Supporting Stroke Families Transitioning across the Care Continuum

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Mitigating Potential Bias

The Provincial Stroke Rounds Planning Committee mitigated bias by ensuring there was no Industry involvement in planning or education content.

To comply with accreditation requirements of the College of Family Physicians of Canada and The Royal College of Physicians and Surgeons of Canada, speakers were provided with Declaration of Conflict of Interest forms, which were reviewed by the Ontario Regional Education Group (OREG) Host member on behalf of the Planning Committee and submitted to the NOSM CEPD Office.

The Ontario Regional Education Group (OREG) Host member on behalf of the Planning Committee reviewed the initial presentation supplied by the speaker to ensure no evidence of bias.

Disclosure, Jill Cameron, PhD

Relationships with commercial interests:
= none

Relevant Nonfinancial Relationships:
= advisory committee member - American Heart/Stroke Association
Learning Objectives

1. Identify caregivers support needs and how they change across the care continuum
2. Implement a model of caregiver support and mechanisms for intervention delivery
3. Describe circumstances in which caregiver programs could be adopted by care systems

Language Disclaimer

- “Caregiver”
  - Family member, friend, neighbour or other individual(s) who provides assistance to someone who is unable to fully care for themselves due to illness
  - Not financially compensated for care
  - Can also be “carer”, “care partner”, “support network”, “informal caregiver”

Why Care for Caregivers?

- 1 in 4 Canadians are caregivers (~9.1 Million, 2016)
- Support stroke survivor recovery, rehabilitation, and community re-integration
- Saving HCS $25-26 billion/year (Hollander, 2009)
- US over $450 billion/year (Feinberg, 2011)
- Many experience stress, burden, poor mental health, quality of life, disrupted life, work, etc...
  - can ultimately impact patient outcomes
- Not standard clinical practice to prepare caregivers
Canadian Best Practices

- Caregiver education
  - Sensitive to change across the care continuum
- Caregiver support
  - Emphasizing transitions and broader than education

What do Caregivers need?

- Information and awareness/insight
- Training
  - Supporting ADLs, rehab therapy, medications…
  - Navigating health care system
  - Communicating with health care professionals
  - Problem solving
- Emotional support
  - Someone to share their feelings
  - Counselling, Psychotherapy

Social Support Context

(Cohen, 1992)

- Emotional
- Informational
- Social Support
- Appraisal
- Tangible & Training
Which caregivers need support?

- Caregivers' psychosocial resources
  - Mastery
  - Social support
  - Resilience
  - Existing knowledge
  - Experience with health care system
- Patients' abilities/needs
  - Target caregivers in need of support

Where can they obtain support?

- Health care professionals
- Family
- Friends
- Caregiving Peers
  - Everyone contributing their specific expertise

When do their needs occur?

- Care continuum perspective!
- Needs specific to:
  - Stroke event
  - Acute Care
  - Rehabilitation
  - Community
  - Institution-based community care
  - Palliative Care
Does it come down to Timing?

Family Caregivers:
- “the information book was too much in the hospital”
- “the information was excellent once home”

Health Care Professionals:
- “it is difficult to know when patients and caregivers are ready for information”

“Timing It Right” Framework

- Comprehensive five-phased approach to support families from the hospital to the home
- Emphasizes the timing of support needs across the care continuum
- Premise: addressing phase-specific needs will enhance family preparedness, ease transitions across care environments, and minimize negative outcomes (e.g., burden)

TIR Phases

1. Event/diagnosis
2. Stabilization
3. Preparation
4. Implementation
5. Adaptation

Acute Care
- Acute/Rehab
- Home

Stroke families have different support needs across these phases
The good news…

- "Educational content should be specific to the phase of care or recovery across the continuum of stroke care and appropriate to patient, family and caregiver readiness and needs [Evidence Level B]. (Cameron & Gignac, 2008)"


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How do you use this framework to improve the timing of support provision?

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The Timing it Right Stroke Family Support Program
**Intervention Development**

- TIR framework provided outline
  - One “chapter” for each TIR phase
  - Consider informational, emotional, tangible and training needs
- Qualitative study (Cameron et al, 2013)
  - 24 family caregivers (15 aphasia), urban and rural,
  - 14 health care professionals, across care continuum
- Leveraged existing educational resources
- Developed new material as needed
- Interdisciplinary review committee
- Reviewed and revised for local context

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**TIMING IT RIGHT**

**STROKE FAMILY SUPPORT PROGRAM**

**TORONTO EDITION**

Table of Contents

- Chapter 1: Introduction
- Chapter 2: My Family Member Has Had A Stroke
- Chapter 3: My Family Member’s Condition Has Stabilized
- Chapter 4: Preparing To Go Home
- Chapter 5: The First Few Months At Home
- Chapter 6: Getting On With Life In The Community
- Chapter 7: Notes And Additional Resources

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**How do you deliver support across care environments?**

