

Supporting Caregivers across the Care Continuum

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Creating Leaders in OT

Learning Objectives

- Understand the important role family caregivers play across the care continuum
- Understand caregivers support needs and how they change across the care continuum
- Consider a model of caregiver support and mechanisms for intervention delivery
- Understand factors that influence caregiver program implementation

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Recommended reading

- 1 Cameron JI, O'Connell C, Foley N, Salter K, Booth R, Boyle R, et al. Canadian Stroke Best Practice Recommendations: Managing transitions of care following Stroke, Guidelines Update 2016. *Int J Stroke* 2016 Jul 21.
- 2 Bastawrous M, Gignac MA, Kapral MK, Cameron JI. Factors that contribute to adult children caregivers' well-being: a scoping review. *Health Soc Care Community* 2015 Sep;23(5):449-66.
- 3 Cameron JI, Naglie G, Green TL, Gignac MA, Bayley M, Huijbregts M, et al. A feasibility and pilot randomized controlled trial of the "Timing it Right Stroke Family Support Program". *Clin Rehabil* 2015 Nov;29(11):1129-40.
- 4 Mayo NE, Anderson S, Barclay R, Cameron JI, Desrosiers J, Eng JJ, et al. Getting on with the rest of your life following stroke: A randomized trial of a complex intervention aimed at enhancing life participation post stroke. *Clin Rehabil* 2015 Jan 27.
- 5 Yeung EH, Szeto A, Richardson D, Lai SH, Lim E, Cameron JI. The experiences and needs of Chinese-Canadian stroke survivors and family caregivers as they re-integrate into the community. *Health Soc Care Community* 2015 Sep;23(5):523-31.
- 6 Grant JS, Hunt CW, Steadman L. Common caregiver issues and nursing interventions after a stroke. *Stroke* 2014 Aug;45(8):e151-e153.

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Recommended reading cont...

- 7 Cameron JI, Naglie G, Silver FL, Gignac MA. Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework. *Disabil Rehabil* 2013 Feb;35(4):315-24.
- 8 Gaugler JE. The longitudinal ramifications of stroke caregiving: a systematic review. *REHABIL PSYCHOL* 2010 May;55(2):108-25.
- 9 Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal primary carers of stroke survivors living at home - challenges, satisfactions and coping: A systematic review of qualitative studies. *Disabil Rehabil* 2009 May 8;31(5):1-15.
- 10 Cameron JI, Gignac MA. "Timing It Right": A Conceptual Framework for Addressing the Support Needs of Family Caregivers to Stroke Survivors from the Hospital to the Home. *Patient Educ Couns* 2008;70:305-14.
- 11 Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal carers of stroke survivors - factors influencing carers: A systematic review of quantitative studies. *Disabil Rehabil* 2008 Feb 19;1-21.
- 12 Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal carers of stroke survivors--factors influencing carers: a systematic review of quantitative studies. *Disabil Rehabil* 2008;30(18):1329-49.

Our Starting Point

- Families have needs beyond medical care post-stroke
- These needs change across the illness trajectory

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
 - 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 health care system \$60 billion/year (Fast, 2018)
- 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



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Canadian Best Practices

- Education
 - Addressing patients and caregivers' needs for education
- Transitions
 - Supporting patients and caregivers as patients transition across care environments



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What are some needs?

- Information and awareness/insight
- Training
 - ADLs, rehab therapy, medications...
 - Navigating health care system
 - Communicating with health care professionals
 - Problem solving
- Emotional support
 - Counselling

