, the Aphasia Buddy volunteers have continued to connect with AWA during the course of the pandemic using their preferred virtual model of choice (i.e. phone, video).
- In-person *Living with Stroke*© (LWS) self-management programs were put on hold. Belleville did offer a virtual LWS program in the spring. The program is offered once a week for 6 weeks. This was the first time LWS had been offered virtually within the southeast and this format received a positive response.
- In addition to producing accessible written informational letters, the LLG SSGF has also produced a video invitation to the stroke suppport groups. These activities recognize that many stroke survivors are living with impairments that may limit their ability to easily understand narrative text.

- The LLG SSGF introduced a pen pal program (*Reach Out and Don't Touch Someone*) for those individuals who were not participating in virtual groups or connecting with the SSGF but were interested in connecting with their peers.
- A virtual regional Stroke Awareness Event targeting all stroke survivors and caregivers across the southeast region was held in June co-hosted by the SSGF. This was the first time a regional event had been offered. The agenda included a variety of guest speakers discussing such topics as the invisible impacts of stroke, post-stroke depression, aphasia, memory loss and supporting services. The event was very successful and has prompted interest in future regional informational and 'meet and greet' events. The SSGF have initiated discussions as to next steps.
- Several activities in addition to the Stroke Awareness Event also occurred in support of Stroke and Aphasia Awareness month in June. These included media articles in the local Belleville paper and a Stroke Month proclamation by the Belleville Mayor. Additionally, in collaboration with the HPE SSGF, five local pharmacies distributed almost 800 FAST cards to the community. In Kingston, the KFLA SSGF partnered with a stroke survivor for an interview on the CKWS Morning Show, Kingston City Hall issued a Stroke Month proclamation and illumination and VON-Greater Kingston also hosted a T-shirt giveway with the inscribed motto of "*Excuse me while I rewire my brain, I am a stroke survivor"* which was developed by stroke support group participants.
- Work is being done to enhance aphasia awareness in the community including the drafting of a letter template that can be shared with local businesses identified by AWA as needing some heightened understanding of this common post-stroke condition. As well, a local SLP will be bringing forward to a provincial ASCG interest group the concept of advocacy training for AWA.
- Belleville is in receipt of a grant from the Starbucks Foundation which will be directed towards programming for stroke survivors (e.g. music therapy). As well, Belleville will be welcoming Recreation Therapy and Social Service Worker student placements.
- The KFLA SSGF continued to leverage the public stroke survivor/caregiver Facebook page to support information sharing.
- The collaborative regional model which includes the three Facilitators as well as representation from the Stroke Network of SEO (SNSEO) continues to support the sharing of best practices, challenges and successes through regular virtual meetings. The frequency of these meetings has been increased during COVID to support timely information sharing. Facilitators also participate in the quarterly meetings of the Community Reintegration Leadership Team (CRLT), a community advisory committee of the Regional Stroke Network.
- The Regional Stroke Steering Committee includes a representative of the CSS sector specifically from a CSS agency supporting the stroke groups (i.e. Shell-Lee Wert, ED, Community Care for South Hastings).
- The SSGF all continue to hold navigation and education roles ensuring links are made to the appropriate community supports and services and providing education on stroke to group participants. As the CSS agencies host the support groups, this also helps with transportation support and connections to various community services. It should also be noted that the SSGF provide navgiation support to referred individuals who opt not to attend support groups at the time of referral. Clients referred for stroke support soon after discharge from hospital often have many conflicting medical/therapeutic appointments which will interfere with their ability to participate in groups or the individual may also not be emotionally ready for this step in their recovery.

