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STROKE NETWORK  
of Southeastern Ontario

***Evaluating the Impact of  
Stroke Survivor &  
Caregiver Support  
Groups on Successful  
Community  
Reintegration***

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- No disclosures or conflicts of interest



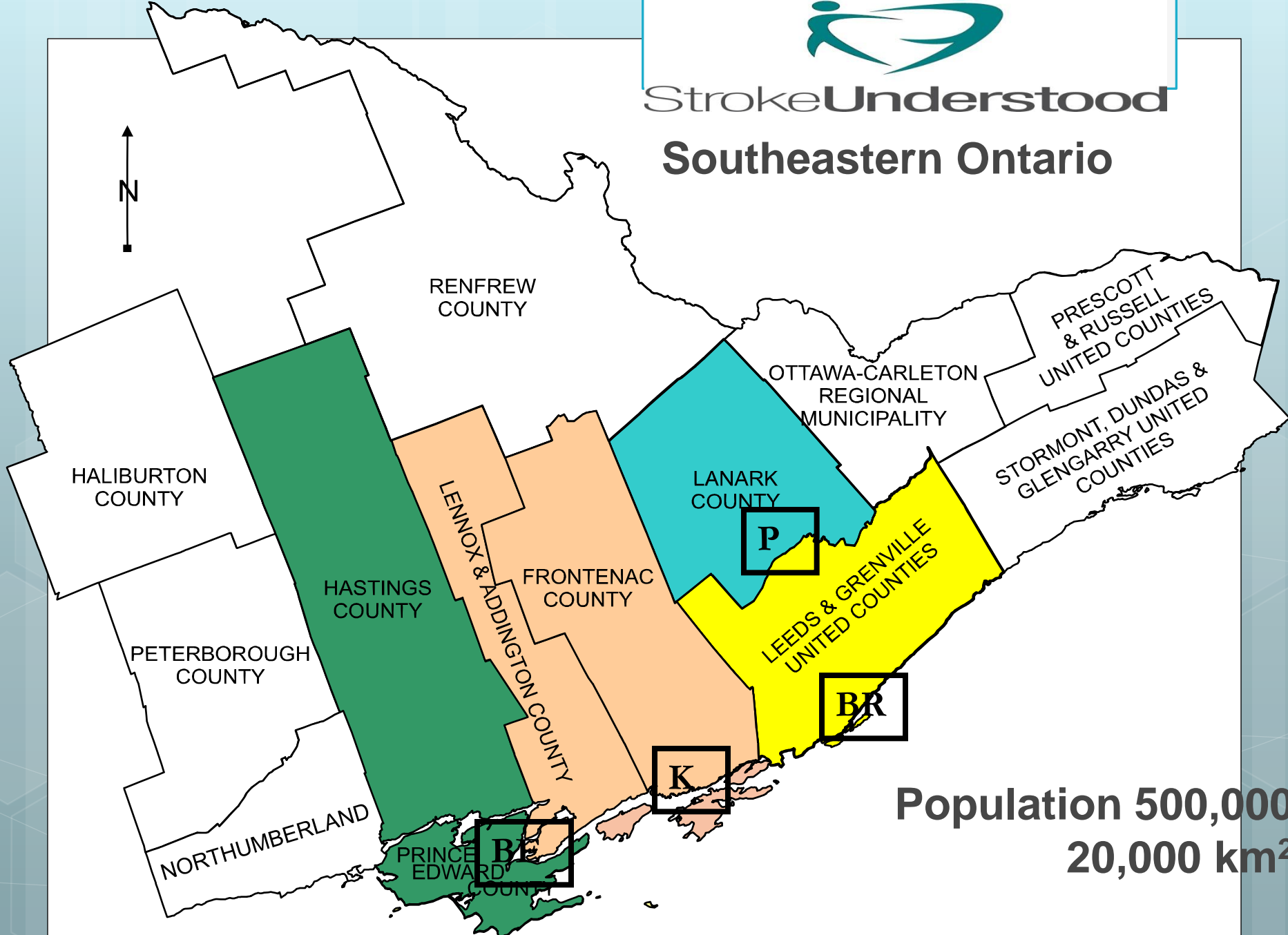
# AGENDA

- Background of stroke support group services provided
- Evaluation
- Challenges and recommendations



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## Southeastern Ontario



Population 500,000  
20,000 km<sup>2</sup>



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**Mission:** to provide community-based support for stroke survivors and their care partners

**Vision:** stroke survivors will continue to maximize their potential with the support of care partners and peers

### Values:

- **Hope:** Promoting the optimism that ongoing recovery is possible
- **Support:** Building relationships with peers and linking with community service providers
- **Peer collaboration:** Sharing tips and strategies with people who face similar challenges
- **Restorative care:** Providing the opportunity to maximize potential
- **Empowerment:** Gaining the knowledge and confidence to take charge of your life
- **Health Promotion:** Maintaining healthy lifestyles to prevent future strokes



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## **Regional Stroke Services include:**

- Professionally facilitated groups for survivors, caregivers and couples. In Brockville and Perth, survivors and caregivers meet collectively. In Belleville and Kingston, there are separate groups for survivors, caregivers and couples.
- Heart and Stroke Foundation Living with Stroke™ program
- Individual support and system navigation



# FACILITATOR ROLE

- Psychosocial counselling
- System navigation
- Outreach to survivors & caregivers
- Education and support for self-management
- Networking with health and social service partners



# EVALUATION

Components:

- Montgomery-Borgatta Caregiver Burden Scale
- Stroke Impact Scale
- Participant Survey
- Individual interviews with couples (Kingston)
- Survivor & caregiver focus groups (Kingston)





