

FICSS

Family Informal Caregiver Stroke Self Management Research Project

Funding provided by Ontario Stroke Network



Partners



FICSS Research Team

- Primary Investigator: Gail Mores, Director of National and Provincial Projects, March of Dimes Canada
- Co-Investigator: Rhonda Whiteman, HHS – Regional Stroke Best Practice District
- Co-investigator: Dr. Jenny Ploeg, Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University
- Coordinator: Laura Klaponski, March of Dimes Canada
- Facilitator: Miriam Cahn, VON Hamilton
- McMaster University Student: Alison O'Byrne



Agenda:

- Background & significance
- Purpose and study design
- Data analysis and Feedback
- Project accomplishments
- Next steps

Background & Significance

“Stroke occurs suddenly without any warning leaving stroke caregivers unprepared to assume the role of caregiver.”

Research has shown that ...

- Caregiver stress is the leading cause of institutionalization of stroke survivors.
- After a stroke, caregiver information and emotional training needs are extensive yet frequently unmet.
- Interventions that help caregivers develop coping skills, problem solving skills, and support seeking skills are most beneficial to decrease negative effects of care giving.

(Ontario Stroke System, FICSS pilot study research grant proposal draft, April 2010)



Background & Significance

In 2007, Hamilton Stroke Community Re-Engagement Network Identified need for education specific to caregivers of stroke survivors:

- Conducted 3 focus groups with stroke caregivers



Background & Significance

- Identified 4 key learning needs:
 1. Balancing changing role responsibilities
 2. Managing cognitive, perceptual and mood changes
 3. Intimacy and sexuality
 4. Linkages to allied health professionals in community
- Include self-management aspect
- Build upon VON Caregiver Education Series, “From Stress to Strength” specific to stroke caregivers



FICSS Project's Design / Methods:

- Pre + post test design
- Caregivers completed:
 - baseline questionnaires
 - quantitative /qualitative evaluations after each module
 - Caregivers evaluated the pilot project at the post focus group session