2020/21 Data

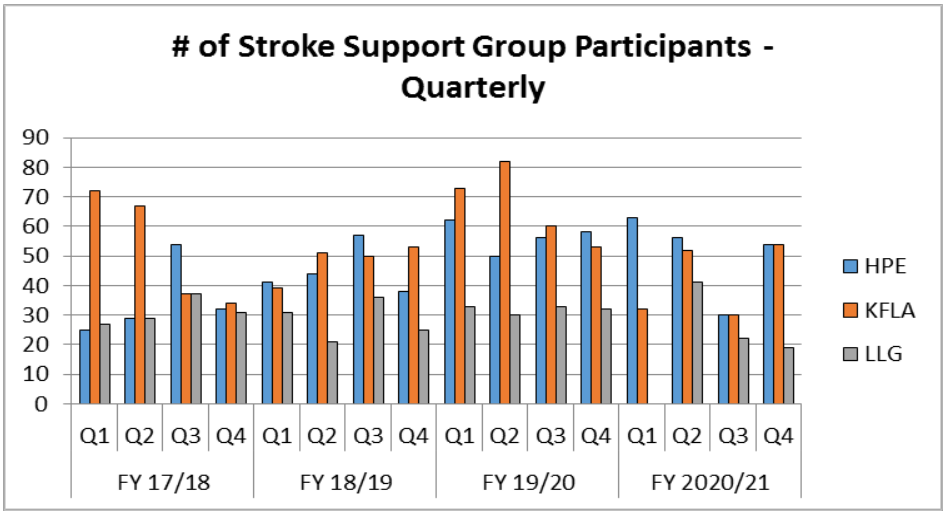
As previously noted, the restrictions to in-person meetings precluded the collection of evaluation data usually included in the annual report. The following data provides limited demographic information. It should also be noted that data capture for this fiscal year was problematic due to the introduction of new support models and periods of working remotely.



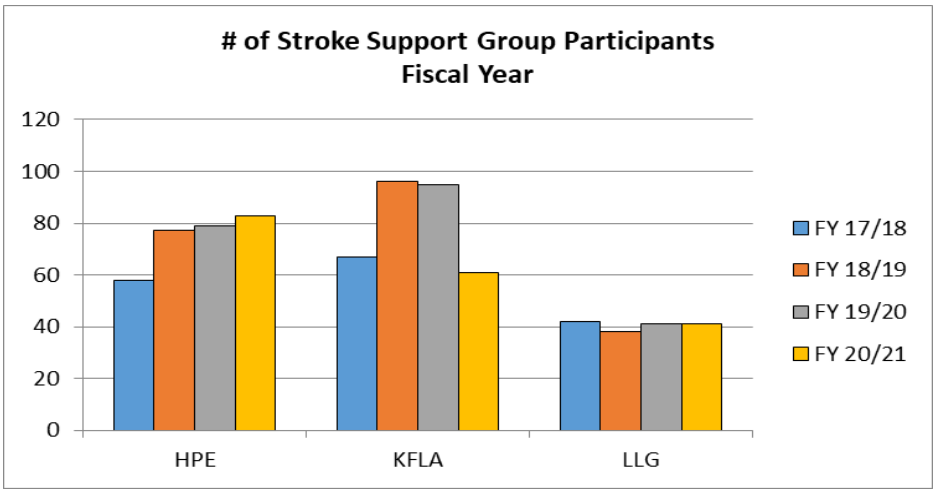
Graph 1

Referrals to stroke support groups have decreased for HPE and KFLA since last FY and remained relatively stable for LLG. This may be attributed to the impacts of COVID where acute, rehab and community referral sources were resource-stressed and focused on immediate client need.

As well, with the cessation of in-person groups, some stroke survivors and caregivers were reluctant to participate in virtual groups especially if they had not had an opportunity to first meet their fellow participants and/or SSGF in person or were not familiar with the virtual environment. Facilitators and hospital partners across the southeast are working towards enhancing discharge linkages and easing transitions to the community through such initiatives as the virtual pre-discharge meetings between stroke survivors and SSGF and the consent for SSGF to connect with stroke survivors/caregivers following transition to the community. Note that Q1 referral numbers for LLG were not available as the SSGF was not able to access that data. As well, Q1 referral numbers for KFLA were estimated as a transition of SSGF was occurring during this time and data was not readily available. (Graph 1)



Graph 2



Graph 3

When looked at by quarter, all areas have demonstrated variability in attendance numbers. This variability has also been seen in previous fiscal years (FY). As compared to the previous FY, HPE was relatively stable with the exception of Q3 which saw a decrease. For KFLA, decreases were seen in the first three quarters followed by a rebound in Q4. In LLG, Q2 saw an increase followed by a decrease in the the last two quarters (note that LLG Q1 data is not available). (Graph 2) When looked at by fiscal year, HPE saw a slight increase, KFLA a decrease and LLG remained stable. (Graph 3)

It must be noted that data collection during COVID has been challenging particularly how 'participant' is defined. Many stroke survivors/caregivers may have opted out of virtual groups but may have received phone check-ins, 'porch pal' visits and/or one-on-one virtual interactions with the SSGF. Not all interactions were included in the data capture so it may be assumed that if using a broad definition of 'participant', the numbers exceed those documented in Graphs 2 and 3. Additionally, it should be noted that individual interactions with clients are often quite time consuming as these are typically clients with the highest needs and/or most complex situations.

