


STROKE NETWORK *of* Southeastern Ontario

CSAH Geriatrics Conference: Aging: Are We Doing it Right?

COMMUNITY REINTEGRATION FOLLOWING STROKE: *SUPPORTING THE JOURNEY*





"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



Background

- 2007 consultation (*Building Capacity to Enhance Community Reintegration of People with Stroke*)
- Validation of results
- Q Sort methodology
- Participants – stroke survivors, caregivers & health care providers (including PSWs)

2007 Consultation





Recruitment

Stroke Survivors & Caregivers

- Support groups
- Partners
- Media

Health Care Providers

- Partners (CCAC, rehab providers)
- CSS agencies



Response

- 107 participants
- 13 individual interviews (survivors & caregivers)
- 7 focus groups (survivors, caregivers, couples)
- urban/rural, male/female, younger/older
- 40 health care providers (electronic format with exception of PSWs)




The Q Sort Process

- Laurentian University
- Ranking process
- 30 Q Statements
- Modified for Southeast
- Inverted pyramid
- Less to more importance



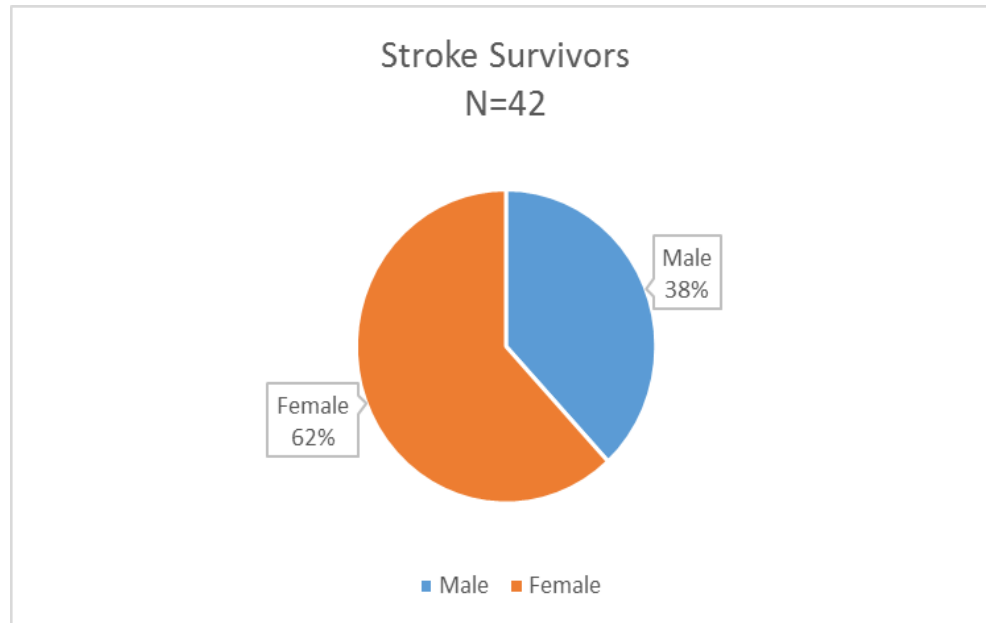
Supporting Questions

- 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?