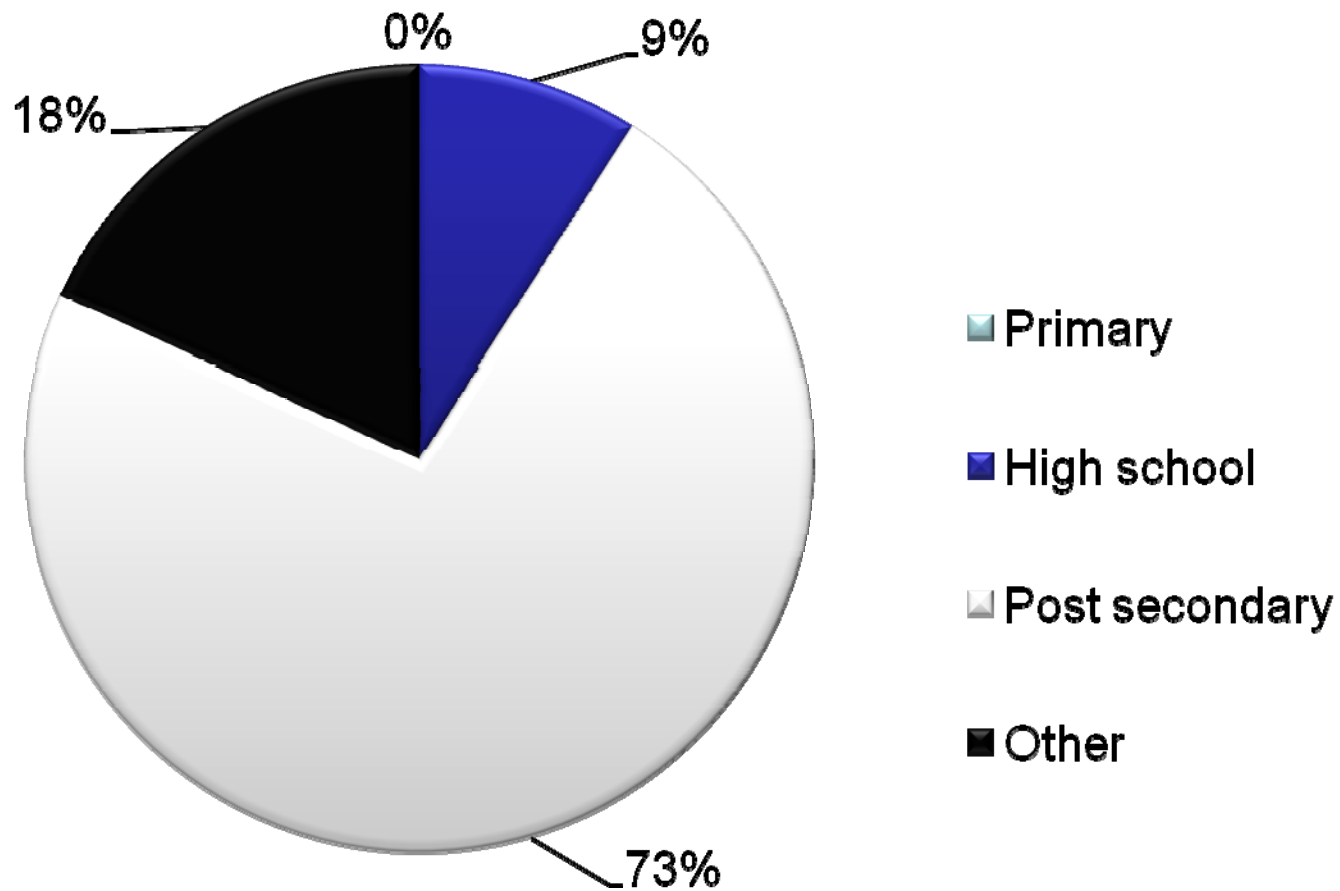


Description Of The Participants:

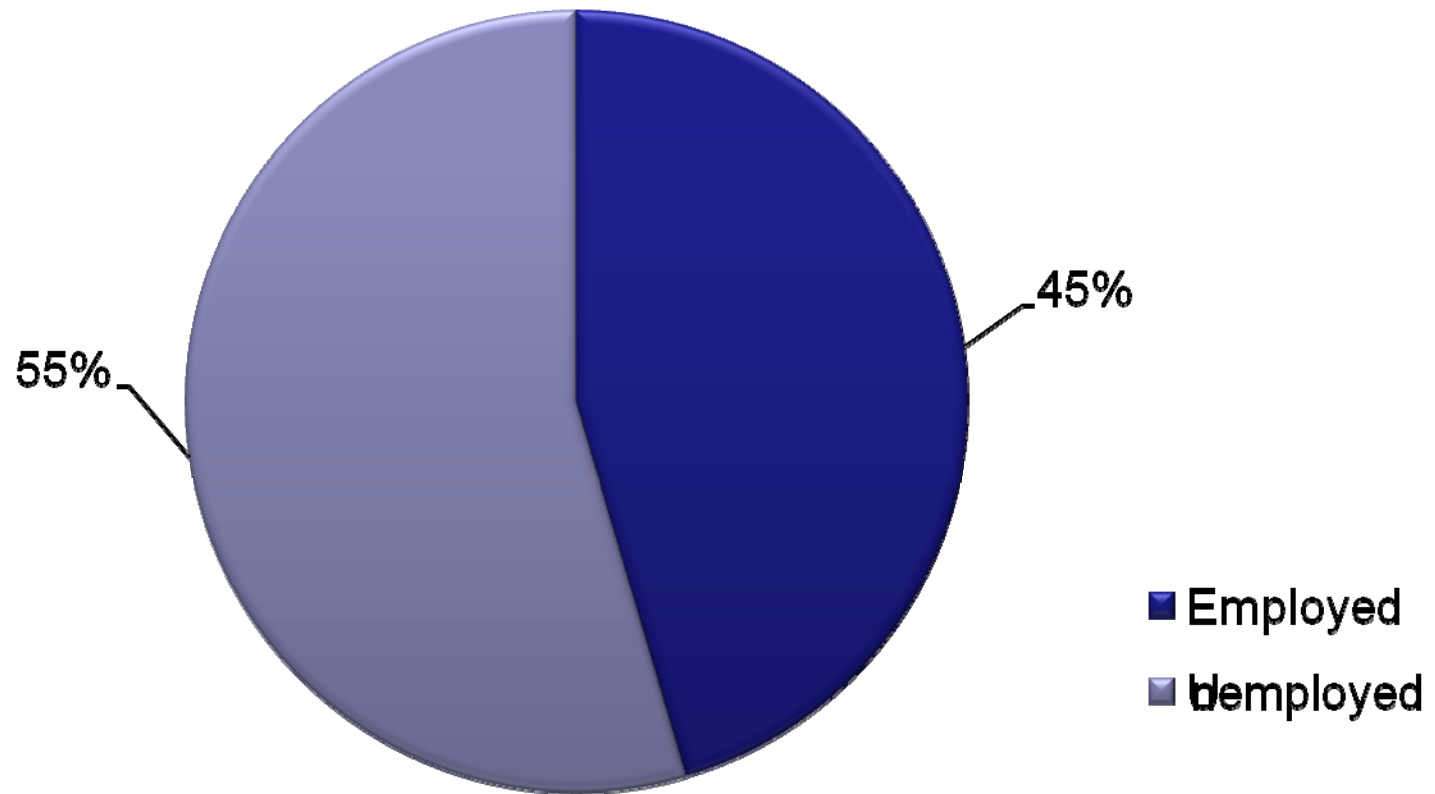
- Gender
 - 1 man: 10 women
- Age (years)
 - Average – 57
 - Median – 55
 - Range – 35 – 70
- Country of origin
 - 9 Canada: 1 Philippines:
1 U.S.A
- All of the participants are spouses of the stroke survivors except one who is the mother of the stroke survivor.
- Every participant lives with the stroke survivor.



