SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS
ANNUAL EVALUATION - 2020
SUBMITTED TO SOUTH EAST LHIN

StrokeUnderstood

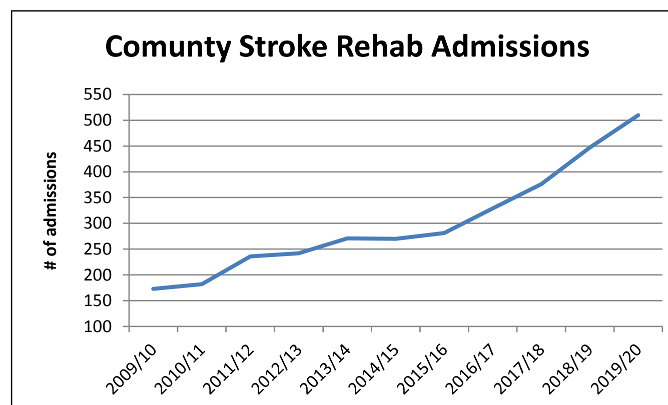
Senior Support Services
Supporting Seniors Independence at Home and in the Community.

STROKE NETWORK
of Southeastern Ontario

ANNUAL EVALUATION FISCAL 2019/20
SOUTHEASTERN ONTARIO REGIONAL STROKE SUPPORT GROUPS

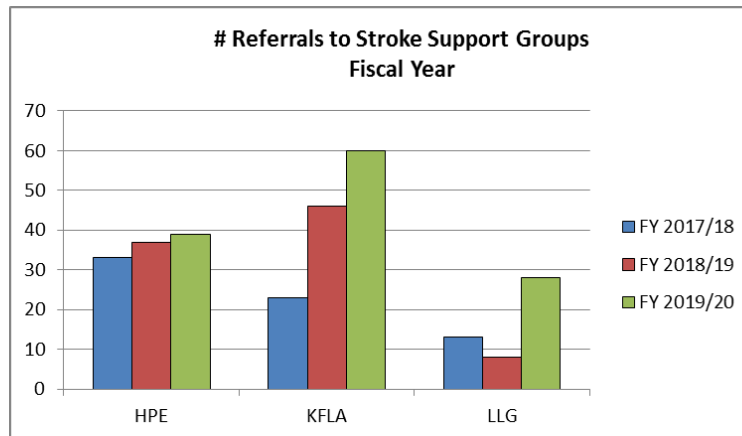
Executive Summary

Stroke volumes have been experiencing a consistent upward trend within the southeast as have hospital readmissions for this population. Both of these factors impact on hospital capacity, the emergence (and normalization) of 'hallway medicine' as a daily reality and the critical need for efficient patient flow processes. Highlighting this escalation in volumes are the increasing admissions to the Community Stroke Rehab Program (195% relative increase from fiscal year (FY) 2009/10 to FY 2019/20). (Graph 1)