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# Summary of Results

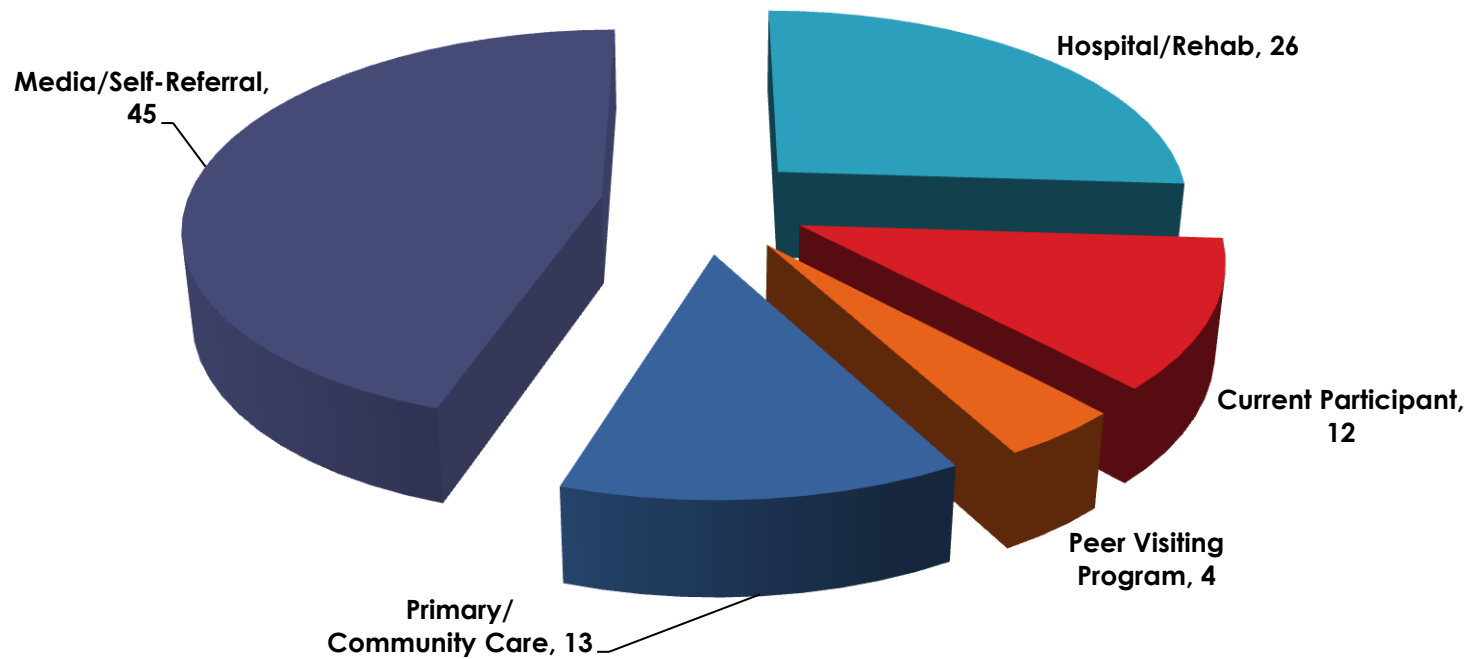
demonstrating value of facilitated support groups

- Growth in referrals and group participation
- Benefits of providing system navigation and support
- Positive effects of group participation on well-being, coping with anxiety/nervousness, depression and stressors for both caregivers and stroke survivors
- Improved post-test scores on the *Stroke Impact Scale* in areas of communication, memory/thinking and perceived recovery
- Decreased objective and subjective caregiver burden using the *Montgomery-Borgatta Caregiver Burden Assessment*
- Strong participant satisfaction
- Rich and positive feedback from focus groups



## Source of New Referrals

### SOURCE OF NEW REFERRALS



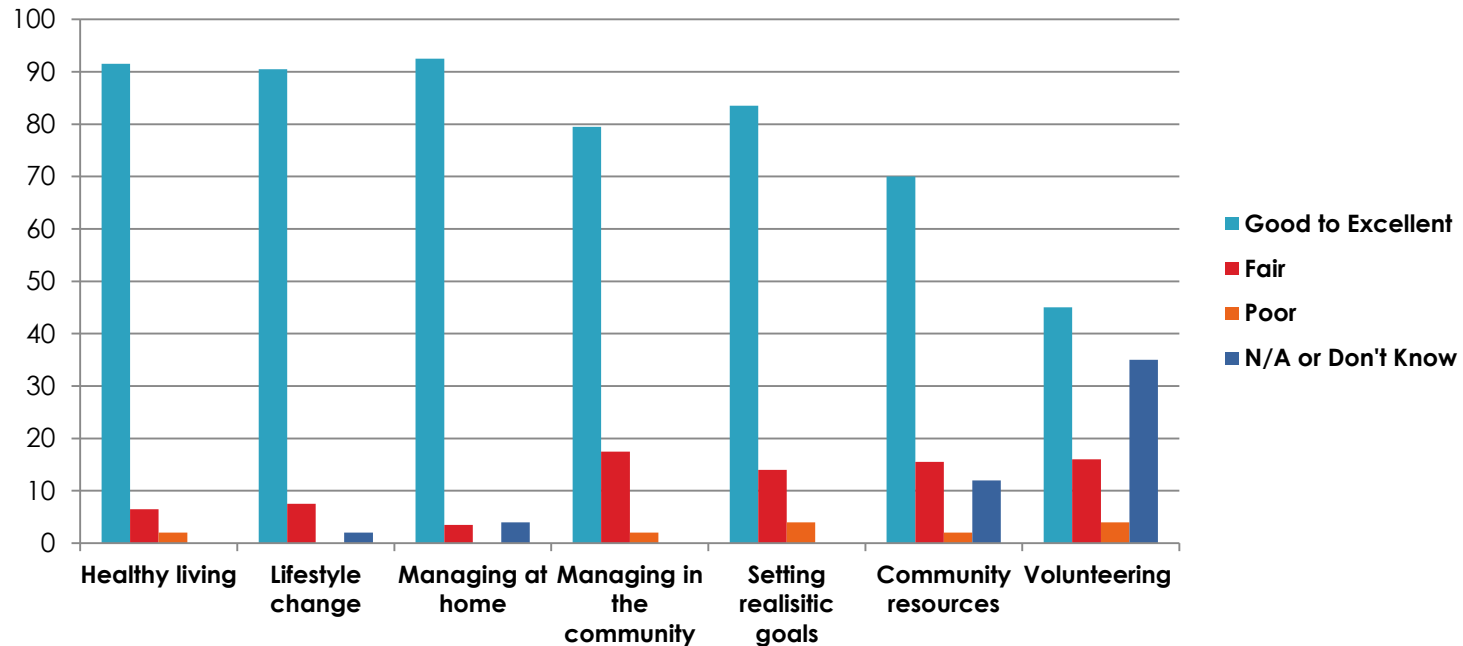
Source: Stroke Services Intake Records



Facilitated Support Groups:

# Promoting Community Reintegration

**COMMUNITY REINTEGRATION - SURVIVORS**  
"How have support groups helped with..."





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## Survivors

*“The amounts of time I spend at these sessions are well worth the time. It helps me mentally which in turn helps me physically; reducing the time spent at my doctors”.*

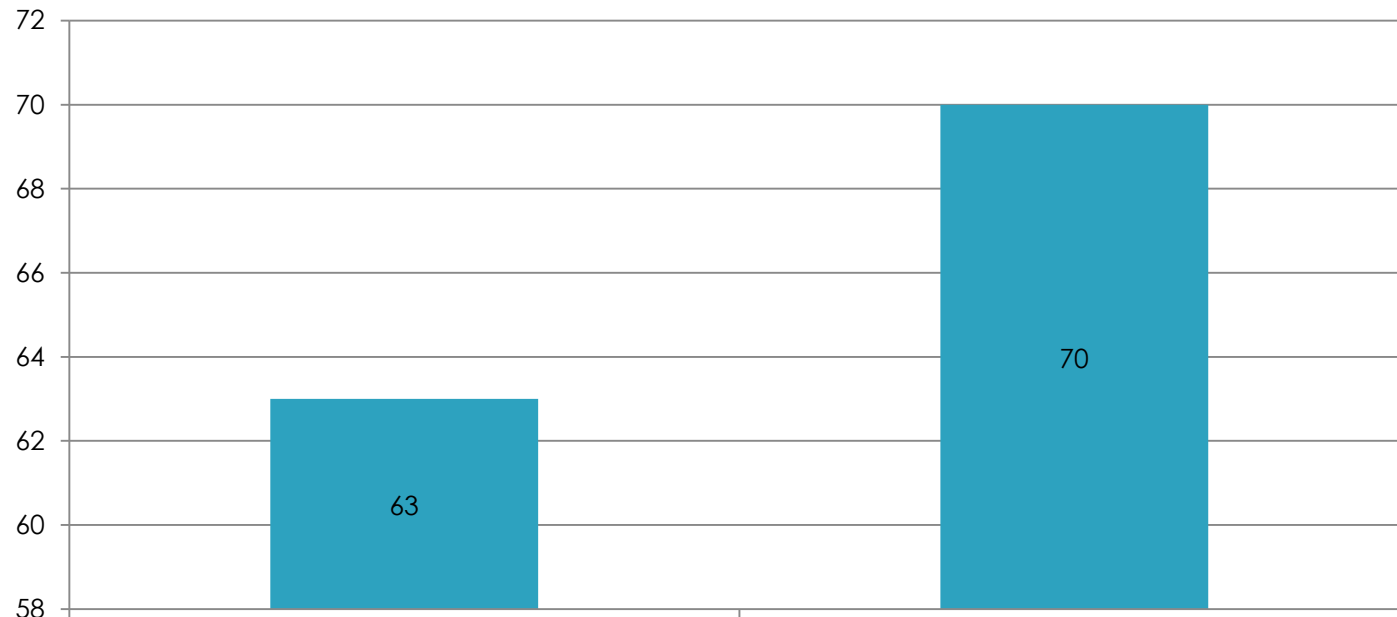
*“I come to the group and I’ve learned so much, I feel much better and the way I look at it, it’s groups like this that kept me from rushing to a hospital thinking there is something wrong, because before I would have situations where I have experienced something for the first time”.*



Facilitated Support Groups:

# Promoting Recovery and Hope

## PERCENTAGE CHANGE IN PERCEIVED RECOVERY SCORES IN STROKE SURVIVORS



Duncan, P.W., Bode, R., Lai, S. M., Perera, S. (2003b). Rasch analysis of a new stroke specific outcome scale: The Stroke Impact Scale. *Arch Phys Med Rehabil*, 84, 950-963.