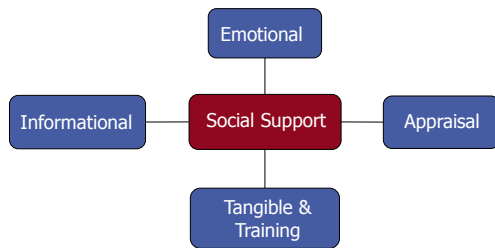


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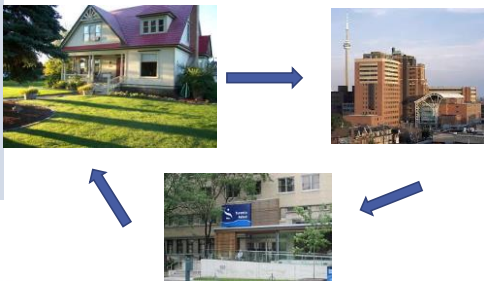
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Social Support Context

(Cohen, 1992)



Stroke Trajectory



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"

Stroke Survivors:
"when we left the
hospital, the door closed
and there was no more
information"

Timing

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)

Cameron & Gignac. Patient Educ Couns, 2008;70:305-314
Cameron et al. Disabil Rehabil 2013;35:315-24

TIR Phases

- | | | |
|--------------------|---|-------------|
| 1. Event/diagnosis | } | Acute Care |
| 2. Stabilization | | |
| 3. Preparation | } | Acute/Rehab |
| 4. Implementation | | |
| 5. Adaptation | } | 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)”

Canadian Stroke Strategy Best Practice Guidelines, 2008, 2010, 2012, 2016

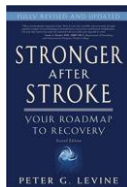
Sources of Support



Support Mediums



<https://www.youtube.com/watch?v=qCBIn470bIM>



Support Mediums

How does the use of different mediums change across the illness trajectory?

- Limited research available

People:

- Support from family/friends tends to decrease over time
- Support from HCPs also decreases over time
- Peers of more interest in the community

TIR Changing Needs

- Informed by qualitative interviews
 - Health care professionals
 - Caregivers
 - Patients
 - Various studies

Event/Diagnosis

Support Needed	Source of Support
Information: diagnostic testing, treatment, medications	Health care professionals
Emotional: sense of being cared for	Family/friends
Instrumental: comforts, form completion, companionship, parking, accommodation, help at home	Health care professionals and family/friends
Training: none	

Event/diagnosis – Information Needs

The nurses and the doctors there, they did keep us well informed of what was going on and what the care would become and how they would switch the medications... which kind of put our mind at ease. *Rehab Caregiver; husband*



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Event/diagnosis – Emotional Needs

you need just someone to prop you up and tell you it's going to be okay, or you know things are going maybe be different. But not to get into to a great detail with you then, you just need some moral support then. Emotional support. *Aphasia Caregiver; wife*



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Event/diagnosis – Tangible Supports

Everybody was very nice... they would get me a chair so I could stay, asked me if I needed a coffee or something or a blanket. *Rehab Caregiver; husband*



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Stabilization

Support Needed	Source of Support
Information: what is a stroke, medical status, expected recovery, rehabilitation eligibility and options, care processes, roles of HCPS	Health care professionals
Emotional: sense of being cared for	Family/friends
Instrumental: comforts, form completion, companionship, parking, accommodation, help at home, transfers between hospitals, arranging rehabilitation	Health care professionals and family/friends
Training: support ADLs in hospital	



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Stabilization – Training

"Then, only a couple of days ago, a nurse just happened to be there when my Mom was getting out of bed. So she showed me the easier way for my mother to get out of bed... the easier way to get her out of the wheelchair... so I would have appreciated knowing all that, at the beginning... because I spend a lot of time here – if somebody had taken the trouble to say, "Look, we can see that you're helping your Mom. This is like the basic things that she's doing on a regular basis during the day, this is how to do them." I think it would have definitely benefited me and my Mother... because I would have been doing the things." Daughter, caregiver



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Preparation

Support Needed	Source of Support
Information: care plan, rehabilitation goals and intensity, home care services, secondary prevention, navigating the health care system	Health care professionals Peers
Emotional: more relaxed and optimistic	Family/friends
Instrumental: participate in rehab, discharge planning, disability insurance application, community care service planning, accessing ongoing rehab, ensuring home safety, coordination of f-u appts, someone asking how caregiver is doing	Health care professionals Family/friends
Training: mobility, transfers, medical care at home, rehab exercises, proving home care, manage behaviour changes and depression, weekend passes	Health care professionals