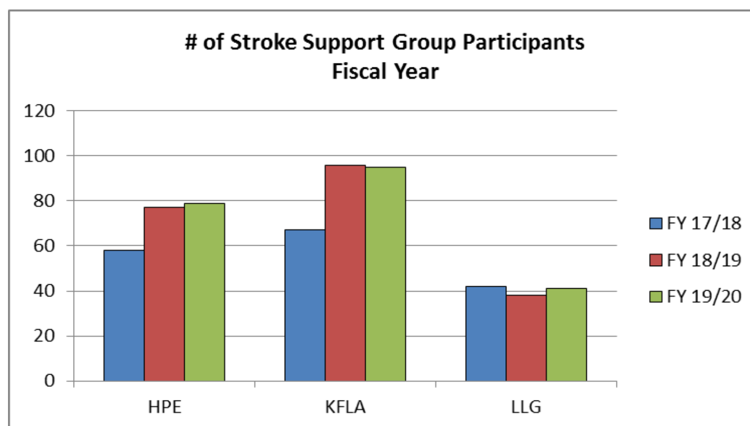


Graph 1

It is universally recognized that the health system cannot effectively operate using a siloed model of care provision; patient illness and recovery are not sector-specific but instead require a cohesive, interdependent, patient-centred approach to achieve optimal outcomes. Stroke support groups (SSG) within the southeast provide essential community-based support to both stroke survivors and caregivers to diminish the risk of readmission, enhance quality of life and contribute to secondary stroke prevention through education, peer support and community linkages. Annual evaluations of the SSG have consistently demonstrated the significant role they play in contributing to post-stroke emotional and physical wellbeing thereby decreasing the hospital burden. Since the introduction of sustained SSG funding in 2013, the community support service agencies have offered a variety of supportive services to both stroke survivors and caregivers assisting with transition to the community and supporting ongoing wellness at home. However, that funding has failed to keep pace with the increasing volumes, increasing complexity and increasing diversity of this population. (Graphs 2 & 3) The growing demand for services has exceeded the capacity of the host Community Support Service (CSS) agencies to effectively reach and support the increasing needs within the community. The prevalence and incidence of stroke continues to increase and this upward trend is, unfortunately, expected to continue as the 'baby boomer' demographic peaks. Reaching this growing population of stroke survivors and caregivers and adequately meeting their many support needs plays a pivotal role in reducing hospital interactions. It should be noted that community has a lengthy (sometimes lifelong) and critical role in the recovery trajectory well beyond the initial transitional period. The skilled Facilitators of the SSG are integral to ensuring stroke survivors and caregivers receive the relevant supports and services as they continue to adjust to this life-changing event.



Graph 2



Graph 3

The disparity between current funding and client need has also negatively impacted on the recrutiment and retention of Stroke Support Group Facilitators for some agencies. Without the appropriate community supports, stroke survivors and caregivers are at increased risk for hospital readmission and Emergency Department visits. Transition to a home setting may become less of a transition and more of a transitory experience if community supports are not in place. This circular journey from hospital to community and back to hospital negatively impacts the client, the family and the health system. Increased funding is needed to ensure an adequate and regionally equitable response to increased volumes, increased diversity of need, increased complexity and limited access to SSG services in rural and remote areas.

As Dr. Dan Brouillard (a stroke survivor, physician and member of the Community Reintegration Leadership Team) noted, *"Adequate funding of stroke support groups is a complex and longstanding issue. It is imperative that the Stroke Support Group Facilitators have stroke expertise as the complexity of clients they will be interacting with and supporting continues to increase. In order to recruit and retain qualified individuals, fair compensation must be offered and this requires sufficient funding from the South East LHIN."*

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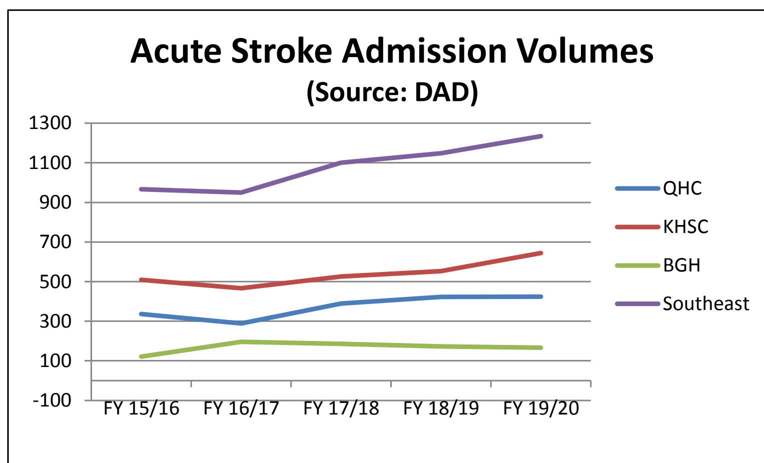
Background

Since 2013, the South East LHIN Regional Stroke Support Groups (SSG) 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, visual 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 include 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. Additionally, the report will provide data supporting the need for increased funding to reflect changes to stroke prevalence and incidence within the southeast.

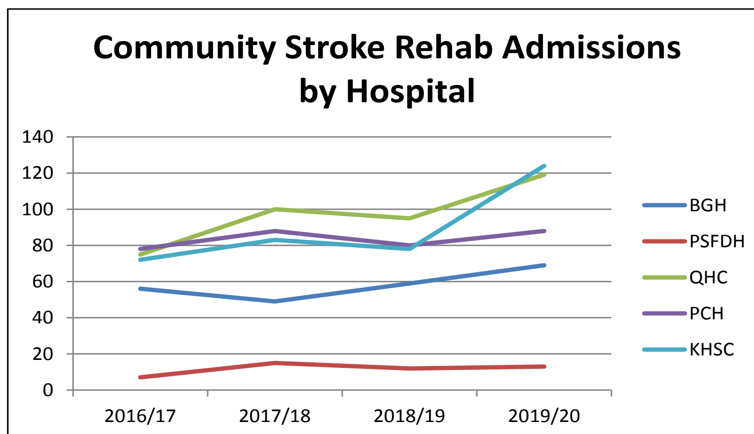
System Implications

The trajectory of stroke recovery is variable and dependent on a myriad of factors including type of stroke, severity of stroke, pre-stroke health and timeliness of interventions. However, despite this variability there is a constant which impacts the recovery trajectory; the critical need to provide a cross-continuum framework of supports. When viewing the recovery trajectory, it is immediately evident that the time spent in hospital (at high financial cost) is relatively short when compared to the extended recovery time in the community setting. A lack of community supports increases the potential for functional and emotional deterioration resulting in an increased reliance on community supports including primary care and, ultimately, an increased risk of hospital readmission and Emergency Department visits. The health care system as an entity benefits through the provision of appropriate, timely community-based supports and services.

