

***WHAT WE HEARD:
CHARTING A COURSE FOR
SUCCESSFUL COMMUNITY
REINTEGRATION AFTER STROKE***

2015 CONSULTATION REPORT



TABLE OF CONTENTS

Executive Summary.....	1
Acknowledgments.....	4
Background: Stroke Impacts and Community Reintegration.....	4
Canadian Perspective.....	4
Southeastern Ontario Perspective.....	5
Context for Consultation on Community Reintegration.....	6
2015 Community Consultation: Listening and Responding.....	7
Process.....	7
Methodology.....	8
Findings: What Stroke Survivors, Caregivers and Providers Value Most.....	10
Theme 1: Person-Centred Skilled Stroke Care & Rehabilitation.....	11
Theme 2: Individual Well-Being & Meaningful Engagement.....	12
Theme 3: Community Co-Navigation.....	13
Theme 4: Supported Mobility in the Community.....	14
Theme 5: Access to Supports and Services.....	15
The Stroke Network of SEO’s Recommendations: Steps Toward Better Community Reintegration.....	16
Future Considerations and Challenges.....	18
Discussion: What’s Next?.....	20

List of Appendices

Appendix A: Community Reintegration Leadership Team (CRLT) Membership.....	21
Appendix B: Stroke Survivor Statements – Q Sort.....	22
Appendix C: Caregiver Statements – Q Sort.....	23
Appendix D: Health Care Provider Statements, Q Sort Survey.....	24
Appendix E: Q Sort Analysis.....	27
..	
Appendix F: What Participants and the Research Say: Detailed responses by group/question, with supporting evidence.....	31
Appendix G: Health System Alignment Chart.....	70
Appendix H: Glossary.....	75
Appendix I: References.....	76

EXECUTIVE SUMMARY

The Stroke Network of Southeastern Ontario (SNSEO) initiated a broad consultation process in April 2015 to identify priority areas for change that would support stroke survivors and caregivers through the challenges of reintegrating into the community following a stroke. This work builds on the outcomes of a previous community consultation held in 2007. The report identifies the SNSEO's patient-centred, evidence-based recommendations for moving forward, and will inform the work of organizations in collaboratively improving community reintegration following a stroke.

Effort was made to bring together input from several different perspectives, but most importantly, from stroke survivors and their caregivers—defined as family, friends and other informal (unpaid) care providers. In total, 107 individuals were consulted, including 43 stroke survivors, 24 caregivers, and 40 health care providers. Stroke survivor and caregiver participants were distributed across the southeastern region and across populations, including participants from rural and urban areas, older and younger age groups, and a mix of genders. Health care provider respondents came from a variety of disciplines and roles, and were representative of each county within the southeastern region.

During the consultation, participants were asked to rank 30 statements about what was important to support community reintegration after a stroke, following a “Q Sort” methodology, the framework for the consultation. The Q statements were derived from information gathered during previous consultations in both the Northeastern Ontario Stroke Network and the SNSEO. The statements were finalized following a review by members of the SNSEO's Community Reintegration Leadership Team (CRLT). Following the Q Sort exercise, consultation participants were then asked structured questions to draw out further details about their responses.

From the diversity of experiences shared, common themes and, consequently, actionable priorities, were distilled. Five key themes emerged from the data collected, reflecting areas where efforts to support stroke survivors and caregivers achieve successful community reintegration can have the most impact. These themes (Figure 1) are:

1. Person-Centred Skilled Stroke Care & Rehabilitation Services
2. Individual Well-Being & Meaningful Engagement
3. Community Co-Navigation
4. Supported Mobility in the Community
5. Access to Supports & Services

Notably, the findings are supported by research literature, demonstrating widespread agreement on how to improve outcomes and experiences for stroke survivors and their caregivers. Based on these themes, the SNSEO identified specific recommendations for improving services and supports. The recommendations reflect the views of consultation participants on what is integral to successful community reintegration following a stroke. These views will inform the SNSEO's regional and local workplan priorities.

The SNSEO’s recommendations (Table 1) focus on: enhancing services; building linkages and connections; supporting service providers with tools and resources; and providing education and raising awareness. SNSEO progress in implementing the recommendations will be monitored by the CRLT and the Regional Stroke Steering Committee (RSSC).

These recommendations have important implications for all individuals and organizations working toward the shared goal of ensuring that stroke survivors and caregivers receive the right care, at the right time, in the right place, to stay well in their own homes for as long as possible.

Engagement of stroke survivors and caregivers, health care providers, social services agencies, municipalities and government ministries is integral to achieving positive outcomes. The reality of recovery as expressed by consultation participants provides a rich resource to support collaborative action on the report’s recommendations.

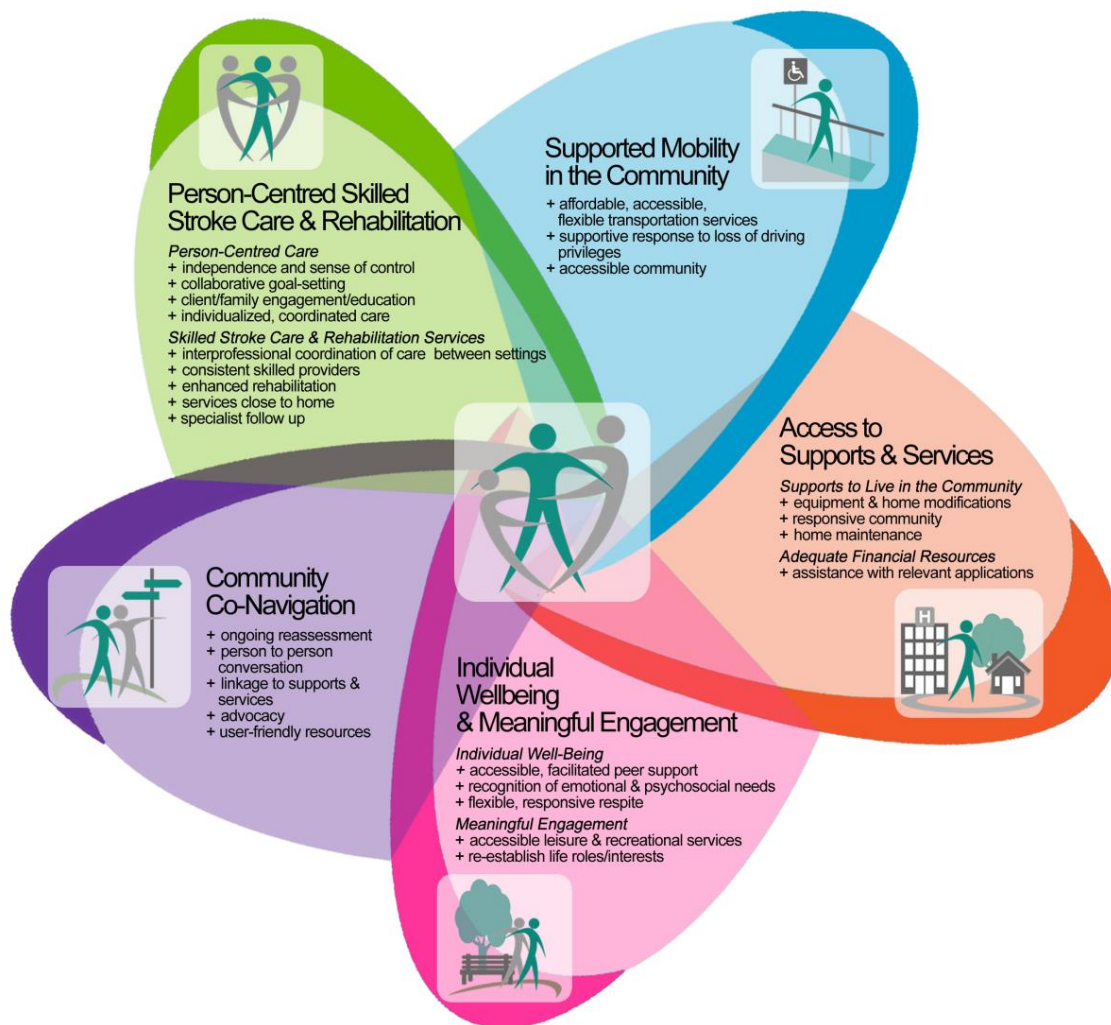


Figure 1 – Theme Summary

**TABLE 1
STROKE NETWORK OF SOUTHEASTERN ONTARIO RECOMMENDATIONS**

Person-Centred Skilled Stroke Care & Rehabilitation
<ul style="list-style-type: none"> • Provide feedback to the CCAC regarding Enhanced Rehab Services: <ul style="list-style-type: none"> -integrating flexible rehabilitation plans to meet individualized needs -including capacity for accommodation in care planning for outliers -increasing awareness of need for Discharge Link meetings to facilitate continuity of care from inpatient to outpatient to community • Support transition from inpatient to community programs • Support providers with tools and resources for collaborative planning, education and decision-making with client & family • Continue to optimize the reach of facilitated support groups. Advocate for funding for continued outreach and expansion of groups in urban settings to recognize therapeutic group size • Support person-centred care through interprofessional education for providers in community, long-term care and other settings (e.g., primary care) • Support the value of ongoing reassessments to identify changing needs and linking to appropriate resources/supports
Individual Well-Being & Meaningful Engagement
<ul style="list-style-type: none"> • Raise awareness among health care providers of: <ul style="list-style-type: none"> - the role of Recreation Therapists in supporting individual well-being and meaningful engagement through assessment and treatment. Explore potential partnerships between LTC and community settings to leverage the existing expertise of LTC recreation therapy - the need to provide flexible, responsive respite that meets the needs of client and caregiver - the need for social work and mental health services throughout the journey to provide emotional support - the need for practical assistance to access/apply for financial supports and services • Support stroke specific and other exercise programs that integrate persons living with the effects of stroke through linkages with physiotherapists with neuro expertise and other educational resources • Support linkages between inpatient and community recreation/leisure services • Build linkages within and across local community services • Promote linkages as appropriate to resources/services to support a return to work or school (e.g. social work, occupational therapy) • Raise awareness of the benefits of vocational rehab services
Community Co-Navigation
<ul style="list-style-type: none"> • Increase awareness of and linkage to rehab supports & services by health care providers to optimize independence • Develop tools and resources for a discharge planning process that includes supported links to recreational/leisure opportunities as well as support groups • Support health providers in providing consistent caregiver education to deliver knowledge and skills for self-efficacy • Implement a strong, consistent link and referral process from hospital to community support groups • Investigate provincial/regional navigation models and regional Health Link Coordinator role and how the SNSEO can support stroke-specific training for navigators/coordinators
Supported Mobility in the Community
<ul style="list-style-type: none"> • Implement provider education to elevate awareness of the psychosocial impacts of the loss of driver's license after stroke • Investigate alignment with Older Adult Strategy and stroke-relevant supports and services • Raise awareness of the need for affordable, accessible transportation options and the need for building age-friendly & stroke survivor friendly communities
Access to Supports & Services
<ul style="list-style-type: none"> • Help to develop tools (e.g. regional 'trigger tool') to assist providers in assessing the changing needs of the stroke survivor and caregiver and linking to appropriate supports. Tool to include information about financial programs to support adaptations and equipment for living successfully in the community. Continue to promote use of Stroke Resources & Vascular Health microsites on SE Healthline • Explore <i>Return to Work Toolkit</i> (SWO Stroke Network) and potential application/modifications for the southeast • Promote the Belleville Communication Support Group and advocate for sustained funding. Advocate for regional expansion, outreach and funding support of Communication Support Groups.
Overarching Recommendations
<ul style="list-style-type: none"> • Execute a comprehensive communication strategy for care providers, health facilities, social services and municipalities that raises the profile of the <i>What We Heard: Charting a Course for Community Reintegration After Stroke - 2015 Consultation Report</i> through dissemination of the report at provincial and regional workshops, conferences, webinars and other educational opportunities • Provide stroke-specific education for Health Link Coordinators, CCAC Care Coordinators and care providers in community, primary and preventative care settings to support linkages to appropriate resources and services

ACKNOWLEDGMENTS

We would like to acknowledge our appreciation to all those who participated in this consultation process for generously sharing their stories—especially those who are living with the effects of stroke, and their families. It is only through such generosity that the system of support for people returning to the community following a stroke can be improved. We would also like to express our sincere appreciation to the Northeastern Ontario Stroke Network for introducing us to the Q Sort methodology, and to Phyllis Montgomery, Victoria Cameron and research associates at Laurentian University in Sudbury, Ontario, who willingly shared their expertise and time to enhance our understanding of this methodology and its adaptation to our region, as well as to analyze the Q Sort data. Finally, we extend our thanks the Community Reintegration Leadership Team—and most particularly, to its members who are stroke survivors and caregivers—who designed the consultation process, reviewed the draft consultation report and contributed valued insights both on the content of the report and the resulting recommendations.

BACKGROUND: STROKE IMPACTS AND COMMUNITY REINTEGRATION

A CAREGIVER'S VOICE

“When he was in hospital, we were told he would never walk again, never eat solid foods again. This was devastating—we were relatively young. ‘What are we going to do now?’ we asked ourselves. ‘How are we going to survive?’”

Canadian Perspective

Nationwide, a stroke occurs every 10 minutes, for a total of 50,000 strokes per year. Nine out of 10 Canadians has at a least one risk factor for heart disease or stroke. While strokes continue to be most common in individuals over the age of 70 years, data now indicate an increased incidence in younger people. In the last 10 years, the number of strokes affecting people in their 50s has increased by 24 per cent, and for individuals in their 60s, the incidence has increased by 13 per cent. This disturbing trend is expected to continue, with an anticipated doubling of strokes among those between ages 24 and 64 in the next 15 years.¹

Within the Canadian population, stroke is identified as the leading cause of adult neurological disability and the third leading cause of death. For every 100 people in Canada who have a stroke, 15 will die, 10 will experience a full recovery, 25 will recover with a minor impairment or disability, 40 will have residual moderate to severe impairments and 10 will have such severe impairments that they will require long-term care. Individuals who have experienced a stroke also have a 20 per cent chance of having another stroke within two years.²

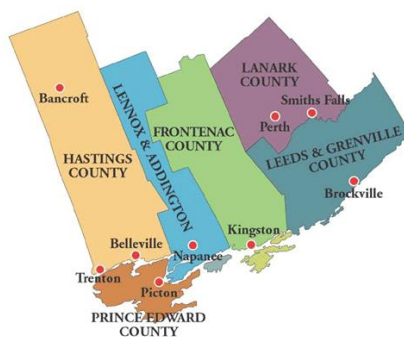
¹ Heart and Stroke Foundation, June 2014

² Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute). MOHLTC and Health Quality Ontario February 2015

Southeastern Ontario Perspective

In Ontario, an estimated 173,000 stroke survivors are living with a disability.³ With respect to southeastern Ontario, according to data derived from the Canadian Institute of Health Information (CIHI), in fiscal 2014/15 there were 1,232 unique visits to Emergency Department in this region for stroke. According to information from the South East Local Health Integration Network (SE LHIN) Data Centre, sourcing self-reports from the Canadian Population Health Survey, approximately 6,800 individuals (age 12 years and older) are living with the effects of stroke in the southeast. Of these, 3,500 are women and 3,300 are men. Of the 6,800 in total, 4,400 are ages 65 and older.

The Ontario Stroke Network (OSN) and the 11 Regional Stroke Networks, including the Stroke Network of Southeastern Ontario (SNSEO), are each guided by a vision of *Fewer Strokes. Better Outcomes* and a mission to continuously improve stroke prevention, care, recovery and reintegration across the continuum of care. Southeastern Ontario covers a large geographic area of approximately 20,000 square kilometers with a population of almost 500,000. (SE LHIN, *Health Care Tomorrow – Putting Patients First Integrated Health Services Plan 2016-2019*.) Health planning for the southeast region is the responsibility of the SE LHIN.



Map of Southeastern Ontario
Note: Red dots indicate hospital locations

Within southeastern Ontario, the Kingston General Hospital is the designated Regional Stroke Centre and the Belleville General Hospital (Quinte Healthcare Corporation) is a designated District Stroke Centre. Acute Stroke Units are located in Belleville, Kingston and Brockville. Inpatient rehabilitation units are located in these same three communities, as well as in Perth. Outpatient rehabilitation services are available in Kingston (partial), Belleville and Perth. Community-based rehabilitation services are available from the South East Community Care Access Centre (SE CCAC) for eligible clients either through the Enhanced Community-Based CCAC Rehabilitation Services for Stroke Survivors or through regular CCAC services. Private rehabilitation services are also available. There are four Stroke Prevention Clinics, located in Perth, Kingston, Belleville and Brockville. Additionally, the southeast has four facilitated Stroke Support Groups for stroke survivors and their caregivers, which are located in Perth, Belleville, Brockville and Kingston. These same four communities also have Stroke Specific Exercise Programs.

The majority of individuals living with the effects of stroke reside in a community setting, where the greater duration of their recovery journey occurs. For this reason, it is imperative that community-based supports and services are available and responsive to the needs of stroke survivors, as well as their caregivers.

³ Ontario Stroke Network, 2015

Context for Consultation on Community Reintegration

The SNSEO's 2015 community consultation follows a previous consultation process undertaken in 2007 across the southeast. Seven years ago, the community consultation also involved stroke survivors, caregivers and health care providers. Facilitated focus groups were held in six areas (Belleville, Brockville, Smiths Falls, Kingston, Napanee and Bancroft), followed

There is an evolving discussion with respect to the best phrasing to use when referring to an individual who is living with the effects of a stroke. For the purposes of this document, the term, "stroke survivor" will be used, but in no way is it intended to negate any preferred terms used by those who have experienced a stroke. Similarly, for the purposes of this document, the term "caregiver" will be used to denote family, friends and other informal (unpaid) care providers.

by one summative group consultation to validate preliminary findings. The results of that consultation process were contained in a report released in December 2007, *Building Capacity to Enhance Community Reintegration of People with Stroke*, [Building Capacity Report](#). The report identified six key directions that would help to support stroke survivors and caregivers as they reintegrated into the community. These six directions were:

1. System Navigation
2. Support in the Home
3. Support to Work Through the Emotions
4. Support for Recovery and Active Engagement
5. Access to Rehabilitation
6. Mobility in the Community

To provide a framework to move these directions forward, the Community Reintegration Leadership Team (CRLT) was formed, including stroke survivors, caregivers and health care providers. The CRLT had its initial meeting in March 2008, and has subsequently met three to four times each year to assess progress on the key directions, inform regional priorities and advise on projects/initiatives of the SNSEO.

Given the recent release of the [Clinical Handbook for Stroke \(Acute and Postacute\)](#) (February 2015, Ministry of Health and Long-Term Care) and given the time span since the 2007 consultation, the CRLT recommended that a new community consultation be initiated to validate and potentially modify or add to the key directions identified seven years ago. The 2015 consultation process would assist in identifying priorities for action in response to the Clinical Handbook. As well, progress had been made with respect to the original directions as evidenced in the CRLT [Biennial Update](#) providing further incentive for validation of the 2007 findings.

The 2015 community consultation once more incorporated the voices of survivors, caregivers and health care providers, and their responses yielded the recommendations detailed in this report for improving the reintegration of stroke survivors into the community.

Process:

The goal of the consultation was to hear survivor, caregiver and health provider voices, and to use their experiences of recovery as the basis to chart a course toward improved community reintegration.

The consultation process involved:

- focus groups comprised of stroke survivors and caregivers
- individual interviews with stroke survivors and caregivers, and
- an electronic survey of health care providers.

Participants were recruited using a multi-pronged approach that included media ads, referrals from health and community partners, and leveraging the regional Stroke Support Groups currently in place (Belleville, Brockville, Kingston and Perth). Seven focus groups were conducted in total and all were comprised of Stroke Support Group participants. Of the seven focus groups:

- four integrated stroke survivors and caregivers (one in Perth, one in Brockville, two in Belleville)
- one included only stroke survivors (Kingston)
- one included only caregivers (Kingston), and
- one was a couples group with stroke survivors and spouses (Kingston).

For the 13 individual interviews, participants variously included stroke survivors and caregivers (i.e., spouses, children, parents) and were conducted throughout the southeast, including in rural areas. All groups and interviews were facilitated by the Regional Community & Long Term Care Coordinator of the SNSEO and followed the same process as the focus groups, in that participants were invited to rank 30 statements about community reintegration following an information and consent component. After ranking the statements from most to least important, stroke survivor and caregiver participants were engaged in a facilitated discussion to support a greater understanding of their responses.

In the case of health care providers, the ranking of 30 statements about community reintegration was completed electronically as an attachment to an email. The email stated that participation in the survey indicated consent. Health care provider participants included Community Care Access Centre (CCAC) Care Coordinators and community-based providers (e.g. physiotherapists, occupational therapists, social workers, speech language pathologists, nurses, support group facilitators, stroke team members, Personal Support Workers (PSWs) and managers/supervisors). Additionally, a small number of rehabilitation providers responded from inpatient rehabilitation settings. One exception to the use of an electronic format for the health care provider component was a facilitated in-person session with community-based PSWs. This session included the ranking process only, due to agency-based time constraints (i.e. there was no supporting discussion or response to questions).

The consultation process was initiated in March 2015 and concluded in October 2015. The SNSEO dedicated additional time to ensuring that all efforts had been expended in recruiting a representative sample that included rural and urban areas, older and younger survivors and a mix of genders.

Methodology

The Q Sort method was used to collect information from participants regarding perceptions about community reintegration (Simons, J 2013; Montgomery, P. 2015; Mossey, S. 2012). Stroke survivors, caregivers and health care providers were invited to rank 30 statements about community reintegration. These statements were originally developed by a research team within the Northeastern Ontario Stroke Network (NEOSN), an aspect of their two-year, three-stage evaluative project of community reintegration (Montgomery et al. 2015).