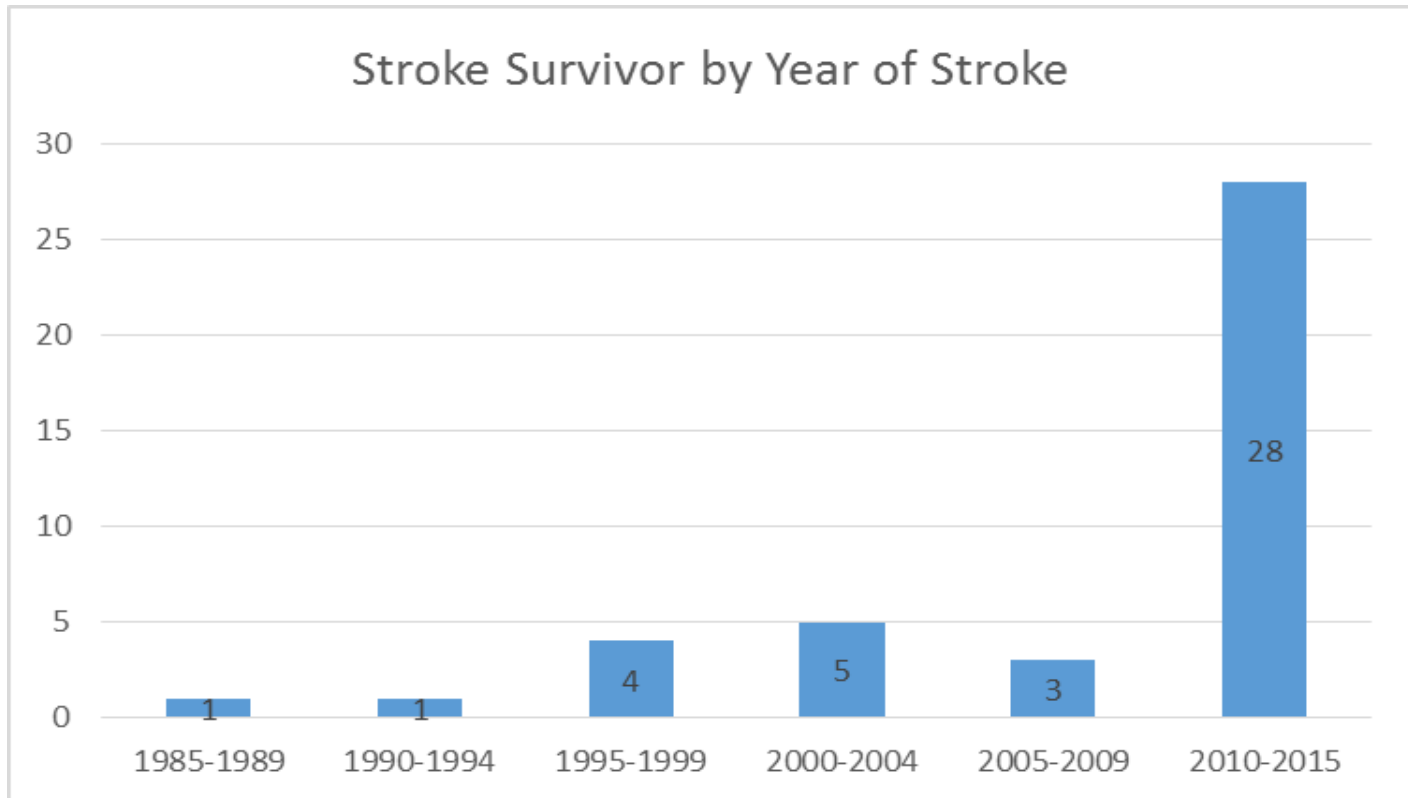
"When he was in hospital, we were told he would never walk again, never eat solid foods again – this was devastating – we were relatively young – all of a sudden you're not in the fast lane anymore – what are we going to do now? How are we going to survive?" ~ Caregiver