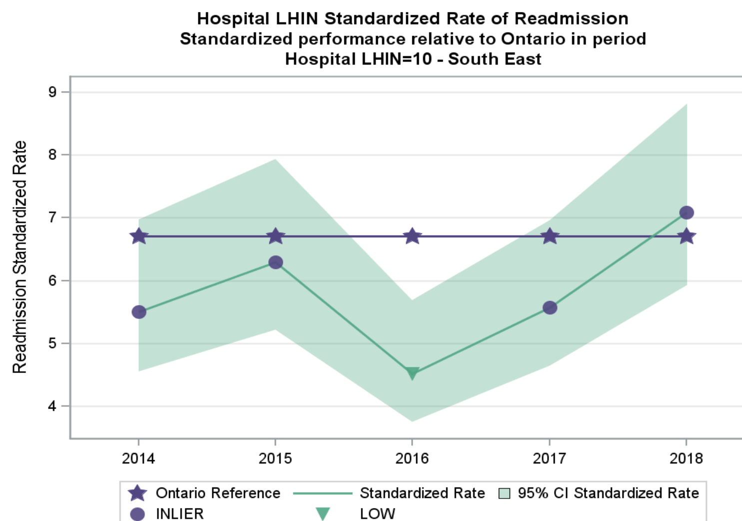
Within the southeast, the prevalence and incidence of stroke is, unfortunately, increasing (Graphs 4 & 5) as are readmission rates (Graph 6).



Graph 4



Graph 5



Graph 6

The increasing demand for (costly) in-hospital care puts a corresponding increased demand on the limited resources within that sector. Hallway medicine has become a common component of hospital care. This is distressing for the patient, the family and the care providers who recognize the potential impacts on quality of care. It is essential that patient flow is maximized to effectively leverage the available resources however this cannot be successfully achieved unless critical community supports are in place. Without these, the 'flow through' simply becomes a temporary measure as the unsupported clients (and caregivers) in community return to an already over-burdened hospital system; an exercise in redundancy. As well, it is not enough to ensure that adequate community supports are in place. It is also essential that patients and families are linked to those supports and services. This is not an easy task given the complexity of care, the growing matrix of supports and the individuality of evolving patient and family needs.

Despite these growing numbers, the regional SSG funding initiated in late 2013 has not realized a parallel increase to meet this significantly higher demand. In addition to the expansion in direct number of participants, SSG continue to reflect diversity in age, gender, severity of stroke, available home supports, co-morbidities, income level and other factors which impact on individual and group needs. The SSGF must be responsive to this evolving matrix to ensure that the appropriate supports are in place but this cannot be effectively done without the necessary funding.

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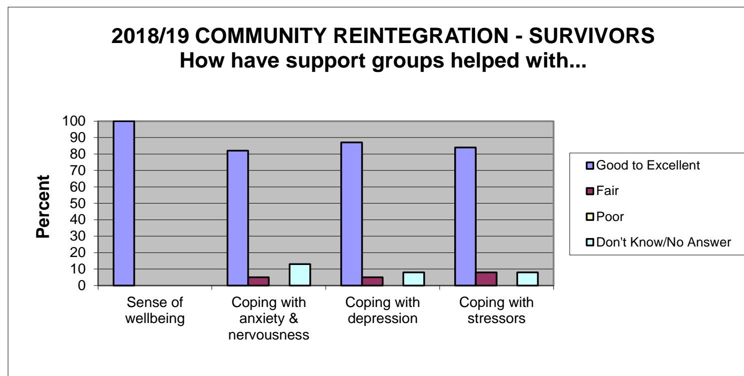
The SSG provide an essential intervention and support mechanism that assists stroke survivors and caregivers to:

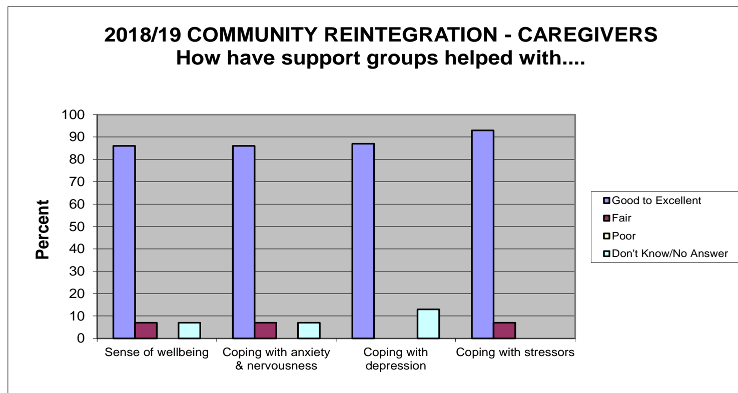
- Connect with the relevant supports and services through the Stroke Support Group Facilitators' (SSGF) navigation role
- Connect with peers who are on a similar recovery journey and can provide experiential knowledge and emotional support
- Learn about stroke including impacts and interventions and, perhaps more importantly, secondary prevention to reduce the risk of a second stroke
- Receive the practical and psychosocial expertise of an experienced and skilled Facilitator

These interventions facilitate community-based recovery as both stroke survivors and caregivers receive information, support and practical assistance reducing the potential for re-entry into the hospital-based care system. Findings from previous reports where in-person meetings supported data gathering, have clearly illustrated the critical role played by the SSG (Graphs 7 to 10).



Graph 7

"I believe this group helped in my recovery and I recommend it any time I can." ~Stroke Survivor



Graph 8

"I learn something new and very applicable at every session." ~Caregiver

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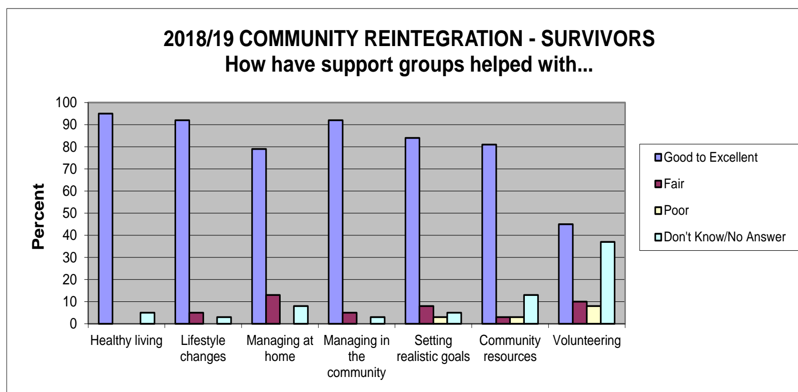
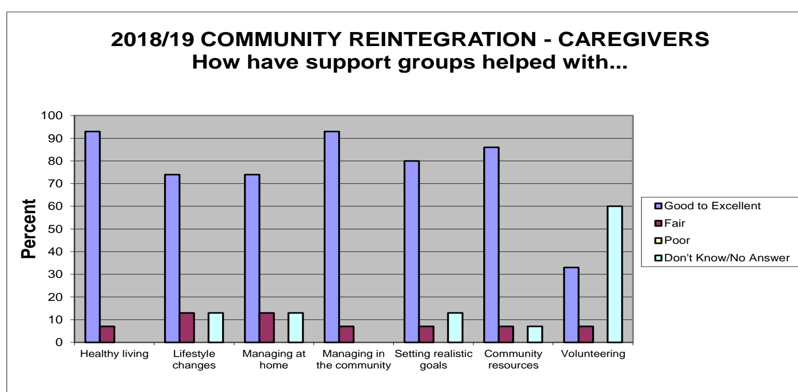


Graph 9



Graph 10

"I've received the most support since joining the stroke support groups; would have joined sooner if I'd known. First meeting I attended was a year after my stroke. I could have used the support earlier." ~Stroke Survivor

To continue offering the supports required to enhance quality of life and health staus while reducing the risk of hospital readmissions and ED visits, adequate funding is required.

COVID Response

With the onset of the COVID-19 pandemic, health and social service providers across the continuum of care had to make rapid and innovative practice changes to continue to meet client and family needs. Within the community setting, stroke support groups adapted to ensure that practical and psychosocial supports remained available and accessible to stroke survivors and caregivers.

Stroke support group meetings are an opportunity for participants to share experiences, learn about stroke and caregiving, establish connections to resources and reduce social isolation. While at this writing, limited in-person stroke support meetings have resumed or are planned, the COVID trajectory remains uncertain making virtual care an important component in a multi-faceted approach. It may well become a preferred intervention in certain **limited** situations (e.g., geographical isolation, seasonal weather impacts). At the same time, it is recognised that participants universally prefer an in-person option and, for some, connecting virtually is not a viable alternative (e.g., communication impairment, lack of internet connectivity, lack of devices, and discomfort with technology).

