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

https://www.stroknetworkseo.ca/
The Numbers

- There are an estimated 25,500 new stroke events in Ontario each year; at least every 30 minutes, there is one new stroke in Ontario.¹

- Of every 100 people who have a stroke:
  - 15 die
  - 10 recover completely
  - 25 recover with a minor impairment or disability
  - 40 are left with a moderate to severe impairment
  - 10 are so severely disabled they require long-term care²

¹ Ontario Stroke Network, 2016
² Quality Based Procedures: Clinical Handbook for Stroke, 2015
The Impact

“We were sitting looking through Christmas pictures of the kids and saying how cute they were and then suddenly she was quiet and didn’t show me any pictures - she didn’t have any movement or sound or conversation, just bang like that – it’s a major game changer.” ~ Caregiver
# The Process

<table>
<thead>
<tr>
<th>2007</th>
<th>2008</th>
<th>2015</th>
<th>2015/16</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community Consultation</strong></td>
<td><strong>Community Reintegration Leadership Team (CRLT)</strong></td>
<td><strong>Best Practice</strong></td>
<td><strong>Community Consultation</strong></td>
<td><strong>Moving Forward</strong></td>
</tr>
<tr>
<td>• facilitated focus groups</td>
<td>• evolved from consultation</td>
<td>• Clinical Handbook for Stroke (Acute &amp; Post Acute) (QBP)</td>
<td>• focus groups, interviews, surveys</td>
<td>• actionable recommendations</td>
</tr>
<tr>
<td>• stroke survivors, caregivers, health care providers</td>
<td>• advance &amp; sustain actions arising from 6 themes</td>
<td>• Canadian Stroke Best Practice Recommendations</td>
<td>• stroke survivors, caregivers, health care providers</td>
<td>• accountability via CRLT and Regional Stroke Steering Committee</td>
</tr>
<tr>
<td>• <em>Building Capacity Report</em> (6 themes)</td>
<td></td>
<td>• CRLT → validate findings of 2007 consultation and alignment with best practice</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute)**

February 2015

**PLAN**
Participants – Stroke Survivors

Overall Mean Age 69 years (SD = 14.2)
Mean Age – Males 69 years
Mean Age – Females 68 years
Overall Median age 69 (Range 25-91)

Rural – 33%
Urban - 67 %
Participants – Stroke Survivors

Stroke Survivor by Year of Stroke

- 1985-1989: 1
- 1990-1994: 1
- 1995-1999: 4
- 2000-2004: 5
- 2005-2009: 3
- 2010-2015: 28
Participants – Caregivers

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall Mean Age</strong></td>
<td>67 years (SD = 14.5)</td>
</tr>
<tr>
<td><strong>Mean Age – Males</strong></td>
<td>74 years</td>
</tr>
<tr>
<td><strong>Mean Age – Females</strong></td>
<td>65 years</td>
</tr>
<tr>
<td><strong>Median age</strong></td>
<td>66 (Range = 16 – 88)</td>
</tr>
</tbody>
</table>

Stroke Caregivers

N=23

MALE 30%

FEMALE 70%

Rural – 42%
Urban - 58 %
Participants – Health Care Providers

50% Front Line
50% Care Coordinator/Supervisor
Q Sort Methodology

- Laurentian University
- 30 Q Statements & Ranking Template
- Modified for Southeast
- In-person (stroke survivors & caregivers) or electronic (health care providers)
Supporting Discussions

- What made your most important areas so important?
- Are/were these areas met when you returned to the community?
- Are there any areas that are important to you that were not captured in this exercise?
- What things/activities/people/organizations have most helped you reintegrate into the community?
- 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?
### Findings - Q Sort - Survivors

**Patient-Centred Skilled Stroke Care & Rehabilitation**

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

*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.* ~ Caregiver
Person-Centred Skilled Stroke Care & Rehabilitation

Person-Centred Care
+ independence and sense of control
+ collaborative goal-setting
+ client/family engagement/education
+ individualized, coordinated care

Skilled Stroke Care & Rehabilitation Services
+ interprofessional coordination of care between settings
+ consistent skilled providers
+ enhanced rehabilitation
+ services close to home
+ specialist follow up