- Qualitative study (Cameron, et al, 2013)
  - “one person to provide support”
  - “follow-up after we have left the hospital”
- What have others done?
  - Telephone support (e.g., Grant, 1999, 2002)
  - Trained nurses (e.g., van den Heuvel, 2002)
  - Family Support Organizers (e.g., Lincoln, 2003)
  - Models of Integrated Service Delivery
    - Case management (PRISMA – Hebert, 2003)
- Stroke Support Person (SSP) – one key individual, in person during acute care, by telephone thereafter.
Stroke Support Person

- Health Care Professional
  - Occupational Therapist
  - Nurse
  - Social Worker
  - Other
- Expertise in stroke management and care options

Key Roles of SSP

For each session:

1. Emotional Support
   - Ask “how are you doing?”
2. Informational Support (Intervention Guide)
3. Tangible Assistance and Guidance
   - Navigate to appropriate resources
4. Appraisal - Feedback on how they are managing
   - “it sounds like you are managing well”

Giving stroke families the support they need when they need it!

Pilot study: Cameron et al Clinical Rehab. 2014
Protocol: Cameron et al. BMC Health Services Research 2014
Lessons Learned from Research

Objective of the Trial
The objective of multi-province randomized controlled trial was to determine if the “TIR Stroke Family Support Program” delivered across the care continuum improves caregivers sense of being supported and emotional well-being.

Intervention Arms:
1. Standard Care (SC)
2. Self-directed (SD)
   - Orientation by Stroke Support Person (SSP)
3. SSP-delivered (SSP)
   - In hospital for first session
   - Monthly by telephone for first 6 months post-stroke
   - Tailored to individual caregiver needs
Hypotheses

1. TIR program – delivered by Stroke Support Person
2. TIR program – Self-directed
3. Standard Care Control – “Let’s Talk about Stroke”

Full RCT Protocol (Cameron et al, BMC Health Services Research 2014)

- Design: Mixed methods, multi-site, longitudinal
- Sample: Goal is 300 “novice” caregivers to stroke survivors ultimately discharged home
- Procedure: Recruit during acute care, complete baseline survey, randomize, begin intervention, 3, 6, 12-month follow-up surveys, qualitative interview at 12-months

RCT Protocol

Data Collection:
- DV – MOS SS, Stroke Knowledge, CES-D, PAS
- IVS – CAS, CIS, Epworth, Mastery, Personal Gain, CNS, Barthel, demographic characteristics (age, gender, relationship, previous caregiving, education level, stroke severity, etc.)
- Stroke Support Person Journals (# sessions, time, resources)
- Qualitative interviews
- Economic – health service utilization, OHIP
RCT Protocol

Data Analysis:
- Descriptive Statistics
  - Caregiver and patient characteristics
  - Intervention delivery (SSP journals)
  - HLM to test hypotheses

Participating Centers for RCT

CONSORT Flow Diagram

Excluded (n=4082)
- Declined to participate (n=883)
- MIS (n=2358)
- Withdrawn before randomization (n=80)
- Not meeting inclusion criteria (n=1511)

Assessed for eligibility (n=4372)

Randomized (n=310)
- Self-directed intervention (n=106)
- Full SSP intervention (n=104)

Enrollment

Allocation

Standard care (n=100)
- Withdrawn (n=11)
- Survey Completed (n=70)
- Survey Missed (n=30)

Self-directed intervention (n=106)
- Withdrawn (n=1)
- Survey Completed (n=85)
- Survey Missed (n=21)

Full SSP intervention (n=104)
- Withdrawn (n=1)
- Survey Completed (n=92)
- Survey Missed (n=12)

3 Month Follow-up

Survey Completed (n=75)
- 4 patients deceased
- 6 caregivers withdrew
- 1 removed by study team

Survey Missed (n=17)

Survey Completed (n=80)
- 5 patients deceased
- 5 caregivers withdrew
- 1 removed by study team

Survey Missed (n=15)

4 Month Follow-up

Survey Completed (n=75)
- 1 patient deceased
- 4 caregivers withdrew
- 1 removed by study team

Survey Missed (n=17)

Survey Completed (n=73)
- 2 patients deceased
- 3 caregivers withdrew
- 1 removed by study team

Survey Missed (n=16)

6 Month Follow-up

Survey Completed (n=72)
- 1 patient deceased
- 7 caregivers withdrew
- 2 removed by study team

Survey Missed (n=16)

Survey Completed (n=69)
- 1 patient deceased
- 9 caregivers withdrew
- 1 removed by study team

Survey Missed (n=24)

12 Month Follow-up

Survey Completed (n=67)
- 1 patient deceased
- 6 caregivers withdrew
- 1 removed by study team

Survey Missed (n=24)

Survey Completed (n=65)
- 1 patient deceased
- 9 caregivers withdrew
- 1 removed by study team

Survey Missed (n=22)
### Interventions Delivery

- **Self-directed (n=106)**
  - 1 meeting, median 32 minutes
  - 42 in person, 50 over the phone
- **Full SSP Intervention (n=104)**
  - 3.5 meetings, median 78 minutes
  - 1st session - 47 in person, 44 by phone