In collaboration with the NEOSN researchers, the statements were modified to ensure issues identified in the 2007 southeast consultation process were included. Statements for caregivers differed slightly from those for stroke survivors to recognize their somewhat different perspectives. (Appendices B & C) Additionally, a decision was made to provide an electronic format of the Q Sort for health care providers to promote accessibility (Appendix D).

Each participating stroke survivor and caregiver was provided with 30 statement cards and a Q ranking template. Each statement card had one typed statement. Participants were asked to rank each of the 30 statements from least (or less) importance to most (or more) importance. Each of the 30 statement cards was placed within one of the 30 boxes on the Q template (an inverted pyramid grid), using the ranking system. For both the electronic and paper-based processes, only one statement (or corresponding statement number) could be placed on any one box and all statements had to be used.



Individual responses were necessarily in the context of the person's own experience (e.g. the severity and impacts of the stroke, the community, family and health supports received, the health of the caregiver, the length of time since the stroke and the recovery trajectory).

From the diversity of experiences and responses, the Q Sort methodology was able to distill common themes and, consequently, actionable priorities. Similar themes also evolved in the analysis of the supporting discussions. This

suggests that while the experience of each individual's stroke event and recovery may vary widely, there are commonalities that speak to system deficiencies and opportunities for change.

Following completion of the Q Sort process, structured questions were used to inform subsequent discussions and to provide a more in-depth understanding of participants' experiences with reintegration. The responses to each question were explored with respect to the relevant respondent groups: stroke survivors, caregivers and health care providers. Note that while stroke survivors and caregivers were asked to respond to all five questions, health care providers were only asked to respond to questions 1, 3 and 5 as these were seen to be most relevant for this respondent group.

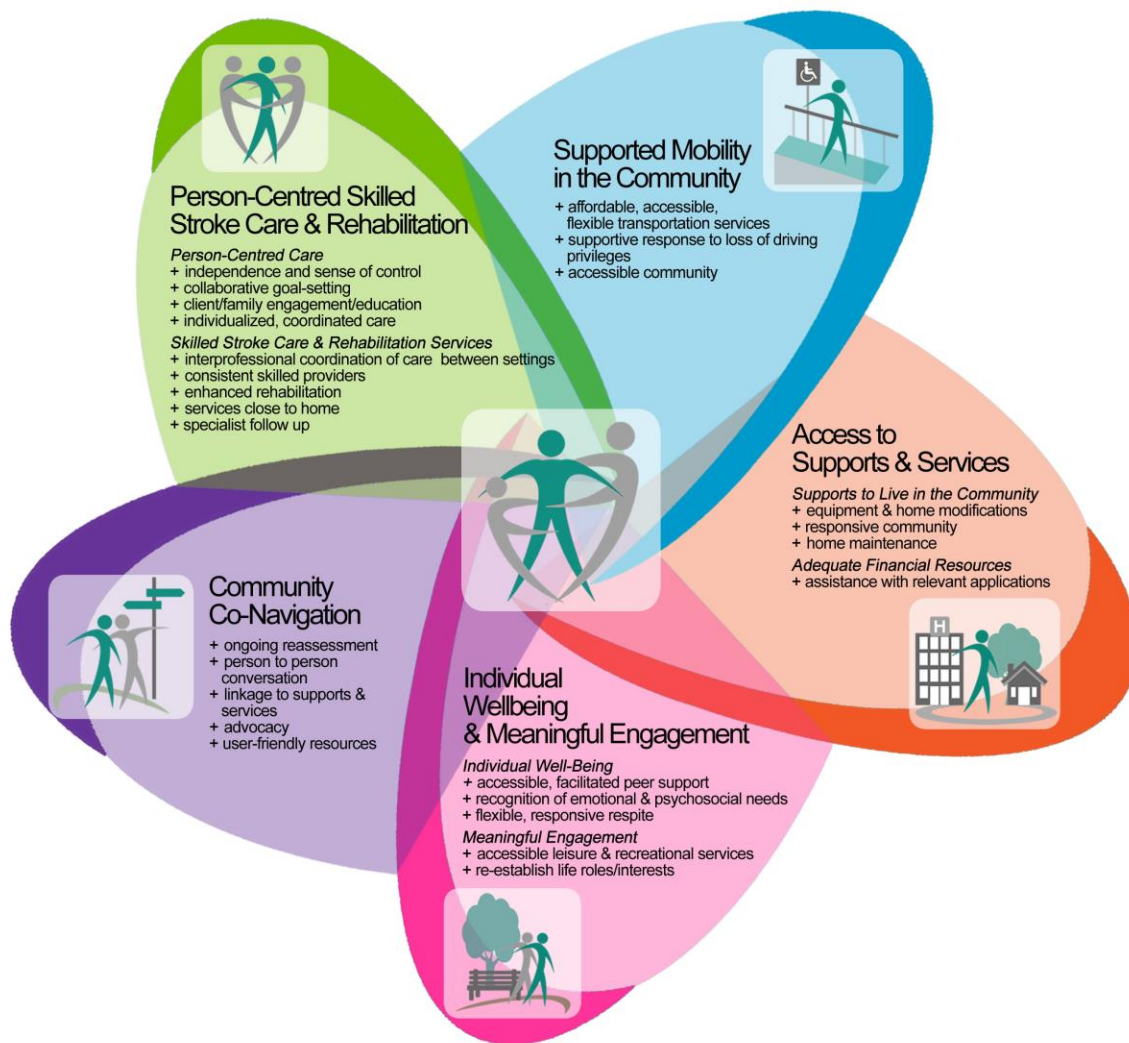
Discussion Questions

1. What made your most important areas so important?
2. Are/were these areas met when you returned to the community?
3. Are there any areas that are important to you that were not captured in this exercise?
4. What things/activities/people/organizations have most helped you reintegrate into the community?
5. What is the single most important thing you would like to see change to help persons who have experienced a stroke successfully reintegrate into the community?

Completed Q Sort templates were analyzed by researchers at Laurentian University, while discussion summaries were collated by the SNSEO team. Results were then integrated into a draft report and presented to the Community Reintegration Leadership Team for feedback on findings, and to inform the recommendations that emerged from the findings/themes. Draft recommendations were discussed by the Regional Stroke Steering Committee and finalized in 2016.

FINDINGS: WHAT STROKE SURVIVORS, CAREGIVERS AND PROVIDERS VALUE MOST

During the SNSEO’s wide-ranging consultation, stroke survivors and caregivers shared their personal experiences relating to community reintegration. Five key themes emerged from analysis of their feedback, and they signpost the way to improvements for stroke survivors. Essentially, the following five interconnected themes reflect the critical enablers of successful community reintegration following a stroke.





Theme 1: Person-Centred Skilled Stroke Care & Rehabilitation

a) Person-Centred Skilled Stroke Care

Responses clearly spoke to the need for person-centred care, supporting full involvement of stroke survivors and caregivers in all aspects of decision-making and care planning, as well as enabling them to direct and participate in care tasks. Integral to this is the concept of collaborative goal-setting, in which stroke survivors actively help identify targets for recovery and rehabilitation, and share their objectives, what is important to them, and what constitutes a driving force for recovery. To support involvement, stroke survivors and caregivers want to receive relevant educational supports.

Participants spoke to the need for skilled care at the right time from the right person, using an approach that respects their needs and preferences. Further, it is critical that all care is individualized to each person and situation, versus standard categorization into predetermined paths or ‘boxes,’ and that there’s effective coordination of the multiple providers involved in supporting the recovery journey.

- | |
|--|
| <p>KEY FACTORS</p> <ul style="list-style-type: none">• independence and sense of control• collaborative goal-setting• client/family engagement/education• individualized, coordinated care |
|--|

b) Skilled Stroke Care & Rehabilitation Services

Participants spoke of the need for continuity of care, including information across settings (i.e. progress towards goals). This concept is further defined by their expressed need for interprofessional coordination of care where disciplines and organizations work collaboratively to share information such as care plans, client preferences and visit schedules to enhance efficiency and effectiveness and reduce duplication.

At the same time, stroke survivors and caregivers want to have providers skilled in stroke care across the spectrum of disciplines (professional and para-professional). There is also a clear call for enhanced rehabilitation services that are more intensive and last for a longer period of time in recognition of the extended (sometimes life-long) recovery journey experienced by many stroke survivors.

Given the largely rural nature of Southeastern Ontario, it is not surprising that participants are also looking for more community services closer to home. For stroke survivors and caregivers, distance to services creates barriers with respect to cost, lack of accessible transportation, inclement weather and time in transit, with the associated fatigue.

As well, respondents wanted access to specialist follow-up care: to be seen by a practitioner skilled in stroke care, rather than a generalist who may not be as well-versed in post-stroke sequelae and associated care needs.

- | |
|--|
| <p>KEY FACTORS</p> <ul style="list-style-type: none">• interprofessional coordination of care between settings• consistent skilled providers• enhanced rehabilitation• services close to home• specialist follow-up |
|--|

A SURVIVOR'S VOICE

"Involvement in decision-making is important. I've gone through a life-changing event, and I want to continue to be a driving force in where my life is going."

"I want a sense of control, someone who sees what I can do for myself and involves me in my care."

A CAREGIVER'S VOICE

"We need consistent, skilled providers with experience and high levels of expertise, including medical, psychological, and social support. It doesn't help the recovery to have different providers: providers need to be committed to the person and follow-up, with one person to coordinate services."

A HEALTH PROVIDER'S VOICE

"With consistent providers who are skilled at what they do, trust can be built, which allows for the ultimate working relationship between the stroke survivor and staff, who can assist the survivors in reaching their full potential."



Theme 2: Individual Well-Being & Meaningful Engagement

a) Individual Well-Being

Participants recognized and personally experienced the diverse benefits of peer support through facilitated community support groups and/or through other peer support services such as peer visiting volunteers in hospital (both acute and rehab settings). The opportunity to interact with others who have experienced a similar life-changing event with its associated challenges is invaluable in terms of psychosocial support and navigation to connect to services.

At the same time, the consultation participants were disappointed with the limited social work/mental health services available within the Southeast, and many said that this component of stroke recovery (for the stroke survivor and caregiver) is both under-recognized and under-treated by providers.

KEY FACTORS

- accessible, facilitated peer support
- recognition of emotional/psychosocial needs
- flexible, responsive respite

Closely related to the need for emotional support is the need for respite services that are flexible, responsive to the individual's needs and provided with greater frequency. Caregivers often provide 24/7 care, which is physically demanding and emotionally draining. Adequate respite is integral to maintaining their health and emotional well-being and, by extension, the health and well-being of the stroke survivor.

b) Meaningful Engagement

A common gap identified by respondents was the lack of accessible leisure and recreational services for stroke survivors, who often need adaptations to fully participate in programs. This is a pivotal component in effective

community reintegration, contributing to social, emotional and physical recovery, yet programs and services that can meet the needs of stroke survivors are often lacking, especially in rural areas.

KEY FACTORS

- accessible leisure and recreational services
- re-establish life roles/interest

At the same time, stroke survivors and caregivers are faced with the emotionally-charged task of re-establishing life roles and interests given that the stroke may have resulted in changed family dynamics, as well as altered vocational and domestic roles. Supports and interventions from various disciplines including counseling (e.g. social work, psychotherapy), speech-language pathology, physiotherapy, occupational therapy, recreation therapy and others can help people to adapt successfully.

A SURVIVOR'S VOICE

"I need help to adapt to my new life."

A CAREGIVER'S VOICE

"I need adequate support, and also time away to do personal things. It's important for both of us."

A HEALTH PROVIDER'S VOICE

"There's so much focus on the physical aspect versus the emotional/social piece. Survivors need the physical fairly close to the stroke event, but further out, they need the emotional/social support."



Theme 3: Community Co-Navigation

Participants felt that there is a lack of follow up, especially in the longer term, yet stroke survivors derive significant benefit from intermittent assessments of changing needs, monitoring deterioration or improvement, and from connecting to the relevant care service (e.g. rehabilitation). Universally, they require more support when navigating the complex and evolving health and social support systems. The preference is to have a personal connection to a knowledgeable, accessible individual versus a paper resource, so that individual needs are assessed and addressed in a timely manner.

KEY FACTORS

- ongoing reassessment
- person-to-person conversation
- linkage to supports and services
- advocacy
- user-friendly resources

Supplementing this, access is needed to user-friendly resource directories in various modalities including web-based and mobile applications. Similarly, the need was expressed for advocacy to support accessing supports and services, influence system change and, at a practical level, provide assistance to retrieve and complete relevant applications.

A SURVIVOR'S VOICE

"One central person to go to is needed, someone to coordinate things and know what's available. You find out by yourself, but it takes a little while. It's frustrating."

A CAREGIVER'S VOICE

"He was discharged with one sheet of paper that had his list of medications on it, and that was all. There was no information package. Everything I've tapped into has been through my own research. I have been the one to find and reach out to programs."



A HEALTH PROVIDER'S VOICE

"Stroke survivors need a capable and knowledgeable person to help them navigate the resources available in their communities. It is the old scenario: You do not know what you do not know. This person needs to be a consistent and long term resource to the stroke survivor. Someone that can be a contact even months or years from the time of the stroke, someone to navigate resources when the need exists."



Theme 4: Supported Mobility in the Community

Lack of supported mobility creates negative impacts relating to all of the other themes. Southeastern Ontario's rural nature means an accessible transportation system that responds to the needs of users, including support to access leisure and recreation programs (and not just services for medical appointments limited to weekday hours),

was important to respondents. The process for removal and reinstatement of driving privileges and the associated impacts to independence and emotional well-being on both the stroke survivor and the caregiver is another key topic. In addition, participants spoke to the need for improved accessibility in the community including fully accessible buildings, wheelchair-friendly sidewalks and accessible washrooms that are not gender-specific.

KEY FACTORS

- affordable, accessible, flexible transportation services
- supportive response to the loss of driving privileges
- accessible community

A SURVIVOR'S VOICE

"Transportation is important. If you have no driver's license then you're in trouble, as it really limits your freedom and independence and your capacity to join things."

"You feel like a burden to others when asking for transportation ... One of the biggest gifts I got was when a friend offered to take me out to breakfast. I had been a prisoner in my own home."



A CAREGIVER'S VOICE

"After his stroke, he lost his driver's license. What if my driver's license becomes compromised?"

A HEALTH PROVIDER'S VOICE

"We need to allow independence and choices around the plan of care, and to provide assistance with finances and travelling needs."



Theme 5: Access to Supports and Services

a) Supports to Live in the Community

Participants said adequate supports in the community were key, including equipment and home modifications to support stroke survivors' independence and mobility. As well, community awareness of stroke survivors, and responsiveness, helps as they

reintegrate. Respondents noted that a lack of understanding by the public about stroke and its impacts on the stroke survivor, individual and family especially with respect to cognitive, mobility and communication deficits contributes to social isolation and has negative impacts on psychosocial well-being.

From a practical perspective, participants said supports such as snow shoveling, meals on wheels, lawn care and housekeeping all enhance their ability to remain in the community.

KEY FACTORS

- equipment and home modifications
- responsive community
- home maintenance

A SURVIVOR'S VOICE

"I need a provider to help me return to work, leisure and volunteer activities—doing what I love to do—and activities and interests are unique to each individual depending on the impairment."

A CAREGIVER'S VOICE

"Practical help is important. This is new to me—I have never been involved with someone who had a stroke before."

A HEALTH PROVIDER'S VOICE

"The very limited funding programs available to assist clients with obtaining the equipment, mobility devices and activities of daily living/ instrumental activities of daily living aids that they require even through local loan equipment services."



b) Adequate Financial Resources

While financial resources varied greatly among individuals, there was consistent recognition of the negative financial impacts that often result from a stroke: loss of employment for stroke survivors, decreased employment hours for caregivers as they shift to providing care to the stroke survivor; home modification and equipment needs, which can be expensive; and supplementing publicly funded care services. Further complicating the financial

situation are complex and multi-step processes often necessary to access financial services, even if there is an awareness of available supports.

KEY FACTORS

- assistance with relevant applications

A SURVIVOR'S VOICE

"You suddenly can't go to work, have decreased money, and the bills are coming in and your credit is gone. You can't find out whom you should talk to. You have to learn to survive on that little bit of money."

A CAREGIVER'S VOICE

"Going from two incomes to one has huge impacts."

Please see Appendix G for more information on themes, questions and detailed quotes and responses from stroke survivors, caregivers and health care providers and also for supporting materials about what the research literature says.

THE SNSEO'S RECOMMENDATIONS: STEPS TOWARD BETTER COMMUNITY REINTEGRATION

The following SNSEO recommendations for improving services and supports for reintegration after a stroke focus on: enhancing services; building linkages and connections; supporting services with tools and resources; and providing education and raising awareness.

Detailed recommendations emerged from data collected during this community consultation, in which five key themes emerged, underlining where efforts to support stroke survivors and caregivers in successful community reintegration can have the most impact. These themes are:

1. Person-Centred Skilled Stroke Care & Rehabilitation
2. Individual Well-Being & Meaningful Engagement
3. Community Co-Navigation
4. Supported Mobility in the Community
5. Access to Supports & Services

The SNSEO's recommendations flow out of these five themes. Recommendations for change reflect consultation participants' views on what is most integral to successfully reintegrating into the community after a stroke. Recommendations were specifically worded in order to be actionable by the network.

STROKE NETWORK OF SOUTHEASTERN ONTARIO RECOMMENDATIONS

Person-Centred Skilled Stroke Care & Rehabilitation

- Provide feedback to CCAC regarding Enhanced Rehab Services:
 - integrating flexible rehabilitation plans to meet individualized needs
 - including capacity for accommodation in care planning for outliers
 - increasing awareness of need for Discharge Link meetings to facilitate continuity of care from inpatient to outpatient to community.
- Support transition from inpatient to community programs
- Support providers with tools and resources for collaborative planning, education and decision-making with client & family
- Continue to optimize the reach of facilitated support groups. Advocate for funding for continued outreach and expansion of groups in urban settings to recognize therapeutic group size.
- Support person-centred care through interprofessional education for providers in community, long term care and other settings (e.g. primary care)
- Support the value of ongoing reassessments to identify changing needs and linking to appropriate resources/supports

Individual Well-Being & Meaningful Engagement

- Raise awareness among health care providers of:
 - the role of Recreation Therapists in supporting individual well-being and meaningful engagement through assessment and treatment. Explore potential partnerships between LTC and community settings to leverage the existing expertise of LTC recreation therapy.
 - the need to provide flexible, responsive respite that meets the needs of client and caregiver
 - the need for Social Work and mental health services throughout the journey to provide emotional support
 - the need for practical assistance to access/apply for financial supports and services
- Support stroke specific and other exercise programs that integrate persons living with the effects of stroke through linkages with physiotherapists with neuro expertise and other educational resources.
- Support linkages between inpatient and community recreation/leisure services
- Build linkages within and across local community services
- Promote linkages as appropriate to resources/services to support a return to work or school (e.g. social work, occupational therapy)
- Raise awareness of the benefits of vocational rehab services

Community Co-Navigation

- Increase awareness of and linkage to rehab supports & services by health care providers to optimize independence
- Develop tools and resources for a discharge planning process that includes supported links to recreational/leisure opportunities as well as support groups
- Support health providers in the provision of consistent caregiver education to provide knowledge and skills for self-efficacy
- Implement a strong, consistent link and referral process from hospital to community support groups
- Investigate provincial/regional navigation models and regional Health Link Coordinator role and how the SNSEO can support stroke-specific training for navigators/coordinators

Supported Mobility in the Community

- Implement provider education to elevate awareness of the psychosocial impacts of the loss of driver's license after stroke
- Investigate alignment with Older Adult Strategy and stroke-relevant supports and services
- Raise awareness of the need for affordable, accessible transportation options and the need for building age-friendly & stroke survivor friendly communities

Access to Supports & Services

- Help to develop tools (e.g. regional 'trigger tool') to assist providers in assessing the changing needs of the stroke survivor and caregiver and linking to appropriate supports. Tool to include information about financial programs to support adaptations and equipment for living successfully in the community. Continue to promote use of Stroke Resources & Vascular Health microsites on SE Healthline.
- Explore *Return to Work Toolkit* (SWO Stroke Network) and potential application/modifications for the southeast
- Promote the Belleville Communication Support Group and advocate for sustained funding. Advocate for regional expansion, outreach and funding support of Communication Support Groups.

Overarching Recommendations

- Execute a comprehensive communication strategy for care providers, health facilities, social services and municipalities that raises the profile of the *Community Reintegration Consultation Report* through dissemination of the report at provincial and regional workshops, conferences, webinars and other educational opportunities.
- Provide stroke-specific education for Health Link Coordinators, CCAC Care Coordinators and care providers in community, primary and preventative care settings to support linkages to appropriate resources and services

FUTURE CONSIDERATIONS AND CHALLENGES

Going forward, there are considerations that merit further exploration for improving community reintegration after a stroke. These include:

1. Recognizing the increasing numbers of younger stroke survivors
2. Responding to the needs of individuals living with communication deficits
3. Responding to the special needs of Long-Term Care residents who have experienced a stroke and their caregivers
4. Engaging survivors and caregivers not currently participating in support groups
5. Assessing the impact of health system changes on the need for supported transitions and co-navigation
6. Engaging stroke survivors and caregivers within the Indigenous population

1. Recognizing the increasing numbers of younger stroke survivors

While recruitment efforts for the study were multidimensional, it remained challenging to ensure a representative sample from all stroke populations. The SNSEO would have liked to have a broader representation from working-age adults to more fully understand the challenges within this group. Participants did speak to the financial impacts felt when the stroke survivor (and, in some cases, the caregiver) was unable to continue to work due to the residual impacts of the stroke (or associated caregiver responsibilities).

Many younger stroke survivors may have subtle cognitive changes that affect their ability to return to work and persisting subtle cognitive changes may not be recognized. A younger stroke survivor may return to work but may not be performing well or perhaps not be performing as well as he or she did previously. Since it is anticipated that the age of individuals experiencing a stroke will continue to decrease (and adults are retiring later), it may be assumed that vocational impacts will assume a greater focus in the community reintegration paradigm, yet vocational rehabilitation is noted as a significant gap in our publically funded system. As well, with working-age stroke survivors, the family context is often different with parental roles still being a critical component of daily activities. The current model of social work for stroke survivors may need to be adjusted in recognition of a different demographic and the associated challenges.

