

From Stroke to Door: Patient and Family Experience Getting to Help

Translating patient experience into Action

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Based on a Patient Engagement Internship Report

By Brendan Murphy, Donna Sharman, and Laurel Ryan

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Instructors: Nancy Marlett PhD and Svetlana Shklarov PhD

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In Calgary, clinicians leading international teams of researchers have made great strides in clinical treatments and improvement to health outcomes for stroke patients by aggressively seeking to decrease the elapsed time from entry into the emergency room (ER) to the initiation of thrombolytic treatment (referred to as time “from door to needle” (Meretoja, 2012; Goyal, 2015). The journey patients take to get to “the door” however, is traumatic, uncertain, and confusing, based on first-person accounts (Taylor, 2006; Miyawgawa, 2011; Boortstein, 2011). While clinicians probe this early chaos to determine the time the stroke occurred and the damage done in these early days has been studied extensively, Patient and Community Engagement Research (PaCER) seemed to provide an opportunity to add a patient and family perspective on the earliest experience of stroke. PaCER is grounded in peer to peer research and there were no PaCERs who had experienced stroke trained to work in this so Michael Hill and Noreen Kamal submitted a CIHR patient engagement research to sponsor a small group of patients and family members to take the PaCER internship.

This project represents the internship research study that enabled us, the authors, to devise a research question and ethics proposal, recruit stroke survivors and conduct participatory grounded theory research with our 14 participants. Survivors and families were involved in refining the direction of the study, sharing their experiences, participating in the analysis, and making suggestions and recommendations from the knowledge obtained. This summary is based on our 40 page final internship report and several hundred pages of data. We hope it will stimulate discussion and further research into this critical but complex time for patients and health care providers.

Engagement Methods

We used the patient and community engagement research (PaCER) method: *set, collect, reflect*, as described and tested by Marlett and Emes (2010). The method is designed to engage patients throughout the entire research cycle. The participants were intrigued and motivated by the process and valued the opportunity to revisit experiences and feelings buried for years. They wanted to be part of a research project that could improve the experience for others who may experience stroke.

We recruited 14 individuals who self-identified as survivors of stroke or family caregivers through the AHS Living With Stroke program and the generous assistance of the INSPIRE (Inpatient Support Program In Recovery from Stroke) volunteers. Survivor and family members were invited to participate together when possible.

We used a participatory grounded theory method that promotes deep and targeted exploration, so that we were able to come to a working theory within our sample. We recruited twice as many survivors as family members, including 6 men and 8 women aged 35 – 73. This provided a unique opportunity to hear a collective survivor voice.

Study Procedures and Sample

SET Co-design process	COLLECT Focus Group	COLLECT Interviews	REFLECT Co-analysis	TOTAL
5	3	6	8 from SET and COLLECT	14

The **SET** co-design process, which was an all-day session, validated the significance of early days after stroke as a research topic and suggested we explore the information available to survivors and family on the ward and after discharge. Participants noted that their symptoms were not defined by the FAST acronym, and we ensured that we were inclusive of all symptoms.

The all-day **COLLECT** focus group agenda included sharing and recording experience, analysis of the experiences, and identifying ideas for the following interviews and for health providers. The data provided rich and detailed accounts of raw experiences that remain vivid even years after the event. We then conducted open-ended individual and family interviews.

The **REFLECT** group enabled participants of SET and COLLECT to reconvene and review the data and preliminary analysis. They hoped someone could use ‘their research’ to help those who will experience a stroke in the future, to get the help they need early enough to improve their chances of survival and recovery.

We analyzed each set of data from transcripts, flip charts and process recordings using open and selective coding, and each set of data fed into the next. Constant comparison, while labour intensive, increases the chances of moving from common themes to theory (Glaser, 1992; Glaser & Strauss, 1967). In the REFLECT phase, we, as a team of researchers and participants reviewed and refined the finding, completing the circle of involving patients and families in all aspects of the research.

Results

We have prepared a sample of responses that is available on the tables for you to enjoy.

We break this journey into a progression of five milestones as determined by the participants, but will focus primarily on the first three stages for this evening's presentation.