Participants – Stroke Survivors

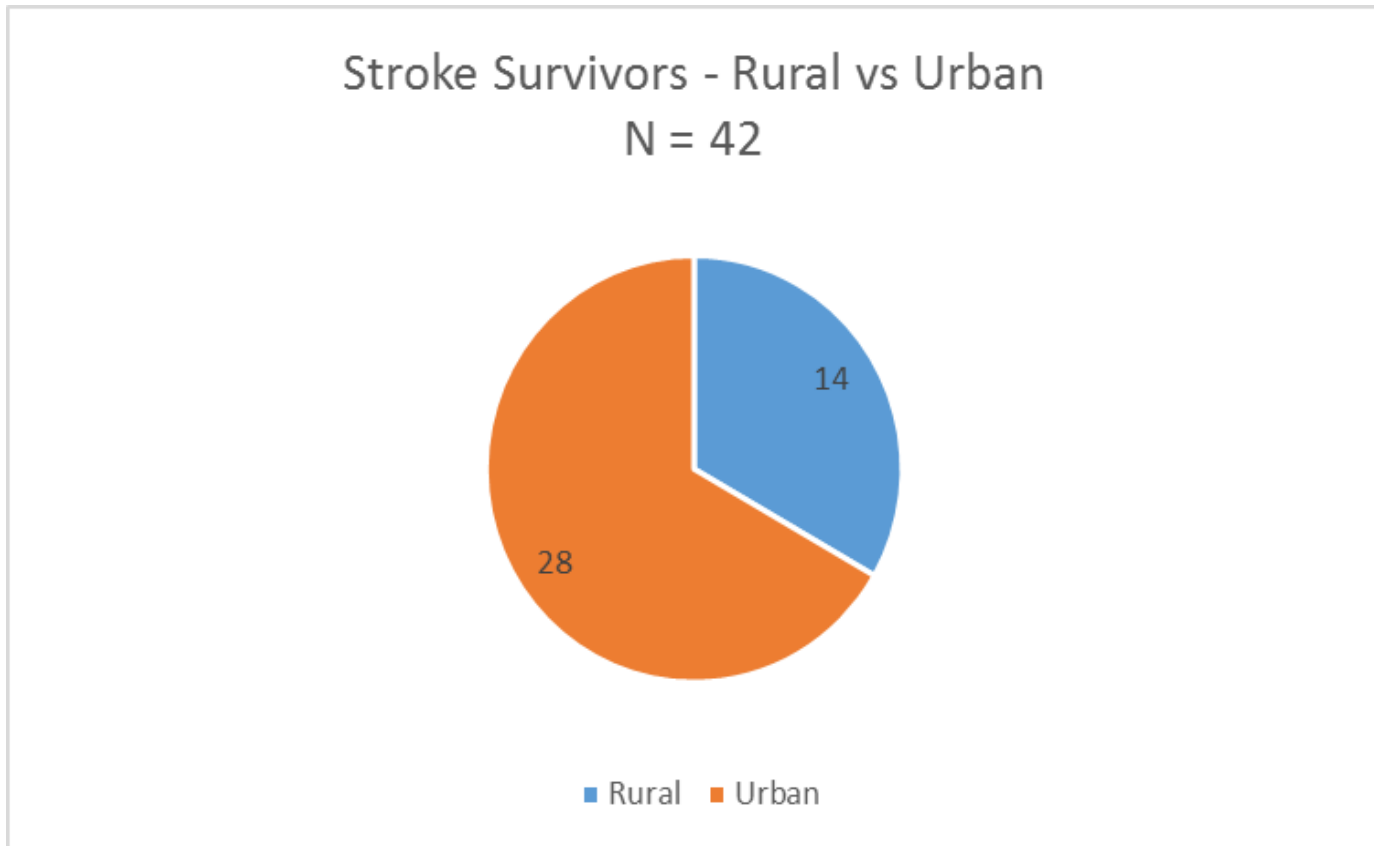


Overall Mean Age	69 years (SD = 14.2)
Mean Age – Males	69 years
Mean Age – Females	68 years
Overall Median age	69 (Range 25-91)