The SSGF across the southeast recognized the risks inherent in the social isolation that was precipitated by COVID. For stroke survivors who are a high risk population and their caregivers (both of whom may already have had limited opportunities for social interaction) the imposition of additional limitations were challenging. In response to this, the SSGF explored innovative approaches to continuing to engage with and provide support to this population. The initial step was to reconnect by phone with each support group participant to ascertain their wellbeing and need for additional supports. These 'check-in' calls have continued with both stroke survivors and caregivers with the frequency of contact being adjusted to meet the needs and preferences of each individual. Peer support phone check-in calls have also been offered for all new stroke survivors and those existing survivors in Kingston who would like some extra support during COVID-19. As it became clear that COVID would be a long-standing situation, other virtual supports were devised and implemented.

Zoom has been adopted as the preferred platform for video meetings. Using this virtual approach has been a mutual learning opportunity for both the SSGF and clients and has required a significant amount of preparation, education and coordination. To date, Zoom has been used for general support group meetings (Kingston & Belleville), aphasia supportive conversation groups (Kingston and Belleville) and caregivers of adults with aphasia (AWA) (Kingston). In Kingston, a Facebook page was also created to support connections and information sharing.

"Zoom has been a lifesaver for [adult with aphasia] during this pandemic. She suffers with difficulty speaking, reading and writing which makes having a conversation on the phone nearly impossible. Staying in contact with her stroke and aphasia group friends during this pandemic would be impossible if not for the video chats that [the SSGF]] schedules on Zoom. These groups are her lifeline, contribute to her health and well being, and help her from being isolated and depressed." ~Caregiver

Video links were not however, a preferred virtual approach for all clients and an option for teleconferenced bingo games was put forward in the Belleville area and has been an ongoing success. This provides an opportunity for social interaction and peer support. In LLG, the option for virtual meetings was offered but most participants were not receptive to and/or did not have the technological capacity for this approach. As a result, small in-person meetings have been held this fall with the option for others to join virtually. Additionally, a LLG virtual falls prevention session specifically for the support group participants is being held in December.

In the LLG area, in-person 'porch pal' visits were also introduced to sustain connections and offer support. 'Porch pal' visits included the distribution of wellness bags containing such items as pens, notebooks and exercise sheets.

As the social isolation requirements related to COVID continue to persist, additional innovations emerge with the most recent being collaborative Zoom meetings between in-hospital stroke survivors at PCH, the Kingston SSGF and community-dwelling stroke survivors in Kingston; in Belleville, a similar virtual collaborative has been established between QHC and the respective SSGF. These meetings are intended to support effective transitions to the community as new stroke survivors will have already been linked to the SSGF and, for Kingston, with fellow stroke survivors as well. While support group participants continue to express a **preference for in-person meetings**, using virtual technology as a stopgap measure has been successful to the extent that some components may continue to be utilized in a future COVID-free context.

"As a proud two-time stroke survivor, if it was not for the Stroke Survivor Group I would be a lost, depressed soul. Having found the group 8 years ago it has made me a better person, it has given me confidence in allowing me to speak up for me and of course all the other survivors in our group . I think us being able to see and meet on Zoom is great especially for those who live in the country; we can see them and vice versa. It lets them know we are here and have their backs." ~Stroke Survivor

The importance of in-person meetings for stroke survivors can be clearly illustrated through the following story. A stroke survivor receiving an in-person visit from a SSGF expressed thanks for the visit however he also shared that this

interaction was not best meeting his needs. As this individual had a background in healthcare, he already had more than adequate access to other health professionals; what he was in need of was that in-person, direct interaction with other stroke survivors who are on similar journeys to recovery and experiencing similar challenges.

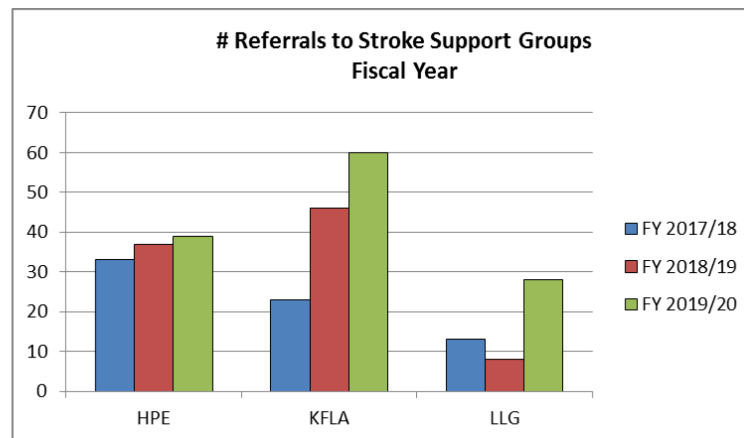
2019/20 Summary of SSG Programs & Services