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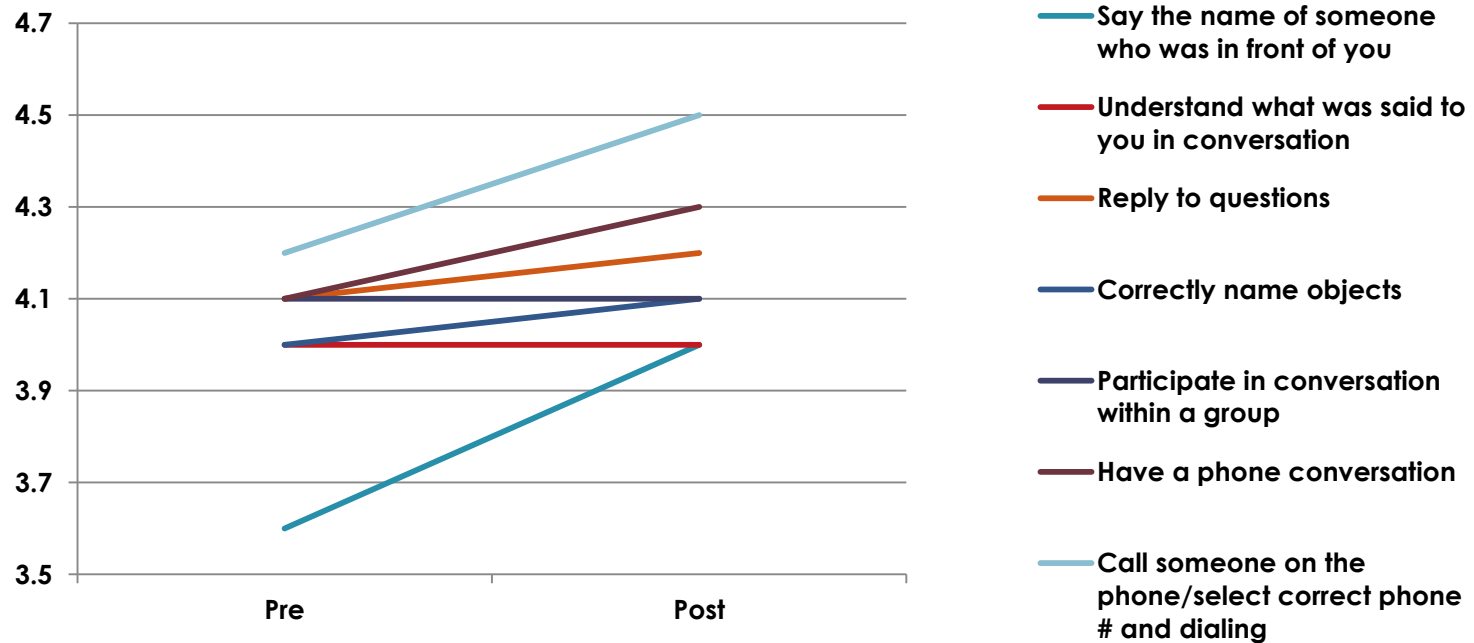
## SURVIVORS

*“I think every time I have got involved with the stroke group, you learn new things. Every person participates and makes people feel better”.*



## Pre-to Post-Test Changes on Stroke Impact Scale - Communication Sub-Scale

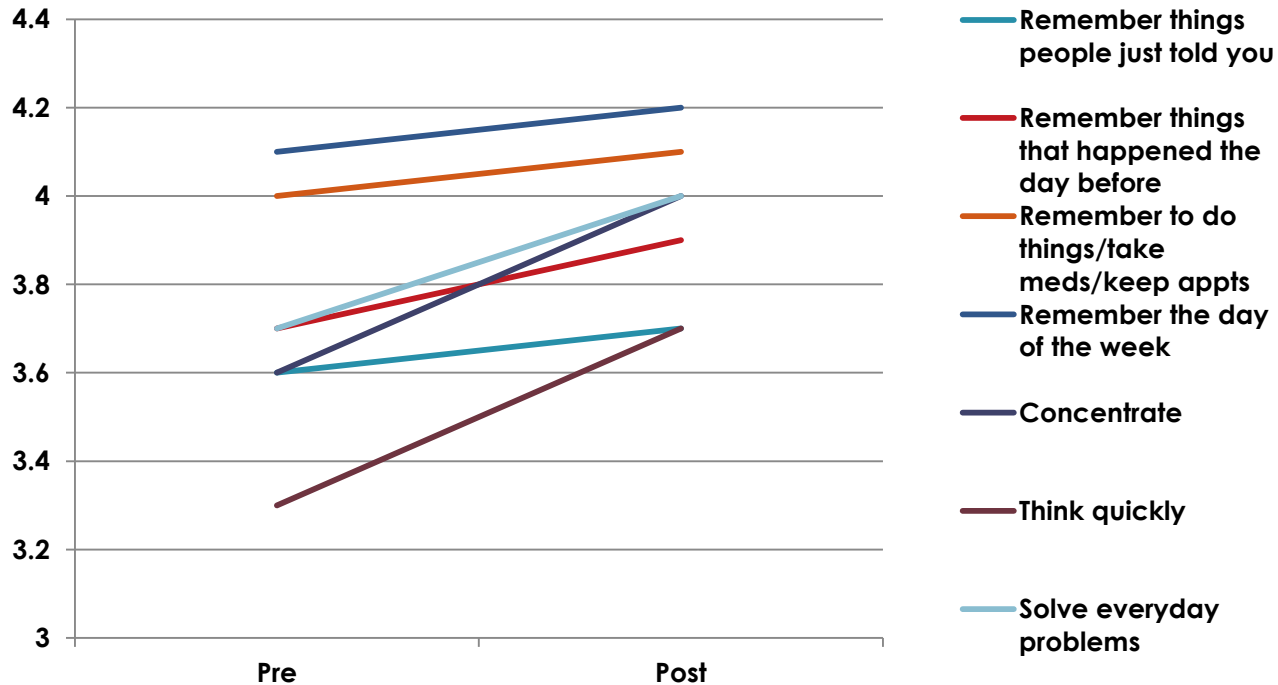
Pre to Post Changes on Stroke Impact Scale - Communication Sub-Scale



Duncan, P.W., Bode, R.K., Lai, S. M., Perera, S. (2003b). Rasch analysis of a new stroke specific outcome scale: The Stroke Impact Scale. Arch Phys Med Rehabil, 84, 950-963.

## Pre-to Post-Test Changes on Stroke Impact Scale – Memory and Thinking Sub-Scale

Pre to Post Changes on Stroke Impact Scale  
Memory & Thinking Sub- Scale



Duncan, P.W., Bode, R.K., Lai, S. M., Perera, S. (2003b). Rasch analysis of a new stroke specific outcome scale: The Stroke Impact Scale. *Arch Phys Med Rehabil*, 84, 950-963.