Participants – Stroke Survivors

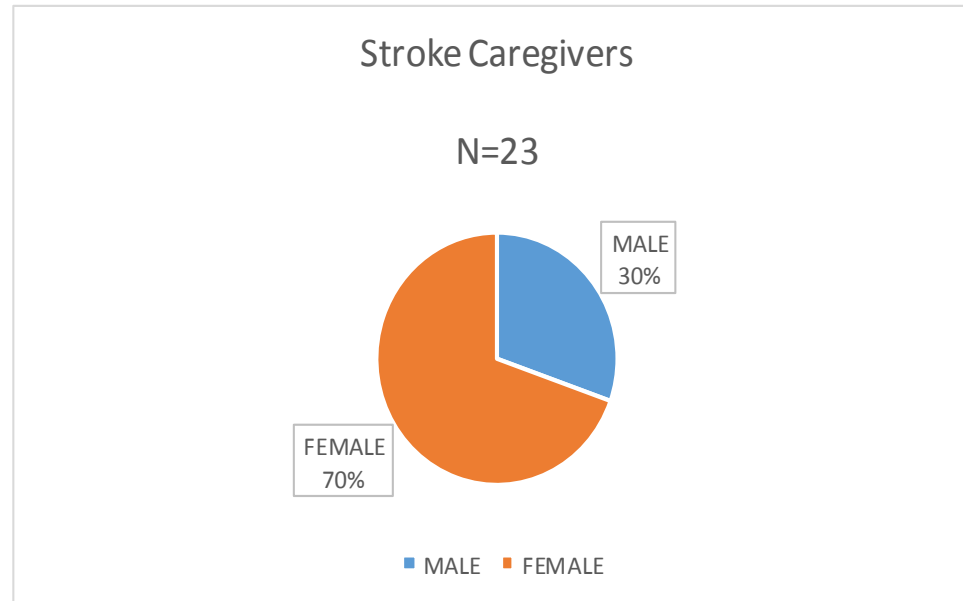


Participants – Stroke Survivors



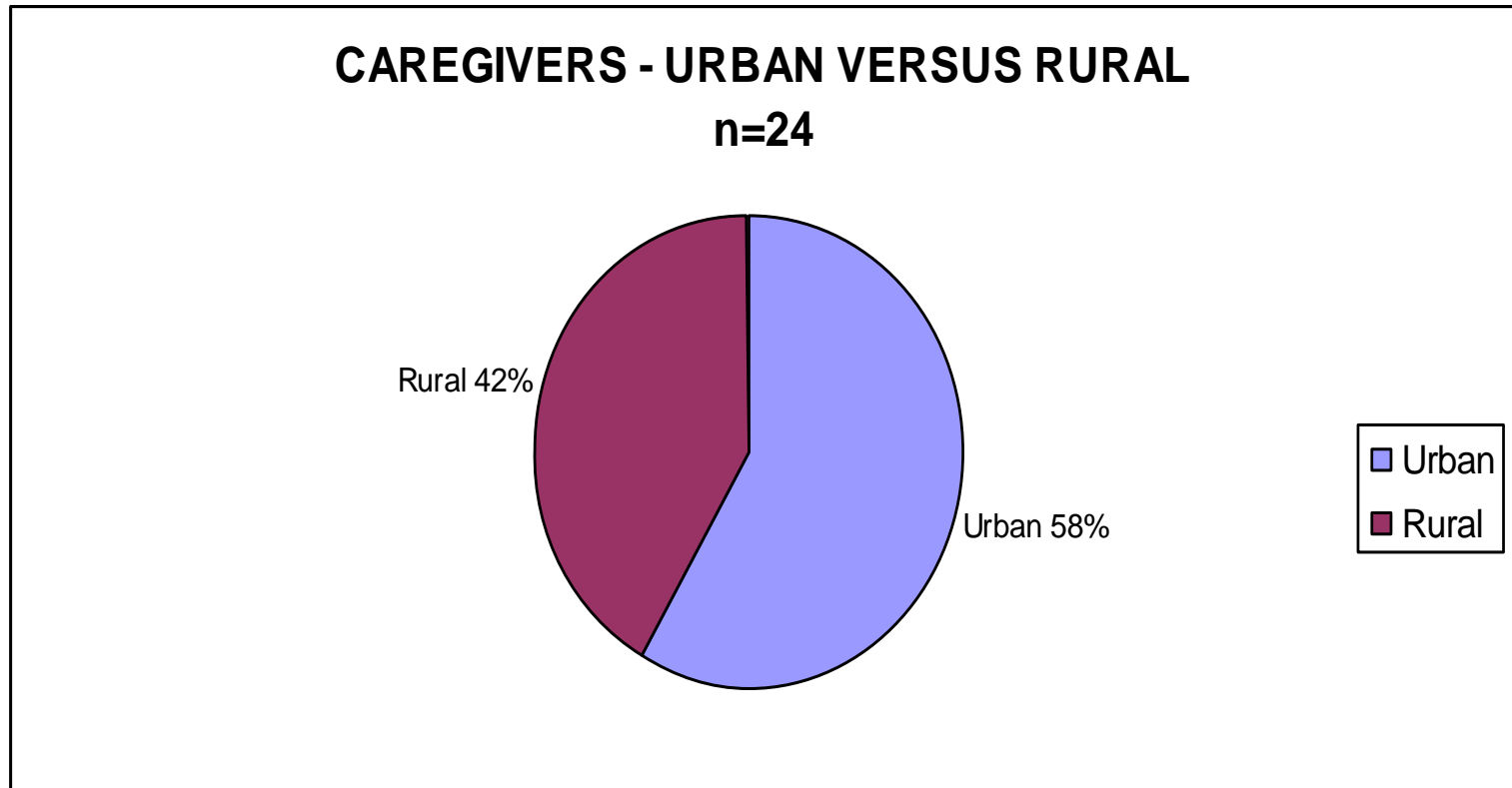
Urban – Belleville, Brockville, Kingston