2. Responding to the needs of individuals living with communication deficits

There was limited participation from stroke survivors with moderate to severe aphasia. In a few of the individual interviews, aphasic stroke survivors did participate with their caregivers, but it was typically the caregiver who actually provided responses on behalf of the stroke survivor due to the communication challenges. Literature tells us that aphasia can have a significant impact on quality of life, social integration and relationships with family and friends. Davidson et al (2008) described language as the “currency” of relationships and found that the capacity to form and maintain social relationships impacts on emotional wellbeing as well as mortality rates and health outcomes. The reduction in social relationships has a domino effect, increasing the risk for depression, and depression then results in increased social isolation. At the same time, stroke survivors with aphasia will often rely

on their caregiver and other family members to fill that social relationship gap, with the consequence that the caregivers assume yet more responsibility. This then can negatively impact their health. Hilari et al (2015) recommended that stroke survivors who have aphasia “need long-term service provision that takes into account their affected mood. Such service provision should aim to target participation and quality of life through community-based interventions, e.g. participation in personally relevant meaningful activities.”

3. Responding to the special needs of Long-Term Care residents who have experienced a stroke and their caregivers

Long-Term Care (LTC) settings are viewed as a resident’s home and are therefore often categorized as community. While the consultation did evoke some comments on the LTC component of stroke care and the challenges of transitioning to LTC, the focus of discussions was on stroke survivors and caregivers who were residing in homes outside of a LTC setting. For this reason, the LTC population that has experienced a stroke merits further exploration as their needs and challenges as well as those of their caregivers may be quite different.

4. Engaging survivors and caregivers not currently participating in support groups

The focus groups were derived from existing Stroke Survivor & Caregiver Support Groups, and therefore responses would be expected to reflect the value of the groups. However, it should also be noted that participant responses during individual interviews also spoke to the need to interact with others who were on similar recovery and life journeys. There would be merit in exploring why individuals elect not to participate in support groups, where and how they receive similar supports and other models of community-based support that may be of value.

5. Assessing the impact of health system changes on the need for supported transitions and co-navigation

There are growing pressures on hospital resources. All patients benefit from the opportunity to receive the right care at the right time in the right place. Health system changes emphasize the need for supported transitions and co-navigation with heightened emphasis on care coordination and support for making effective connections to community services. Reduced hospital lengths of stay and changes in acute and rehabilitation hospital staffing models translate into a greater and earlier need for community care. An example would be decreased hospital resources for Social Workers, Discharge Planners, and Recreation Therapists necessitating greater community support for community reintegration. An exploration of how these changes are impacting on stroke survivors and caregivers reintegrating into the community as well as how community agencies are able to respond to these changes would be of benefit.

6. Engaging stroke survivors and caregivers within the Indigenous population

The needs of stroke survivors and caregivers within the Indigenous population warrants a more focused exploration to ensure that programs and services reflect their needs and distinct culture. Engaging with stroke survivors, caregivers and community leaders to discuss how best to collaboratively provide these supports would enable the SNSEO and the broader health & social support system to respond effectively. This is of particular importance given the disproportionate rate of stroke (and related vascular diseases) within the Indigenous population.

DISCUSSION: WHAT'S NEXT?

The Stroke Network of Southeastern Ontario (SNSEO) will use the findings and recommendations emerging from this report to help drive regional priorities and influence local change. Specifically, the SNSEO will integrate the report's recommendations into the SNSEO Regional Stroke Workplan for 2017 onward; and report on workplan progress to both the Community Reintegration Leadership Team (CRLT) and Regional Stroke Steering Committee (RSSC). These two committees serve to ensure the accountability of the SNSEO in responding to the findings of this report and to moving the recommendations forward into actionable priorities.

It is telling that the responses from stroke survivors, caregivers and health care providers derived from this consultation echo recommended best practices for stroke care as well as priorities for change identified in local and provincial health planning documents.

This report's findings and recommendations are supported by evidentiary best practice recommendations found in such seminal documents for stroke care as: *Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute)* (2015), and *Canadian Stroke Best Practice Recommendations* (2013). Alignment with the Ministry of Health & Long-Term Care (MoHLTC) discussion paper, *Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario* (2015), *Ontario's Action Plan for Seniors* (2013), *The Older Adult Strategy* (2015) and the South East LHIN's *Integrated Health Services Plan 2016-2019* (IHSP4) is also clearly evident and is illustrated in Appendix G. There is also abundant research supporting the results and recommendations and links to relevant research may be found in Appendix F.

There seems to be universal agreement on what is needed to improve the outcomes and experiences of stroke survivors and caregivers reintegrating into the community; however the daunting challenge is in the implementation of broad system change to support the specific actions emerging from this report. There is a need for collaboration and communication between Ministries (e.g. health and social service ministries) and between Ministries and municipalities. Substantial change may also require a broad cultural shift in how care is defined and delivered, and how patient-centred care can actually be driven by the users of the system (i.e. stroke survivors and caregivers).

It is imperative that the valuable information so willingly shared during this consultation by those who are living with the experience of stroke and those involved in the provision of care and supportive services stimulates a collaborative 'call to action' to improve community reintegration for survivors and their caregivers.

APPENDIX A

COMMUNITY REINTEGRATION LEADERSHIP TEAM MEMBERSHIP

NAME	ROLE
Deborah Bowes	Person with Lived Experience LLG
Dan Brouillard	Person with Lived Experience KFLA
Gwen Brown (Chair)	Regional Community & LTC Coordinator, Stroke Network of Southeastern Ontario
Patti Dixon-Medora	Manager, Client Services, Hospital Access, South East Community Care Access Centre
Shelley Huffman	Regional Rehab Coordinator, Stroke Network of Southeastern Ontario
Greg Killough	Health Promotion Specialist, Eastern Ontario, Heart & Stroke Foundation
Sandra Kioke	Long Term Care Best Practice Coordinator, South East LHIN 10, Registered Nurses Association of Ontario
Lee Marchildon	Stroke Services Coordinator/Volunteer Coordinator, Community Care for South Hastings Inc.
Cally Martin	Regional Director, Stroke Network of Southeastern Ontario
Shannon McCallum	ABI System Navigator. Southeast Ontario, Community Brain Injury Services
Bonnie Molinski	District Stroke Coordinator, Quinte Health Care
Kathleen Pratt	Stroke Services Coordinator, VON Greater Kingston Site
Jennifer Rider	Person with Lived Experience KFLA
Dorothy Ritchie	Person with Lived Experience LLG
Beth Steinmiller	Director of Clinical Services, Quinte & District Rehabilitation Inc.
Patty Tye	Health Promoter, Stroke/Caregiver Support, Community & Primary Health Care Lanark, Leeds and Grenville
Florence Whiten	Person with Lived Experience HPE

APPENDIX B

STROKE SURVIVOR STATEMENTS – Q SORT

1	Having a provider who helps me plan to reach my goals.
2	Having a provider who sees what I can do for myself and involves me in my care.
3	Having a provider who recognizes and responds to my emotional needs.
4	Having consistent providers who are skilled in what they do.
5	Having a provider help me to connect with and coordinate the services required to meet my needs.
6	Having a provider who can help me to get available financial supports (e.g. disability, tax credits, veterans' affairs).
7	Having a provider who understands and respects my personal choices and beliefs.
8	Having a provider who "checks-in" with me.
9	Having a provider visit me in my home.
10	Having a provider assist me by telephone.
11	A sense of control.
12	Involvement in decision making about my life.
13	Having a provider who communicates well with others.
14	Getting the right care at the right time.
15	Having clear information.
16	Getting services, equipment and supplies in a timely manner.
17	Getting help to adapt to my "new life".
18	Having a provider who can assist me with a return to work, school, leisure and volunteer interests.
19	Opportunities to think about and express my needs.
20	Involvement with others who have had a stroke.
21	Help for me to explain the effects of my stroke to others.
22	Recognition of successes and hopes for my future.
23	Adequate financial resources.
24	Receiving the practical assistance needed to remain at home (e.g. meal preparation, snow removal).
25	Having adequate support for my family including time away (respite).
26	Having transportation to do what is needed or wanted.
27	Being active to build energy and strength.
28	Having family members involved in my care and my life.
29	Being with people I enjoy spending time with.
30	Doing what I love to do

APPENDIX C

CAREGIVER STATEMENTS – Q SORT

1	Having a provider who helps my loved one with their goal planning.
2	Having a provider who sees what my loved one can do and involves them in their care.
3	Having a provider who recognizes and responds to our emotional needs.
4	Having consistent providers who are skilled in what they do.
5	Having a provider help us to connect with and coordinate the services required to meet our needs.
6	Having a provider who can help us to get available financial supports (e.g. disability, tax credits, veterans' affairs).
7	Having a provider who understands and respects our personal choices and beliefs.
8	Having a provider who "checks-in" with us.
9	Having a provider visit us in our home.
10	Having a provider assist us by telephone.
11	A sense of control.
12	Involvement in decision making about our lives.
13	Having a provider who communicates well with others.
14	Getting the right care at the right time.
15	Having clear information.
16	Getting services, equipment and supplies in a timely manner.
17	Getting help to adapt to our "new life".
18	Having a provider who can assist my loved one return to work, school, leisure and volunteer interests.
19	Opportunities to think about and express our needs.
20	Involvement with others who have had a stroke and those who are caring for them.
21	Help to explain the effects of the stroke to others.
22	Recognition of successes and hopes for our future.
23	Adequate financial resources.
24	Receiving the practical assistance needed to remain at home (e.g. meal preparation, snow removal).
25	Having adequate support including time away (respite).
26	Having transportation to do what is needed or wanted.
27	Being active to build energy and strength.
28	Being involved in the care and life of the person with stroke
29	Being with people I enjoy spending time with.
30	Doing what I love to do

APPENDIX D

HEALTH CARE PROVIDER STATEMENTS, Q SORT SURVEY

COMMUNITY REINTEGRATION OF PERSONS WITH STROKE Q STATEMENT SURVEY

Before you begin the survey, please tell us:

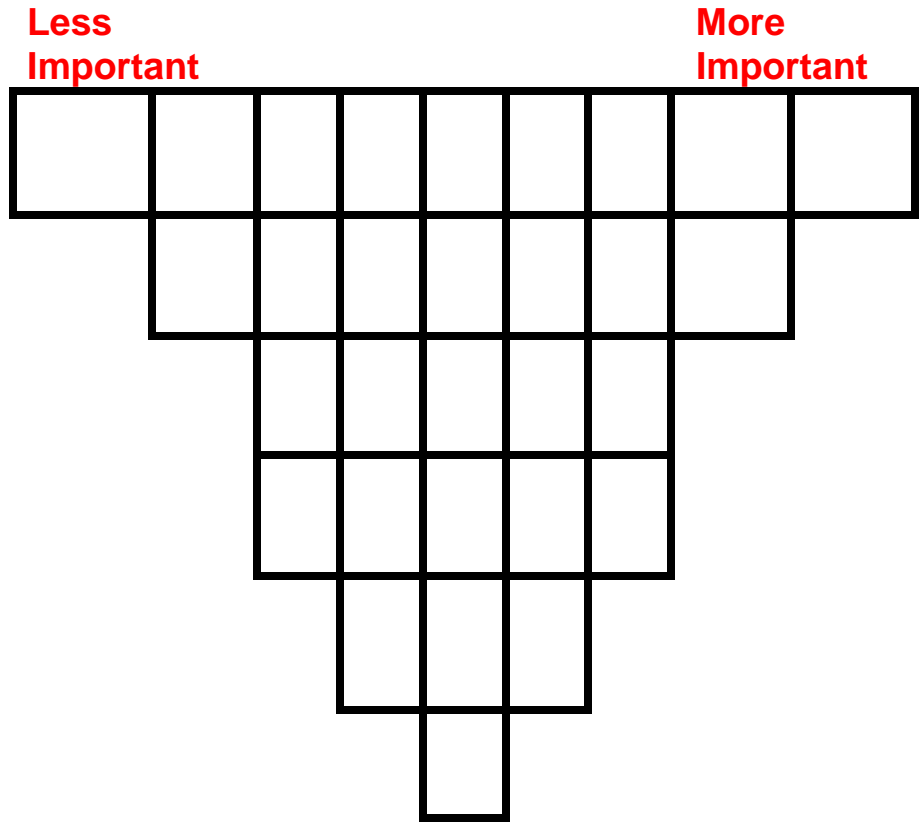
- a) The county or counties you work in (e.g., Lanark, Kingston, Hastings)

- b) Your role (e.g., Care Coordinator, Supervisor, Direct Care Provider)

- c) Your discipline (e.g., RN, PSW, SW, OT, PT, SLP)

Survey Instructions: You will find 30 important statements listed in random order below that support the community reintegration of stroke survivors. You are asked to rank these statements from less important (left side of diagram) to more important (right side of diagram). **Do not worry about vertical ranking.** Rank the statements according to what YOU believe is more (and less) important for the community reintegration of stroke survivors. Place the number for the corresponding statement into the appropriate box - there must only be **ONE NUMBER PER BOX**. To ensure you do not repeat numbers, cut and paste the number from **Column B** into the diagram. There are no right or wrong answers. There are three additional questions following the survey. While these questions are optional, any information you could provide would be appreciated and would add to our understanding of what supports community reintegration following stroke. Once you have completed the survey, please save and return as an attachment to Gwen Brown at browng2@kgh.kari.net. Alternately, you may choose to print the survey and return by fax to 613-548-2454, Attention Gwen Brown or by mail to Gwen Brown, Stroke Network of Southeastern Ontario, Kingston General Hospital, 76 Stuart St. Watkins 3 Room 4-3-401, Kingston ON, K7L 2V7. Thank you.

A		B
1	Having a provider who helps me plan to reach my goals.	1
2	Having a provider who sees what I can do for myself and involves me in my care.	2
3	Having a provider who recognizes and responds to my emotional needs.	3
4	Having consistent providers who are skilled in what they do.	4
5	Having a provider help me to connect with and coordinate the services required to meet my needs.	5
6	Having a provider who can help me to get available financial supports (e.g. disability, tax credits, veterans' affairs).	6
7	Having a provider who understands and respects my personal choices and beliefs.	7
8	Having a provider who "checks-in" with me.	8
9	Having a provider visit me in my home.	9
10	Having a provider assist me by telephone.	10
11	A sense of control.	11
12	Involvement in decision making about my life.	12
13	Having a provider who communicates well with others.	13
14	Getting the right care at the right time.	14
15	Having clear information.	15
16	Getting services, equipment and supplies in a timely manner.	16
17	Getting help to adapt to my "new life".	17
18	Having a provider who can assist me with a return to work, school, leisure and volunteer interests.	18
19	Opportunities to think about and express my needs.	19
20	Involvement with others who have had a stroke.	20
21	Help for me to explain the effects of my stroke to others.	21
22	Recognition of successes and hopes for my future.	22
23	Adequate financial resources.	23
24	Receiving the practical assistance needed to remain at home (e.g. meal preparation, snow removal).	24
25	Having adequate support for my family including time away (respite).	25
26	Having transportation to do what is needed or wanted.	26
27	Being active to build energy and strength.	27
28	Having family members involved in my care and my life.	28
29	Being with people I enjoy spending time with.	29
30	Doing what I love to do	30



OPTIONAL QUESTIONS

1. What made your most important areas so important?
2. Are there any areas that are important that were not captured in this exercise?
3. What is the **single** most important thing you would like to see change to help persons who have experienced a stroke successfully reintegrate into the community?

APPENDIX E

Q SORT ANALYSIS

Analysis of the Q Sort was conducted using the three distinct participant streams—stroke survivors, caregivers and health care providers. For each participant stream, three themed areas were identified with each theme or factor comprising several Q Statements (i.e. the computer program combines statements that look alike and organizes them within a theme using rankings ranging from +4 to -4). For each of the themed areas, an overarching focus emerged when reviewing the statements included within that theme. It should be noted that not all of the completed Q Sorts were included in the analysis as the program selects those responses which best represent that participant group (e.g., 30 of the 43 Q Sorts completed by stroke survivors were included in the analysis). Other respondents were defined as outliers as their responses did not correspond to the general perceptions of that respondent grouping. At the same time, some respondents might be included in more than one theme. The ultimate purpose of the Q Sort is to identify what the respondents are thinking; what their perceptions are relative to community reintegration supports. The theme or factor titles are then derived from the collective meaning of the ratings (positive, negative and neutral). The Q Sort tables include statements that achieved rankings of +4, +3, +2, -2, -3 and -4. Statements receiving middle rankings were excluded to support ease of interpretation.

STROKE SURVIVOR Q SORTS (n=30/43)

The three Q Sort tables for stroke survivors highlighted the themes of:

- Person-Centred Skilled Stroke Care & Rehabilitation
- Individual Well-Being & Meaningful Engagement
- Community Co-Navigation

Table 3 - Person-Centred Skilled Stroke Care & Rehabilitation

Item	Ranking
A sense of control	4
Having clear information	2
Receiving the practical assistance to remain at home (meal preparation, snow removal)	2
Recognition of successes and hopes for my future	-2
Help for me to explain the effects of my stroke to others	-2
Having a provider assist me by telephone	-2
Having adequate support for my family including time away (respite)	-3
Having a provider who checks-in with me	-3
Having family members involved in my care and my life	-3

Table 4 - Individual Well-Being & Meaningful Engagement

Item	Ranking
Having family members involved in my care and my life	4
Being with people I enjoy spending time with	3
Doing what I love to do	3
Having a provider who recognizes and responds to my emotional needs	2
Getting help to adapt to my "new life"	-2
Having a provider assist me by telephone	-3
Having a provider who can help me to get available financial supports (e.g. disability, tax credits, veterans affairs)	-4

Table 5 - Community Co-Navigation

Item	Ranking
Getting help to adapt to my "new life"	4
Getting services, equipment and supplies in a timely manner	3
Having consistent providers who are skilled in what they do	2
Being active to build energy and strength	-2
Having a provider who recognizes and responds to my emotional needs	-2

CAREGIVER Q SORTS (n=17/24)

The three Q Sort tables for caregivers highlighted the themes of:

- Access to Supports & Services
- Individual Well-Being & Meaningful Engagement
- Person-Centred Skilled Stroke Care & Rehabilitation

Table 6 - Access to Supports & Services

Item	Ranking
Having adequate support including time away (respite)	3
Adequate financial resources	2
Having a provider who understands and respects our personal choices and beliefs	-3
Having a provider who "checks-in" with us	-4

Table 7 - Individual Well-Being & Meaningful Engagement

Item	Ranking
Doing what I love to do	3
Involvement in decision making about our lives	2
Having a provider who sees what my loved one can do and involves them in their care	-2
Having a provider visit us in our home	-3
Having adequate support including time away (respite)	-3

Table 8 - Person-Centred Skilled Stroke Care & Rehabilitation

Item	Ranking
Being involved in the care and life of the person with stroke	4
Having consistent providers who are skilled in what they do	3
Having a provider who helps my loved one with their goal planning	3
A sense of control	2
Getting the right care at the right time	2
Doing what I love to do	-2
Being with people I enjoy spending time with	-2
Adequate financial resources	-3

HEALTH CARE PROVIDER Q SORTS (n=25/40)

The three Q Sort tables for health care providers highlighted the themes of:

- Individual Well-Being & Meaningful Engagement
- Person-Centred Skilled Stroke Care & Rehabilitation
- Community Co-Navigation

Table 9 - Individual Well-Being & Meaningful Engagement

Item	Ranking
Involvement in decision making about my life	4
A sense of control	3
Doing what I love to do	3
Having a provider who sees what I can do for myself and involves me in my care	2
Having consistent providers who are skilled in what they do	-2
Having a provider who can assist me with a return to work, school, leisure and volunteer interests	-2
Having a provider assist me by telephone	-2
Getting help to adapt to my "new life"	-2
Having a provider who communicates well with others	-3

Table 10 - Person-Centred Skilled Stroke Care & Rehabilitation

Item	Ranking
Having a provider who helps me plan to reach my goals	4
Having a provider who sees what I can do for myself and involves me in my care	3
Having adequate support for my family including time away (respite)	-2
Adequate financial resources	-2
Being with people I enjoy spending time with	-3
Doing what I love to do	-3

Table 11 - Community Co-Navigation

Item	Ranking
Receiving the practical assistance needed to remain at home (e.g. meal preparation, snow removal)	4
Adequate financial resources	3
Having a provider help me to connect with and coordinate the services required to meet my needs	3
Getting services, equipment and supplies in a timely manner	2
A sense of control	2
Having a provider who can help me to get available financial supports (e.g. disability, tax credits, veterans affairs)	2
Doing what I love to do	-2
Having a provider who recognizes and responds to my emotional needs	-2

APPENDIX F

WHAT PARTICIPANTS AND THE RESEARCH SAY: DETAILED RESPONSES BY GROUP/QUESTION, WITH SUPPORTING EVIDENCE

The results of the discussion questions are explored using the five identified themes.