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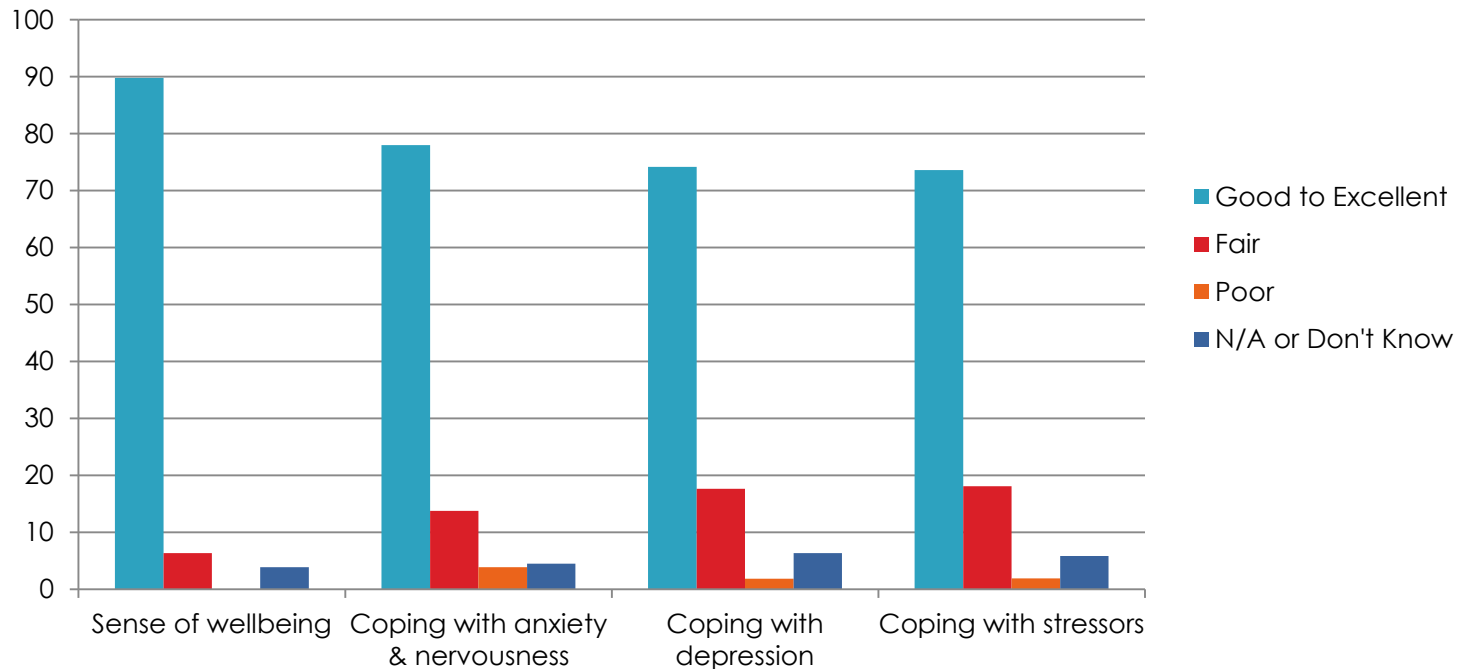
*“Family helps tremendously if you have a good family life but not everyone has this support, so the stroke group is great because you can voice your fears and anxieties and most of them can understand”. ~ Survivor*



Facilitated Support Groups:

# Supporting Mental Health

## COMMUNITY REINTEGRATION - SURVIVORS "How have support groups helped with..."



Source: Stroke Services Evaluation Tool



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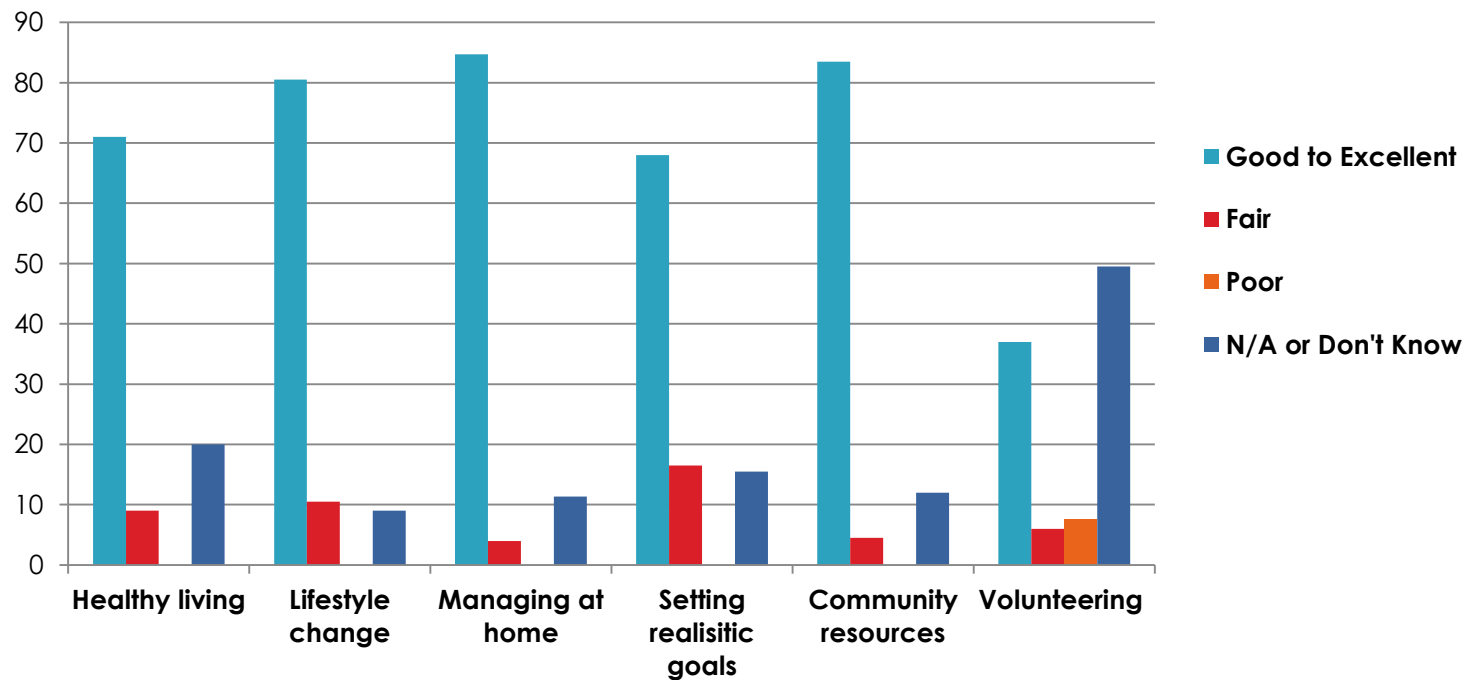
*“Our facilitator has the knack to make us feel comfortable and relaxed; does not treat us as handicapped; I enjoy this group – the info I receive, the friendships we have formed... we look forward to the meetings. I am so happy my spouse can attend with me and learn with me” ~ Survivor*



