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Research Project :
The First Days Following Stroke

Patient and Community Engagement Research Program – PaCER

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This Internship Research Project was Supported by:

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- Noreen Kamal, P.Eng, PhD
Principal Co-Investigators

- Nancy Martlett, PhD, Director, PaCER
Program (CRDS - CHS/Cumming School of
Medicine)

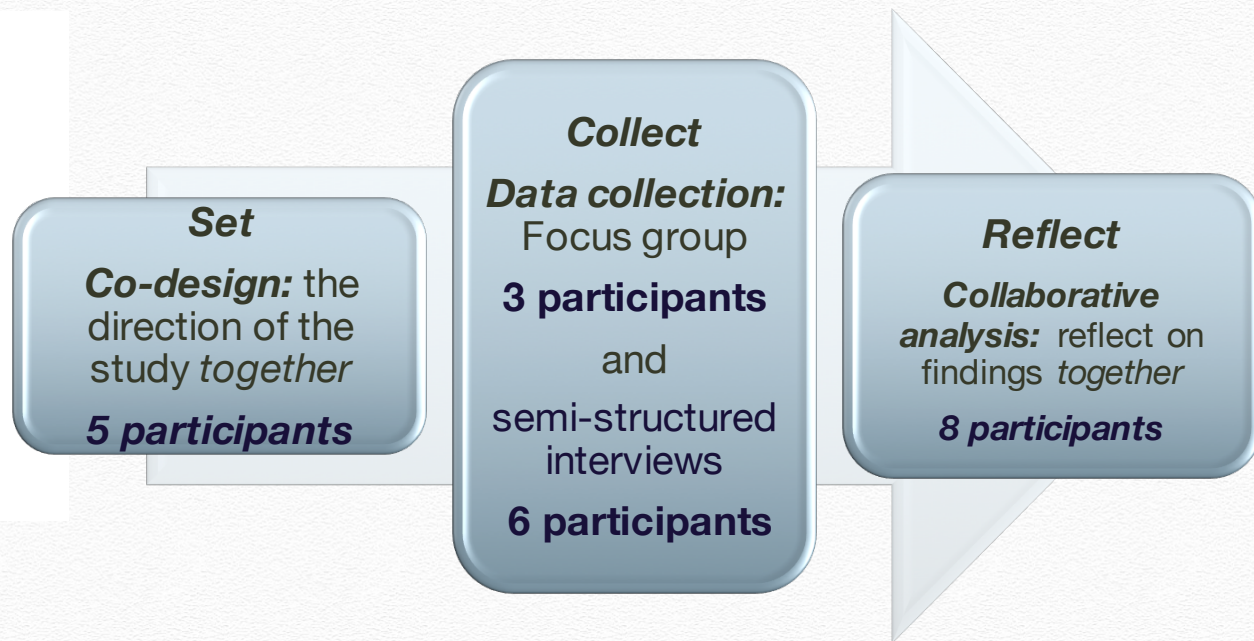
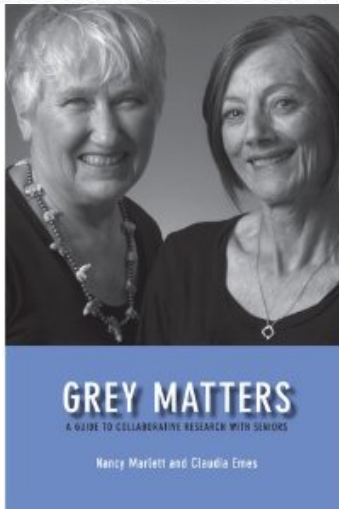
- QuICR Program, Dr. Michael Hill, MD
Noreen Kamal, P.Eng, PhD



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The PaCER Research Method

A Participatory Grounded Theory Method within a Collaborative Framework for Engaging Patients in Research



**14 participants in total = 9 stroke survivors + 5 family members
2x survivors as family; 6 women; 8 men**

Marlett, N. & Emes, C. (2010). *Grey Matters. A Guide to Collaborative Research with Seniors.* University of Calgary Press, <http://uofcpress.com/books/9781552382516>



Methodology

Each set of data informs the collection and interpretation of subsequently collected data, in a cascading fashion.

- **SET:** co-design with patients as advisors, pointed out the need to look beyond FAST and include the entire experience (from symptoms to how I got help to what life is like after stroke)
- **COLLECT:** what was it like for stroke survivors and families?
 - Focus group (3 participants)
 - In-depth semi-structured interviews (6 participants)
- **REFLECT focus group:** participants from earlier stages re-convene to:
1) review findings and refine analysis, and 2) *suggest knowledge utilization and recommendations*



Recruiting for Collaborative Research

- Challenging
- Lucky to have an engaged survivor of stroke and INSPIRES peer supporter on our team
- Four participants from INSPIRES
- In-Patient Support Program in Recovery from Stroke (I.N.S.P.I.R.E.S)
- Living Well With Stroke Program (could be co-taught by survivors?)



Recruiting for Collaborative Research

PARTICIPANTS:

Pervasive desire to help others (survivors *and* family)

Keen to know what would happen with their stories

Not looking for a therapy group (focus groups were sometimes perceived that way)

Approached as peers (patients ourselves) rather than knowledge experts with Ph.D.'s

Events like tonight may help to build credibility in support of future recruitment.