- New SSGF was retained for the LLG area
- The SSGF in LLG attended The Aphasia Institute for training courses in supportive conversation (SCA™)
- The collaborative regional model which includes the three SSGF as well as representation from the Stroke Network of SEO continues to support the sharing of best practices and strategies through regular virtual meetings. The frequency of these meetings has been increased during COVID to support timely sharing of challenges and successes. 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 representatives of the CSS sector specifically from the CSS agencies supporting the stroke groups (i.e. Shell-Lee Wert (CCSH) and Lynda Lennox (VON-Greater Kingston)
- 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.
- Four *Stroke Specific Community Exercise Programs* had been ongoing in Belleville, Trenton, Brockville and Kingston pre-COVID.
- Peer Visiting Volunteer Programs are in place in Perth (PSFDH Rehab and Day Hospital) and Brockville Rehab and Belleville is in the planning process with volunteers having completed the training program. Kingston is currently recruiting for a peer visiting program. Kingston also has peer visiting with a stroke survivor in LTC.
- Processes are in place across the region to obtain inpatient consents for SSGF to contact the stroke survivor subequent to hospital discharge. This ensures linkages to support groups and other supports and services.
- Aphasia Supportive Conversation Groups were in place in Belleville, Kingston and Brockville pre-COVID.
- *Living with Stroke*© (LWS) programs were put on hold as was the annual Belleville Stroke Awareness Day and annual Stroke Social (anticipated in December).
- Belleville had several projects in place prior to COVID including a collaborative art project with Queen's and PCH, creation of a *Caregiver Welcome Package* by the caregivers' group and creation of a booklet on explaining stroke to young children by the young survivors' group.
- Kingston and Belleville completed a project on *Stroke Journey Trees* (a visual representation of stroke recovery). It is anticipated that Belleville stroke group participants will be involved in a dedication event when the *Stroke Journey Trees* (currently dislayed in the CCSH rectpion area) become a permanent display in the QHC Integrated Stroke Unit.
- The Kingston SSGF collaborated with St. Lawrence College to have stroke survivors participate in Therapeutic Recreation education sessions.
- The LLG SSGF collaborated with Brockville General Hospital (BGH) in the development of their new integrated stroke unit. Due to COVID restrictions, the approach used was the sharing of the BGH Integrated Stroke Unit Caregiver and Stroke Patient Survey during all porch pal visits.

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 & healthy living 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 navigation 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 clinical/therapeutic appointments which will interfere with their ability to participate in groups and some may also not be emotionally ready for this step in their recovery.

2019/20 Data

As previously noted, the restrictions to in-person meetings precluded the collection of evaluation data usually included in the annual report. However, limited data was available which provide a high-level picture the current SSG status.



Graph 11

Referrals to stroke support groups have increased since FY 17/18 (Graph 11). Facilitators and hospital partners across the southeast have worked towards enhancing discharge linkages and easing transitions to the community. Processes are now in place in each area to obtain client consents prior to hospital discharge allowing the SSGF to connect with the client/caregiver subsequent to transition. This connection typically occurs at least several weeks after discharge. At this point, other community-based services may be terminating, the client and caregiver have begun to settle into their ‘new normal’ and there may be more readiness to join a support group. The SSGF also leverage this connection to assess if other supports are needed and to facilitate the appropriate connections.