Facilitated Support Groups:

# Promoting Community Reintegration

## COMMUNITY REINTEGRATION - CAREGIVERS "How have support groups helped with..."





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*“We find the group very friendly and supportive. It’s just so nice to be with people who get it, to hear other stories and see progress others are making month to month”*

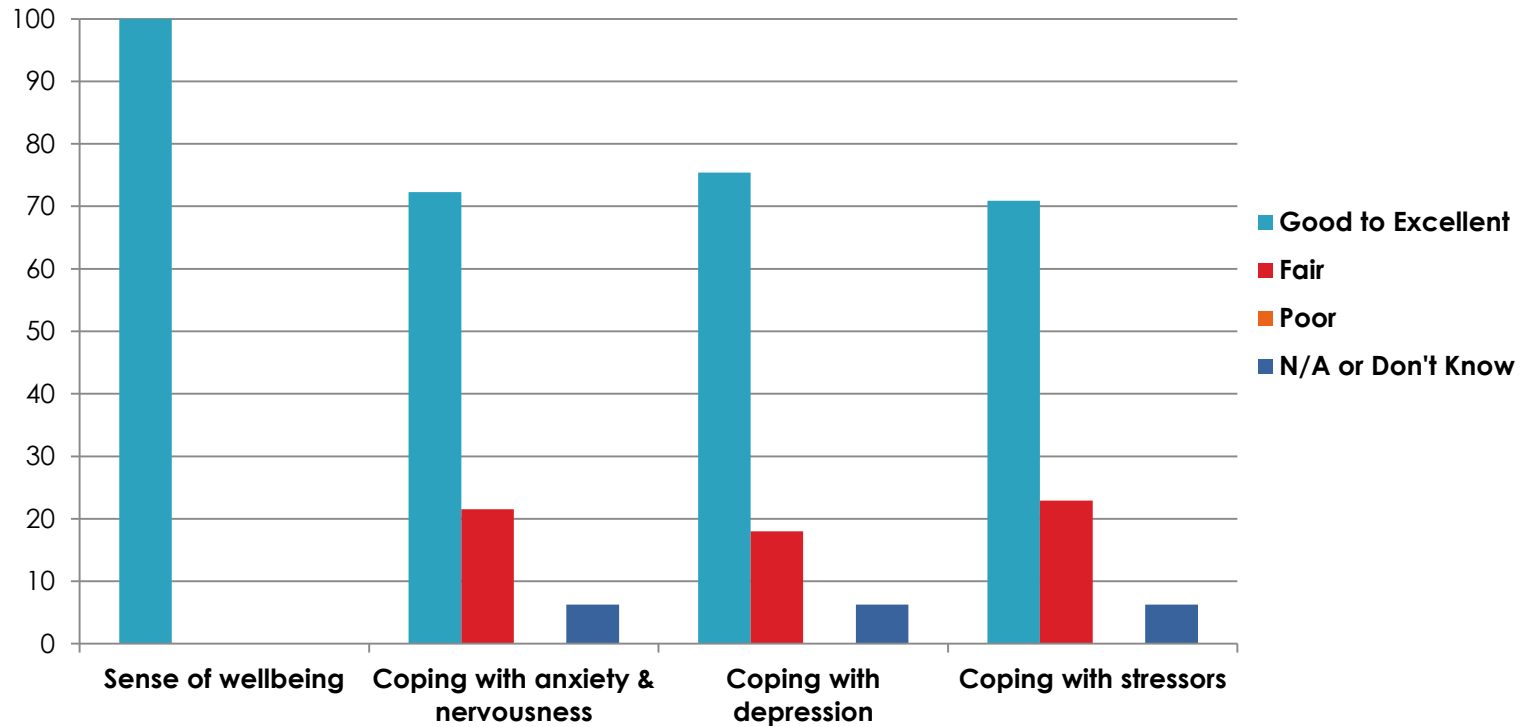
*~ Caregiver*



Facilitated Support Groups:

# Supporting Mental Health

## COMMUNITY REINTEGRATION - CAREGIVERS "How have support groups helped with..."



Source: Stroke Services Evaluation Tool



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# CAREGIVERS

*“You’re absorbing all the information of what everybody else is going through because I may need that in the future.”*



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# CAREGIVERS

*“Our group is able to open up regarding their emotions and frustrations which I think is very important.”*