- Initial objective was to explore the experiences of survivors of stroke, and their family members, in the first days following stroke.
- Survivors and family had much to say about the full pathway of the experience from initial recognition through to release from the hospital and beyond. They saw this in five milestones:





Something is not right...

- ❖ *“I knew I had to call for help, but I wasn’t very good at calling for help ... It was like letting someone know I wasn’t feeling well.”*
 - ❖ I had a general feel of unease...
 - ❖ Leaned over and felt that half of my body was not working...
 - ❖ My leg gave out on me...
 - ❖ Out of body feeling – watching myself...
 - ❖ Lost sight in one eye...
- **Discussion Points**
 - ❖ Broad public messaging to reinforce identification of stroke symptoms and the need to act quickly
 - ❖ Messaging from AHS that encourages patients with stroke symptoms to call EMS immediately



What the heck was happening?

- ❖ *Fell down – collapsed, then got back up and continued my day*
- ❖ *I lost my language and started speaking in my mother tongue*
- ❖ *I dropped a glass, started to swear and didn't recognize the words coming out of my mouth*
- ❖ *I had a bad cramp in my leg and arm*
- ❖ *When I looked back much later, I had “googled” stroke on my computer, but didn't remember doing that*
- ❖ *I'll just take some aspirin and that'll make it better*

Discussion Points

- ❖ **How to help individuals recognize that these could be stroke symptoms**
- ❖ **Self-diagnosis and treatment to not bother others with vague symptoms**



BUT...

- ❖ *I didn't have pain...*
- ❖ *There's no way I could have had a stroke (stigma?)*
- ❖ *I'm too healthy (or young) to have a stroke – (no risk factors)*
- ❖ *I have to go to work, it's the first day of a new job!*
- ❖ *ER is too busy, I'll have to wait for hours there!*
- ❖ *"Suck it up" society*
- ❖ *I'll just lay down and maybe it will go away*
- ❖ *I don't want to burden family, friends, or the healthcare system*
- ❖ *I'll just shake it off, start the day over, maybe it will go away*

Discussion Points

- ❖ Put a face to stroke, use the patient's experience and language to illustrate public education
- ❖ How to get past denial and fear of stroke?



The Tipping Point

“And thank God the [land]lady came out...to check on me and I was lying on the floor and couldn’t get back up... She phoned the ambulance and they took me to the Peter Lougheed.”

- ❖ Wound up being dependent on a **bystander to take action** on our behalf

Discussion Points

- ❖ Help identify the barriers to reaching out for help and encourage action
- ❖ Potential EMS costs
- ❖ Fear of admitting that the experience is stroke
- ❖ Reluctance to burden the system



First Contact with Help

- ❖ *Once the decision to seek help was made, we may have perceived a delay with EMS transporting to the emergency*
- ❖ *Sense of time, sense of urgency – I've taken action – now let's get going!*
- ❖ *Contact with EMS and ER was clearly successful for most and was appreciated*
- ❖ *Getting to FMC was critical. Less successful at other facilities*

Discussion Points

- ❖ **Reduce the time to the ER door**
- ❖ **Ensure that Health Link training includes translation of natural lay language into a medical context**
- ❖ **EMS should describe the process that is going on in the ambulance to the patient**



On the Ward

“If I didn’t have visitors I would walk backwards and forwards all the time, I’m very active, so I couldn’t stop and do nothing.”

- ❖ *Great medical care on the ward*
- ❖ *Family felt they needed to be there as much as possible: families want to be engaged, informed, and listened to*
- ❖ *Connectivity issues for family to allow remote working and information gathering*
- ❖ *Not clear what activities survivors should or shouldn't be doing and it was difficult to gauge progress*

Discussion Points

- ❖ **Provide more guidance for survivors with respect to appropriate activities, expected progress**
- ❖ **Investigate varied sources and formats of information to help survivors and family understand the condition**
- ❖ **Ronald MacDonald house for family that are not resident in Calgary**



Over and Out – Short Term

“This place [the hospital] reacts to emergencies; once you’re past all that they sort of lose interest.”

- ❖ *Transition from hospital wards to home is stressful –*
- ❖ *Worries for survivor and family – will I re-stroke?*
- ❖ *Will I be perceived as a burden if I try to ask medical professionals to keep answering my questions?*
- ❖ *Am I getting enough/the appropriate/ANY rehabilitation? What can I do about this? What about cancellations?*

Actions

- ❖ **Develop FAQ type information that includes common questions that survivors and family typically ask over the first six months after release**
- ❖ **In addition to printed forms, deliver information such as the Passport in various formats (e.g., digital, video)**
- ❖ **My Passport is a smartphone application that could potentially be modified to reflect local resources**



Over and Out – and Longer Term

- ❖ *When will I be able to drive, to work, to resume my pre-stroke life?*
- ❖ *I can't go back to the work I used to do...what CAN I do?*
- ❖ *Adjusting to life post-stroke – getting used to the new “normal” – what supports are there and how do I have to present myself to access them?*

Discussion Points

- ❖ **Living Well With Stroke – presented by Survivors and Family?**
- ❖ **Online course (LWWS)?**
- ❖ **How to access Human Services/Employment and re-enter the work force in a different capacity**
- ❖ **Mental Health supports**

Discussion