### Protocol Deviations

<table>
<thead>
<tr>
<th>Group</th>
<th>Randomized (n)</th>
<th>SC</th>
<th>SD</th>
<th>SSP</th>
<th>Received (n)</th>
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<tbody>
<tr>
<td>SC</td>
<td>100</td>
<td>--</td>
<td>+13</td>
<td>+13</td>
<td>126</td>
</tr>
<tr>
<td>SD</td>
<td>106</td>
<td>-13</td>
<td>-7</td>
<td>+8</td>
<td>94</td>
</tr>
<tr>
<td>SSP</td>
<td>104</td>
<td>-13</td>
<td>+7</td>
<td>-8</td>
<td>90</td>
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</tbody>
</table>

### HLM Results

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Depression</th>
<th>Psychological Wellbeing</th>
<th>Perceived Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intention to Treat</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>SC vs SSP</td>
<td>.04 (.14, .8)</td>
<td>.03 (.13, .8)</td>
<td>.15 (.23, .5)</td>
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<tr>
<td>SC vs SD</td>
<td>.14 (.14, .3)</td>
<td>.08 (.13, .6)</td>
<td>.06 (.23, .8)</td>
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<tr>
<td>SD vs SSP</td>
<td>-.10 (.14, .4)</td>
<td>-.04 (.13, .7)</td>
<td>.08 (.23, .7)</td>
</tr>
<tr>
<td><strong>Received</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SC vs SSP</td>
<td>.11 (.13, .4)</td>
<td>-.05 (.13, .7)</td>
<td>.08 (.22, .7)</td>
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<tr>
<td>SC vs SD</td>
<td>.16 (.14, .2)</td>
<td>.05 (.13, .7)</td>
<td>-.00 (.24, .9)</td>
</tr>
<tr>
<td>SD vs SSP</td>
<td>-.05 (.14, .7)</td>
<td>-.10 (.14, .4)</td>
<td>.09 (.24, .7)</td>
</tr>
</tbody>
</table>

*Estimate (SE, p-value)*
Qualitative Themes

N= 39 (13 – SC; 10 – SD; 16 – SSP)

Four themes:
1. Variability in personal situation influenced caregivers’ needs for or use of external supports
2. Variability in caregivers’ insight informed their engagement in support
3. Variability in availability and consistency of support
4. Experience of intervention not being part of standard care

Variability in Personal Situation

- Characteristics of the stroke
- Trust in health care system
- Personal resources
- Ability to ask questions
  “You know, okay, why do you do this? And that helped me. I wasn’t shy about asking why they were doing things.”

Variability in Insight

- Leveraged non-stroke caregiving experiences
- Developed over time as the caregiver performed their role
  “I learned to ask for what I needed and … [sighs] tell people what I didn’t need.”
- Learned from caregiving peers
  “…love to have a conversation with a bunch of other people who have been through the same experience to sort of compare notes and see”.

Department of Occupational Science and Occupational Therapy
Variability in Available Support

- Emotional support from friends and family
- Information from the healthcare team
  "the opportunity to ask questions wasn’t great […] there should be a family liaison person, somebody that talks just to the family, […] who might be more candid with you if you weren’t in the room with the patient."
- Need for post-hospital follow-up

Intervention Not Standard Care

Problems related to:
- Intervention starting “late”
- Addition of the intervention on top of standard care added to caregivers’ confusion
- SSP not knowledgeable about the patients specific condition
  “I just felt it wasn’t enough for me. I didn’t really know what I was up against … what he was supposed to do or not to do, even with his diet. I didn’t really get a lot of information on what he should or shouldn’t have.”

Contribution

- No significant difference between groups on outcome measures.
- Difficulties delivering intervention as planned
  - Telephone contact used for first meeting
  - Caregivers trying to get desired intervention – more or less contact (SD or SSP)
- Variability across caregiving situations regarding support
  - needs, insight, availability
  - need to identify and target caregivers in need
Changing the system to support Caregivers

- What factors influence adoption of caregiver education, training, support, etc, into standard clinical practice?
- PhD thesis of Victrine Tseung
- Papers to be submitted this summer

The Ontario Context

- "What is it going to take?"
  - Qualitative study with multiple stakeholder groups from the Ontario Stroke System (n=72)
- System level
  - establish why caregiver programs are necessary
  - adopt a journey of care perspective
  - delineate ownership and responsibility for implementation
  - address regional variations
- Program level
  - Fit with existing infrastructure, routine practice, program must be flexible and adaptable, tracking support provision

Concluding thoughts

- Caregivers are a unique group in need of support
- Support needs change across care continuum
- May need to "target" caregivers in need
- Support needs to be:
  - Part of standard care
  - Integrated across care continuum
- Timing it Right Stroke Family Support Program is a start to addressing these needs
## Research Team

**Investigators:**
- Dr. Jill Cameron (PI), Toronto
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- Carole MacKibben, Heart PSI, Prince Edward Island
- Beverly Powell-Vinden, Heart and Stroke Foundation of Ontario
- Elizabeth Woodbury, Executive Director, Canadian Stroke Strategy

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Thank you!

Questions?

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