*“I find going to the Caregiver and Couples group has held my depression”.*

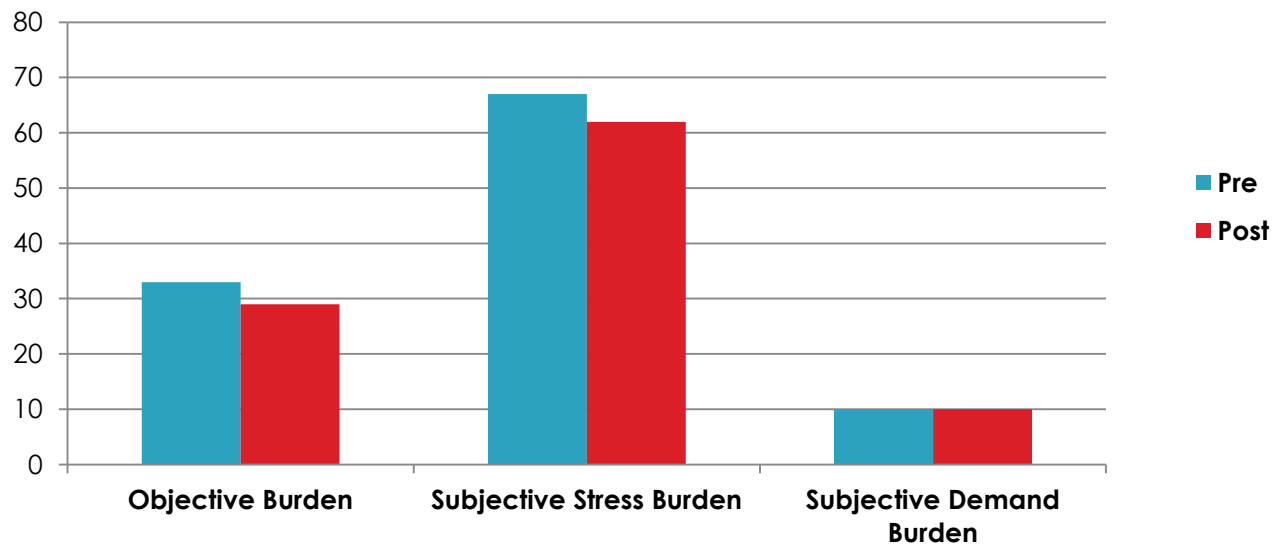




Facilitated Support Groups:

# Reducing Caregiver Stress

## % Caregivers Exceeding Cutoff for Intervention



Montgomery, R., Stull, D. E., & Borgatta, E. (1985). Measurement and the analysis of burden. *Research on Aging*, 7, 329-361.



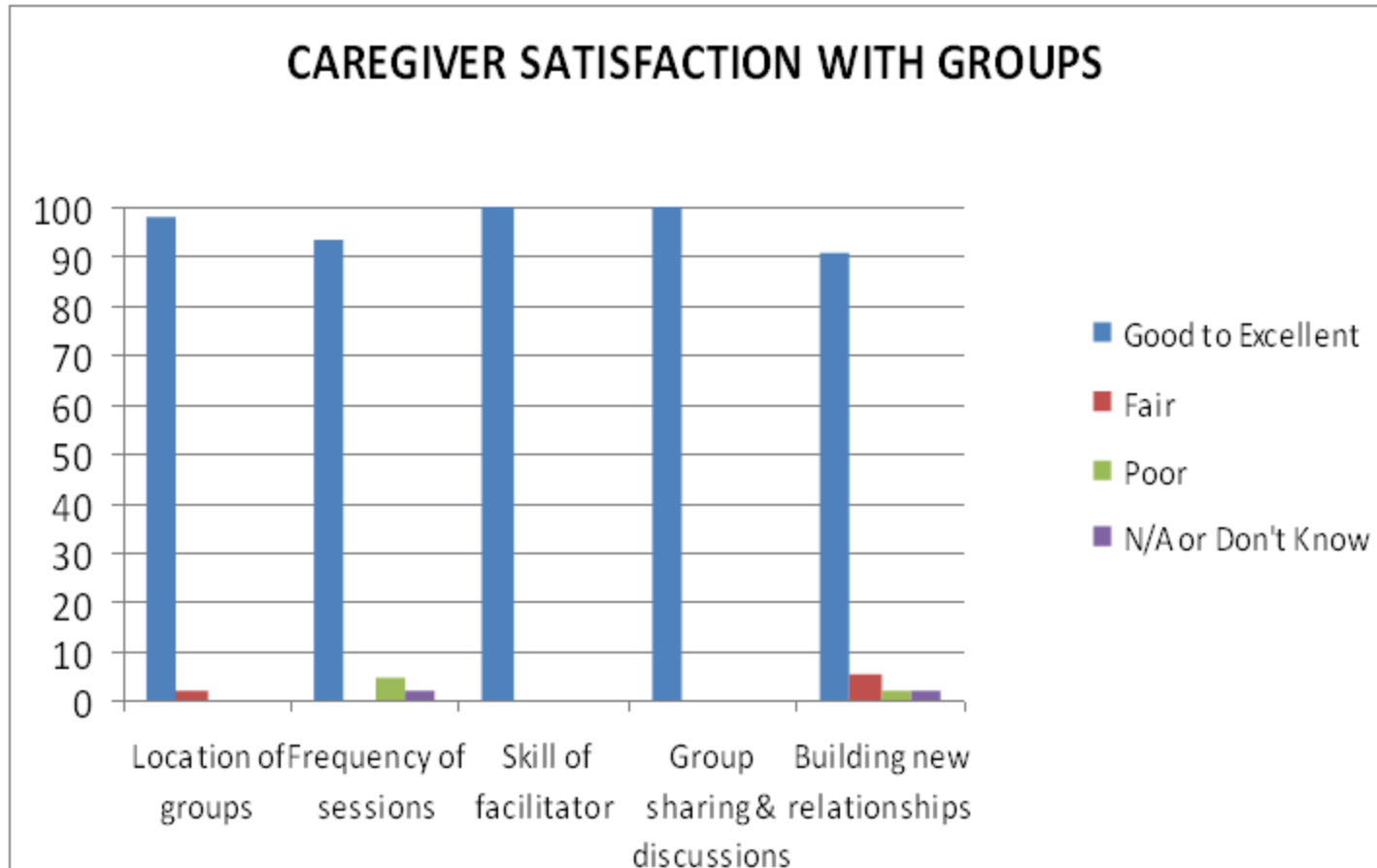
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## CAREGIVERS

*“When you are in the group and a new person comes in and you see how overwhelmed and frazzled they are, you think “that was me, I understand what they’re going through and then you realize, oh I’ve come a long way”. I calmly deal with things now instead of hyper-panicking”.*



