UNIVERSITY OF CALGARY

CUMMING SCHOOL OF MEDICINE

Patient and Family Experiences: The First Days After Stroke
Patient Engagement Research Study report

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Background and Rationale

This project was part of an internship undertaken within the Patient and Community Engagement Research (PaCER) training at the O'Brien Institute for Public Health, Community Health Sciences, Cumming School of Medicine. This initiative was supported by the Strategic Clinical Networks within Alberta Health Services. It was also supported by the partnership with the Quality Improvement and Clinical Research – Alberta Stroke Program (QuICR) led by Dr. Michael Hill and Dr. Noreen Kamal.

This research study explored the experiences of survivors of stroke and their family members in the first days following stroke. The research question guiding the study was: ***What are the experiences of survivors of stroke and their family members in the first days following stroke?***

In Canada, as in much of the developed world, stroke is one of the three leading causes of death and a significant source of persistent disability (Rosamond, Flegal, & Friday, 2007) Annually, of the estimated 15 million incidents of stroke world-wide, only about nine million patients survive, and five million of those will experience permanent effects. In fact, stroke is the leading cause of disability (Science Daily, 2014).

It is expected that one in four Albertans will experience a stroke by the time they reach their 80th birthday (Lozano, 2012). 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). As the clinical research continues to move forward, the "lived experience" of stroke patients and their families in those first few days has had limited focus and is less well understood. For patients and their families, the first days following stroke may be traumatic, uncertain, and confusing, based on first-person accounts (Taylor, 2006; Miyawgawa, 2011; Boortstein, 2011).

An examination of the peer-reviewed literature of patient experiences of stroke focuses heavily on the rehabilitation period. Many studies use quantitative measures (objective measures based on survey questionnaires, for example), but these are limited by researchers pre-determining what should be measured. There may be differences between how descriptions of the status of patients are understood by professionals on the one hand, and the patients and families on the other (Gray et. al, 2014). Not all studies include family members' perspectives as in a recent study on how to support

communication between health care professionals (HCP) and patients (O'Halloran, 2012). Qualitative studies using interviews, focus groups and/or participant observations may be better able to capture the experiences of the individuals (Clarke, 2009). There is little in the peer-reviewed literature that represents a lived experience perspective with respect to treatment, information and aftercare. Even when interviews and surveys are used in research, they are generally analyzed by use of standardized computer programs with no feedback loop to the participants. Many surveys used are standardized, with scales and yes/no answers (Cunningham, 2003). A review of published research indicates that some of the studies on patient experience come from interviews with practitioners acting as proxy for patients. There is one recent study (Xian et. al, accepted manuscript , 2015) that used patient-centered research, but it focused on comparing the effectiveness of treatments, and not on the experience of the patients and families in the hospital setting.

In response to these challenges, we planed to engage survivors of stroke and their family members to gain a deeper understanding of their experiences in the first days following stroke. The PaCER program trains peers and community members to engage in health systems research from a grounded theory perspective (Marlett & Emes, 2010). Survivors and families were involved in refining the direction of the study by sharing their experiences, reviewing findings and participating in the analysis, and making suggestions and recommendations from the knowledge obtained. Information was gathered using 3 focus groups of up to 6 patients and family members per group and 4 semi-structured interviews with individuals. The data collected was reviewed and analyzed for themes with a concluding focus group made up of the participants focus groups and interviews to review and validate the findings. The goal of this collaborative qualitative study was to give voice to patients' and family members' experiences. We are collaborating with the QuICR (Quality Improvement and Clinical Research) – Alberta Stroke Program, hoping that this study will inform this Program's Quality Improvement efforts to consider the patients' and caregivers' needs.

Stroke can clearly be a traumatic and confusing event for both the patient and family. Not only are they living through a health crisis, they are frequently not familiar with or at ease in clinical settings. They report experiencing anxiety, for example, when information is not shared amongst professionals and they are repeatedly asked the same questions by various health care practitioners (HCPs). Additionally, patients often express frustration at not being treated as a whole person, but a list of symptoms to be managed (Morris, 2007).