Supported Mobility in the Community
+ affordable, accessible, flexible transportation services
+ supportive response to loss of driving privileges
+ accessible community

Community Co-Navigation
+ ongoing reassessment
+ person to person conversation
+ linkage to supports & services
+ advocacy
+ user-friendly resources

Access to Supports & Services

Supports to Live in the Community
+ equipment & home modifications
+ responsive community
+ home maintenance

Adequate Financial Resources
+ assistance with relevant applications

Individual Wellbeing & Meaningful Engagement

Individual Well-Being
+ accessible, facilitated peer support
+ recognition of emotional & psychosocial needs
+ flexible, responsive respite

Meaningful Engagement
+ accessible leisure & recreational services
+ re-establish life roles/interests
“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 – all of a sudden you’re not in the fast lane anymore – what are we going to do now? How are we going to survive?” ~ Caregiver
Person-Centred
Skilled Stroke Care & Rehabilitation
Access to Supports & Services
Individual Well-Being & Meaningful Engagement
Community Co-Navigation
Supported Mobility in the Community

Section 1 *Supporting patients, families and caregivers through transitions following stroke.*
Section 2 *Patient, family and caregiver education following stroke.*
Section 3 *Interprofessional communication and discharge planning.*
Section 4 (6.5) *Community reintegration following stroke.*

"I want a sense of control, someone who sees what I can do for myself and involves me in my care." ~ Stroke Survivor
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. ~ Stroke Survivor
MoHLTC & LHIN Alignment

- *Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario (2015)* Ministry of Health & Long-Term Care (MoHLTC)
- *Older Adult Strategy*
- *Integrated Health Services Plan 2016-2019 (IHSP4) (South East LHIN)*

“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.” ~ Caregiver
“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.” ~ Survivor

“Being involved in care and life of loved one [is important]. We are life partners or soul mates. Of course I need to be there first and foremost. I am his and he is mine.” ~ Caregiver
Well-being of survivors is enhanced with active involvement in care planning and perception of adequate support. (Ellis-Hill et al, 2009)

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. (Walsh et al, 2014)

Potential need for a change in the focus of rehab as the stroke survivor transitioned to the community [from] motor learning and functional independence of the disabled body ... towards “social learning and societal participation of the disabled self.” (Nanninga et al, 2014).

Social activity should be incorporated into other therapies, thus reciprocally enhancing the effects of each. (Lyons, 2002)
“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.” ~ Caregiver

“I remember my grandfather crying a lot after he had a stroke but not understanding why. Now I understand.” ~ Survivor

“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.” ~ Stroke Survivor
Supporting Research

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)

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)

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)
Community Co-Navigation

“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.” ~ Survivor

“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.” ~ Caregiver
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.” (Montgomery et al, 2015)

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. (Lutz et al, 2010)
“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.” ~ Survivor

“Practical help is important – this is new to me, I have never been involved with someone who had a stroke before.” ~ Caregiver
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.” (Egan et al, 2015)

“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.” (Lyons, 2002)

While friends and family may provide good support to the caregiver initially; those same caregivers reported receiving few supports one year post-stroke. (Salter et al, 2013)
Supported Mobility in the Community

“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.” ~ Survivor

“For a very brief time a worker was able to drive [the stroke survivor] on local errands like to get groceries and for [the 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.” ~ Caregiver
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)

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)
Future Considerations

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

The SNSEO’s recommendations emerging from this consultation focus on:
- enhancing services
- building linkages and connections
- supporting service providers with tools and resources
- providing education and raising awareness.

The recommendations will:
- inform regional priorities and influence local change
- be integrated into the SNSEO Regional Stroke Workplan

Accountability for workplan progress through Community Reintegration Leadership Team (CRLT) and Regional Stroke Steering Committee (RSSC).

These recommendations also 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.
References


- 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.


Questions

What We Heard: Charting A Course for Successful Community Reintegration After Stroke
Contact

Gwen Brown
Regional Community & LTC Coordinator
Stroke Network of Southeastern Ontario
(613) 549-6666 X 6867
browng2@kgh.kari.net
https://www.strokenetworkseo.ca/