PERSON-CENTRED SKILLED STROKE CARE & REHABILITATION

THE SURVIVOR'S VOICE

- *As soon as I had the stroke then most decisions were out of my hands so involving me in that decision making gave me a sense of control. [I was] feeling very helpless, no one advocating for me at the time as no partner or family member and if no one there to advocate for you then tough.*
- *Involvement in decision making was important. I was going through a life changing event. I felt I had dictated to life up to that point and want to continue to be driving force in where my life is going.*
- *I want to know what's going on and why things are being done to me. I need a sense of control. I did a lot of reading and learned – [spouse] gets mad if I like to do [a task] – he'll say let me do this because he wants to help - we both like to have a sense of control.*
- *Most women work and take care of the home and take care of their husband – they had a lot of control over decisions – bothers me that I'm not there any more – I have to sit and listen to what others say.*
- *Involvement in decision making versus being told what I can and can't do. I need to be involved in it, have a sense of control.*
- *I need providers to see what I can do. I resent it deeply when people just jump to conclusions, thinking there are things I can't do anymore. Let me try first and see if I can do it myself.*
- *I need a sense of control of my life. I live on my own so have to take care of all the financial needs and looking after the house and am still responsible for my husband. He is in a nursing home, but I am his voice, his decision maker.*
- *Just being involved in my care and having the provider see what I can do for myself – not having people say “let me do that for you” – lost use of right hand and ataxia but hung that clock – just putting that nail in the wall with the hammer– years ago I could do things without thinking but now it requires real concentration, have to think about what you're going to do*
- *Sense of control – feel helpless, fully dependent on other people and nobody likes that kind of feeling*
- *Heard a speaker from Queen's University talk about how many brain cells we lose after age 35 (100,000 a day) but also said there were still lots left and lots of unused*

- *Setting goals together very important. My goal was to walk again outside. I didn't need to be an expert, didn't need to do cartwheels but wanted a sense of mobility back and so goal was to work on this.*
- *I need a provider who involves me in care and goal-setting, assesses where I am and listens to where I want to be. The provider needs to be good with where I'm at and where I am going, they need to be very clear on what I need to work on and where there are possible deficiencies, need to look to the future. I want to be sure that I don't end up back in the hospital because I need a knee or hip replacement.*
- *Took me a long time in my mind before I asked the PT, "When do you think I can go home?" – PT asked me what I needed to be able to do before I could manage at home – we then collaboratively picked a discharge date – this gave me a goal*
- *Being active, having energy and strength. You need to grow to be able to go anywhere. If I don't get going then begin to feel low but if you do have energy you can go forward and avoid depression*
- *Important to have a chance to exercise your own interests as opposed to having them done for you – if I decide to eat out, would like that to be my own decision.*
- *Had a stroke three years ago and ...[now my] outlook has changed from one of victim to one of survivor*
- *Need to set goals and a schedule of how to achieve them, for example how many times walk to kitchen and back*
- *The more I can look after myself and the better I get, the less I need.*
- *Need encouragement...stroke survivors need to be encouraged to be independent.*
- *It's more important that the provider relates well with me versus communicating with each other.*
- *I want to be an advocate for stroke care*
- *Therapists think of me as the gadget lady as I create new things to help me at home. I manage to figure things out.*
- *I have only good things to say about community care I received*
- *When I came home from hospital I had therapists as long as I wanted*
- *I got the help I needed; the CCAC came and helped me. Best of all were my husband, children and grandchildren – my angel wings.*
- *Generally met but more services are going to be required*
- *To an extent they were met. I had CCAC and the PSWs were very good.*
- *Services that are needed are not always the ones provided*
- *Seldom had the same therapist in rehab*
- *There are discrepancies in care received. My daughter works in health care so she knew where I should be and so I had PT, OT and Rec Therapy, but this should be automatic.*
- *One lady had problems getting the health care provider to come at the proper time during the day and when she called, the coordinator told her that beggars can't be choosers.*
- *I was given rigorous physiotherapy when I was in the hospital and I enjoyed that but then it was just cut off when I was discharged.*
- *I was kicked out of [hospital] way too early. I went from not being able to get to bathroom or get dressed and being in a wheelchair to walking with a cane and sent out the door.*

- *I came home with a PICC line and was not told who would be removing it. I called [community provider] and they needed permission from hospital where it was inserted. Then had to go to [a local hospital] to get it removed. This should have been arranged before I came home; hospitals not linked.*
- *Needed to understand medications. Why on the meds and the dosage.*
- *[I feared] a second stroke. I was told that no one ever has just one stroke.*
- *[There is] value to day and weekend passes*

There was a great deal of discussion related to a sudden role reversal from decision-maker and 'doer' to a situation where the power dynamic had shifted and, with that shift, came a loss of independence. It was important to the stroke survivor that s/he be involved to the maximum in life and care roles. Reflected in some responses was a sense of helplessness that was connected to self-esteem and self-confidence. The stroke survivor saw a sense of control directly linked to recovery and successfully adapting to an adjusted life trajectory. Walsh et al (2014) spoke to how the loss of control following a stroke was associated with "uncertainty, changes in self-identity, self-consciousness, reduced self-esteem and reduced confidence" in stroke survivors. Further, the loss of confidence in their bodies then contributed to fear, anxiety, anger and frustration. A study by Ellis-Hill et al (2009) found that the "well-being of survivors is enhanced with active involvement in care planning and perception of adequate support" further emphasizing the link between self-control and recovery. (Montgomery 2015). As noted in some of the following quotes, the capacity to set goals (and strategies to achieve the identified goals) also contributed to self-confidence and a sense of independence. Wood et al (2010) examined the impact on stroke survivors when initiating new goals and found that while these transitions to new challenges tended to result in an initial decrease in confidence, the impact was relatively transient. As stroke survivors continued to move through challenges, confidence in community living also increased due to the stroke survivor's expanded experiences combined with exposure to "other confidence-building sources." In a study by Chau et al (2009) it was found a strong link between self-esteem and depressive symptoms. In fact, the study found that there was a stronger relationship between self-esteem and depression than between depression and functional ability. The study further recognized the negative impacts that depressive symptoms (and age) exerted on activity participation.

Family involvement as a source of support, motivation and inspiration clearly emerged under this theme:

- *Having family members involved. I had a lot of family support in the hospital and at home. Just family being there helps.*
- *I'm relying on my wife.*
- *Provider wasn't important for me, I didn't need one, I had family support.*

- *My grandson was born one week before my stroke. I was afraid he wouldn't know who I was. It was very important to me that my grandson was brought to me in hospital and I could hold him, feed him. This was a tremendous part of rehab for me at the beginning.*
- *Family, those are the people who have helped me.*
- *Having family involved in my care and their support, love and understanding.*
- *If you have a strong family....the family thing is really important.*
- *[You need to be] "nagged with love".*
- *Family is very important as these are [the people] who you live with and who will be helping you when the providers leave, helping to meet the goals that you set together.*
- *If you're older and do not have family around then you go downhill.*
- *Family being involved in my care was not that important for me because I am by myself so I have to be the one that is in control. I have to speak for me.*

Participants in this consultation process represented a diversity of living arrangements and the importance of family involvement necessarily varied with the family dynamics of each individual. For some, family support was a critical component in their recovery and successful transition to the community. In fact, there was a tendency in some situations to (reasonably) attribute more value to the impact of effective family support on successful recovery versus any professional health care intervention. As with many of the supports that contribute to community reintegration, their respective value is necessarily evaluated in the context of each individual situation. For instance, rural residents without accessible, affordable transportation will rate this component very high, while urban residents who may have available, accessible transportation (or a family member who supports transportation needs) may evaluate this as less important. Similarly, stroke survivors who have strong, supportive family relationships will rate this item at a higher level than those either without or with only minimal family support. In some situations, family relationships have been so negatively impacted by the stroke event and the residual impairments that the family dynamics have changed significantly (e.g., spousal separation, family estrangement). Wood et al (2010) reported that study participants were "upset to see others assume roles and responsibilities that they could no longer perform...Participants unable to fulfill previous roles, such as employment, were also the same participants that described being unmotivated to engage socially... Participants with smaller social networks often felt like a burden to others, had low motivation and fewer opportunities to engage in meaningful activity. The interruption in meaningful activity had a significant impact on well-being..." (Wood, 2010) In such situations where social supports decrease, family involvement assumes even greater importance.

- *Having the right care at the right time probably saved me. I recognized that I was having a stroke and called 911. The female ambulance driver overruled the male driver and they took me to [regional stroke centre]*

- *If you can get the right medicine at the hospital right away then that will help. Everyone should know this.*
- *It's important because if you don't get [the right care at the right time] then that can cause so many more complications.*
- *The thing that helped me the most when I first experienced my second stroke was the care I received in the hospital. I woke up at home at 5 am and couldn't move. I tried calling my neighbours but no answer so called 911 and I have nothing but praise for the 911 operator who was so supportive and wonderful and reassured me that help was on the way.*
- *You need the right care at right time, if not then you are in serious trouble and/or the care is ineffective*

Many participants continued to reflect on the initial stroke event regardless of how much time had since elapsed. It was evident that 'telling the story' continued to rightfully assume a prominent place in contextualizing their present experiences. Some participants also reflected on how receiving the right care at the right time when the stroke event actually happened and during the immediate after care, significantly impacted on all that followed including transition to the community. As well, there was a sense of accountability and advocacy in the retelling in that the survivors (and caregivers) felt a moral obligation to improve the experiences of future stroke survivors.

Once the stroke survivor had transitioned to the community, the need for skilled stroke care assumed a greater focus on rehabilitation and other less acute supports (e.g. support to remain at home). Participants spoke to the importance of having skilled, collaborative, consistent care providers as well as the value of home-based (or easily accessible) care services. Nanninga et al (2014) spoke to the potential need for a change in the focus of rehab as the stroke survivor transitioned to the community with the suggestion that while the primary focus tends to be on motor learning and functional independence of the disabled body perhaps a beneficial shift might be towards "social learning and societal participation of the disabled self" (Nanninga, 2014). Wood et al (2010) perceived a link between the lack of a 'group effect' [such as group day rehab settings] post-discharge in that opportunities for "mastery of physical tasks and modeling from peers are reduced and availability of social persuasion varies for each individual. Hence, the transition to the community poses a substantial challenge for stroke survivors due to reduced sources of self-efficacy and fewer opportunities to develop confidence for community living." (Wood, 2010)

- *Good providers are important, as then you feel more at ease, more in control of your life day to day. It gives you more motivation/encouragement to do things by yourself to get better.*
- *Consistency in care providers is important otherwise I have to explain my care each time the provider comes in. If I'm doing something, let me do it. If they don't know how to help me properly then their 'help' can cause me to fall, I can go down very*

easily. I have a PSW come in 6 days a week and it's a different PSW each day. Some are very good and with some I would get better care in a car wash... I'm not sure if it's communication as much as paying attention and having an interest in what you're doing.

- *Makes a difference if the care you need is at a distance (either acute care or care in community)*
- *I have had a few [providers] just following a list of things to do instead of assessing me as an individual and what would be of benefit to me.*
- *Very good to have rehab in the home – in the hospital you are often one in a group of many people but at home, the therapist is dedicated to you and what/how you are doing as an individual.*
- *PSWs coming in to start breakfast, dressing me, bathing me, helping my young daughter get ready for school and exercises at first. Spotting me to make sure everything was okay.*
- *Trial living at home was good (day pass, weekend pass). It's a great return on investment for health system.*
- *I was given 45 days to “get with the program”. I had a goal, had set my sights on the goal so put more effort out and then got more effort from providers.*
- *The therapist went above and beyond in rehab and I was eager to get myself mobile. The therapist set the bar high so that gave me motivation.*
- *Timing of therapy is important. I got rehab on the day I had my stroke. This is motivating.*
- *Nurses at the hospital who became my friends*
- *I had a referral to a psychologist and I didn't understand why. I do now. It was part of the healing.*
- *The [area] Health Link Coordinator is fantastic. I didn't not have her when I first had my stroke.*
- *Can't say enough about SMOL. They were really good, the physiotherapist was really good.*
- *Physiotherapy and occupational therapy were really good at SMOL and at home. The fact that they came to my home was important as it meant I didn't have to go anywhere. It's hard to get places when you have had a stroke and it takes 45 minutes just to get to Kingston. The Enhanced Therapy was very good.*
- *Husband and therapists were really important and the [community agency] found a cleaning lady for me and will provide transportation if my husband can't take me.*
- *Staff at [rehab]. Certain ones continue to be involved in my care. I reached out and they were there. They understood me overall.*
- *Home therapists and doctors [were very helpful].*

Stroke survivors recognized that the provision of skilled health care was a very important component of the community reintegration process. Health care was variously defined by the participants and included personal support services and coordinators as well as in- and out-patient health care professionals.

- *Change to the 30-day time frame. When I left [rehab] I was told I would have 30-days and then would be on my own. I live by myself so that was the scariest,*

scariest time. I can't afford what I need and it's up to me to call to ask for help but this is embarrassing. It's like there's a 30-day expiry date; most people may be good at 30 days but there will be outliers.

- Thought that my body would be working better if I had more physio.
- More OT and PT. They only came once a week when I got home and I was used to having them every day in the hospital. I could use more help with balance and walking.
- Would really like more therapy even just for my arm so I could do more for myself
- Very important to get physio immediately. Feel strongly that once limbs have been paralyzed, it's important to get them stimulated and working again.
- Need a better evaluation of when you should be released from hospital/rehab. I felt I was let out way too early. One day you're all happy and things are fine and the next day you have a stroke.
- Hospitals are losing key help especially therapists to help patients progress; need more people to help you get mobile again and the cost of equipment is high even if government pays 75% especially when you may not need that equipment in a few months and can't get money back... Some people can be in a very tough spot. I would like to see tax dollars used properly and hospitals fully used (some parts now not being used). Some people need more help than others; I had the will to do it [get better].
- In hospital I had no physio over the Christmas holidays and then only had it for 30 minutes/day. I just needed someone to help me walk. PT just needs to teach us how to walk. I taught myself to walk; used verbal self-instructing initially and then quiet self-talk. In community I needed to pay for physio as only had the standard allotted time rather than according to need. Intensity of physio is lacking – the work is cut short.
- Needs to be a process where providers see patient's house before discharge to understand environment. Also, you have so many hours of therapy in hospital and initially at home and then there is a sudden decrease but you still need those people. You need someone there weekly to see how you are doing.
- There is less and less over the years... people used to stay in hospital longer and get better, deeper therapy but now if you're able to stand then you are sent home.
- Stroke clinic where I can be seen 3 to 4 times a year by a specialist rather than a GP. Sometimes you don't know what you need so need a specialist who can assess you...having a stroke specialist who would see me every 2 or 3 months and look at all of me; do an assessment and formulate a treatment plan with practical suggestions (e.g. how am I walking). Need someone who would know what treatment is available and where to access it. My GP walks into the room, looking at her watch and picks up a pen to write a prescription.
- Need services closer to home. Need the right services at the right time to support recovery and need to know how to access them.
- After care is really important and the getting the right medication
- [There is] so much aftercare for cardiac and us stroke survivors are left there hanging. I have family members who had heart attacks and they are still involved in rehab. Rehab is lacking for stroke versus cardiac.
- They treat stroke like chicken pox; let it run its course and it's gone.
- Could have used a social worker. I ended up calling mental health and was referred to a wellness recording when I needed something that day. They need to give me a

social worker until I say I don't need it. Stroke is a traumatic experience and not everyone understands it.

- *Mental health used to TBI, schizophrenia, bipolar – issues with stroke are totally different and stroke also makes mental health issues more complex*
- *Need to know about risk of depression*
- *When I walked into the emergency, the triage was poor, they didn't realize I was having a stroke*
- *As much as I was in hospital, I never had anyone who sat down and explained the process to me (where I was at and where I could be). No one explained the reason I was there, what they are looking at. There was no one to retrain your brain and tell you here's how to do it. For example, I didn't know how to protect my arm.*
- *Tremendous importance of communication of information between the hospital providers, the patient and family.*
- *Need to include the stroke survivor and family in all discharge planning and transitions...the "mountains of paperwork" can be very confusing (CPP etc).*
- *Need education to self-manage. I always had high blood pressure. I didn't think anything about it, I just kept going, I had kids, it wasn't going to happen to me. A lot of people don't even know that high BP causes stroke.*
- *In [hospital], left in a cave (no windows) for 10 days except for some friendly nurses. At [rehab] there was literature (too much literature) available in my room on my windowsill. Otherwise my wife was having to find out on her own how to prepare the house, etc.*
- *The discharge planning program could be enhanced*
- *Increased funding for education of providers*
- *Providers forget that most patients don't come into office/ER stating what their diagnosis is or having read medical books. They may not have classic symptoms. I'm concerned re outliers. You need to educate people re outliers.*
- *Need more understanding of the fatigue that comes with stroke*
- *The individual experiences fear at discharge [so it's important to prepare] the individual for a positive experience after discharge; ensuring services and equipment are in place in one's own community with follow-up home based care. [It's important to ask] the individual "What do YOU need to go home?" and then including the person in the planning to give the person some control.*
- *If I had someone to check up on me then I would not have had to suffer with the lethargy. If I don't want to read a book then I know something's wrong. I needed the doctor to explain the side effects of the medication; that what I was feeling was from the medication and not the stroke.*
- *[Need] ongoing access to patient and family education throughout the journey including links to technology and applications.*

Within this discussion, there was an emphasis on the critical importance of rehab and the sense that rehab was either decreased too quickly or dropped altogether sometimes due to a perceived early hospital discharge. Also emerging in this discussion was the need for emotional support from the health care team. Walsh et al (2014) found that "Evidence to date indicates that patient priorities for community reintegration after stroke differ from those of healthcare providers [stroke survivors] place a strong emphasis on the social aspects of recovery, including

“normality”, re-establishing former identity and resuming previous occupational, family, social and recreational roles. (Walsh 2014) Participants did voice how some health care providers suggested that recovery reached a plateau early and no further progress should be expected even though research does not support this perspective. It may be that the current therapy model needs to be adjustment in light of this.

THE CAREGIVER'S VOICE

- *Could not imagine life without my husband. I need to be involved in his care; whatever is needed to make that happen, to keep him at home.*
- *It was all about her, not us. I needed to be involved in her care and her life. I spent all my time at hospital.*
- *First instinct is about her.*
- *Important to help your loved one with goal planning. [Family member] was always on the go before her stroke and we had so many plans....*
- *The stroke survivor is relying on the caregiver so it's important for them to be involved.*
- *Being involved in care and life of loved one. We are life partners or soul mates. Of course I need to be there first and foremost. I am his and he is mine. I needed to be there [when he first had his stroke] and I need to be there everyday to make sure he is fine, especially since he was non-verbal since the stroke I needed to be there to ensure he was getting the care he needed. I would never want to be non-verbal for an extended period in the healthcare system.*
- *I need to be involved in the care and life of my spouse. It's important that I like what I'm doing. I like the big smile I get when I present her with an apple pie.*
- *Now, it's a month later and he is slurring words and becoming forgetful. I need to be involved in his care. If he sees doctor by himself then I don't know what's going on.*
- *Need sense of control, needed transportation help, needed to be involved in the care and life of the person who had the stroke.*
- *I need to be involved in his care and life. This is my husband and he is the most important person to me. He never complains, is the easiest person, has said that there are worse people off than me. It didn't hit me or [spouse] for a while what having the stroke meant.*
- *Need a sense of control. My [spouse's] memory is good and he is has no problem reminding me if I forget something. I have to be in control of the people coming in and out of the house not just for healthcare. There have been changes in [our] roles since the stroke; he used to be the chef and now it's me, now I am doing most of the tasks. I have learned the difference between a hammer and a screwdriver.*
- *If feeling out of control about what is happening to the person experiencing the stroke and the family [this] causes anxiety.*

The role of caregiver necessarily speaks to an involvement with the stroke survivor. Family involvement was seen to be a critical link to ensuring quality care. The need to be involved was both practical and emotional. As reported by Salter et al (2013), “relatively few [patients and caregivers] receive adequate information about topics they perceive to be important. Caregivers

rarely receive adequate training in skills they require to care for the stroke survivor. Healthcare professionals involved in stroke care may acknowledge the importance of education for patients and carers; however, relatively few provide adequate information based upon the information needs of the recipients. In addition, written materials should be suited to the educational/reading level of the intended recipient.” (Salter, 2013) Simply put, “Caregiver-oriented, individualised discharge planning improves caregiver preparedness.” (Salter, 2013)

- *Services closer to home make it better for the family.*
- *Rehab is very important. [Family member] had 2 months and was allowed to have some extra visits to rehab when the doctor asked but she could have done with another month or two. She did have a dramatic improvement with the therapy especially with her leg but then “boom” you’re done. She was really looking like she was making progress and really starting to move when therapy ended.*
- *He had A triple plus care in ICU then vastly different care on the floor and then even less with return to community. Day rehab was having him do things that he had already been doing for months and for him it’s like I’ve already done this so let’s build on this now. This is frustrating for him and me; it feels like it’s maintenance and not a continuation. If this was a giant organization, I could understand but, this is a very small facility and I don’t know if the problem is that the notes just aren’t written well enough whether people here aren’t reading them. [The providers] pass each other in the hallway every day, meet for lunch and also there should have been some sort of overlap, some sort of transfer, what do they call it, co-treatment before he was discharged. Because he was there for so long, there should have been at least one opportunity for the therapists to co-treat. They could see what he was doing, how this team works. I think the investment is different between the inpatient rehab team and [outpatient] team and maybe it’s just because of the different clients they see.*
- *Need to have consistent providers skilled in what they do. For instance, this past week our regular PSW was on vacation and we had four different people in during the 6 working days. So, really this was of no benefit as I had to explain what to do to each one – what needs to be done and how to do it. This is hard on my spouse; it’s tiring and impacts on communication since he has aphasia. I ended up cancelling my respite on Thursday and Monday...– started cancelling provider for those alternate weekends when regular provider is off. We have had one PT that is great (through insurance).*
- *Consistent provider was important. Initially we had 5 providers a day but are now down to 1 who really goes beyond and is very compassionate.*
- *Physiotherapy was really important in the hospital and when he came home. He really wanted to go fishing again, to be able to put a hook on the fishing line and it was a bonus that he was so determined but he would get very frustrated. The doctor told him to just walk away when that happened but he would never do that; his vocabulary got a lot worse. His fine motor skills are still a problem. He struggles with things like getting dressed (e.g., with buttons) and he also has problems with short term memory although his long term memory is fine. He keeps trying to defeat it.*
- *It’s important to get help as quickly as possible. He was having breakfast and he muttered and I knew something was wrong and called for help right away.*
- *We had a great provider and then she left. Changes in providers are a problem.*
- *Consistent/skilled providers with experience and a high level of expertise including medical, psychological, social work. It doesn’t help recovery to have different*

providers. Providers need to be committed to the person and to follow up. You need one person to coordinate services as there are lots of things.