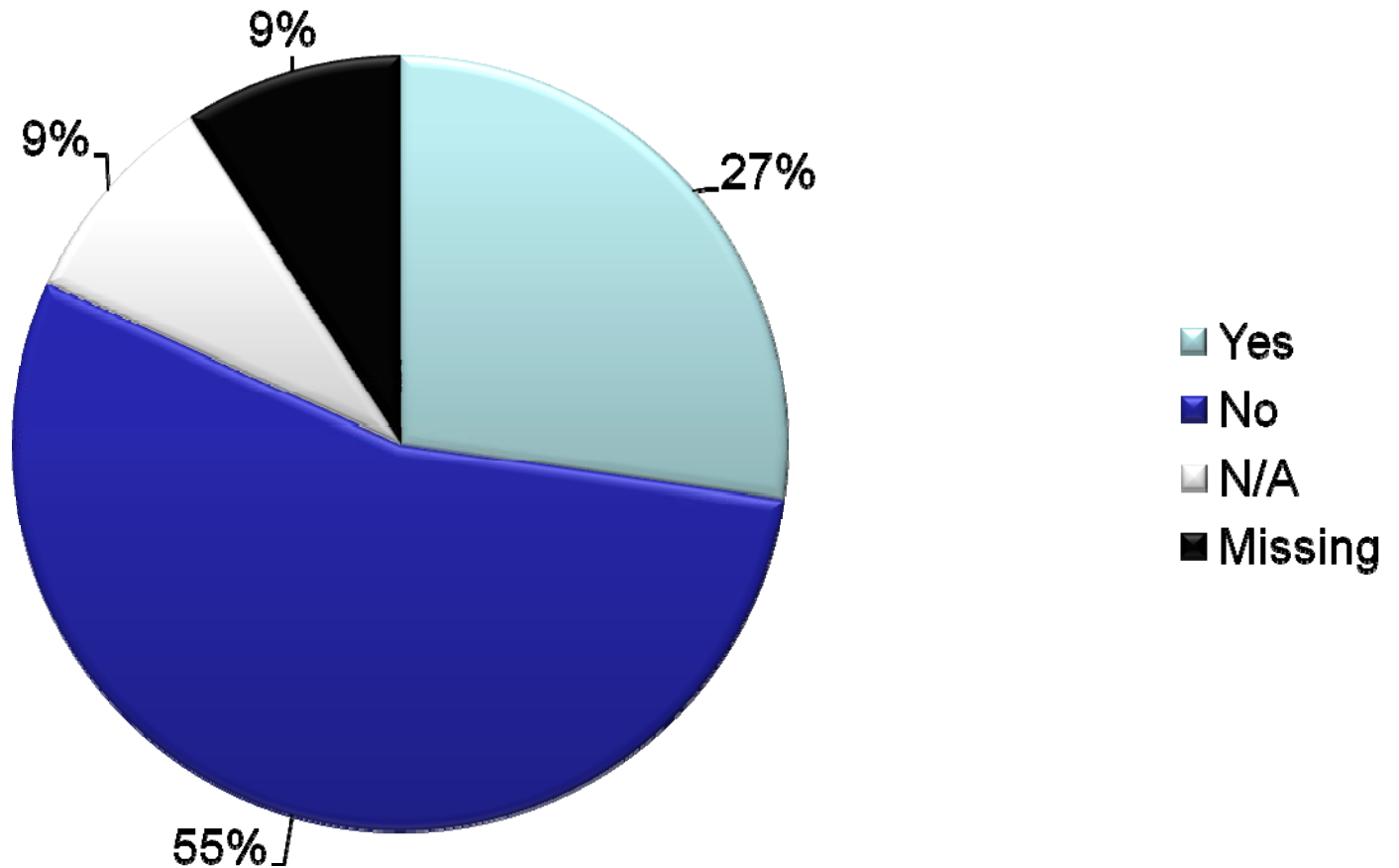
Education Background



Employment Background



Do They Feel Their Work/Volunteer Status Changed Since Care Giving?



How Long Have The Participants Been Care Giving?

- 3 years (average)
- 2 years (median)
- 3 months – 10 years (range)

Community Support Services?