Participants – Caregivers



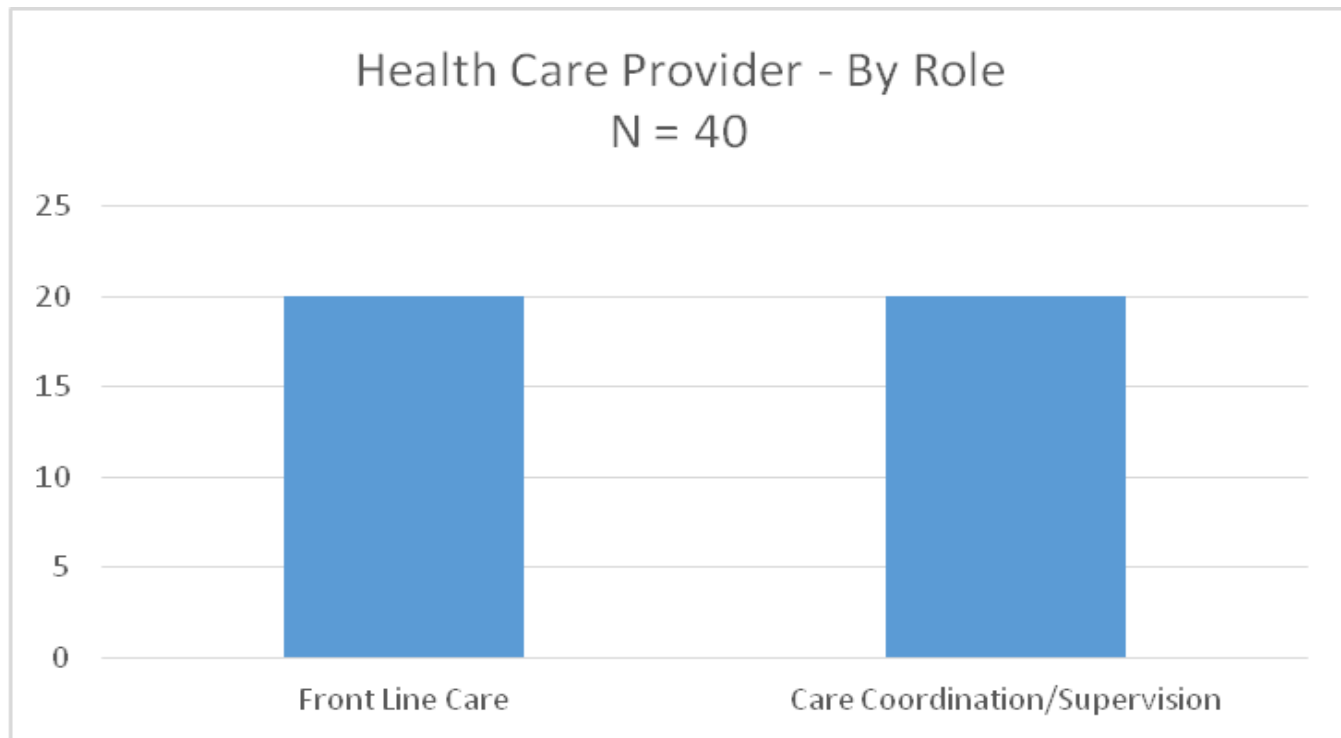
Overall Mean Age	67 years (SD = 14.5)
Mean Age – Males	74 years
Mean Age – Females	65 years
Median age	66 (Range = 16 – 88)