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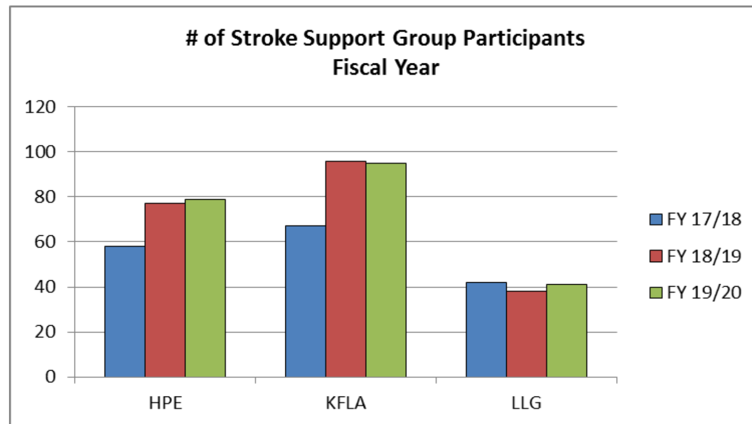
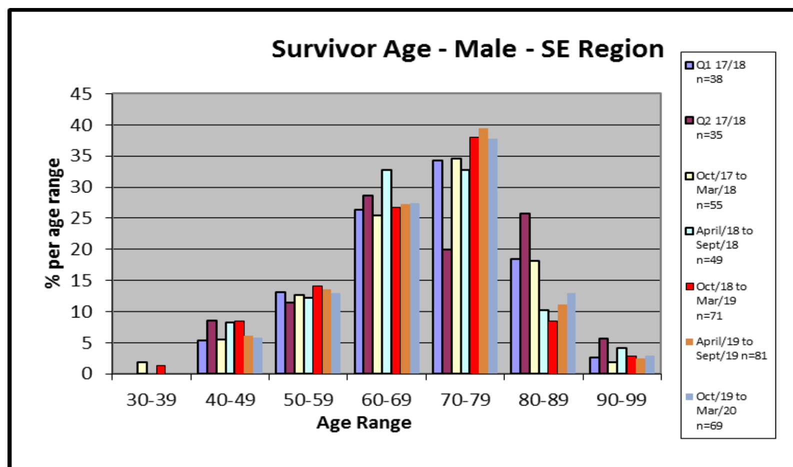


Graph 12

The number of stroke support group participants has increased in HPE and KFLA since FY 17/18 and has remained relatively stable in LLG (Graph 12). Participant numbers can be impacted by various factors including referral processes, consistency of facilitator (i.e. retention), geography of area, respite options and transportation supports. Stroke survivor and caregiver members of the the Community Reintegration Leadership Team (CRLT) (a community advisory committee of the SNSEO) have identified ongoing service gaps including connecting with stroke survivors who experienced their stroke event several years prior to the initiation of regional support groups and enhanced transitional communications. These individuals may not be aware of the available supports and services which puts them and their caregivers at risk for negative physical, emotional and psychosocial impacts.

An additional group that has been highlighted in CRLT discussions is the young caregiver (caregivers 18 years of age and under) who have very limited (if any) supports and services. This group may struggle with home and school responsibilities and bear a significant emotional burden. A final group that warrants further attention is the younger stroke survivor. These individuals have very different needs from the older stroke survivor; they may still be raising young children, have significant financial obligations and may also either be working or wish to return to work. These gaps are currently being further explored by the CRLT and the SNSEO.



Graph 13

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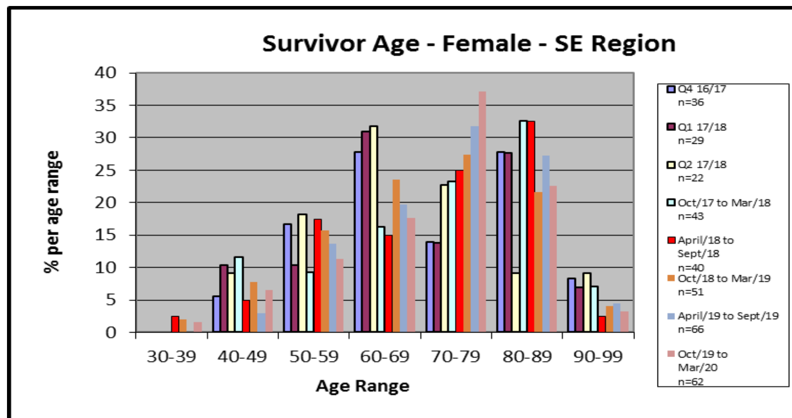
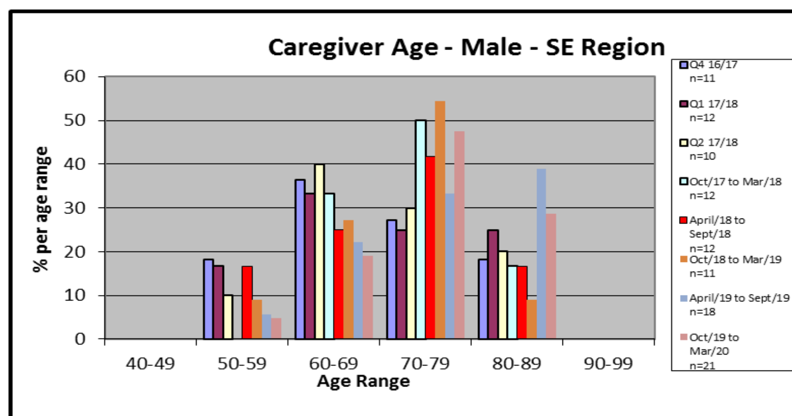
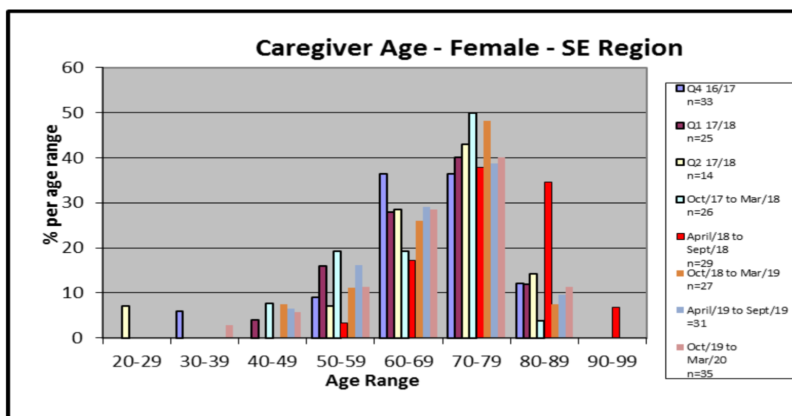