- *Right care at the right time very important (i.e. tPA). [It would be a] completely different story if [my partner] did not receive tPA.*
- *You need the right care at the right time. With CCAC it seems like everyone has to fit into a box. For example, you will get 18 visits because that's what everyone gets, but it's important that it's different for everyone. You need to assess and reassess each individual.*
- *Need clear information and the right care at the right time by consistent providers. If that doesn't happen right at the beginning then you are losing right from the start. If I don't get off on right foot then I'm left behind. .*
- *Need the right care at the right time. I can't do my job if I don't have the help I need.*
- *Discharge from the stroke doctor and your regular doctor is not an expert [is difficult]*

Care of the stroke survivor is an inherently challenging task for caregivers and the challenges are compounded if the caregiver feels disconnected from the health care team or in a situation where information is limited. Within this theme of quality care was also the concept of advocacy. The caregivers expressed a need to speak for the survivor, to advocate for the best care and to try to navigate through an unfamiliar system in the midst of considerable trauma. This was especially significant in situations where the survivor was aphasic and/or had cognitive changes. Caregivers often expressed a feeling of entering a black hole on discharge home, feeling adrift in a complex, uncoordinated system of supports and services. As Lutz et al (2010) stated, "patients and their informal caregivers transition from having intense therapy and nursing case management to having little or no assistance. Even with the case management and discharge planning services received during inpatient rehabilitation, they describe having to figure things out for themselves with little or no formal support after discharge."

- *Consistency of providers was good at the beginning. We even had a PSW visit the evening that [spouse] was discharged home. Had the same provider for that first year.*
- *We were very well looked after from the social worker at the hospital right down through our current provider. After in-home therapy was finished, the therapist connected us with the Revved Up Program which was very good.*
- *It's been a good experience in a bad situation.*
- *It was always a fight to get rehab and some people don't have someone to fight for them and why should someone need to fight for rehab?*
- *Need to have certain standard questions to make sure that all services/needs are considered like need for a wheelchair or speech. [Assess if they] should they be discharged home or do they need LTC? They need to sharpen the system.*
- *Some more help would have been nice. I had a PSW initially but then pulled quickly. Respite was great but cut off very quickly even though I was still not comfortable leaving [spouse] for 2 hours but had to anyway.*

- *When [spouse] first came home he needed two PTs and one OT just to help him sit up. Thank goodness we had federal benefits to supplement the PT services provided through CCAC.*
- *He was discharged on Friday and started in [day rehab] on the Monday. That was a huge adjustment because he was the only one of his age and stamina in the hospital so was getting lots of therapy (2 times/day five days/week). To immediately drop down to twice a week 45 minutes sessions with brand new people who on the surface seem like they have never spoken to the therapist on the rehab floor ...and now you're outcast, you're not allowed to talk to anyone on the rehab floor. He had the stamina in hospital for therapy twice a day five times a week but as soon as he began [day rehab] it dropped to 45 minutes twice a week. Seems to be a disconnect between inpatient and outpatient departments; never felt like there was a continuation of therapies...now it feels more like maintenance rather than moving forward. Everyone was stupefied with his daily gains in hospital and then he was just tossed into maintenance mode which is a tragedy for him. I am deeply rooted in this, I hear professionals say how important therapy is, but it seems like it is just important to be said rather than to be done.*
- *We have had lots of people come in but this caregiver knows what work is. Some come in and can't do certain things or don't know how to do them or don't do what we want. Having different people drives me crazy.*
- *Had no PT when came home but did have SLP for 5 years which really helped and helped [stroke survivor] to go to social group*
- *Was important that I was able to keep my husband at home and could only do that because I had so much support from my friends*
- *[Stroke survivor] was discharged at beginning of September but then did not get any outpatient physio for a month so she had deteriorated by then; also we only had a loaner wheelchair that wasn't fitted for her so had to use cushions and there was no arm support. Now we have one for in the house that is fitted for her but just a regular one for when she goes out as needed one that would fold up – her fitted one almost needs to be taken apart to fit into the car.*
- *If it's not the consistent worker then sometimes they come in blind. We had a worker who didn't even know she had a stroke; finally asked during the visit what was wrong with her.*
- *There is an expectation that we do exercises with [stroke survivor] but they show you once and then it's in one ear and out the other and I'm afraid of hurting her when I just want to help her. I feel bad because I can't help her and am afraid that I will make it worse and not better.*
- *Feel that more could be available. I need to be free to transport spouse.*
- *Good that there are things out there now that weren't there 30 years ago like sidewalks, accessible doors, etc. I'm getting to know the businesses, restaurants, etc, that are accessible.*

There is a significant care burden placed upon caregivers as the stroke survivor transitions back to the community. They are often expected to assume care tasks that, at least, initially, seem quite overwhelming. They enter a fast-track learning process where they must become familiar with what they believe the stroke survivor needs in terms of health and community supports and quickly understand how pivotal these may be in maintaining the health of the stroke survivor as well as themselves. Impacts experienced by caregivers particularly in the context of early

supported discharge include increased strain, family dysfunction and alteration in employment. (Lyons, 2002)

- *Therapists, PSWs, outreach program, neighbours*
- *Social worker, ParaMed, VON and CCAC who helped to initially evaluate and coordinate the services. I have been getting respite care but could always use more and then he had a TIA two weeks ago so my respite was increased.*
- *My doctors really helped as my blood sugars would be crazy high because of the stress and I was depressed. They always provided support.*
- *[Rehab] helped a lot, the front line providers got my [spouse] what he needed. Even when the higher ups said he was done, the providers continued with speech, etc. Now, it's 6 years later and he's still getting better.*
- *We live in a country setting where everyone knows everyone else. When we came home from the hospital there was someone came from the [community provider] to set up some help and put things in place. We had PT and PSW in our home and bathroom modifications.*
- *Paramedics have been great. When I call they don't just take him to the hospital they assess him and then he is usually good to stay at home. It's a great support system.*
- *The PSW from [community provider] and the orthotics person who was very helpful; CCAC Care Coordinator just did paperwork and only saw us once at the beginning and then not again for 6 months. Now we are also getting a social worker from CCAC for 10 visits which is the limit.*
- *March of Dimes come in and help with cleaning and with exercises for [stroke survivor].*

As the person who is providing care on a 24/7 basis, it was clear that the caregivers valued the support provided by health professionals and fully recognize the benefits of those interventions for both the stroke survivor and the positive impacts on their own health.

- *Good to have more therapy and have it closer to home*
- *More accessible therapy. We are fortunate as have additional benefit plan that provides more therapy. There is also only limited outpatient therapy services.*
- *Continuity of therapy. Inpatient and outpatient should co-treat prior to discharge so there is continuation of therapy and building on what has already been accomplished.*
- *System should provide for rehab in LTC and it should be provided when it's most appropriate especially in those who are slow to recover*
- *More services for stroke survivors. At St. Mary's staff have been decreased, no return to driving services, no wood shop. There's also seems to be a time frame for discharge regardless of how you're coming along.*
- *[Stroke survivor] has not had any therapy since finished in outpatient. We have no funds for private physio therapy.*
- *Need more places like SMOL where everyone wants to go; more of those kind of beds.*
- *Hard when you get a worker that has no knowledge of stroke and the complexity.*
- *Caregivers need to know that the providers don't always know. [Stroke survivor] can get better even when [the providers] don't think so.*

- *Every patient is different and it's not fair if they need the care and can't get it – initially in the hospital they need help to do the things they want to do.*
- *Doctors only hear one side of the story. They need to hear what [the stroke survivor] says and not assume that they know what she's thinking.*
- *Fighting, fighting, fighting. Us against them all the time. You run out of energy and the will to fight.*
- *Need more help to help people decide which LTC to choose. I was told I could make three choices so I'm running around checking out Homes. I used the Extencicare checklist which was good and my daughter who is [in healthcare] helped but her decision differed from mine and once you're in the LTC then you're there and you're already totally stressed.*
- *Partner was discharged home too early for the things they want you to do, wasn't ready and now when I'm asking for those services I am told it's too late. He can't get the services unless he gets worse (can't get the services to help him get better now that he is ready for them and seems to be improving). Enhanced CCAC services were available at discharge but that was too soon. He improved slowly over long time frame so he needed rehab later.*
- *Fundamental problem in hospital is that some providers aren't labeled and they don't introduce themselves and have no bedside manner; others do it just right.*
- *Hard to get services. The attitude seems to be why send someone in if you don't have to. It's always about money. CCAC seems to be about lightening the load instead of providing the care that is needed. The system is crazy; one person gets 5 hours and another gets 2.*
- *Shorter wait time for admission to LTC. I'm ready to collapse waiting for him to be admitted to LTC. They are offering more help but I don't need more help, I need him out of the house.*
- *Educating the rest of the family. Caregiver gets information but it is hard to educate other members of the family*
- *Should be more done before you leave hospital to make sure everything is in place at home.*
- *More help and more education about stroke and about how to help [the stroke survivor]. They didn't teach us anything or give us any classes. We got a book but that was it.*
- *We were originally told that after 3 months post-stroke we would likely not notice any further changes. Not true, it surprised our doctor when we saw him again after 2 or 3 years.*
- *Providers afraid to give false hope. I understand that recovery is variable but need to advise that there is potential for recovery. No one told me he would talk again. Don't close the door, need to give hope.*
- *In the hospital, [stroke survivor] really tried hard and staff took extra time with her which is the main reason she came out so well; her willpower. Initially they didn't think she would make it through the night Doctors said she was going to die without surgery or in OR and if survived would never talk or walk again. I wish those doctors could see her today.*
- *Spouse told by ICU doctor that if her husband was not getting worse and was holding his own then he (doctor) was happy – not helpful information.*
- *Having multiple illnesses in stroke survivor and caregiver causes a lot of complexity*

This theme elicited responses from caregivers that were similar to those heard from stroke survivors. Included in caregiver responses was the need for increased therapy services, challenges related to LTC transitions and the need for compassionate, skilled providers knowledgeable about stroke.

THE HEALTH CARE PROVIDER'S VOICE

- *If I were in this situation, I would want as much control over my care and involvement in what is happening around me. With this I would feel as though I had a sense of control over my life.*
- *Having choices to my own care with the equipment and support needed to reach my goals would be important to me*
- *[Need to] promote client focused care with the client at the centre of the care plans.*
- *The care needs to be based on client-centred goals in order to be meaningful*
- *I find patients do best when they are involved in the planning of their care, as well as their family.*
- *To allow independence and choices around plan of care. To assist with finances and travelling needs.*
- *Need for independence, help with acceptance of limitations.*
- *Client's involvement in his/her own care.*
- *Involvement of client/patient in decisions, goals and ensure quality care, active lifestyle with abilities.*

Health care providers spoke to the need to ensure that the client is fully involved in the care planning process which then contributes to a sense of control and independence. It was of interest to note that some respondents answered this question in the first person.

- *I thought "Getting the Right Care at the Right Time" encompassed many other statements; "Right Care" means qualified, trained staff with appropriate resources allocated. "Right Time" means service that is appropriate and needed presently - not a year down the road or six months ago. This involves a good awareness of where the patient is on the rehabilitation journey and what services or supports are appropriate at the present time to maximize their independence, recovery, and quality of life.*
- *Basic needs being met in order to remain home is a key factor in being able to reach other goals, such as spending time with family and doing things that are loved and reducing stress*
- *There are certain aspects that are essential to a successful reintegration back to home and community and these things need to happen in a timely fashion. Services and supports need to be in place upon discharge so that the client doesn't fall off the radar once returned home from hospital.*
- *Having consistent providers who are skilled at what they do – trust can be built. This allows for the ultimate working relationship between the stroke survivor and staff. Skilled staff are best able to assist the survivors reach their full potential (Evidence Based Practice)*

- *From working in the community I have received feedback from clients who find it challenging/frustrating when they have different service providers coming into the home and there is not consistency. It is so important that the therapists are experienced in stroke rehab or have access to a therapist to do joint visits or consult for therapy ideas*
- *Communication is PARAMOUNT. This skill is the most obvious, yet often is lacking, particularly when there is more than one caregiver involved, or when there is a sudden change in providers. Also, the skill of communicating with someone who has a communication impairment after stroke is pivotal.*
- *...having clear information...such as knowing one's discharge date as early as possible and knowing what services will be in place. I do think that sadly people don't internalize that information always on the first try, so information needs to be given repeatedly, and in various forms, to patients and their family members in a timely manner. Also...people often meet or speak with someone from CCAC very close to discharge, but we notice that as clients approach discharge, they become anxious about not knowing what will be in place, so having that meeting with CCAC a few days earlier would be beneficial to alleviate anxiety.*
- *Sometimes, a planned therapy session needs to focus on the client's emotional needs which is why it is important to be aware of these emotions.*
- *Discharge barriers often include clients not having even basic equipment to perform basic ADLs or assistance to get meals in place, etc. So, I think access to those tangible resources (both equipment and possible PSW needs) are critical.*
- *Access to proper resources is important too as people don't always know where to look.*
- *Having a good provider from all disciplines will help the individual meet all their needs.*

Person-centred skilled care was essentially defined as care being provided by consistent providers with expertise in stroke care and supported by the necessary equipment and supplies. The critical role of communication between providers and between provider and client was also highlighted.

- *The system [needs to be] able to provide them with the amount of ministry covered care that the client actually needs, rather than what policies suggest they may need.*
- *Need appropriate inpatient/outpatient therapy coupled with realistic expectations (from doctor/therapists) explained to patient & family regarding pt's prognosis (expected physical/cognitive gains) over what period of time*
- *Persons who have had a stroke should get as much enhanced stroke therapy as they are promised instead of getting their services cut*
- *Need ongoing enhanced therapy services to stroke clients and more frequent visits if possible (such as 3 x per week) more frequently even for the mid-range RPG [functioning] clients, so they can maximize their functional outcome in that critical period after having had the stroke.*
- *Ensuring caregivers/clients know what resources were available prior to leaving the hospital and who to contact*
- *Ongoing (once or twice) per year evaluation by rehab professional (PT/OT) to support and assist with management of stroke impairments – needs assessment.*

With respect to therapy, suggestions were made to make the system more responsive to each individual's needs as well as additional therapy services (e.g. enhanced frequency).



INDIVIDUAL WELL-BEING & MEANINGFUL ENGAGEMENT

THE SURVIVOR'S VOICE

- *I remember my grandfather crying a lot after he had a stroke but not understanding why. Now I understand.*
- *I needed help to adapt to my new life. 'Help' can mean so much, it can mean physical or support. The old [me] isn't here anymore. It's important to realize that I'm in the wrong body. You need to accept the new you.*
- *It's important that my caregiver's needs and interests are also cared for, to know that someone is looking out for my husband.*
- *Knowing that the provider cared [was important].*
- *[Important to] recognize success and hopes. To know what I want and provide positive feedback, notice changes, tell me I'm going to get better, comment on the changes that happen.*
- *I didn't understand stroke until I had one*
- *No one ever explained to me what a stroke was; people would talk over my head. It was two years later that I found out. This [support] group has been a godsend.*
- *It's important to be able to do what you love, to find something that you love in this life. It gives you a sense of accomplishment, a reason for existence.*
- *You have to tell people to 'do it'; if they always hear that they can't do it then they will give in and begin to believe it.*
- *I read a lot and kept very active all of the time, music was a good healer, calming. This was good as I felt agitated at times as you can't do what you want to do.*
- *Important to be with people I enjoy spending time with. At home, they don't always know or understand. I enjoy coming to [the support group] and listening to what they do, what they're finding is different.*
- *Important to be with people I enjoy but my friends have moved away or, because they're older, they have passed away. I can be independent but I like to also be with people, to laugh, to be with people more like me*

Individual well-being and meaningful engagement were threaded through many discussion points including quality health care, independence and family support. Experiencing a stroke event immediately and significantly changes the life path of the stroke survivor and the caregivers.

Stroke, unlike other significant vascular events such as heart attack, can result in long-lasting disabilities that are experienced by both the survivor and the caregiver.

Recovery may well become a life-long journey and, after the initial relatively rapid improvement, the survivor may make only small gains over long periods of time. Caregiving is a 24/7 experience and, in situations of cognitive or behaviour changes, the loved one is not the same person as before the stroke. As well, there is often a feeling of isolation in that an empathetic understanding of the challenges for the survivor and caregiver can only be truly understood by others in similar situations; connection with like-minded others becomes a lifeline. This is where the value of support groups and participating in leisure activities connect to emotional well-being. Eskes et al in the *Canadian Stroke Best Practice Recommendations* (2015) states that “Patients and families should be given information and education about the potential impact of stroke on their mood and that of family and caregivers; patients and families should be provided with the opportunity to talk about the impact of stroke on their lives at all stages of care... [and] have their psychosocial and support needs assessed as part of ongoing stroke management.” (Eskes, 2015) While post-stroke depression is estimated to occur in up to 60% of stroke survivors within the first year post-stroke, it can also pose a long-term risk (Eskes, 2015). This risk for post-stroke depression is believed to be associated with a variety of post-stroke sequelae including high functional dependence, cognitive impairment, aphasia, pre-stroke history of depression and social isolation. (Eskes, 2015) Chau et al (2009) suggested that rehabilitation services need to recognize the imperative of including depression screening and treatment in their care planning. The link between depression and reduced participation in social activities negatively impacts on recovery. Additionally, “assisting stroke survivors in redefining their identity after stroke could be an important aspect in stroke rehabilitation. Improving communication with stroke survivors and carers, and avoiding categorising stroke survivors by their deficits, could help to enhance stroke survivors' self-esteem and in turn contribute to the societal participation” (Chau et al 2009).

- *Support groups and other community services helpful*
- *Support group; it's helpful to hear others' experiences.*
- *Support group helped me a lot. Other people asking questions that I hadn't thought of. All strokes are a different experience and we can help each other. Sometimes just the talking helps.*
- *Support group very important*
- *It can be depressing but it's uplifting to hear from others [in support group]*
- *Support group and the facilitator helped a lot – find you're not alone*
- *Being among people who have had a stroke and understand – lots of commonalities; learn a lot which means less fear*
- *Support groups are great. Only someone who has been in your shoes can really understand and provide support.*

- *Support group is most important and is a big plus. You are with people who get it, who understand [and you can] get information.*
- *Church*
- *Activities Coordinators in our building helps us to meet other people and participate in activities like BBQs, bingo, coffee.*
- *Contact with support services was good. It has to be more a vocation than a job; have to treat it as a career rather than a job.*
- *YMCA. There was person there who believed in and pushed me. She got me to believe in myself and she got me to swim and to walk again. She gave me my legs. There are probably others out there like her but you have to find them.*
- *The Y exercises are good. One time I took a class for people who had had a stroke for about a year but most people in the class were of a different age.*
- *Since I had my stroke my main external activity is going to the Y.*
- *I mentor students at Queen's. They learn from me rather than just read a book. I tell them not to get a 'god complex'.*
- *Perth Enrichment Program. They adapt the program to the individual and have a program for older adults. It provides an opportunity to socialize and talk to people in a comfortable setting with friends, providers. It gives spouse some respite and helps with aphasia as we keep talking. Helps with cognitive development. They have exercises, field trips, nutrition information.*
- *Bowling group. It's older adults including people with stroke and provides encouragement. I had bowled with group prior to stroke. We call ourselves the 'gimp gang'. Three members have had a stroke, one is an amputee. We also have lunches, go to movie. It provides socialization.*
- *Friends, CCAC, neighbours, the seniors' community. Great to be surrounded by neighbours and have activity programs but you have to join, you can't isolate yourself.*
- *I did go to ABI but everyone there was so sick. I don't want to be around sick people. I did find a meditation class but no one told me about it.*
- *Need a real purpose. I do volunteer coaching.*
- *I love to bake and [others] enjoy my baking. We seniors support the food bank which also looks after other... programs like children's Christmas stockings....it's fun and enjoy the sense of giving back to the community.*
- *Family never went away and never will*
- *Had tremendous support from my family. This is the most important thing you can have and their understanding. It motivates you, makes you want to get back to where you were. Not everyone has family but can look at the support group as family.*
- *I enjoy tremendously my set of friends.*
- *Having all my friends around me is important. My daughter is [at a distance] so it's difficult for her to get here.*
- *Important having friends in to visit. I did use providers for the first year or so after my stroke but except for the first 3 months it did not make a significant difference.*

This group of responses generally looked at support groups, exercise opportunities and volunteering. It was evident that effective reintegration into the community requires support from

and understanding by the community. Stroke survivors often struggle to return to previous activities and/or to participate in new activities. There are challenges related to transportation, self-esteem related to changes in body image and function and available activities that are or can be adapted to the stroke survivors' needs. The value of support groups was evident in the responses; having an opportunity to share the journey with others who have lived experience provided an important emotional and navigation role. Kessler et al (2014) reported that peer support provided social validation and promoted feelings of empowerment. At the same time, peer support was found to be associated with "decreased loneliness and feelings of difference, as well as enhanced social competence, social acceptance, and increased acceptance of chronic conditions." Kessler et al saw peer support as a source for "emotional, instrumental, informational and affirmational social support for people with chronic conditions." As well, many of the participants spoke to the critical role played by family. In fact, it is often the family support that sustains the stroke survivor as health and community supports may very well be quite short-lived relative to the life journey.