Many studies indicate a gap between the concerns and focus of HCPs and those of patients and patients' families. Stroke patients and families are often reluctant to ask

questions due to a lack of knowledge and uncertainty about sources of information. There is also a widely-held perception that HCPs are too burdened to take time to answer questions, so many questions remain unasked until the patient is discharged; at the very point where contact with the primary specialist may be lost (Cunningham, 2003).

Stroke patients can be confused and disoriented, and may be unable to recall all the details of their stroke. Family members may experience similar feelings to patients (uncertainty, abandonment, vulnerability, fear, unimportance, and loss of control). However, they might better remember the details of the experience (Morris, 2007; McKevitt, 2004). Something that seems clear to all is the importance of the role of family in maintaining continuity in a situation where there may be significant cognitive gaps for the survivor. For these reasons, we felt that including both patients and family members as an “experience cohort” in our research study was an essential aspect that will add knowledge and understanding to this under-researched topic. A main tenet of the PaCER program is to give a voice to patients and family members. Given the uniqueness of every individual’s involvement with stroke, we expected that a significant proportion of the "shared experience" will be dependent on collaborative patient/family member pairing in these sessions.

Primary Objective

Conceptualized and shared the experiences of survivors of stroke and family members in the first days following stroke, and expand the understanding of these experiences from the point of view of what matters to patients and their families.

Additional objectives

1. Engaged survivors of stroke and their family members in the exploration of their experiences of early days after stroke.

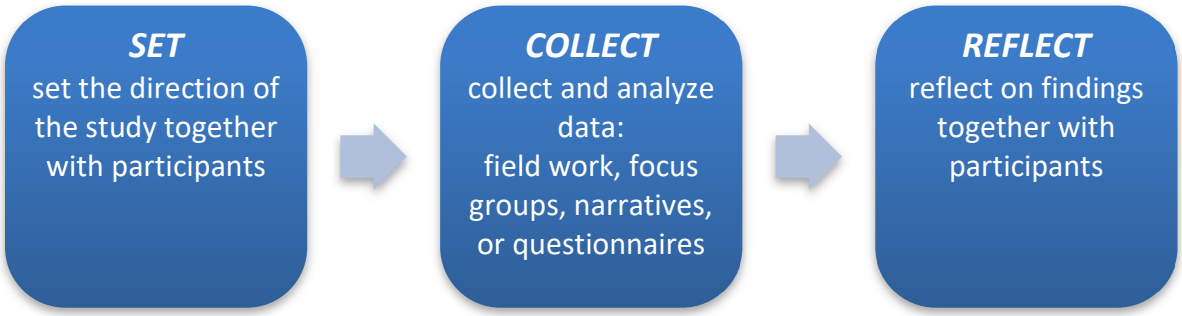
2. Engaged patients who represent a variety of backgrounds and experiences and capture the shared themes and common stories.

Research Methods and Procedures

We used the patient and community engagement research (PaCER) method of *set, collect, reflect* as described and tested by Marlett and Emes (2010). The method is designed to engage patients in all steps of the research process, and has a ten-year history of testing and successful implementation in the study of seniors' resilience and more recent experience in various health care settings. The primary objective of our research was to explore in detail the experiences of survivors of stroke and their family

members in the first days following stroke. Based on the data collected in our initial SET focus group, our question was further refined. Ultimately, our collaborative goal was to improve the experience of survivors of stroke and their families.

The PaCER method has a distinct procedural structure built on peer-to-peer inquiry by researchers with shared experiences. The procedures are designed in such a way that research participants are meaningfully engaged at all research stages and become an active part of the process, not merely subjects. In general, the standard procedures of the PER method are as follows.



1. SET: This initial phase involves a focus group of invited representative participants who share relevant experiences. They become advisors to help set the study's direction and goals by clarifying protocols (recruitment, locations, alliances), questions and data collection.

2. COLLECT: This phase involves the selection of data collection techniques and analysis that best suits the study's purpose and research questions. These could include field observation, participant observation, questionnaires, surveys, focus groups, semi-structured interviews or a combination of methods.