Summary & Recommendation

Since sustained funding for the stroke support groups was initiated in 2013, the participant numbers, complexity and services offered have expanded. The allocated funding has not kept pace with these changes. Stroke survivors (and caregivers) are often socially isolated, adjusting to a dramatically changed new 'normal', navigating financial challenges and bureaucratic networks and experiencing emotional upheaval. It is critical that these individuals are not only able to connect with the appropriate community supports and services that meet their individual needs but it is also imperative that the Stroke Support Group Facilitator (who is often the cornerstone for successful community reintegration) is a consistent presence. The challenges with retention of SSGF within the southeast need to be addressed through adequate compensation and full-time hours. Evidence has shown that effective community supports reduce hospital readmissions, ED visits, caregiver 'burnout' and transitions to LTC. Best practice research supports the benefits of support groups from both an individual perspective and for the broader health system. "When the psychosocial needs of patients and their caregivers are regularly addressed through social support, improved outcomes are observed, including reduced caregiver burden, reduced incidence of anxiety, reduced emotionalism and depression, reduced hospital re-admissions and failed discharges, and facilitated reintegration of the patient in family and social roles." (Anderson, 1992; Duncan et al, 2005). Similarly, Clarke et al (2002) found that the presence and size of social support networks as well as the perceived effectiveness of the social support network had a positive influence on physical recovery and quality of life post stroke. (Clarke et al, 2002)

The Canadian Stroke Best Practice Recommendations defines support for individuals, families and caregivers following stroke as including *meeting emotional (e.g., providing comfort, listening to problems), instrumental (e.g., providing training, organizing services, helping with household chores), informational (e.g., providing information about illness and services), and appraisal (e.g., providing feedback about their caregiving activities/needs). In addition, support refers to providing direct care, access to required services, and facilitating linkages to resources to ensure that the needs of the individual, family and caregiver are met throughout the continuum of stroke care. Support needs change across the illness and recovery trajectory and are most beneficial if it is closely matched to individuals' current needs. The goal of individual, family and caregiver support is to enable each person to manage their recovery or the recovery of the person with stroke and optimize participation and fulfillment of life roles.*[1] This definition includes many components of support that are put into practice by the SSGF.

Given the information provided by the data in this report, the input from our patient experience advisors, feedback from stroke care partners and best practice evidence, the following recommendation is offered for your consideration:

[1] Anita Mountain (First Author) et al on behalf of the Transitions and Community Participation following Stroke Best Practice Writing Group, and the Canadian Stroke Best Practices and Quality Advisory Committee; in collaboration with the Canadian Stroke Consortium and the Canadian Partnership for Stroke Recovery. Transitions and Community Participation Following Stroke *Module 2019*. In M. Patrice Lindsay, Anita Mountain, Gord Gubitz, Dariush Dowlatshahi, Leanne K Casaubon, Andrea de Jong and Eric E Smith (Editors), on behalf of the Canadian Stroke Best Practices and Quality Advisory Committee in collaboration with the Canadian Stroke Consortium and the Canadian Partnership for Stroke Recovery. Canadian Stroke Best Practice Recommendations Sixth Edition, 2019; Toronto, Ontario Canada: Heart and Stroke Foundation.

Recommendation

A review of and **adjustment to the current funding structure is recommended.**

This recommendation is predicated on the following:

1. Initial funding structure did not include the many subsequent enhanced services provided to ensure that the diversity of need is met.
2. It is strongly recommended that all Stroke Support Group Facilitator positions be funded as full time at a compensation level reflective of the skills and knowledge required for the position.
3. Support for the growth of existing groups while ensuring that group size remains within recommended therapeutic numbers. This may require more groups to ensure that therapeutic ratios are respected and, consequently, more Stroke Support Group Facilitator time.
4. Increasing diversity of needs within the stroke survivor and caregiver population including the needs of younger stroke survivors, younger caregivers (including children) and adults with aphasia must be addressed to ensure inclusivity. This would include expansion of the Aphasia Supportive Conversation Groups.
5. Initiation of hybrid models of service delivery which would require additional planning, coordination and facilitation. A hybrid model respects the preferences of participants and supports equity of service for rural residents. This may also require support for the required technology such as a lending library of laptops/tablets with internet connectivity.
6. Recognition that virtual connections will not be the best approach for many individuals and for these stroke survivors and caregivers, funding is required to support in-person outreach groups.
7. Stroke Support Group Facilitator retention faces challenges at the same time that the complexity of stroke survivors in the community is increasing. Adequate compensation will help to support the recruitment and retention of qualified SSGF.

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