- *Would be helpful to have a visitor who understands what you are going through; provide you with their number and you can call when you're ready (peer visiting).*
- *Support group. There is knowledge in the group where may not be understanding outside of the group. Makes you stronger.*
- *Importance of rehabilitation and support groups post discharge, and value of transportation services to access them.*
- *We need the support of others going through the same recovery.*
- *Local social, recreational and health information re programs like PEP [a community-based program for older adults]. Makes people active, feel successful and gives caregiver a break.*
- *I'm not working and I miss that. I have attended other programs and was the youngest person there and others had Alzheimer's. You need more programs that meet needs of people with stroke. I wish I could be earning some money.*
- *Each person should be told about the support group before discharge from hospital. I received a call about the Pathways group and that led to my first experiences with the stroke group.*
- *Need knowledge of the support groups. You need to get the information right from the start in the hospital so I know what to look into. Also get information out through things like health fairs.*
- *Sharing of suggested speaker topics and other successful activities among support groups and a shared listing of resources for facilitators.*
- *Need to know about stroke support groups. Lots of people need it but are afraid to go out; to show the effects of their stroke.*
- *Fear of losing my caregiver*
- *I have been relying heavily on my faith to pull me through this....prayer support is very helpful and the church is supportive.*

Referral to support groups/peer visiting was again cited here as a valuable resource but there was also mention of the need for improved accessibility and recreational and leisure opportunities that are appropriate for stroke survivors. The availability of leisure and recreational activities for the stroke survivor can provide benefits beyond the reduced social isolation and lowered risk of depression; it can also positively impact on the preservation of cognitive function. Given that stroke survivors are at increased risk for dementia, interventions that are believed to mitigate cognitive decline assume a critical importance. A study by Liu-Ambrose (2015) demonstrated “that an exercise and recreation program can significantly benefit executive functions in community dwelling chronic stroke survivors who are mildly cognitively impaired—a population at high risk for dementia and functional decline.” Leisure activities can also “create commonality of experience” (Lee et al 2001). It is the social interaction inherent in leisure activities that provides the additional benefit of “two individuals [that] accommodate each other and create a mutual interest that triggers relationships.” (Lee et al, 2001) After a stroke, survivors often report that old friends drift away and it can be challenging for the survivor to pursue new relationships. Participation in activities of mutual interest provides a framework for the introduction of new friendships. Lyons et al (2002) states that, “As time progresses, stroke survivors become more homebound and less socially active. Social networks continue to be important to the overall health of stroke survivors. Social functioning is intimately linked with physical, emotional, psychological, and cognitive recovery. Social activity should be incorporated into other therapies, thus reciprocally enhancing the effects of each. (Lyons, 2002) Lyons also looks out to later phases of recovery with the suggestion that as new challenges arise in the recovery journey of the stroke survivor, “follow-up educational and counselling sessions should be established. Education programs alone are better than nothing; however, the best results are seen when education and counselling are paired.” (Lyons, 2002).

THE CAREGIVER'S VOICE

- *Never really had help with the emotional part and we had other things happening as well. Strange as it may seem we used to laugh a lot to preserve our sanity especially when trying to help our [family member] like helping her to manage the bathroom.*
- *Respite is very important as I do most everything so get at the end of myself sometimes. Even when we go away on a holiday, it's not really a holiday; it's just me in a different place.*
- *We both need time to get away but it is not easy.*
- *Even though you're a caregiver, you're still wanting to have a life yourself even if it's self-centred. It's important that I can do the things I love to do, have time for your own personal interests. But then I feel guilty if I am putting that high up.*
- *Being with people I enjoy. If I don't have friends to talk to then I will be a mental case. I was also looking after [another family member] at the time who had mild*

Alzheimer's. After husband had the stroke, people were afraid. Even his hunting friends didn't want him there anymore because he wasn't the same [survivor's name].

- *Having adequate support and time away. I'm ready to collapse.*
- *Good support to stay in touch with friends when looking after [family member]*
- *Family is important. We don't smoke or drink and we have a farm so that reduces the number of friends you have and then after the stroke there were even less.*
- *Need adequate support and also time away to do personal things. It's important for both of us.*

Given the life-changing event that the caregivers are experiencing with the stroke survivor, it is not surprising that emotional support was seen to important. How that emotional support was perceived varied with the individual and the source of emotional support may have been derived from diverse sources including friends, family and/or respite. Nanninga et al (2014) found that "the family members of participants with cognitive, communication or behavioral problems longed for support and recognition in dealing with the changed personality of their spouses, and in re-defining their life and relationship." (Nanninga, 2014) Salter et al (2013) examined caregiving for stroke survivors and found that respite was a critical support as "Carers cite the inability to get enough rest or time to fulfill all their obligations created by the need for constancy and vigilance in managing the needs of the stroke survivor as a key impact of caregiving. (Salter, 2013) As caregivers struggle to find their "new normal", they may also be seeing a narrowing of their world as "their social life and interests" become limited. (Salter, 2013)

- *Weren't a lot of connections; we used to be more active but that changed after the stroke...people with stroke have to get out and do things. It makes you part of the community ...if you don't have people to support you then....*
- *Sometimes feel trapped then feel guilty because of that, but life totally changes. In many ways lost life of both people. Everything revolves around stroke survivor because you've had to cope with change and caregiver's life fades to background.*
- *Need grief counselor to help work through the losses and find a way to come to terms with changes for both people.*
- *Public doesn't understand stroke (versus heart attack) and that its impacts are long term. Public remembers old vision of stroke where person was bedridden. They don't relate to the current picture of stroke. [Spouse] is up walking and they think it's all fine. This is why this [support] group is so important as they "get it" and understand current life*
- *Also need social times that involve families, where you can pretend you never had a stroke and you just get know each other*
- *Also need support groups for the families of stroke survivors – a place where they feel free to air their concerns*
- *Family activities in hospital are also important – this is helpful healing especially an outside activity like ones organized by Rec Therapy*
- *Having multiple illnesses in stroke survivor and caregiver causes a lot of complexity*

- *It's such a shock when it happens. She had her stroke on Saturday evening and when we saw her Sunday morning, she couldn't do anything, she couldn't even talk.*
- *We had no respite at all. When we asked about getting respite, we were told to call our church so we didn't have any. Even if you ask in the community it costs money. This impacted on my health big time.*
- *Did attend some seminars through ABI/March of Dimes which were okay but the distance was too far. Just didn't have the time to go down for the sessions.*

Caregivers are navigating an emotional roller coaster from the time of the stroke event through the transition home and onwards. The need for emotional support/respite was clear in this discussion. Life and vocational roles often change, new household duties may need be assumed by the caregiver, friends often drift away as those activities that once connected them are no longer feasible and the stroke may have caused dramatic changes in the stroke survivor; they are not who they used to be. In a study by Persson et al (2015) the disability level (cognitive, physical and emotional) of the stroke survivor had an impact on the perceived quality of life of the caregiver. It was further noted that if the stroke survivor was displaying depressive symptoms (a common sequelae of stroke), it would also negatively impact on the emotional wellbeing of the caregiver, particularly over the long term. Lutz et al (2010) stated that up to 70% of caregivers "have clinically significant depressive symptoms and of those, between one-quarter and one-half have major symptoms of depression...The impact on physical health also is profound... These caregivers also experience high levels of frustration and stress, which may lead to harmful behaviors. Because they have less time to care for themselves, family caregivers also are less likely to engage in health promotion and prevention activities." Lutz et al (2010) also found that the research indicated that "stroke-patient outcomes are strongly influenced by the ability of the family caregiver to provide emotional and instrumental support and assistance with ADLs. As a *caregiver's health declines*, the patient's health and recovery also are likely to suffer." (italics mine)

- *Caregiver support group. I saw poster at [rehab].*
- *Information learned in the support group either from the facilitator or other members. Being with others who have also had their lives turned totally upside down.*
- *Support groups. All of them, the couples, the caregivers and the stroke survivors, facilitator is very caring.*
- *Good neighbours*
- *Used to go to a social gathering with other stroke survivors and families in area but now only maybe twice a year. Good to go because everybody understands everybody*
- *Went to the support group for first time and I was like a sponge as haven't been able to talk to anyone non-clinical since he had the stroke – also great for him as another male there with aphasia who had recovered a lot – for the first time I could see it in his face. I tell him all the time and [doctor] can tell him that this is going to get better and you will walk and talk again, whatever but when he was actually listening to someone who said he couldn't walk or talk at all [after his stroke] and now he has*

come so far, just being around people he can relate to. I would have loved to have been able to swap contact information with these people. [One participant] was asking if I had been hooked up with this and that and I didn't even know what she was talking about and she said "oh, geez do I ever have a lot of information to give you".

- *Once I found out about support group then I was able to link in to other services and supports like additional care and a scooter for my husband. This meant he could go out without me; it increased his independence and safety. You have to take your hands off at some point and let the person be free.*
- *Sometimes [people] may be reluctant to try a support group but once introduced then enjoy it. Having another man in group helped my (husband) attend.*

Support groups were again recognized for the role they can play in bringing the survivor (and caregiver) back into the community, reducing social isolation and enhancing self-confidence. One participant referenced the lack of co-navigation commenting that the only services received were, "The ones I paid for and found myself or by accident."

- *More affordable respite. I have to have time to myself or I will get sick. My diabetes is already out of whack and I don't want him to feel bad. He has short term memory problems and problems with common sense so he doesn't really understand. I found a retired nurse by accident who I can pay what I can so I can get away but before I found her I tried everywhere to find affordable respite.*
- *Matching people who have the same interests and help people to discover new interests.*
- *My husband is depressed. He needs to go out and meet people; needs to find an activity that interests him and that he would enjoy but it's hard to find these things. Especially hard if can't speak.*
- *Something that would help to make a match between stroke survivor and available activities [like a] volunteer bureau. Challenging to find an activity where hours fit, transportation is available, person enjoys the activity and you can afford to participate.*
- *[Stroke survivor] is more confined to the house now which is not good for me. He needs to get out from underneath my feet. If the caregiver gets sick then what happens? I took [stroke survivor] to see a nursing home and he said don't you ever put me in a place like that.*
- *If I had it to do over, I would not have brought him home. Most of the time I feel like I don't have a life. Only way I'd get him into help now is if I walked out.*
- *Important to have a social worker come in. Someone more trained that you can talk to. To help get things off my (or her) chest. [Stroke survivor] always looked forward to them coming.*
- *Would be good to meet other people in the same situation but there are no support groups in our area.*
- *Should be some way that in hospital the caregiver has immediate access to information, maybe peer visiting. Need to know how to live when you get home.*
- *Once you return home, but are no longer working and can no longer do some previous activities (e.g. curling club), people fade away*

- *What do you do when the person with stroke cannot return to work but that was whole life before stroke? What if no hobbies, leisure activities, what if limited what he can participate in because of impacts of stroke?*
- *Getting connected back into life and the community. Sometimes he would just sit there, be in another world and then he would say something but it was not connected to what we had been doing or talking about. I tried to think of what would help...there's a lot of isolation after a stroke – it kind of closes doors, it's different.*
- *Partner doesn't go to support group because he thinks he doesn't need it*
- *Another tough thing was the kids and school. The youngest really didn't understand and the middle one went to school but the older one was most affected. The school actually sent a teacher to our home for while so he could be home-schooled which really helped.*

Salter et al (2013) reported on the importance of caregiver supports and found that while friends and family may provide good support to the caregiver initially; those same caregivers reported receiving few supports one year post-stroke. Additionally, should the stroke survivor develop new care needs as the result of a change in health status, the caregiver must assume (sole) responsibility for the additional demands. The burden is greatest for those providing care to stroke survivors with cognitive or emotional challenges versus physical impairments. (Salter 2013)

THE HEALTH CARE PROVIDER'S VOICE

The final grouping that emerged from this set of responses referenced the need for a broad base of community supports that will address the needs of stroke survivors and caregivers beyond the 'standard' therapies including those clients discharged to LTC.

- *Offer them practical solutions so that they can have a sense of value/worth and success. They matter. They are not viewed only as a victim.*
- *More support to allow individuals to live where they would like with best quality of life possible. Current home support is limited and demands that family carry a heavy burden of support. Conversely when individuals opt to live in Long Term Care their access to community services is cut off and they do not have the opportunity to maximize their independence or maintain gains they have made through rehab.*
- *[Need] more support for/to family caregivers*
- *Emotional support [should be] increased.*
- *Spiritual need [can be important]*
- *[Need to address] the struggle by caregivers to care for an individual who is often now so cognitively different than before*
- *[They need to] have FUN. Having a provider who is empathetic, caring, supportive...Having someone who is not rushed or has unrealistic time expectations.*
- *Intimacy[needs to be addressed]*

Health care providers recognized that there is a lack of ongoing emotional supports to assist both the stroke survivor and caregiver as they struggle to adjust to a new life reality. If emotional needs are not met then there are significant impacts on the other components of recovery and quality of life. These include rehabilitative therapies and social re-engagement. The need to support a holistic rather than medical model of care is critical in supporting the recovery journey.



COMMUNITY CO-NAVIGATION

THE SURVIVOR'S VOICE

- *You don't get told what is available, they just give you pieces of paper...you have to think of things yourself. [They] don't really explain things, you're given a book and they make an issue out of things that aren't important and don't address things that are.*
- *It's important to know that when I have a problem I can phone [my Care Coordinator] at the CCAC and she will come to my house. We can sit down together and work things out.*
- *Important that I have a provider who can connect and coordinate the services*

For community co-navigation, the participants were largely consistent in visualizing this as a person rather than a self-directed paper or electronic resource. Montgomery et al (2015) suggested that providing system navigation provided several benefits including “lessening social isolation, supporting care partners and symptom management and decreasing use of both acute and long term care services.”

- *I had a social worker visit me in hospital, had the equipment I needed provided and had a care coordinator seeing me for 30 days although she did not share that time frame. She was older and experienced. I wonder if that makes an impact.*
- *Sometimes they let you know what community supports are available but then leave you to make the connections. It would be good to do this before discharge; this would make an easier transition. To integrate the post-discharge links (e.g., support groups) into the rehab process. Have the workers visit the patient in rehab before discharge.*
- *May be lots of things to keep you busy but you have to find them.*
- *I didn't have anyone phoning me to see how I was. I was sitting there like a zombie thinking that if this is stroke then it is hell. I had no energy, not even to read a book. After 3 months I had my appointment with the stroke specialist and I asked why I was so listless, had no energy and he said it was due to the medication. After he changed the medication it was like being reborn; with the new med I was like me.*

- *I needed to have someone come hospital to explain what stroke was and the resources available; explain the avenues where you can get help and what is available. I heard of the support group from friends.*
- *If you don't have the support of your family and have them fighting for you then what happens? Who will ask the questions; find out what's going to happen?*
- *You're in total confusion in the hospital and everyone is busy so not much information. I didn't have my stroke diagnosis until 6 weeks after the event.*
- *Insurance/tax breaks were not clear. I missed things because of time constraints. I was just handed a book and told to read it.*
- *I was given pamphlets, books, etc. but you are in survival mode, traumatized, in shock. You need time to adjust to the event and then someone to speak to face-to-face. A third person present when [I was being] provided with information is helpful (family, friend, provider). I couldn't retain what doctors were telling me.*
- *Need someone to sit down and explain what happened and need this information when are able to absorb and understand it.*
- *Someone to explain what had happened. Will it heal? Will I get it back? I was told that if not back in a year then not coming back. Another survivor was told three months. Don't explain it in first month, do it later when you can understand.*
- *I didn't know what to ask the doctor and may not have understood the answer*
- *I suggest to have a notebook to track all the information you receive (e.g., appointments) as this allows you to go back and review. To listen and write it out at the same time is problematic. There is a very fast information flow.*
- *I had some help from friends but it would have been great to have some kind of government organization or if I had have had the Quinte Health Link Coordinator right at the beginning. Friends did what they could but they also had jobs.*
- *[The most important services were] the ones I paid for and found myself or by accident*
- *Felt like we were racing against the clock completing forms which caused panic and a lot of stress. Not only caring for spouse but also had additional decision making – I (stroke survivor) was in “la la land” but spouse was stressed*

Community co-navigation was an area where needs were often not met. There was a sense of being dropped into a complex system with little support and limited knowledge of what was available and how to access supports and services. Several participants spoke to a large amount of (paper or verbal) information being provided and feeling overwhelmed when trying to process it all in timely manner. There was reference to the potential to re-evaluate the timing of the information provided as well as providing the information in more manageable portions. Salter et al (2013) reference a study by O'Hare et al (2006) where participants generally “felt that more information was needed about stroke, living with stroke and access to services in addition to a broader range of issues including networking opportunities, environmental adaptations and benefits advice. Overall, patients reported persisting needs, including need for information and support, which were not being addressed by available sources.” (Salter, 2013)

- *Would be nice to have one central person to go to. One central person, if he or she is keen on what they are doing, they can be most useful. Someone to coordinate things and know what's available ...you find out by yourself but it takes a little while.*

I didn't know I was eligible for Veterans Affairs. It's frustrating. You pretty much have to listen to the people that do it and follow their instructions and don't get their back up, because then that will take a long time.

- *Sometimes you need to know the loopholes in the system to get the services you need but it shouldn't be about knowing the loopholes to get the help you need because people who have had a stroke need that help*
- *Someone to help me connect with services I need (e.g., help with taxes) as it is hard to use the phone book.*
- *Services are disconnected*
- *There is so much you need to know and it needs to be available when you are ready to learn*
- *At transition period you lose all providers, there is no continuity of care and your GP is not involved, the FHT is not involved. What magical thing happens at 30 or 60 days? You need to speak to a real person, someone who knows you.*
- *You need a person to assess you re what stage you are at and what your current needs are. You're cut off and then you have to start all over again.*
- *It's important for the provider to contact you and make connections*
- *Often get voice mail but need a person. If leave message then end up having to sit around all day waiting for response and may be told that I can only leave one message which irks me.*
- *You are asked for SIN which I don't like giving but if you don't then you can't get help and you have to put up with them being rude as need the help.*

The challenges associated with finding and linking to services and supports negatively impacts on community reintegration. After leaving a very structured hospital setting that is providing supports and services 24/7, the sudden dramatic drop in services is traumatic for the stroke survivor and caregiver. Quickly linking to those community supports that will help to bridge that transition can reduce anxiety and social isolation while positively impacting the recovery journey. Community co-navigation provides that link. Stroke survivors and caregivers are still processing the stroke event and resultant life changes and the energy and focus it takes to navigate a complex and often uncoordinated health and support system can be overwhelming.

THE CAREGIVER'S VOICE

- *Important where you start the process – not good if you start without information, with not knowing where to turn – you are not talked to as an adult – you get behind, you feel like you're behind the 8 ball – you end up waiting a long time without knowing things*
- *Had a really good social worker who told us what was available to us – we had no shortage of help and it was good help. I appreciated it. We also had extra coverage through work insurance plan*

Lyons et al (2002) suggested a “family support organizer” who would provide education, emotional support, and [act as a] liaison to other services. Lyons also spoke to the potential underuse of services which is reflected in comments from the consultation participants who are often not aware of available services or how to access them. Lyons proposes that “Lack of education or the absence of a liaison with community services already available may contribute to the under use of important services available to stroke survivors. Not all services are appropriate for all stroke survivors, and evaluation on a case by case basis by health care professionals may help identify which patients are in need of what programs. Education programs may facilitate appropriate use of available community services.”(Lyons, 2002)

- *[There was] discomfort with going from hospital to home and what services are available. I didn't know services existed like financial.*
- *When first was out of hospital I felt that we fell through the cracks. No one was there to help us. I saw an ad in the paper for the support group.*
- *Survivor cannot complete forms so if no caregiver available then who does it? Forms are complicated and confusing to complete and they are time-sensitive. I was not aware of what the restrictions are to qualification.*
- *Information given in hospital is not that useful as are in crisis. Need the right information at the right time.*
- *Should be given a list of things that should be looked into, what is most beneficial for each individual. Information on services like respite, rehab, physio, government pensions.*
- *[You need a] three to six month follow up in your home to find out what needs are outstanding. Your doctor does not do this.*
- *CCAC Care Coordinator was not a positive experience, did not connect me with services. Talking to a stranger on the phone. This is a hard thing to talk about, emotional. You need face-to-face visits.*
- *Insurance company discussions are hard. They focus on what can't do versus what can do. Discussions by phone with insurance people who are not skilled or understanding stroke.*
- *No one told me anything about respite services.*
- *After I left [hospital] I was told that someone would call [from CCAC] but after 5 days still had no call so I called and was told that my partner had declined the services when asked in hospital. They took his word for it; he gets to make that decision but I'm the caregiver.*
- *It was only about two years ago that I found out that Veterans Affairs would cover four hours/week of services when the CCAC was cutting back on hours. We went from 60 hours/month to 40 hours/month.*
- *The day he was discharged, he was discharged with one sheet of paper, literally, one sheet of paper and it had his list of medications on it and that was all. There was no information package...the fact that he was in rehab for months, there should have been some sort of information package that left with him about resources in the community and I don't mean streamlined for us in our particular situation, just in general. There are a million things in my brain on a daily basis. Everything I have tapped in to I have tapped into because of my own research. I have been the one to find and reach out to programs.*

- *Everything was taken care of out of the hospital including in-home equipment. Every patient is different so really need someone to come out to the house initially to see how you're doing.*
- *Nobody mentioned any supports. If things were available I was unaware at the time and am still unaware. No CCAC [didn't know what acronym was]; never heard of it.*
- *When [stroke survivor] was going to be discharged they didn't give us any options. We had to say that she would come home with us even though we didn't have adequate supports to bring her home. What would have happened if we hadn't been there? Where would she have gone? They never told us.*

The theme of community co-navigation came out strongly in responses from caregivers. It is often the caregiver who is tasked with navigating a very complex system that can even challenge those who work within that system. Caregivers have been thrust into a complex new world of multiple care providers, community supports and bureaucratic mazes requiring complicated paperwork. This at a time when they are also experiencing all the emotions associated with a life-changing event. As well, the new expectations and tasks are added to existing responsibilities that continue to need attention. Wood et al (2010) found that, "Improving community reintegration requires greater collaboration between health care providers and stroke survivors. Patient priorities for recovery differ from those of health care providers and focus on the social context of recovery, including 'normality', re-establishing former identity and resuming roles. In contrast, health care providers focus primarily on the execution of discrete physical tasks." (Wood, 2010)

- *Make a community resource list available. I had to do an enormous amount of work on my own. The timing of information needs to be right; maybe in discharge package not early in hospital. You come home and you lay out all this stuff and you say, okay, now I need to look at all this stuff. Probably got it earlier in hospital but at that time he couldn't even talk.*
- *Need information about everything. If there is no information then we have to dig and help ourselves. This [support] group provided [so much] help.*
- *Need to get the information at the right time. Sometimes we don't ask the doctor, we don't question, we don't know what to ask. Maybe don't ask because of our age.*
- *Changes are important for people coming in behind us. They need help right out of the gate. Not one or two weeks later; it is an immediate need.*
- *There needs to be someone at the hospital who talks about and arranges services before discharge.*
- *There were things I didn't know that I found out as we went along. For example, it was only after [spouse] had been home for a few months that I called the CCAC Case Manager and asked if it was possible for someone to be here for part of a day so I could do some things. I didn't know there was respite .*
- *Had a speech and OT reassessment several years after [spouse's] stroke when I asked but I also didn't know that this could happen.*
- *Need to know where you go to get help. There are too many things and nobody knows where to go. It's critical that there is someone who knows what is available and what can be done. There seems to be a lot of money out there but nothing is coordinated. We need to get together to make it work. I heard of a lady here whose*

family is fundraising to get her a ramp. Why do they have to fundraise? Why isn't this provided?