## Caregiver Satisfaction Evaluation Tool Results



Source: Stroke Services Evaluation Tool



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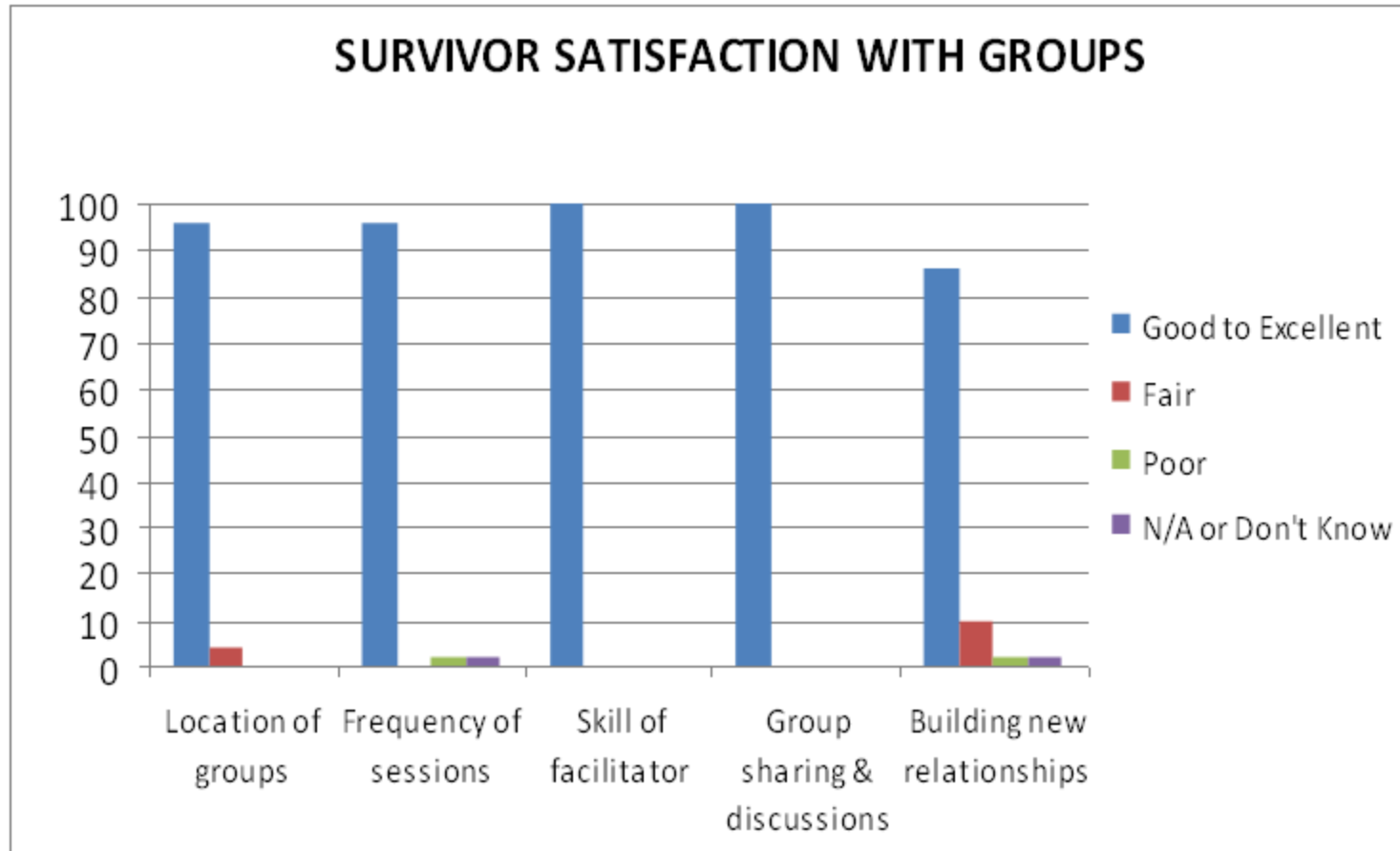
## *Satisfaction in their own words...*

*“Very helpful when participants share the problems they are facing and suggestions for dealing with them. It would be great if everyone in the group would make this meeting a priority. The more attending makes it better!”. ~ Caregiver*

*“I am a new participant in the programme and enjoy the opportunity to socialize with others and look forward to attending many more meetings”. ~ Survivor*



## Survivor Satisfaction Evaluation Tool Results



Source: Stroke Services Evaluation Tool



# CONCLUSIONS

## **DEMONSTRATED VALUE OF FACILITATED SUPPORT GROUPS:**

- Growth in referrals and activity;
- Provision of system navigation support;
- Positive effects of group participation on well-being, coping with anxiety/nervousness, depression and stressors for both caregivers and stroke survivors;
- Improved post test scores on the *Stroke Impact Scale* in areas of communication, memory, thinking and perceived recovery;
- Decreased objective and subjective caregiver burden using the *Montgomery Borgatta Caregiver Burden Scale*;
- Strong participant satisfaction;
- Rich and positive feedback from focus groups.



# Challenges and Recommendations

- Impact of funding uncertainty
- Capacity to expand groups to meet demand is limited
- Inability to respond to needs in rural areas due to lack of resources.
- Difficult to meet unique needs of younger survivors and couples
- Limited ability to provide transportation



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# RECOMMENDATIONS for SUCCESS

- Maintaining the existing groups
- Additional informal social support for long-time group members
- Recruitment and intake of new participants
- Professional group facilitation, health education and system navigation
- Ongoing evaluation
- Outreach to health and community service providers
- Delivery of Living with Stroke™ series
- An aphasia conversation group in collaboration with the CCAC and Stroke Network of SEO
- Enhanced hospital peer visiting program
- Enhanced regional collaboration to develop best practices for community-based support groups and services for stroke survivors and caregivers





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## THE FINAL WORD...

*“As soon as I joined the stroke group, my initial hope was strengthened by the success stories of other stroke victims. With determination, exercising and the positive vibes I received at each meeting. I met my goal of regaining almost full equilibrium and good mobility. It is a well-run program that I know has helped many people in my group to continue to look forward and be happy and successful in our ‘new life’” ~ Survivor*



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# QUESTIONS



Copy of full evaluation report at: [www.strokenetworkseo.ca](http://www.strokenetworkseo.ca)



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