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Preparation – Training

Interviewer: Did they teach you anything as you prepared to go home?
Caregiver: Not really, not a lot and I guess because I wasn't there everyday at that point and the days that I was, I could go and watch him (in therapy). But that was about it.
Rural Caregiver, wife

Implementation

Support Needed	Source of Support
Information: secondary prevention, where to go with questions, how to care and support rehabilitation at home, realistic expectations regarding outpatient therapy and recovery, community reintegration, community-based programs/ services to support caregiver	Health care professionals Peers
Emotional: sense of being cared for, sharing experience with peers	Family/friends Peers

Implementation continued...

Support Needed	Source of Support
Instrumental: case manager, home safety, more home care services based on needs of survivor and caregiver, respite care, day programs, assistance at home, follow-up call from in-patient HCP to check on survivor and caregiver, person to contact with questions, visits from family and friends, organize long-term care papers	Health care professionals and family/friends
Training: managing rehabilitation at home, communication (aphasia), stroke survivor mental health, support community reintegration, managing the unexpected (e.g. problem solving skills)	Health care professionals
Appraisal: need for feedback on their care-giving skills	Health care professionals

Implementation – Training/Appraisal

My needs were “Tell me that I’m doing things right.” And that’s what I didn’t get. *Aphasia Caregiver, wife*



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Adaptation

Support Needed	Source of Support
Information: communication, stroke affects the whole family, life after stroke, community reintegration, preventing or coping with future health events, long-term care options, caregiver respite opportunities	
Emotional: emotional comfort, sense caregiver is being cared for	Peers
Instrumental: re-assessment for community and rehabilitation services, need for supports received during implementation to continue, respite, peer support groups	Note: Health care professional support not evident
Training: communication, prevention of future events, learning to live with the chronicity of stroke	Family/friend support decreases over time



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Adaptation – Information Needs

... refresher course, refresher appointments... but if there were some way of having smaller groups with ongoing once a year training. *Aphasia caregiver, wife*



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Adaptation – Emotional Needs

Interviewer: What do you think about when you think to the future?

Caregiver: I'm very frightened because, I've watched... the last little while you can see him going downhill. I wonder constantly when another one is going to happen. My own well being. Just last week, I was to the doctor and I have high blood pressure now. *Rural Caregiver, wife*



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How do we tie all this together
to support stroke families
across the care continuum?



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One possibility: The Timing it
Right Stroke Family Support
Program



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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

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

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
- Trained volunteer?

Key Roles of SSP

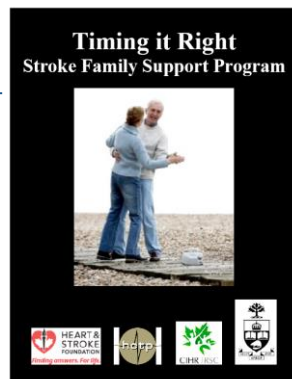
For each session:

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

Note: SSP does NOT replace existing services but helps families connect to services

➤ 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



Knowledge Translation Study (V. Tseung)

Key Informant (n=12) and Qualitative descriptive (n=73) studies with knowledge-users – Ontario Stroke Network

1. A deeper understanding of caregivers and the importance of implementing caregiver programs is warranted.
2. Evidence supporting the value of a caregiver program is essential.
3. Stakeholder engagement is important.
4. Incorporating caregiver education and support into clinical practice is complex.



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Questions

- What can you take from this to your own practice?
- Population?
- Care environment?



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Take home messages

- Support is multi-dimensional
- Support needs change across illness trajectory
- Many sources and mediums of support
- “Timing it Right Stroke Family Support Program” is one model to address changing needs
- “Timing” is the lens



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