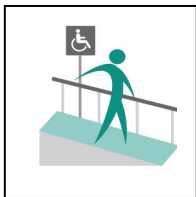
Community co-navigation emerged again as an area of focus; the need to have pre-arranged supports in place on transition home, a knowledgeable person who connects with the stroke survivor and caregiver to assess what the needs are and facilitate the coordination of services. The caregiver is often operating in survival mode during the immediate transition period; overwhelmed with what the reality of providing 24/7 care to a loved one looks like 'on the ground'. There is a sense of information overload in some cases, but the information is neither provided at the most appropriate time nor is it user-friendly.

THE HEALTH CARE PROVIDER'S VOICE

- *Stroke survivors need a capable and knowledgeable person to help them navigate the resources available in their communities. It is the old scenario: You do not know what you do not know. This person needs to be a consistent and long term resource to the stroke survivor. Someone that can be a contact even months or years from the time of the stroke, someone to navigate resources when the need exists.*
- *One person/educator/advocator is assigned to a person to follow and assist navigation thru system/hospital/to home*
- *Smooth transition home. Their lives have been turned upside down enough; the last thing that is needed for them to deal with is not knowing where to turn for help.*
- *OTA/PTA/PSW to accompany stroke survivors to initial community resources such as support group, community exercise programs (Revved Up, VON Stroke Specific, YMCA). Some stroke survivors need this to just get them there for the first visit – then it will be up to each individual whether they will continue or not.*
- *I think having family involved, having that support system really makes a difference, but also needing the right resources to help involve and educate the family.*
- *Not as much focus as there should be on community reintegration – there are lots of gaps in information sharing even getting the information out about [support] groups – and sometimes there is no information sharing within agencies*

With respect to community co-navigation, respondents noted the need for a person that would provide the long-term supports needed to ease transition home for both the client and caregivers. Goldberg et al (1997) found that while community services may be in place, they are not “centrally coordinated or well-publicized, and tend to provide little more than disjointed limited services often without access to opportunities for therapeutic recreation and other avocational pursuits that draw the patient and the caregiver back into the community. Stroke survivors and their caregivers frequently have difficulty obtaining timely access to stroke-related information and educational activities.” Hoffman et al (2003) cites a similar finding in a study by Wilkinson et al where a follow up was conducted on stroke survivors five years post-stroke which found that even

for those survivors “who were independent in self-care, difficulties were experienced with leisure and social participation and instrumental ADL.” The authors concluded that health and social service provision for the patients and their families was inadequate, and that there was a need for coordinated management of services across sectors to enhance long-term outcomes for people after stroke. (Hoffman, 2003) Other suggestions from health care providers revolved around transportation needs, supportive communication and the need for effective information sharing between health care settings and providers to reduce gaps and redundancy in assessments and support continuity of care and care plans.



SUPPORTED MOBILITY IN THE COMMUNITY

THE SURVIVOR'S VOICE

- *I live in the country and have had my own car since I was 15 years old. After the stroke I lost my driver's license and there's no accessible transportation in the country and a taxi is very expensive. You need transportation for what you need or want to do.*
- *You feel like a burden to others when asking for transportation. Friends say okay but after 7 or 8 times....or my husband has to take time off work. One of the biggest gifts I got was when a friend offered to take me out to breakfast. I had been a prisoner in my own home.*
- *Motorized wheelchair was a big plus as well as good accessible public transportation*
- *Transportation is important. If you have no driver's license then you're in trouble as it really limits your freedom and independence and your capacity to join things.*
- *Transportation was very difficult at first. I was a year getting my driver's license back and, at that time, I was still working. There was no reason why I should have lost my driver's license except I had a stroke and some guy in Toronto read a book and shut me down without testing me. I had to pay \$800 to get it back and they didn't give me any more of a test that what they would give to an 18 year old who was just learning to drive and getting his license for the first time*
- *I had to move out of my house in the country and into an apartment in the city as that makes it easier for therapy. I also lost my driver's license so transportation was very difficult in the country.*

It was clearly stated by participants that supports are of no value if you cannot afford to get to them (or them to you) or if you do not know that they exist. Removing a driver's license had a significant impact not only on mobility for the stroke survivor but also on the associated sense of

independence; “inability to drive may be associated with disruption in lifestyle, an inability to participate in the community, resume pre-stroke roles or maintain independence and autonomy...Stroke patients who do not resume driving report that this decision negatively impacted social activities and wellbeing.” (Salter, 2013)

- *Access to transportation was not met*
- *The driver’s license process [removing and reinstating] is not done with dignity or understanding. There is a demeaning aspect which is the last thing you need after having experienced a stroke. The process lacks a human touch; there is a lack of understanding that it is a human being standing in front of [the driver’s licensing person]...this time is very emotionally charged. [Going through the re-licensing process is] like going to a funeral home that doesn’t have grief counselors. They also don’t discuss the options available.*
- *I had to give up my driver’s license and then it was too expensive to get it back so I never did. It’s very hard. I sat one night and cried. They don’t understand how important it is to me.*
- *I was advised that I would have mini strokes so I didn’t feel safe to drive. What would happen if there was an accident? I would never forgive myself.*
- *Pretty well met when I returned to community. The only thing missing was inexpensive transportation. The [accessible] transportation cuts off early and is primarily available only 5 days/week so not available on weekends.*
- *There is no thought of continuity of care or distance to travel. Two days notice is needed for a community drive and sometimes medical appointment dates change...it costs \$80 to go to Kingston or my son has to take the whole day off, rearrange his schedule.*

This theme elicited considerable discussion particularly around the removal and reinstatement processes for drivers’ licensing which is an inherently emotional issue with its close links to independence and sense of control. Wood et al (2010) found that “Not being able to drive made participants feel like they were inconveniencing others as well as limiting their ability to get around... Poor standardization surrounding the procedures of resuming driving was also reported. For those that did resume driving during the first year post rehabilitation, it was critical to regaining control and independence.” Finestone et al (2010) echoes this link between driving and autonomy and also suggests that it “facilitates maintenance of social relationships and allows engagement in productive and recreational activities. As a result, driving cessation, whether voluntary or involuntary, may compromise stroke survivors’ community integration. (Finestone, 2010) Finestone goes on to state that while, alternative transportation may be available (e.g., friends, family, public transportation) they are not equal to the flexibility of independent driving and additionally points out that, for many stroke survivors, walking is not an option especially in rural locations. (Finestone 2010)

- *Sidewalks are not good if you are running around in a wheelchair. Know now why they name roads after politicians, they look smooth to begin with but most are*

cracked. Ramps on the sidewalks pull you into traffic and they're too short. They need to be tapered more down from the corners in both directions; it would be a lot safer.

- *Accessible public washrooms. If they're accessible, the support on one side is fine if you can use that side. I can't for the life of me understand what the bar at the back of the toilet is for. Empty space on the other side of the toilet could be used for the other bar.*
- *Making sure buildings are made accessible for people with mobility issues. Good now where public buildings like libraries and churches even have elevators.*
- *Driving restrictions mean less ability to get out on own.*
- *Volunteer drivers are helpful.*
- *More transportation and available for later hours so I could go out more easily, go out in evening for dinner and a drink.*
- *I'm not in community as can't get into stores, up steps so can't fully reintegrate*
- *[Re system for reinstating a driver's license]. Even if the policy can't be changed, perhaps there could be change/impact to the process through the private businesses who do not seem compliant with accessibility requirements. My vision is that the system provides the best and fairest chance to be assessed with dignity and without being demeaned. Otherwise you are left with bitterness. I found this the most demeaning part of experiencing a stroke. When I couldn't do something in therapy, I wasn't demeaned for my lack of ability. The driver's licensing people need education. We are very good with educating health care providers, but not with private business – they are isolated from rebuttal.*

Access to flexible, affordable, accessible transportation was seen to be a crucial component for rejoining a meaningful life journey. Leisure, recreational and support groups are of no value even the stroke survivor is unable to get to the location.

THE CAREGIVER'S VOICE

- *My job is not done at 4:30 so usually just have the evening free so no one available during the day to take (name of survivor) places – even if something is available in Kingston, that's a long way to go and don't want to go to city unless have to*
- *Transportation costs so much – have to pay \$50 just to go play euchre*
- *Transportation is important – he lost his license and doctor was adamant that he would not get it back but the PT helped – you really need a car and to be able to drive when you live in the country – PT said there was no reason why he couldn't drive so she did the letter...would be nice if there had been someone who would come by and just take him for a drive*
- *[Stroke survivor] lost his driver's license. What if my driver's license becomes compromised? I need my driver's license and my health to provide transportation when needed. The lack of a license is very restrictive*

The critical role played by accessible, affordable transportation in community reintegration was again discussed. The limited availability of accessible transportation that is able to be managed within restricted budgets can significantly impact on the capacity of the stroke survivor and caregiver to have time away from the confines of their own home and engage in broader social interactions. Even if transportation is available, it typically operates within Monday to Friday daytime hours and must be prearranged and may also be limited (or prioritized) to medically-related appointments. This is very different from the public transportation which is available at a nominal cost to the able-bodied population. Such inequity of services further segregates and isolates those who are living with the effects of stroke.

- *Transportation is an issue. Tried to use it once in winter and when I provided my address they said they did not provide service to that area even though I have seen the bus drive by. We are right on the border line so have no services. This would be a huge issue if I didn't drive as we are on road most days for various medical appointments, activities and errands.*
- *Transportation. Only one person in the family drives and if they are not available then no transportation. I think there is community van but you have to book in advance and there is a cost.*
- *Wish there was some other men's groups/activities and transportation available to support attendance.*
- *For a very brief time a worker was able to drive [stroke survivor] on local errands like to get groceries and for [stroke survivor] this was the most wonderful thing. They had to stop because of liability. So now, she may be invited to lunch but can't go because has no way to get there.*
- *Wish there were more accessible washrooms specifically for people with disabilities. Not separate male and female ones as that makes it hard for me as he needs help in the washroom.*
- *[Need] accessible bathrooms. Often it is a male or female bathroom so I can't always go in and he needs help to get dressed after using washroom. Sometimes I have to wait outside the bathroom to help him get dressed in the hallway.*

Not surprisingly, improvements to transportation systems and accessibility were voiced in these discussions. The challenges encountered with washroom facilities that were either not accessible or were gender specific were also discussed. These challenges can negatively impact on self-esteem, independence and a sense of control.



ACCESS TO SUPPORTS & SERVICES (STROKE SURVIVORS)

THE SURVIVOR'S VOICE

- *The hospital made an assumption that I would be going to a LTC Home and the Home wasn't even in [our area]. If I didn't have a son at home then I would have gone to LTC. People just assume that my son and his wife will be available as helpers but they're not there regularly and it's an unfair assumption as they have other obligations.*
- *I needed practical assistance to remain at home. I was in several residential places (including LTC) before I came back home and that was only through my own determination. I needed help with things like laundry and housekeeping.*
- *I need a provider to help me return to work, leisure and volunteer activities – doing what I love to do – activities/interests are unique to each individual depending on the impairment.*
- *Practical assistance is important to stay at home. Now I live in condo so I don't have to worry about snow removal. I don't want to move or to go to LTC. I am independent now and I want to stay that way. I would hate to see one of us have to go to LTC, not be together. That would bother me.*
- *My friends were there and my family never went away*
- *My needs were met through my wife rather than a paid provider. Things came true because my wife loves me, inspires me, walks with me.*
- *Neighbours just take care of each other and don't think anything about it; they just do it.*
- *I was amazed at how little support you get in time of need from (community/volunteer) organizations that you belong to. When you can't attend, you lose interest in them and they lose interest in you.*
- *Having to pay for personal care needs like cutting nails [is hard]. This is done for free for people with diabetes. I can't do my own nails due to stroke.*
- *How do I get the right people around my house to do the things I need (grass cutting, cleaning up yard)? Sometimes I pay and then they don't come or they come early in morning and when they leave it looks the same. Dealing with home needs (e.g., TV, computer). You may be told it's 'free of charge' but then there is a cost for something else; sometimes you have to depend on when family can come to address things.*

Transition home can be a time of significant adjustments for both the stroke survivors and caregiver. As Nanninga et al (2014) stated “While “going home” is seen as an important milestone in the rehabilitation process, “being home” is accompanied by the development of greater self-awareness of deficits. Stroke survivors increasingly come to realize that their pre-discharge expectations of life do not match real-life experiences. Many of them experience a

downward spiral of physical decline, social isolation and depression after discharge from the rehabilitation clinic...Living with disabilities after a stroke, at home and in the community, needs to be regarded as a lifelong effort.” The authors went on to explore how the attempt to resume pre-stroke roles was fraught with challenges. Some “explained how they needed all their energy to perform daily activities that they used to do pre-stroke without even thinking...Other participants felt frustrated because their bodily impairments were not always visible to significant others.” (Nanninga, 2014)

Not all stroke survivors return home to the support of family and friends. Some live a distance from family, others may have a partner who is also experiencing health concerns and so has limited ability to provide care and support, while others may be estranged from family. These survivors face particular challenges as they may be expected to manage the complexities of finding and accessing appropriate services while, at the same time, struggling to adjust (physically and emotionally) to their altered state, effect a safe transition home and do all this in the context of significant fatigue.

- *I have a very small income. I had two businesses but the stroke ended that. There is a shortage of ongoing money as I am having to pay for treatment (e.g., physio, acupuncture)...Things are expensive like special door handles. There are costs for things like splints and a wheelchair and things don't last forever, they need to be replaced or adjusted. .*
- *Need adequate financial resources. You suddenly can't go to work, have decreased money and the bills are coming in and your credit is gone. You can't find out who you should talk to. You have to learn to survive on that little bit of money.*
- *A delay in drug benefits meant we owed thousands of dollars.*
- *Financial is also important as it's all connected. My tastes seem to cost money; now not as much eating out regularly.*
- *You need adequate financial resources. Lots don't have enough money and if you don't then that's a worry and that doesn't help.*
- *What's important depends on your practical situation. We have excellent health insurance plan that provides for everything we needed. Without it we would have been bankrupt (e.g., plan aid 80% of an \$8500 mattress).*
- *Financial resources are important. I didn't have to worry about myself or family but others do. They may worry about rent, bills, etc. worry about finding another job.*
- *Lots of people may want to help/volunteer but can't afford to (e.g. time off work, cost)*
- *After my stroke, I had to renovate my house which was expensive*

Having adequate financial resources provoked considerable discussion. As described above, selection of this component was very much linked to each individual's personal situation. At the same time, there was also verbalization by participants who did not personally have challenges in this respect to recognize the impact it could have on others. Stroke is an expensive experience that can linger on throughout the life of the individual. The survivor usually does not return to work, the caregiver may have to modify their work commitment to support the survivor,

adaptations to the home or vehicle are unlikely to be fully reimbursed, nor are specialized mobility aids. Egan et al (2015) referred to an American study that found a link between lower socioeconomic status and declining functional activity two years post-stroke. Further, individuals in low income neighbourhoods experienced increased challenges to participating in leisure/recreational activities. Lack of affordable transportation options proved to be a barrier even to those activities which may be offered at no cost. As stated by Egan et al (2015) “higher income may provide a needed buffer against the stresses created by the illness; without such a buffer, latent psychological problems, such as depression, may emerge, creating further barriers to engagement in valued activity.”

- *Caregiver works part time and provides care which is very challenging.*
- *I never heard of CCAC.*
- *Community support is also very important as is family support. I was already well integrated into the community when I had my stroke.*
- *It's not fair to expect my husband to do everything. We have it down to a science and work together but you need support somewhere along the line for the caregiver.*
- *If the stroke survivor could wear a sign saying 'I'm a stroke survivor' then this might help others to help them. Then a person may ask/find out how to communicate to stroke survivor. If you don't see the impairment....If you do go out it gives a positive image of a stroke survivor/person with disabilities. You are a person first. It would be good to educate students – I would like to do a presentation on being inclusive in minor sports for those with a disability (players and coaches).*
- *Need to integrate people with a disability. Community has to understand. People are scared of us, of our disability.*
- *Need education in schools so they understand what a stroke is and how to prevent it and how to respond to it.*
- *People need to know what to do in the event of a stroke – to call 911 immediately*
- *The people I call up don't recognize that I have had a stroke, what that means.*
- *Would be good to have people who have had stroke on committees. One thing that could be done by some kind of organization is to encourage the disabled who have done things/redesigned things to make things better for themselves to pass on that information to others so there is a common source for everybody. Could be a website, could be community care who has a list of people who can do things.*
- *Community is sometimes not an easy community to go back into. We need to change the face of the community, need to educate about stroke, what it is, how to support people who have had a stroke. We need to be conscious of people who struggle to get back to work*

The value of supports and services in the context of community reintegration was also voiced by the stroke survivors. There was also reference in these discussions to education and advocacy. There is a sense that both health care providers and the community at large would benefit from increased knowledge re stroke. The lack of understanding within the broader community of how stroke can impact an individual erects additional barriers to community reintegration. If a stroke survivor is not feeling comfortable in the community, is not receiving the support and

understanding necessary to resume (adjusted) life roles, the impacts can be significant (e.g., social isolation and depression).

THE CAREGIVER'S VOICE

- *Found it very hard to bring [stroke survivor] back and forth to rehab three times a week especially as it was in winter. One hour travel each way plus cost of parking and meals but there was no way we were going to miss physiotherapy to get where she is now. Got some funding from ODSP but it was still very costly and stressful.*
- *Practical help is important – this is new to me, I have never been involved with someone who had a stroke before*
- *With initial discharge home we really needed help as kids were younger and had to manage farm. This was when we really needed lots of services; had so many things on your plate.*
- *We had our own business so everything was tied up. We were told to go on welfare but I really didn't want to do that. Even today I find it hard to talk about it; we had to get rid of some things. Biggest problem was financial. It was important to get disability in place which was hard and then every year we have to go back to doctor to get form filled out again and if there is any change on the form then he may not be qualified and then what do we do? At one point the doctor said there were jobs he could do like run a elevator, but that is not what he wants to do and even if he did how would we get him to Kingston?*
- *Going from 2 incomes to 1 has huge impacts*

As with the stroke survivors, caregivers felt that community supports held a primary place in effective community reintegration. While access to adequate financial resources was discussed as a stand alone topic, it is also threaded through the discussion of other areas such as transportation, lack of private insurance and/or the ability to afford private pay services. Salter et al (2013) spoke to a study by Smith et al (2004) where caregivers were reporting spending seven days a week providing care to the stroke survivor and almost half of the respondents reported spending more than 160 hours per week caregiving. Salter goes on to state that reports have suggested that more than 25% of caregivers under 65 years of age necessarily either reduce their number of paid working hours or leave their employment completely. (Salter 2013)

THE HEALTH CARE PROVIDER'S VOICE

- *The very limited funding programs available to assist clients with obtaining the equipment, mobility devices and ADL/IADL aids that they require even through local loan equipment services.*