3. REFLECT: This final phase invites participants in the SET focus group to review the findings and analysis with the PaCER team and make recommendations regarding information utilization and need for future research. The study results are prepared and shared with relevant people within the health system.

The SET and REFLECT phases are noted features of the PaCER method to reinforce the goal of meaningful patient and community involvement and provide contextual validity.

Participant Selection

We recruited survivors of stroke and their family members. The survivor and a family* member participated together, and as such there was more than one person from a family in both focus groups and interviews.

Participant recruitment criteria for focus groups and interviews included:

- Patients self-identifying as having had a stroke within the past five years from the time of recruitment, and their family members*
- Age 18 years and over
- Fluent in English
- Consented to take part in focus groups and/or individual interviews.

No exclusion criteria were applied.

*The word "family" refers to "two or more persons who are related in any way – biologically, legally or emotionally. Patients and families define their families" (Institute for Patient- and Family-Centered Care, 2010).

Sample Size

****** (Laurel, I think this is the data you are providing for this Final report) *****

Our SET and REFLECT focus groups will each have up to 12 participants (with REFLECT group including same individuals who participated in previous stages). The COLLECT phase will consist of up to two further focus groups (12 x 2 – up to 24) and up to 20 individual semi-structured interviews, depending upon data saturation. In total, we estimate that this study will include up to 56 participants in focus groups and interviews.

SET Focus Group	COLLECT Focus Groups and (possibly) individual Interviews	REFLECT Focus Groups	TOTAL PARTICIPANTS
Up to 12 Participants	2 focus groups x up to 12 participants in each = up to 24 participants Up to 20 individual interviews with focus group participants OR new participants = up to 44 participants	Up to 12 participants to be selected *from SET and COLLECT participants*	Up to 56 participants

This is a qualitative study with a relatively small sample size; thus obtaining a complete representative sample is very difficult. However, efforts were made to obtain a diverse sample regarding age and gender. Participant information is monitored using our procedure of collecting contact and demographic information (Appendix I. Contact Form and Appendix J. Demographic Information Form).

The goal of qualitative research is not to generalize the findings to individuals outside of the participants in the study (Creswell, 2009). Thus a relatively small sample size is usually sufficient for researchers to fully describe the themes and meanings of participants within the context of the study (Starks & Trinidad, 2007). Our sample size will allow in-depth analysis of all the data and should be sufficient to reach data saturation, the point at which no new themes or concepts would emerge from subsequent data gathering.

Recruitment

Participants were recruited in three ways:

- Personal contacts of the PaCER researchers: we identified potential participants among our personal contacts and provide potential participants with the information (see Participant Invitation Letter, Appendix E, and Recruitment Poster, Appendix F). The poster and invitation letter were provided with the contact information of the PaCER researchers, so potential participants could call or e-mail them. The researcher then explained the procedures, answered their questions, and obtained their consent.
- Our PaCER research team met with Ms. Lori Beaver, who is the I.N.S.P.I.R.E.S. Program Lead at the Foothills Medical Centre (FMC) Stroke Unit. I.N.S.P.I.R.E.S. stands for Inpatient Support Program In Recovery From Stroke and is an innovative program in which trained peer supporters, who are survivors of stroke (and in some cases, a family member), make casual visits to meet with new survivors and families who are on the FMC acute and rehabilitation units to serve as a voice of experience. We provided the I.N.S.P.I.R.E.S. Program Lead and our and QuICR partners with a Recruitment Facilitation Letter (Appendix G), a Recruitment Poster (Appendix F), and Consent to Contact Form (Appendix H). The I.N.S.P.I.R.E.S. program members and QuICR partners were asked to display or forward the Recruitment Poster to potential participants, and either 1) ask them to contact our research team member, if they are interested, or 2) ask them to give their permission to be contacted by a PaCER intern by completing the Consent to Contact Form, so our research team member can contact them. The PaCER researcher then provided potential participants with the Participant Invitation Letter and Participant Consent Form, explaining the procedures to the potential participants, answered their questions, and obtained their consent.
- Recruitment Posters (Appendix F) were distributed in high volume locations such as the Stroke Units at the Foothills Medical Centre. The poster provided the contact information of the PaCER researchers, so potential participants could call or email the researchers. A PaCER researcher then, provided potential participants with the Participant Invitation Letter and Participant Consent Form, explained the procedures, answered their questions, and obtained their consent.