- **Something's not right** begins with a common, vivid and memorable feeling that something serious and unfamiliar is happening. We are disoriented and confused, by new and strange experiences such as not being able to pick up a glass, loosing sight in one eye or any of the FAST symptoms. There was uncertainty about the reality or seriousness because there was no pain and it hadn't happened before. It continues as the person attempts to minimize or 'get over' the feelings by sleeping, getting back to work, searching the computer or taking aspirin. At this stage we had an inkling that it may be a stroke but can't figure out what to do about it. The fear that it may be a stroke led us to search for indicators that what we were feeling was not a stroke.
- **Tipping point:** Describes breaking through the confusion, usually with the intervention of someone else, family, friend, good Samaritan. This is a difficult stage because it signals a loss of control and fears of what may lie ahead, the cost of an ambulance, the reluctance to burden the Emergency room if the symptoms are not real or lasting.
- **First contact with help** is usually EMS/First Responders but some call health link to confirm the need for EMS. While this is appreciated, we need to know what is taking place and why it takes so long get the 'bus rolling'. Patients sometimes don't feel acknowledged and need fears to be acknowledged in the transition from home to the ER.
- **On the ward** was not part of the original plan but it was clear from their responses that families and patients have very different experiences and often don't talk about these. Families commit to being there to speak for their loved one, trying to learn as much as possible. Patients want to know how they are doing, how to return to being active. There was a common appreciation of the care received and a need to find ways to communicate in hospital.
- **Over and out** captures both the appreciation of the "passport" concept (with alternate platforms) and the assistance for patients without social supports or resources, along with a feeling of being left on their own to start life over. There are many ideas about community, peer support and access to information.

Getting to the Door: A working theory of the first three milestones

A working theory at this stage of **getting to “the door”** of the hospital includes the following sequence:

1. **Wandering or lost in stroke**
2. **Being found, and**
3. **Help is called.**

Where most grounded theory categories are about actions, our theory is about being acted upon, and needing the guidance of others. While in most patient engagement health research patients are searching for more say and control, this working theory is in stark contrast. It indicates the security and trust of the patients and family members in the research that allowed them to speak openly about their inability to think straight and willingness to suggest actions that could help others.

1. **Wandering or lost in stroke.** Given that stroke affects our brain and alters our thinking, it was difficult for us to recognize what was happening and what to do. We suggest including this feeling that something is wrong and very strange (e. g., FAST plus) and that confused thinking and inability to act are important signs of stroke.

Patients are willing to be involved in the co-design of this work and suggest that survivors become the spokespeople to put a human face on the experience and on the outcomes when treatment is available quickly.

2. **Being found.** Quick action depends on patients being visible to others who can take action and an understanding that a strange, disconnected feeling with FAST-plus symptoms is an **emergency**. People at risk for stroke are at extreme risk when living alone, and there needs to be some thought given to how to build safety nets that alert family and Good Samaritans to possible catastrophic outcomes of inaction.

Patients should be included in ways to get to someone who can help and to ensure that health services are able to act during a time when we are reluctant and confused.

3. **Help is called.** Patients and families noted serious barriers to making the call: being unwilling to act on unfamiliar symptoms, the potential costs and worry of family or friends, fear of burdening the emergency departments (Health Link messages), not being able to communicate with 911 and Health Link, and reluctance for bystanders and family to take action when patients refuse.

Patients want a clear and supported Good Samaritan action plan. We feel that knowing what other survivors did and the results of their actions would encourage quicker and more effective bystander and family response. Patients understand that there are concerns about interfering with someone who appears to be ‘not in control’ but these must be addressed.

Thoughts for Discussion and Action Tonight

Based on participant recommendations that include patients and families in stroke care

- 1. Include patient experience in public awareness campaigns**
- 2. Counter or refine messages from AHS about not going to Emergency unless it is a 'real' emergency – stroke symptoms are an emergency**
- 3. Create a Good Samaritan (bystander, family) action plan that addresses reluctance to take action**
- 4. Patients could work with EMS to be able to further explain time delays and process**
- 5. Include patients and family members in thinking about their worries on the ward and preparing to be discharge**
- 6. Expand the accessibility of the “passport” concept to include public access, alternate formats and content**
- 7. Explore peer support, information resources and navigation of the ‘next life’ after stroke**
- 8. Include warnings about anti-coagulants and surgeries and dental work, cautions about other treatments that could be related to stroke – for professionals to post in their offices, for patients to know**
- 9. Work with patients to put together activities that are useful on the ward**
- 10. Ideas from the floor**