Graph 14



Graph 15



Graph 16

Table 1

	Youngest (years)	Oldest (years)
Male Stroke Survivor	46	96
Female Stroke Survivor	39	95
Male Caregiver	57	85
Female Caregiver	32	89

In looking at the ages within the support groups, there is a significant range both for caregivers and for stroke survivors (Graphs 13 to 16 and Table 1). This further highlights the diversity of needs within the stroke population; this is not a homogeneous group. For example, the younger demographic may still be raising children, pursuing vocational and/or educational goals and managing a mortgage while the older demographic may have concerns about fixed incomes, aging at home and losing those close to them. Responding to the needs of such a large age demographic can be challenging and this challenge becomes further pronounced given that there are also gender differences within age groups. It should also be noted that the impacts of the stroke itself can be so wide-ranging that it is impossible to create a one size fits all model of care and support.

Summary & Recommendations

Stroke volumes and hospital readmissions have been trending upward. Sustainable funding for the stroke support groups was initiated in late 2013 but since that time, the participant numbers and services offered have expanded to a significant degree. The allocated funding has not kept pace with these changes. At the same time, the complexity of stroke survivors transitioning to the community has increased and responding to these complexities requires focused expertise not only in understanding stroke impacts but in effectively building trusting relationships.

Stroke survivors (and caregivers) are often socially isolated, adjusting to a dramatically changed new 'normal', navigating financial challenges and bureaucratic networks and experiencing emotional turbulence. It is critical that these individuals are not only able to connect with the appropriate supports and services in the community that meet their individual needs but it is also imperative that the SSGF (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 FTE on a regional basis.

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…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.

[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

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 recommendations are offered for your consideration.

A review of and adjustment to the current funding structure for the stroke support groups in recognition of the following:

1. Rising stroke volumes and readmissions within the southeast which speak to an imperative need to ensure that adequate and accessible community services are in place to support wellness at home. Increasing stroke volumes result in increased referrals to the support groups with a resultant ever-increasing number of participants. Future expanded base funding would support the growth of existing groups while ensuring that group size remains within recommended therapeutic numbers.
2. Diversity of needs within the stroke survivor and caregiver population including the needs of younger stroke survivors.
3. Equity of service in rural and remote areas of the southeast. The emergence of COVID has resulted in the introduction of virtual connections with community-dwelling stroke survivors and caregivers however several barriers exist. With high indices of material deprivation within the southeast, many individuals are not able to afford devices to support this approach increasing the disparity for underserviced individuals. As well, 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.
4. SSGF retention challenges are occurring at the same time that the complexity of stroke survivors in the community is increasing. SSGF must have the expertise needed to ensure that stroke survivors and caregivers receive timely, relevant and effective support and navigation. Turnover of SSGF negatively impacts on the client/facilitator trust relationship and understanding of individual needs which is built over time. Adequate compensation will help to support the recruitment and retention of qualified SSGF.
5. Up to 38% of stroke survivors experience communication impairment (e.g., aphasia). This condition can lead to social isolation, depression, negative family relationships, job loss and other negative impacts. Participation in facilitated supportive conversation (SCA™) groups not only provides "…speech–language and psychosocial benefits…[but also] may result in interpersonal flourishing and reduced stress, thereby improving a critical outcome for participants: positive health and longevity." (Ellman, 2007) In the southeast, the regional Aphasia Supportive Conversation Groups have limited capacity especially with respect to rural and remote areas and additional funding is required to promote regional equity.

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.