In the end, recruitment required significant effort and relied heavily on relationships that one of our researchers has with members of I.N.S.P.I.R.E.S. Many survivors declined to participate in the focus groups out of a concern that the focus group would somehow resemble a group therapy session. As an alternative, our recruiter was able to persuade some of these survivors and family to participate in semi-structured interviews. We suspect that there may be a common reluctance to participate in group sessions due to

unfamiliarity with this type of research. We also feel strongly, however, that participation in research such as this will gain more support as PaCER and other groups are shown to positively impact the role of patients in health and health care. “it's been a long time since I opened the doors for those memories so yeah coming back to that”. Virtually all the participants expressed gratitude for the opportunity to relive the experience and to garner more insight particularly through participation and input by family members.

Potential participants might have been be familiar with the researchers through personal contacts, support groups or other programs they attend together. However, there were no client-provider, teacher-student, or any other relationships that could compromise the freedom to decline. We made it clear to potential participants, both through intermediary contact and in the consent procedure, that we are part of an independent PaCER group and are not affiliated with any health service agency, and their decision to participate would not affect their ability to receive services or treatments from any organizations. The PaCER method is based on equal peer to peer relationships between the participants and the researchers (who are patients or community members themselves). It was up to the participants to freely respond or decline the study invitation.

In we followed the protocol as presented to the ethics committee. Due to the difficulties associated with recruitment, we had fewer participants than expected but still enough to pursue the study. The focus group model of set collect and reflect was followed. In addition we conducted four structured interviews with patients and family.

Our original proposal anticipated focusing on the first few days following stroke. As we engaged with the Practice, Set & Collect focus groups and individual interviews, it became clear that 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. We felt it was natural to break this journey into a progression of four identifiable milestones. We labeled these milestones:
Something is not right
The Tipping point
First contact with help
On the ward
Over and out.

Something is not right
At some point survivors and/or family recognize that this "experience" is something more than feeling a bit off with the flu, being stressed out or just being overly tired. In these early stages of recognition survivors and families start to ask themselves questions such as "what the heck is happening" or "knowing I needed to do something trying to figure out what it was".

What?
Most of the survivors we spoke with have recollections that, at the time of the stroke, there was a level of understanding that something was significantly abnormal: "I said something to myself that I didn't understand", "I dropped a few things which is unusual", "I fell back into my mother tongue – my English was gone".

Most were either not aware of general stroke symptoms (FAST) or felt that what they were experiencing, unusual as it was, did not fit their understanding of stroke. An example of this was sudden loss of vision. One survivor did have enough general knowledge to identify common stroke symptoms (FAST), but sudden loss of vision in one eye was not something he associated with stroke. The result of this was that he self-diagnosed a detached retina and only after seeing his optometrist a few days later was he directed to the ED for examination and subsequent diagnosis of stroke. As an aside, some Individuals in the group, who also participate as I.N.S.P.I.R.E.S. volunteers on the stroke unit, have noted that many survivors tell them that they were sent to the ED by an optometrist. Association of stroke with a loss of vision does not seem to be well known in the general population.

Can't be
Even after acknowledging that there is something clearly wrong, both survivors and family struggle with the notion that the "something" could be a stroke. "Feeling of disbelief knowing something is wrong" and "I didn't know what it was. She can't have a stroke" or "I was able to communicate, I was able to move so I didn't think it was all that serious "

Survivors and family may believe that because they were in generally good health, combined with low risk factors like normal blood pressure, normal lab results or the fact that they were non-smokers " I figured only people that smoked 4 packs a day get stroke", made it difficult to accept or acknowledge that the sensation(s) being experienced required immediate medical attention.