**APPENDIX G
HEALTH SYSTEM ALIGNMENT CHART**

PERSON-CENTRED STROKE CARE & REHABILITATION SERVICES			
Canadian Best Practice Recommendations for Stroke Care (2013)	Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute) (2015)	MoHLTC & SE LHIN Initiatives	Health Quality Ontario <i>The Reality of Caring</i>
<p><u>Recommendation 5.3 Delivery of Inpatient Stroke Rehabilitation</u> vii. Regular interprofessional meetings</p> <p><u>Recommendation 5.4 Outpatient and Community-Based Stroke Rehabilitation (including Early Supported Discharge)</u> 5.4.1 Outpatient & Community-Based Rehabilitation i., ii, iii Early, frequent specialized stroke services in appropriate setting by interprofessional team. Person-centered care and goal setting. Team communication. Reassessments.</p> <p><u>Recommendation 6.1 Supporting Patients, Families and Informal Caregivers Following Stroke</u> 6.1.1, 6.1.2 Transition planning, screening and assessment with appropriate referrals (e.g., mental health experts, social services, etc.). Person-centred individualized rehab plan, discharge planning include training, equipment and home modifications. Access to restorative care and active rehabilitation in LTC. The use of telemedicine technology to increase access</p> <p><u>Recommendation 6.2 Patient, Family and Informal Caregiver Education</u> 6.2.1, 6.2.2, 6.2.3 Assess learning goals, current knowledge; develop learning plan; document. Include self-management, training, individualized to survivor/caregiver need; document.</p> <p><u>Recommendation 6.3 Interprofessional Communication</u> Timely and effective transfer of relevant patient-related information. Up-to-date care plan for survivor and caregiver. Care plan is patient-centred and updated. Written discharge instructions.</p> <p><u>Recommendation 6.4 Discharge Planning</u> Person-centred goal-oriented discharge planning. Include home visits, interdisciplinary collaboration, caregiver training, passes. Post-discharge follow-up plan and communication between settings.</p> <p><u>Recommendation 6.5 Community Reintegration Following Stroke</u> 6.5, 6.5.1, 6.5.2 Provide information, support and access to services. Regular, ongoing follow-up. Capacity to re-access rehab over long-term. Use of telemedicine to increase access.</p> <p><u>Recommendation 6.6 Transition of Patients to Long-Term Care Following a Stroke</u> 1.6 Continue to have their physical, functional, emotional, cognitive and social needs addressed.</p>	<p><u>Module 5 Secondary Prevention</u> 5.10.1 & 5.10.3 Ongoing assessment & referral to community resources</p> <p><u>Module 6 Predischarge/Discharge Planning</u> 6.1.1 Pre-discharge assessment for survivor and caregiver 6.2.1, 6.4.1, 6.4.2 Transitional & discharge care/goal planning in collaboration with survivor & caregivers 6.3.1, 6.3.2, 6.4.6 Linking to supports and services. Follow-up.</p> <p><u>Module 8 Community Assessment</u> 8.7, 8.7.4 Depression screening & treatment All patients should be screened for depression with a validated tool.</p> <p><u>Module 9 Community Treatment</u> 9.1.1, 9.2.1, 9.2.2, 9.3.2, 9.3.3, 9.3.4, 9.4.1, 9.4.2, 9.4.3, 9.4.4 Early rehab with front-loading in first 6 months by coordinated, interprofessional team specialized in stroke care. Team meets regularly. Coordination between hospital and community. 9.4.5 Care coordination and sharing of information 9.5.2, 9.6.2 OT, SLP and PT 2-3 visits/week for 8-12 weeks. Increased as needed. 9.8.1, 9.8.2, 9.8.4, 9.16.1 Survivor/caregiver education 9.16.1, 9.16.2 Depression screening & treatment</p> <p><u>Module 10 Cross Continuum Processes</u> 10.1.2, 10.4.1 Regular and ongoing follow-up by a specialized team. Interprofessional team should receive education and training to promote stroke expertise 10.2.1, 10.3.1, 10.6.1 Person-centred goal-setting, education and tailored interventions.</p>	<p><i>Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario</i> Access Improve access - providing faster access to the right care. Inform Support people and patients - providing the education, information and transparency Ontarians need to make the right decisions about their health. A responsive health system where:</p> <ul style="list-style-type: none"> • care providers work together to provide integrated care, • patients and their caregivers are heard and play a key role in decision making and in their care plans, • people can move easily from one part of the system to another, • someone is accountable for ensuring that care is coordinated at the local level. <p>SE LHIN IHSP4 Equitable access to quality care</p> <ul style="list-style-type: none"> ▪ fair distribution of resources, based on need - patients receive the services they require <p>An integrated, patient-centred continuum of care</p> <ul style="list-style-type: none"> ▪ sharing information & wrapping the system around the needs of the patient. <p>Older Adult Strategy</p> <ul style="list-style-type: none"> • Caregiver well-being • Early high risk identification & intervention • Care coordination • Support for dementia, behavioural and mental health issues 	<ul style="list-style-type: none"> ▪ Recommended measures such as better preparation and instruction of caregivers for the responsibilities they are taking on; better coordination of home care services so that the burden of organizing care will not fall so much on caregivers; provision of clear information on what home care services are available and who is entitled to them; more consistent and reliable delivery of services; more services for high-needs patients; and more consideration of caregivers' needs and respect for the important role they play.

INDIVIDUAL WELL-BEING & MEANINGFUL ENGAGEMENT

Canadian Best Practice Recommendations for Stroke Care (2013)	Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute) (2015)	MoHLTC & SE LHIN Initiatives	Health Quality Ontario <i>The Reality of Caring</i>
<p><u>Recommendation 5.11 Life Roles & Activities</u> Return to Vocation- Assess for RTW early. Include in care planning. Access to vocational rehab. Leisure Activity – Assess and support return to leisure activities with targeted therapeutic interventions. Link and refer including peer support.</p> <p><u>Recommendation 6.1 Supporting Patients, Families and Informal Caregivers Following Stroke</u> 6.1.2 Patient, Family and Caregiver Support v. If LTC transition include counseling and ongoing assessment; refer to peer support. vii. Use telemedicine technology to increase access</p> <p><u>Recommendation 6.2 Patient, Family and Informal Caregiver Education</u> 6.2.1, 6.2.2, 6.2.3 Caregivers assessed for understanding of ongoing survivor needs and caregiver capacity. Self-management and training. Goal-oriented, individualized, interactive; documented & ongoing. Evaluate for RTW, return to leisure activities and relevant modifications for re-engagement in roles/activities.</p> <p><u>Recommendation 6.4 Discharge Planning</u> Early discharge planning. Team member designated to facilitate ongoing planning, including reviews and updates up to discharge.</p> <p><u>Recommendation 6.5 Community Reintegration Following Stroke</u> 6.5.1, 6.5.2 Primary care follow-up including mental health/depression/cognitive screening. Use of telemedicine technology modalities to increase access. 6.5.3 Early vocation assessment and counseling including financial counseling in unable to RTW. . Work with employers/educators to devise an appropriate RTW plan. Use of telemedicine technology to support RTW and skills attainment. Assess for rehabilitative needs to resume leisure activities. Link to community-based aerobic and leisure activities. 6.5.4 Family and Caregiver Support and Well-being Regular, ongoing assess of physical, psychosocial, mental well-being. Information on/linking with peer support groups and hospital-based peer support visit programs.</p> <p><u>Recommendation 6.6 Transition of Patients to Long-Term Care Following a Stroke</u> 6.6.3 Patient and Family Support and Education Offer peer support information and counseling.</p>	<p><u>Module 5 Secondary Prevention</u> 5.4.5, 5.4.6 Exercise</p> <p><u>Module 6 Predischage/Discharge Planning</u> 6.3.1 Survivor/caregiver role changes and service linkages</p> <p><u>Module 8 Community Assessment</u> 8.7, 8.7.4 Depression screening & treatment</p> <p><u>Module 9 Community Treatment</u> 9.6.3, 9.13.1, 9.13.2, 9.13.3, 9.13.4, 9.25.1, 9.25.2 Individually prescribed exercise program, support for leisure & physical activities & referral to support groups 9.14.1, 9.14.3, 9.14.4 Vocational assessment and counseling</p> <p><u>Module 10 Cross Continuum Processes</u> 10.1.2, 10.1.3, 10.5.1, 10.6.2 Regular, ongoing follow-up by a specialized team including psychosocial and support needs and information on peer support 10.1.4 Monitor & assess for depression 10.5.2 referrals & linkages to community supports; access to contact person for post-discharge queries</p>	<p><i>Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario</i> Access Some families find home and community care services inconsistent and hard to navigate, and many family caregivers are experiencing high levels of stress.</p> <p><i>Older Adult Strategy</i></p> <ul style="list-style-type: none"> • Caregiver well-being • Support for dementia, behavioural and mental health issues 	<ul style="list-style-type: none"> ▪ Recommended measures such as greater availability of respite services such as adult day programs; more services for high-needs patients; and more consideration of caregivers' needs and respect for the important role they play

COMMUNITY CO-NAVIGATION

Canadian Best Practice Recommendations for Stroke Care (2013)	Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute) (2015)	MoHLTC & SE LHIN Initiatives	Health Quality Ontario <i>The Reality of Caring</i>
<p><u>Recommendation 5.3 Delivery of Inpatient Stroke Rehabilitation</u> Discharge planning to support self-management and system navigation.</p> <p><u>Recommendation 5.11 Life Roles & Activities Leisure Activity</u> Provide information on/link to leisure activities and peer support groups</p> <p><u>Recommendation 6.1 Supporting Patients, Families and Informal Caregivers Following Stroke</u> 6.1.1 Provide information, education, training, emotional support, and link to community services 6.1.2 Patient, Family and Caregiver Support Early discharge planning including expectations re role changes and information on available supports and services. Access to post-discharge contact person including post-discharge telephone follow-up. Referrals to community agencies such as stroke survivor groups, peer survivor visiting programs. If transitioning to LTC, access to contact person in LTC for individualized care and rehabilitation planning, re-engagement in social and leisure activities.</p> <p>6.2.2 Delivery of Individualized Patient, Family and Informal Caregiver Education Provide information on/link to supports and services.</p> <p><u>Recommendation 6.3 Interprofessional Communication</u> Timely, effective transfer of relevant patient-related information. Designated team member should facilitate transfer of information, patient referrals and ensure educational needs have been addressed.</p> <p><u>Recommendation 6.5 Community Reintegration Following Stroke</u> 6.5.3 Reintegration to Social and Life Roles Following Stroke C. Disability Supports in the Community - Social workers or case managers should ensure timely access to services and equipment and help with navigation</p>	<p><u>Module 6 Predischarge/Discharge Planning</u> 6.2.1, 6.3.2, 6.4.6 Transitional care planning and education tailored to need and follow up call</p> <p><u>Module 9 Community Treatment</u> 9.4.5 Care coordination, linkages, reassessments, support for self-management</p> <p><u>Module 10 Cross Continuum Processes</u> 10.6.3 Ongoing support</p>	<p><i>Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario Access</i> Health services fragmented affecting the patient experience, inefficient use of patient and provider time and resources, poor health outcomes.</p> <p><i>Patients First: Action Plan for Health Care</i> (February 2015), Connect Connect services - delivering better coordinated and integrated care in the community closer to home.</p> <p>PROPOSAL #1 Care that is more integrated and responsive to local needs. In their expanded role, LHINs would:</p> <ul style="list-style-type: none"> • Work with providers across the care continuum to improve patients' access to services, and make it easier for both patients and providers to navigate the system. <p>PROPOSAL #3 Strengthen accountability and integration of home and community care.</p> <ul style="list-style-type: none"> • The ministry proposes to move all CCAC functions into the LHINs to help integrate home and community care with other parts of the health care system, and to improve quality and accountability. The proposed shift will create opportunities to embed home and community coordinators in other parts of the system. <p><i>Older Adult Strategy</i></p> <ul style="list-style-type: none"> • Early high risk identification & intervention • Access to supports to stay in community • Care coordination 	<ul style="list-style-type: none"> ▪ Caregivers should not have to endure added, avoidable distress as a result of not getting the help they need or being left feeling abandoned and isolated ▪ Recommended measures such as better preparation and instruction of caregivers for the responsibilities they are taking on; better coordination of home care services so that the burden of organizing care will not fall so much on caregivers; provision of clear information on what home care services are available and who is entitled to them.

ACCESS TO SUPPORTS & SERVICES

Canadian Best Practice Recommendations for Stroke Care (2013)	Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute) (2015)	MoHLTC & SE LHIN Initiatives	Health Quality Ontario <i>The Reality of Caring</i>
<p><u>Recommendation 5.3 Delivery of Inpatient Stroke Rehabilitation</u> Pre-discharge needs assessment may include home visit and assessment of safety, need for equipment and/or modifications.</p> <p><u>Recommendation 5.11 Life Roles & Activities Return to Vocation</u> Assess for RTW and provide counseling including advice on relevant issues such as health and disability benefits and legal rights</p> <p><u>Recommendation 6.1 Supporting Patients, Families and Informal Caregivers Following Stroke</u> 6.1.1 Assess caregiver care capabilities and experience; resource issues and social supports. 6.1.2 Provide information re role changes and the availability of services and resources within changing care environments. Access to a contact person. Referrals to/linking with community agencies including stroke survivor groups, peer survivor visiting programs</p> <p><u>Recommendation 6.4 Discharge Planning</u> Early discharge planning and may include home-visits for patients being discharged to the community to identify home modifications required for access and safety.</p> <p><u>Recommendation 6.5 Community Reintegration Following Stroke</u> 6.5.3 Reintegration to Social and Life Roles Following Stroke C. Disability Supports in the Community Provide information and linkages regarding access to disability support services. Develop a mobility access plan. Counseling re disability legislation and guidelines and complete appropriate documentation and applications. Social workers or case managers to support access to appropriate services and equipment and help navigate through the system.</p>	<p><u>Module 9 Community Treatment</u> 9.5.3 Exercise, environmental modifications for high-risk elderly 9.10.1 Care coordination and personal support services</p>	<p><u>SE LHIN IHSP4 Working with partners towards achieving a high performing health care system</u></p> <ul style="list-style-type: none"> ▪ better health depends on many factors outside the health care sector, such as housing, employment and food. <p><u>Older Adult Strategy</u></p> <ul style="list-style-type: none"> • Access to supports to stay in community 	<ul style="list-style-type: none"> ▪ Recommended measures such as provision of clear information on what home care services are available and who is entitled to them; more consistent and reliable delivery of services.

SUPPORTED MOBILITY IN THE COMMUNITY			
Canadian Best Practice Recommendations for Stroke Care (2013)	Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute) (2015)	MoHLTC & SE LHIN Initiatives	Health Quality Ontario <i>The Reality of Caring</i>
<p><u>Recommendation 6.5 Community Reintegration Following Stroke</u> Support access to appropriate public transportation that supports people with disabilities. Programs need to be in place that support timely and affordable access to mobility and other assistive devices.</p>	<p><u>Module 8 Community Assessment</u> 8.1.2 Driver training</p>	<p><i>Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario Access</i></p> <p>PROPOSAL #1 Care that is more integrated and responsive to local needs. In their expanded role, LHINs would:</p> <ul style="list-style-type: none"> • Work with providers across the care continuum to improve patients' access to services, and make it easier for both patients and providers to navigate the system. <p><i>SE LHIN IHSP4 Working with partners towards achieving a high performing health care system</i> better health depends on many factors outside the health care sector, such as housing, employment and food.</p> <p><i>Older Adult Strategy</i></p> <ul style="list-style-type: none"> • Access to supports to stay in community 	

APPENDIX H: GLOSSARY

CCAC	Community Care Access Centre
CIHI	Canadian Institute of Health Information
CRLT	Community Reintegration Leadership Team
HPE	Hastings, Prince Edward
KFLA	Kingston, Frontenac, Lennox & Addington
LHIN	Local Health Integration Network
LLG	Lanark, Leeds, Grenville
LTC	Long Term Care
NOSN	Northeastern Ontario Stroke Network
OSN	Ontario Stroke Network
OT	Occupational Therapist
PSW	Personal Support Worker
PT	Physiotherapist
QBP	Quality Based Procedures
Q Sort	Research method used to collect information from participants with regard to their perceptions about community reintegration
RN	Registered Nurse
RPN	Registered Practical Nurse
RSSC	Regional Stroke Steering Committee
SE	Southeast
SNSEO	Stroke Network of Southeastern Ontario
SLP	Speech Language Pathologist

APPENDIX I

REFERENCES

- Blomer, AM., van Mierlo, M.L., Visser-Meily, J.M., van Heughten, C.M., Post, M.W. Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? *Archives of Physical Medicine and Rehabilitation* 96, 456-63, 2015.
- Chau, JPC, Thompson, D.R., Twinn, S., Chang, A.M., Woo, J. Determinants of participation restriction among community dwelling stroke survivors: A path analysis. *BMC Neurology* 2009, 9:49.
- Chen, YK., Qu, JF., Xiao, WM., Li, WY., Weng, HY., Li, W. and Xiang, YT. Poststroke fatigue: risk factors and its effect on functional status and health-related quality of life. *World Stroke Organization*. 10, 506–512, 2014.
- Cruice, M., Worrall, L., Hickson, L. Reporting on psychological well-being of older adults with chronic aphasia in the context of unaffected peers. *Disability and Rehabilitation*, 33(3): 219–228, 2011.
- Davidson, B., Howe, T., Worrall, L., Hickson, L., Togher, L. Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation*. 2008. 15(4): 325-340.
- Dijkers, MP. Correlates of life satisfaction among persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*. 1999 Aug;80(8):867-76.
- Egan, M., Kubina, LA., Dubouloz, C.J., Kessler, D., Kristjansson, E., Sawada, M., Very low neighbourhood income limits participation post stroke: preliminary evidence from a cohort study. *BioMed Central*. 15:528, 2015.
- Eskes, GA., Lanctôt, KL., Herrmann, N, Lindsay, P, Bayley, M, Bouvier, L and Swartz, RH. *Canadian Stroke Best Practice Recommendations: Mood, Cognition and Fatigue Following Stroke* practice guidelines, update. 2015.
- Finestone, H.M., Guo, M., O'Hara, P., Greene-Finestone, L., Marshall, S.C., Hunt, L., and Jessup, A. Driving and reintegration into the community in patients after stroke. *American Academy of Physical Medicine and Rehabilitation*, 2, 497-503. 2010
- Goldberg, G. Segal. M.E., Berk, S.N., Schall, R.R., Gershkoff, A.M. Stroke transition after inpatient rehabilitation. *Top Stroke Rehabilitation*, 4(1). 1997.
- Hilari, K. The impact of stroke: are people with aphasia different to those without? *Disability and Rehabilitation*, 33:3, 211-218, 2011.
- Hoffmann, T., McKenna, K., Cooke, D., Tooth, L. Outcomes after stroke: Basic and instrumental activities of daily living, community reintegration and generic health status. *Australian Occupational Therapy Journal*. 225–233. 2003.
- Hommel, M., Carey, L., Jaillard, A., Depression: Cognition relations after stroke. *International Journal of Stroke*. 10: 893-896. 2015.
- Kessler, D, Egan, M, Kubina, LA Peer support for stroke survivors: a case study. *BMC Health Services Research* 2014, 14:256
- Lee, Y, McCormack, BP., Austin, DR. Toward an engagement in social support: A key to community integration in rehabilitation. *World Leisure* No. 3, 2001.

Liu-Ambrose, T., Eng, J.J. Exercise training and recreational activities to promote executive functions in chronic stroke: A proof-of-concept study. *Journal of Stroke and Cerebrovascular Diseases*, 24:1, 130-137, 2015.

Lutz, B.J., Young, M.E. Rethinking intervention strategies in stroke family Caregiving. *Rehabilitation Nursing*. 35:4 2010.

Lyons, R., McDonald, A., Babin, P., Harrison, E., LeBlanc, J., MacKay-Lyons, and Phillips, N. Critical Appraisal of Current Best Practices Literature Concerning Stroke Rehabilitation. *Community Alliance for Health Research*. 2002.

Martinsen, R., Kirkevold, M., Sveen, U. Younger stroke survivors' experiences of family life in a long-term perspective: A narrative hermeneutic phenomenological study. *Nursing Research and Practice*. Volume 2012.

Mas, M.A., Inzitari, M., A critical review of Early Supported Discharge for stroke patients: from evidence to implementation into practice. *International Journal of Stroke*. 10:7–12, 2015.

Mayo, N., Wood-Dauphanee, S., Cote, R., Gayton, D., Carlton, J., Buttery, J., Tambllyn, R. There's no place like home: An evaluation of early supported discharge for stroke. *Stroke* <http://stroke.ahajournals.org/>

McPherson, K.M., Siegert, R.J. Person-centred rehabilitation: Rhetoric or reality? *Disability and Rehabilitation*. 29(20 – 21): 1551 – 1554, 2007.

Montgomery, P., Jermyn, D., Bailey, P., Nangia, P., Egan, M., Mossey, S., Community reintegration of stroke survivors: the effect of a community navigation intervention. *Journal of Advanced Nursing* 71(1), 214– 225. 2015.

Moreland, J.D., DePaul, V.G., Dehueck, A.L., Pagliuso, S.A., Yip, D.W.C., Pollock, B.J., Wilkins, S. Needs assessment of individuals with stroke after discharge from hospital stratified by acute Functional Independence Measure score. *Disability and Rehabilitation*, 31(26) 2009.

Mossey, S., Montgomery, P. Raymond, J. Killam, L. Typology of Undergraduate Nursing Students' Unsafe Clinical Practices: Q-Methodology. *Journal of Nursing Education*. 51: 5, 2012.

Murtezani, A., Hundozi, H., Gashi, S., Osmani, T., Krasniqi, V., Rama, B. Factors associated with reintegration to normal living after stroke. *MED ARH* 63(4), 2009.

Nanninga, C.S., Meijering, L., Schonherr, M., Postema, K., Lettinga, A.T. Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disability and Rehabilitation*, Early Online: 1–10 2014.

Obembe, A., Mapayi, B., Johnson, O., Agunbiade, T., Emechete, A. Community reintegration in stroke survivors: Relationship with motor function and depression. *Hong Kong Physiotherapy Journal* 31, 2013.

Pang, MYC, Eng, J.J., Miller, W.C. Determinants of satisfaction with community reintegration in older adults with chronic stroke: Role of balance self-efficacy. *Physical Therapy* 87:3 2007.

Persson, J., Holmegaard, L., Karlberg, I., Redfors, P., Jood, K., Jern, C. And Forsberg-Wärleby, G. Spouses of stroke survivors report reduced health-related quality of life even in long-term follow-up: Results from Sahlgrenska Academy Study on Ischemic Stroke. *Stroke*, 2015.

Salter, K., Allen, L., Richardson, M., Teasell, R., Foley, N. Community Reintegration, *Evidence-Based Review of Stroke Rehabilitation*, 19, 2013. www.ebrsr.com

Simons, J. An introduction to Q methodology. *Nurse Researcher*. 20:3, 2013.

Walsh, M.E., Galvin, R., Loughnane, C., Macey, C., Frances Horgan, N.F. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. *Disability and Rehabilitation*, Early Online: 1–10. 2014.

Wood, J.P., Connelly, D.M., Maly, M.R. 'Getting back to real living': a qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation*, OnlineFirst, 2010.

Wood-Dauphinee, S., & Williams, J. I. (1987). Reintegration to normal living as a proxy to quality of life. *Journal of Chronic Diseases*, 40(6), 491-499. 1987.