Participants – Caregivers

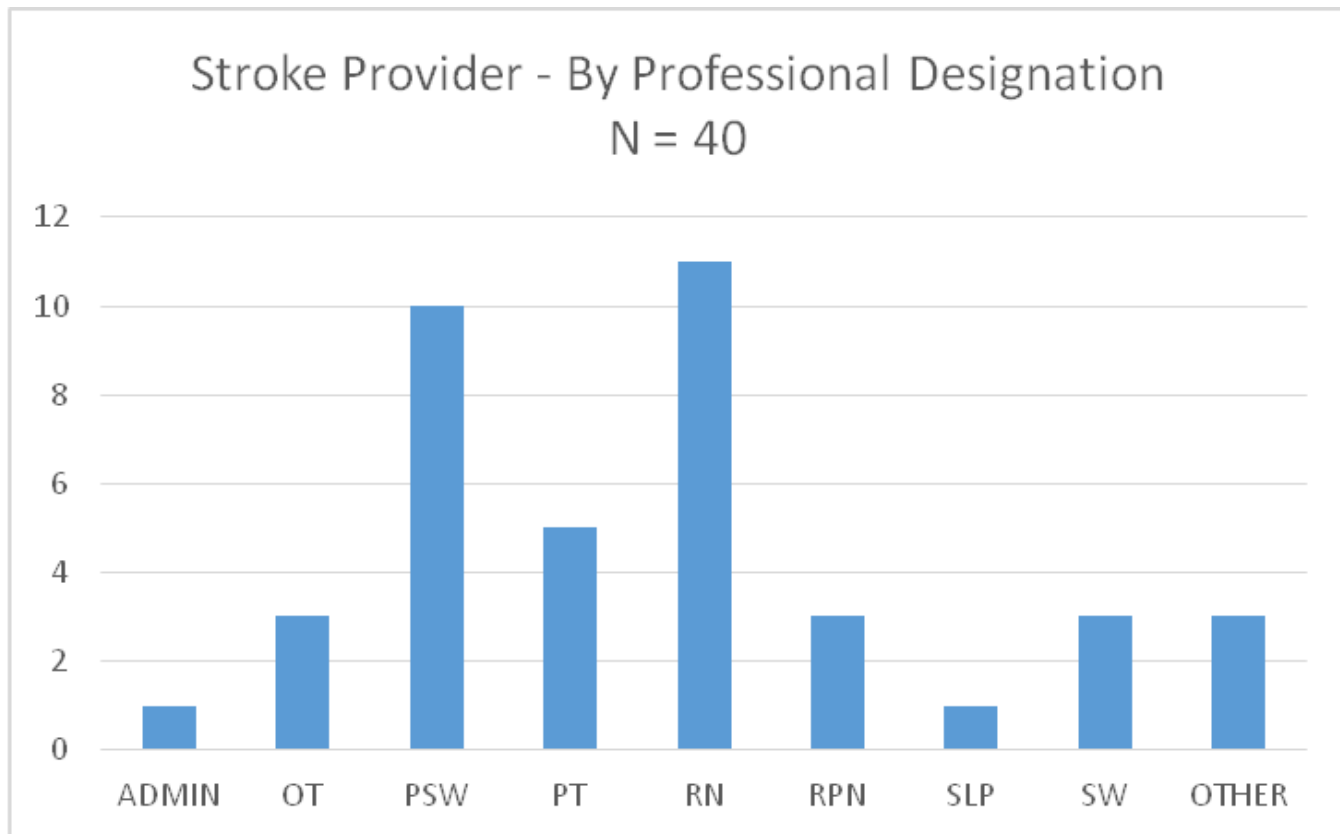


Urban – Belleville, Brockville, Kingston

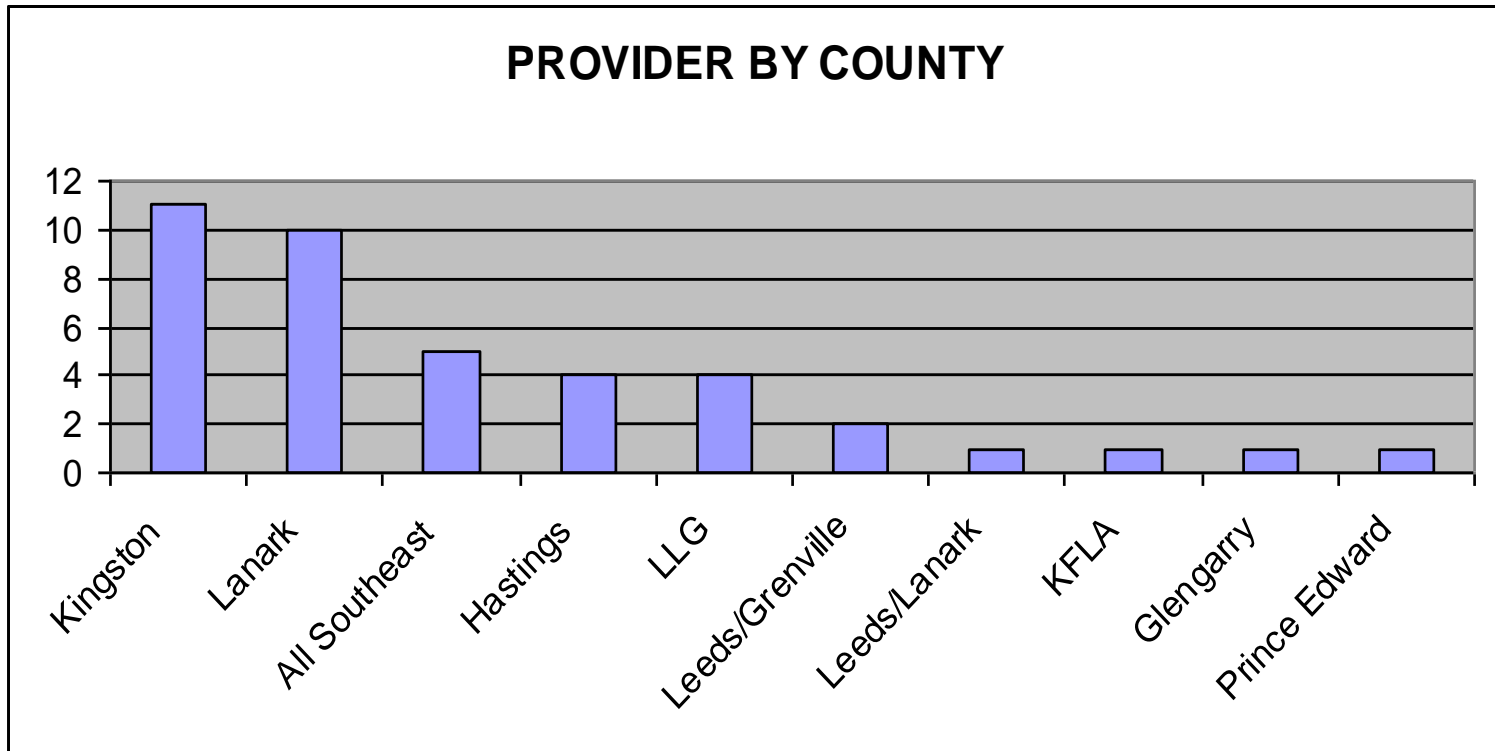
Participants – Health Care Providers



Participants – Health Care Providers



Participants – Health Care Providers



Q Sort – Stroke Survivors n=30/43)

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 them	-3
Having family members involved in my care and my life	-3

Q Sort – Caregivers (n=17/24)

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

Q Sort – Health Care Providers n=25/40)

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

SUCCESSFUL COMMUNITY REINTEGRATION THROUGH:

Person-Centred Stroke Care & Rehabilitation Services

Person-Centred

- independence and sense of control
- collaborative goal-setting
- optimizing client and family involvement
- education supports for client/family in stroke and care provision
- individualized, coordinated care