***Are The Caregivers Or Stroke Survivors
Receiving Any Community Support Services?***

3 - yes

6 - no

2 – missing

***Does The Caregiver Or Stroke Survivor Attend A
Stroke Recovery Peer Support Group?***

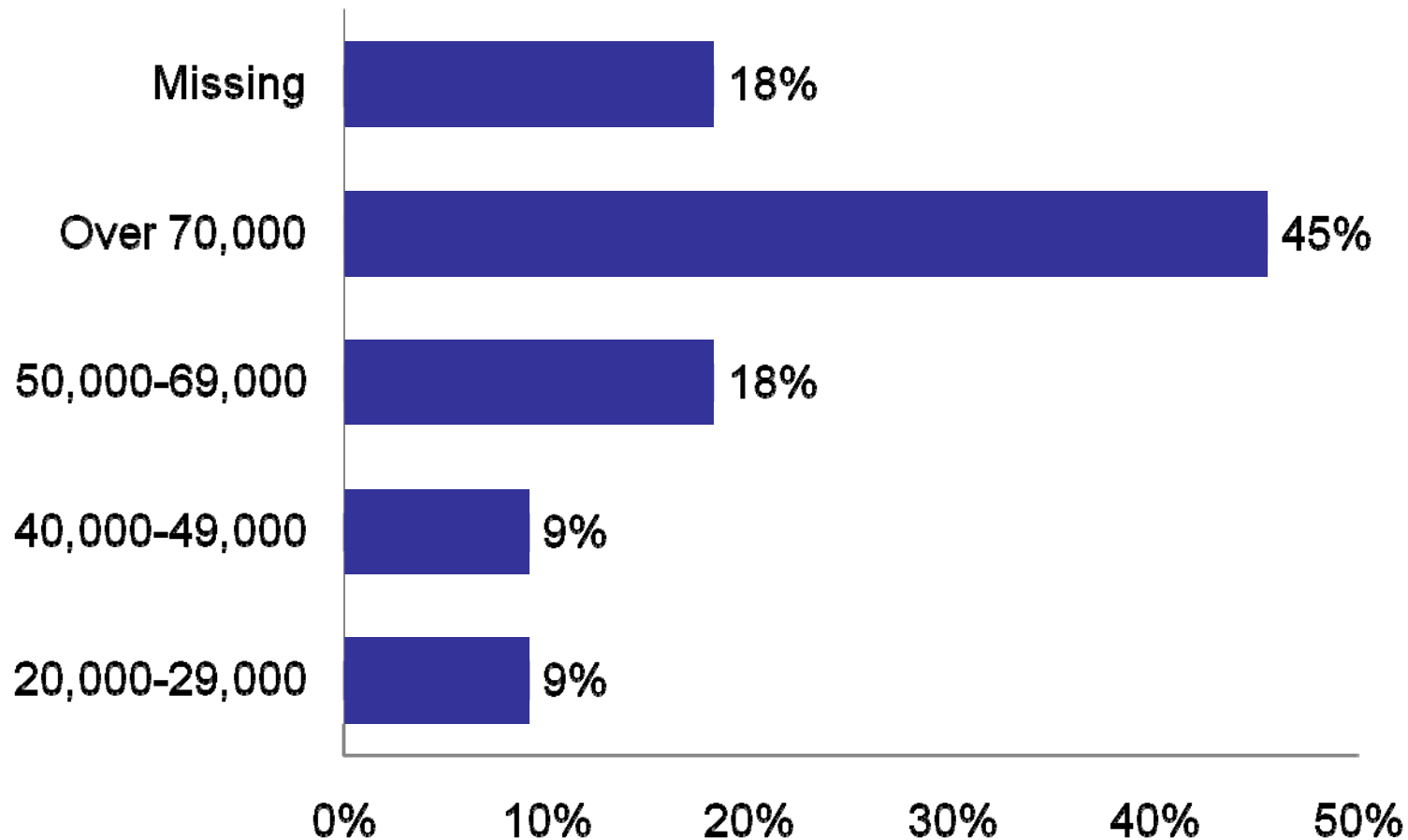
8 – yes

2 – no

1 – missing



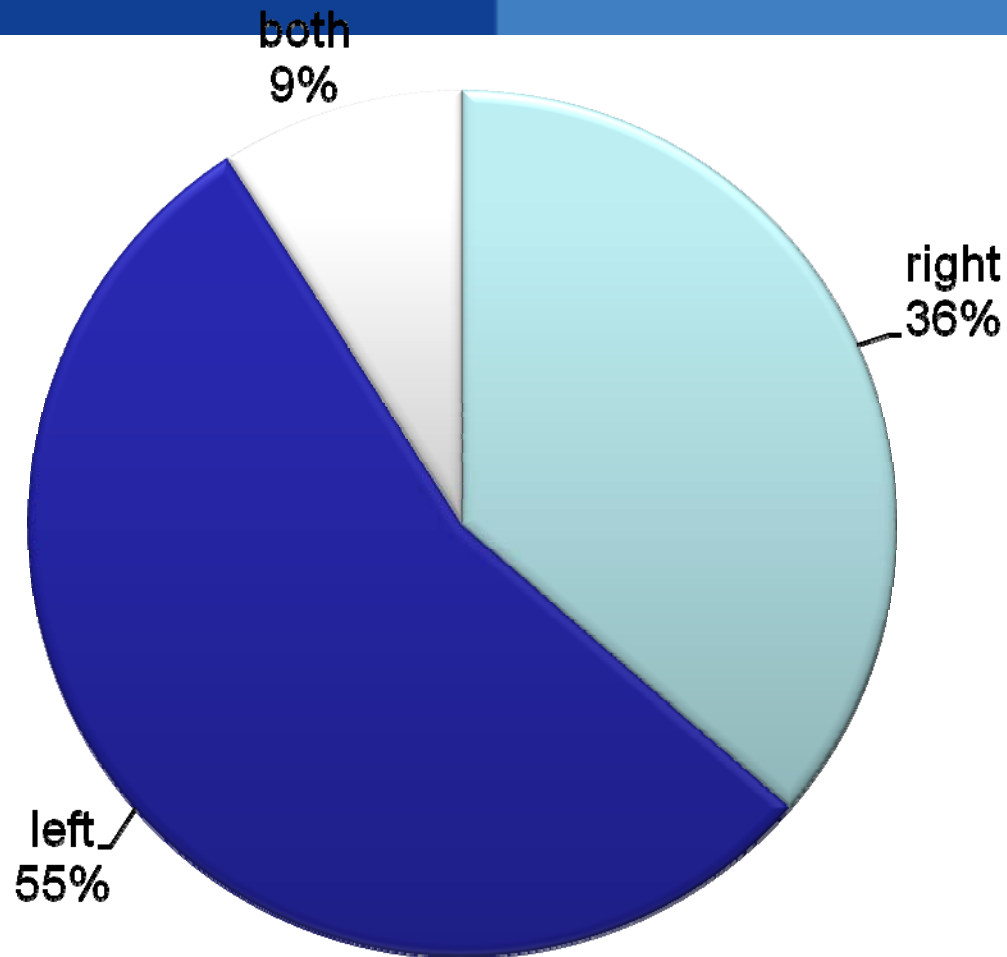
Family Income Background



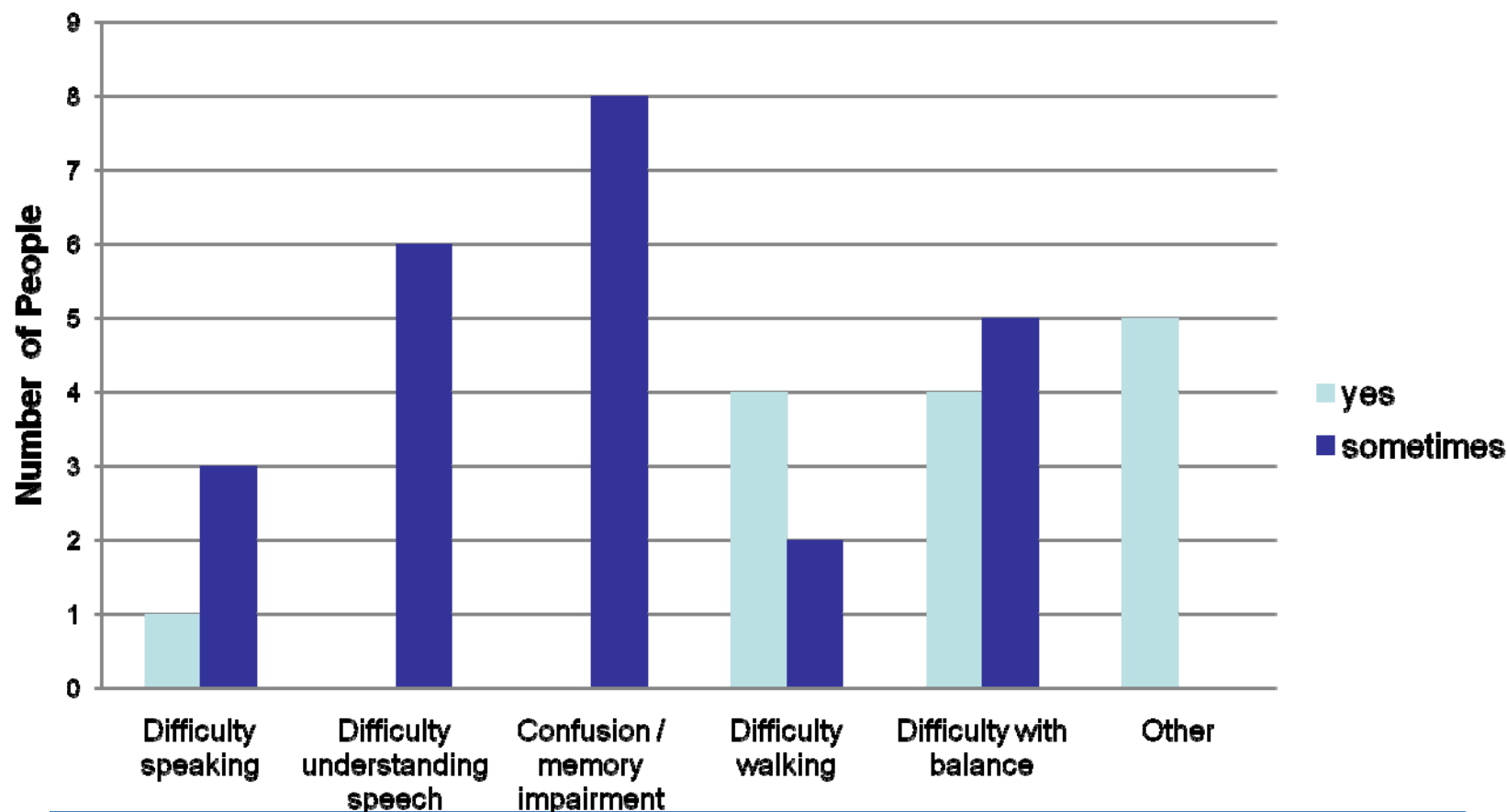
Stroke Survivor Gender & Age

- Gender
 - 2 women
 - 9 men
- Age (years)
 - 57 (average)
 - 56 (median)
 - 25 – 71 (range)

Which Side Of The Stroke Survivor's Body Was Affected?



Impairments Of Stroke Survivors':



Oberst Caregiver Burden Scale

- Measures the level of time & difficulty for 15 care giving categories
- Time and difficulty are each ranked from 1-5:

Time scale

1 = None

2 = A small amount

3 = A moderate amount
difficult

4 = A large amount

5 = A great amount

Difficulty scale

1 = Not difficult

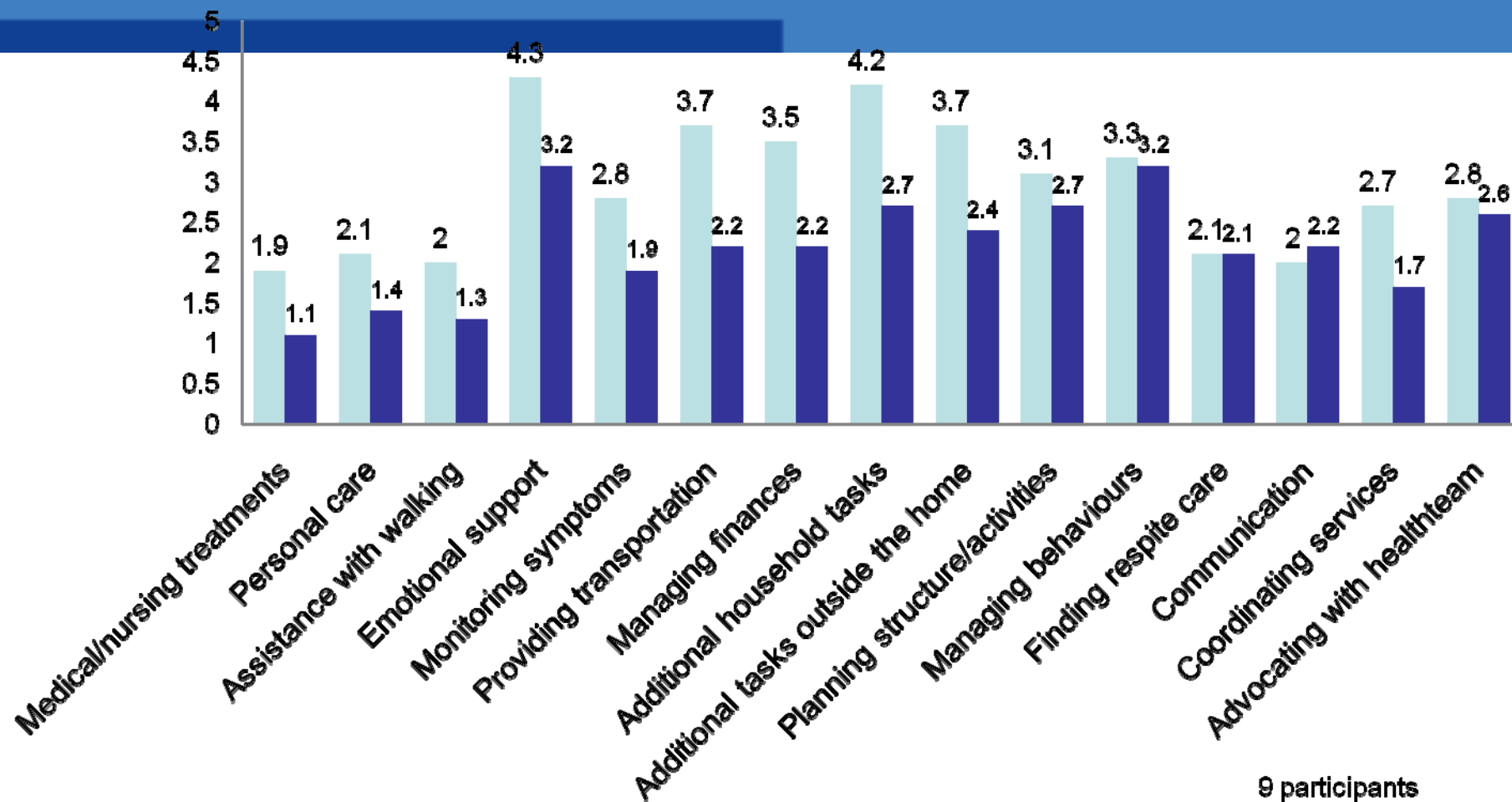
2 = Slightly difficult

3 = Moderately

4 = Very difficult

5 = Extremely difficult

Oberst Caregiver Burden Averages:



9 participants completed this questionnaire



■ Time ■ Difficulty

Feedback and Analysis

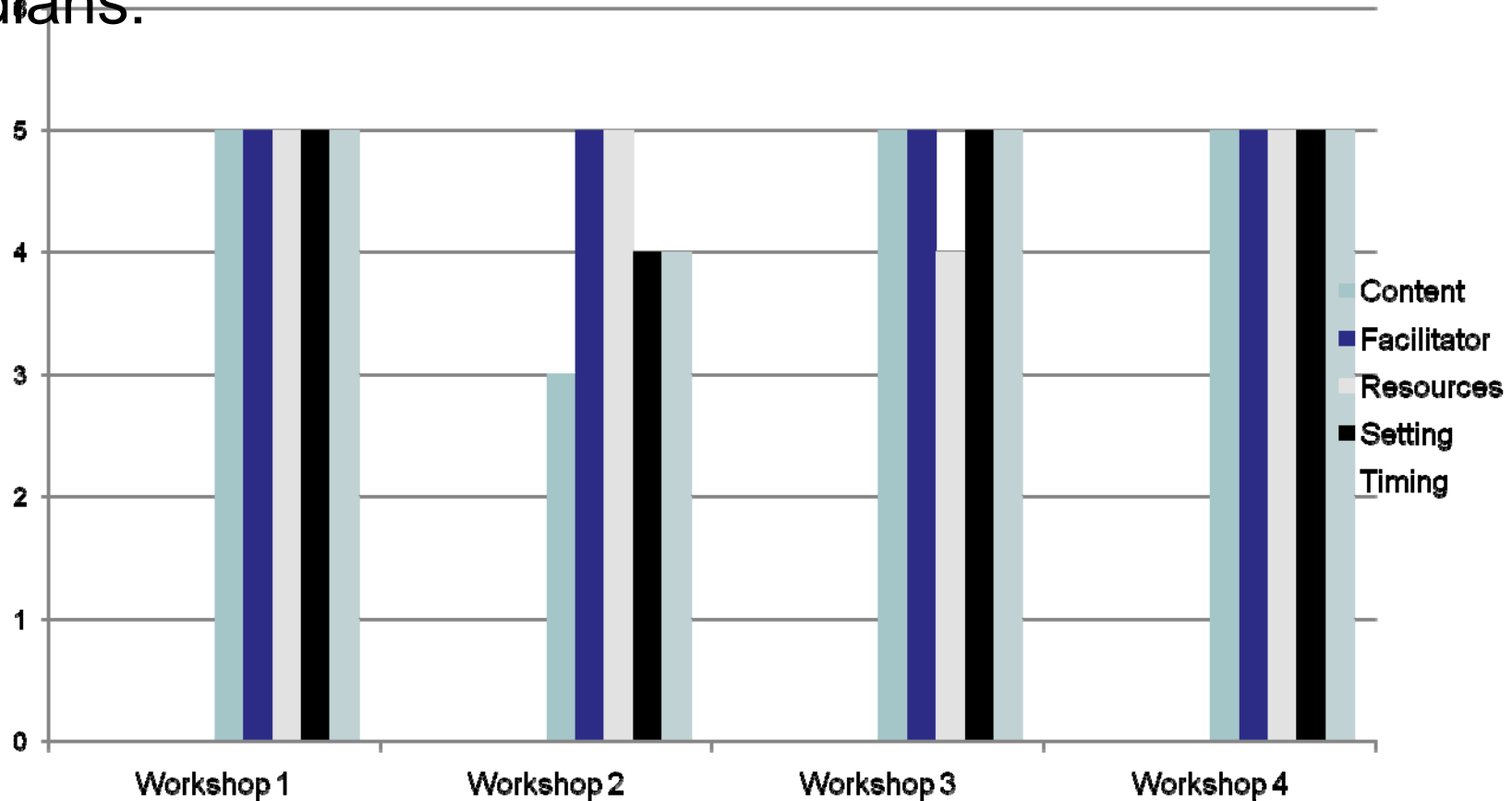


Summary Of Workshop Qualitative Themes:

1. Balancing changing role responsibilities
2. Managing cognitive, perceptual and mood changes
3. Intimacy and sexuality
4. Linkages to allied health professionals in community

Workshop Quantitative Summary:

Medians:



Summary Of Workshop Qualitative Themes:

Workshop # 1	Workshop # 2	Workshop # 3	Workshop # 4
Sharing stories / Open discussion – 5	Sharing stories/Open discussion – 5	Facilitator/Feedback – 3 Open discussion – 2	Sharing/Open discussion - 3 Informative – 2



Focus Group Analysis:

Attendance:

- 8 out of 11 participants attended
- One participant sent online feedback

What Did They Like Best About The Program?

- “Opportunity to share and brainstorm and share knowledge of resources and strategies”
- “The safest place to be in months”
- “I am learning to balance both the physical and emotional sides of his recovery, and we are working together as a partner...I can truly say now I am coping with my stress/frustrations by keeping my cool when overwhelmed...and when I lose it, it's OK”



What Did They Like Least About The Program?

- Sexuality and intimacy session
 - Homework
- Not enough chance to share
 - “Didn’t like being read to”

What Impacted The Group's Energy?

- “When we were sharing stories, learning from each other”
- “It was helpful to be with a diverse group”
- “Energy went down when we were asked to do homework...but went up when we were given the opportunity to share/brainstorm, share resources”
- “We were really fired up when we were able to critique the healthcare system”



Feedback Themes:

- Less structured format
 - “Not doing anything different...it should be more of a support group...and have a little structure in the beginning”
 - “Give people a chance to bond in the beginning”
- Timing
 - “Having this program earlier on in the care giving experience”
 - Make sure caregivers are available to attend the sessions
 - Flip session 4 (Connection with community service providers) to beginning”
- Make sure input from caregivers:
 - “Get the group back together to design the program – needs to come from those who are living the experience”
- Include more topics in content:
 - Healthcare terminology, how to be an advocate, dealing with grief , anger and loss, relationship changes, how to navigate the system
- Respite:
 - Continue to offer, but make sure in separate facility



Would They Recommend This Project To Others?

Yes (unanimous)



What Did They Say They Learned?

- Hope
 - “More hope and patience since attending the program”
- Advocacy
 - “We were able to talk about advocacy skills...which is important”
- Sharing
 - “Has given me a place to go and share my experience and learn”
 - “I have much more awareness now...and I want to help other caregivers now”
- More informed
 - Most were already aware of services available but some learned more about what was available.
 - Some learned about the Stroke recovery support groups and will go as they know someone in the group



Summary Recommendations:

- Delivery of program should be around 3-6 months after the patient is discharged from hospital
- Respite:
 - in order to attend is not as important after 3 months
 - It was agreed that if respite were necessary, it would be best to be at a different venue to increase impact of the care giver program
- Offer community resources module earlier on in project
- Less structure and be able to share stories
- Do not include sexuality module
- Avoid assigning homework
- Include other topics such as grief and navigating the system



FICCS Project Accomplishments:

- They would recommend this program to others.
- They bonded and developed a support network.
- They would like this program to continue on.
- They learned coping skills and resources from the workshops and each other.
- This Feedback helps validate the FICSS module content.



Next Steps:

- Phase 1 (Pilot) completed
- Phase 2:
 - Approved for funding from OSN
 - Update content to reflect feedback
 - Scheduled roll-out of 4 series of program in April – June 2011
- Phase 3: Evaluations (Spring 2012)
- Phase 4: Report back to stakeholders



Thank you

Laura Klaponski
FICSS Project Coordinator
1-800-263-3463 x 7212

lklaponski@marchofdimes.ca

Funding provided by Ontario Stroke Network



Partners