Skilled Stroke Care

- continuity of care from inpatient to outpatient to community
- interprofessional coordination of care
- consistent providers skilled in stroke care
- enhanced rehab services
- services close to home
- access to specialist follow up care

Individual Well-Being & Meaningful Engagement

Individual Well-Being

- accessible, facilitated support groups
- peer support
- social work/mental health services
- recognition of emotional/psychosocial needs as an integral part of stroke care across the continuum
- flexible, responsive respite service

Meaningful Engagement

- accessible leisure & recreational services
- re-establish life roles/interests

STROKE SURVIVOR AND CAREGIVER

Community Co-Navigation

- ongoing reassessment of needs
- person to person conversation (“just talk to me”)
- linkage to supports & services and assistance to complete relevant applications
- advocacy
- user-friendly resources in various modalities

Supported Mobility in the Community

- affordable, accessible, flexible transportation services
- loss of driving privileges
- accessibility in the community

Access to Supports & Services

Supports to Live in the Community

- equipment & home modifications
- responsive community
- home maintenance

Adequate Financial Resources

- financial application services
- access to financial supports for services, equipment and home modifications

Comparative Chart

	What made areas important?	Were important areas met?	What most helped with integration?	Single most important change.
Person-Centered Stroke Care & Rehabilitation Services	Stroke Survivors Caregivers Health Care Providers	Stroke Survivors Caregivers	Stroke Survivors Caregivers	Stroke Survivors Caregivers Health Care Providers
Individual Well-Being & Meaningful Engagement	Stroke Survivors Caregivers	Caregivers	Stroke Survivors Caregivers	Stroke Survivors Caregivers Health Care Providers
Community Co-Navigation	Stroke Survivors Caregivers	Stroke Survivors Caregivers		Stroke Survivors Caregivers Health Care Providers
Supported Mobility in the Community	Stroke Survivors Caregivers	Stroke Survivors		Stroke Survivors
Access to Supports & Services	Stroke Survivors Caregivers	Stroke Survivors		Stroke Survivors

Person-Centred Stroke Care & Rehabilitation Services

- *"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. 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

Person-Centred Stroke Care & Rehabilitation Services

Person-Centred

- independence and sense of control
- collaborative goal-setting
- optimizing client and family involvement
- education supports for client/family in stroke and care provision
- individualized, coordinated care

Skilled Stroke Care

- continuity of care from inpatient to outpatient to community
- interprofessional coordination of care
- consistent providers skilled in stroke care
- enhanced rehab services
- services close to home
- access to specialist follow up care



Individual Well-Being & Meaningful Engagement

"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



Individual Well-Being & Meaningful Engagement

Individual Well-Being

- accessible, facilitated support groups
- peer support
- social work/mental health services
- recognition of emotional/psychosocial needs as an integral part of stroke care across the continuum
- flexible, responsive respite service

Meaningful Engagement

- accessible leisure & recreational services
- re-establish life roles/interests



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



Community Co-Navigation

- ongoing reassessment of needs
- person to person conversation (“just talk to me”)
- linkage to supports & services and assistance to complete relevant applications
- advocacy
- user-friendly resources in various modalities

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 [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." ~ Caregiver



Supported Mobility in the Community

- affordable, accessible, flexible transportation services
- loss of driving privileges
- accessibility in the community



Access to Supports & Services

"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



Access to Supports & Services

Supports to Live in the Community

- equipment & home modifications
- responsive community
- home maintenance

Adequate Financial Resources

- financial application services
- access to financial supports for services, equipment and home modifications



Limitations

- Younger stroke survivors
- Individuals living with aphasia
- Focus groups/support groups
- LTC as community



Finalizing Report/Recommendations

- Q Sort data analysis (Laurentian)
- Discussion analysis (Stroke Network)
- Review by Community Reintegration Leadership Team
- Review by Regional Stroke Steering Committee
- Refining recommendations

Contact

Gwen Brown

Regional Stroke Community & LTC Coordinator

Stroke Network of Southeastern Ontario

Phone: 613-549-6666 X 6867

613-548-2454

browng2@kgh.kari.net

Questions