But
Apart from the self-evaluation there are a number of other factors that come into play. There may be a lack of pain, there may be reluctance to reach out and ask for help "I knew I had to call for help but I wasn't good at calling for help it was like letting someone know I wasn't feeling well" or there may be fear that calling an ambulance will result in significant expenses. Many of the participants also expressed the sentiment that this was just a really inconvenient time. Whether motivated by work ethic or by a fear of losing employment some choose to ignore the obvious signs and press on "I'm not going to miss my first day of work so I went in".

For one survivor, multiple experiences with a local, non-Calgary, ED that failed to diagnose a prior condition left the Survivor and Family member unwilling to go back to the ED. "we went back and forth enough times that we hated going there" "So anyway in and out of the hospital with the same symptoms" "and "My crowning memory of the one doctor that came in and said "you know you're the mystery patient of the month" we cannot figure out what's wrong with you".
The family had questioned the local ED about getting advice from a major center such as FMC to help diagnose the precursor event - "Come on guys don't you talk to anyone else? Like at foothills or anybody? oh no no we don't there's no need for that. "
The system was effectively conditioning the survivor and family that reaching out for help will not deliver resolution to their medical issue(s).

These are important things – maybe add some quotes, more detail, and develop this part a bit?

The Tipping Point

While many chose various strategies to deal with this new experience - including taking aspirin, going back to bed, or tried to ignore it and go about about their daily routine - in the hopes that the symptom would pass. Eventually the survivor or the family member recognized that there is something exceptionally wrong and called for help. In the end, most of the survivors we spoke to actually got to the point where they required someone else to make the call for help on their behalf. Having family or others around that understand the symptoms of stroke was a critical factor in getting to help for most of the participants in our study. The tipping point for most of the survivors we spoke to was an obvious deficit that the family member recognized as serious: the survivor was any

unable to speak or had fallen over and/or was unconscious and this resulted in a call to EMS.

Interestingly, two of the survivors that did not have family or a third party close by, had actually gone to their computers and typed in queries to gather information about stroke "trying to search on computer, searching 'having a stroke' ". Both of these individuals understood they were experiencing stroke-like symptoms but one reached out to a relative that is three hours away for advice on calling EMS and the second, who does not have relatives even that close by, waited for the symptoms to escalate to the point where she knew she had to call EMS - " The thing that happened was my thinking got scrambled". This seems to imply a reluctance to take an action such as this without input from those we trust. This is all very well written – you might only want to add more quotes, more examples, to describe the experience in its natural variety – in all sections.

First contact with help

For most survivors and family, first contact with help is through EMS and this was clearly the most successful avenue into the ED for diagnosis and treatment to begin. One survivor was taken to the ED by car and was sent home and told to return if he wasn't feeling better. He had barely reached home when he had to return to PLC and was immediately put in an ambulance to FMC. This significantly delayed treatment.

"they looked at her even kind of like..Okay. Sure. And I was like she said she is having problems"

There is some sense that stoke patients that arrive on their own may not be treated with the same efficiency and urgency that those that come by ambulance do.

Do Something

Once survivors decided to get help then time was of the essence in getting to the hospital. Once EMS is called we all expect that they arrive and immediately take us to an appropriate hospital. The protocol that the EMTs follow can seem like an eternity to all of us if it seems arbitrary or the EMTs do not believe us or are not listening to us.

Believe me

Survivors with few or no health issues and few known risks of stroke struggle convincing medical staff that they are having a significant issue. "I'm like, why are we sitting here guys?" or "I had weakness and he goes all in all it's probably not a stroke". When the issues identified has to do with stroke, it may not be sufficient to rely on the capacity of laypeople to give medical staff an accurate description of what they're feeling. One survivor actually called Alberta Health Link and, based on his description of his symptoms, was advised to take two aspirins and see if that helped – which in the case of cerebral bleeding could have been fatal advice. One week later he actually had a massive stroke. For another "landlady took me to PLC. My blood pressure was a little High (over 200) but they released me and said to come back if I didn't feel better. Landlady took me home but we were back immediately."

It occurs to us that educating the general population in recognizing all the nuances of stroke is a monumental task. In any case, the nature of stroke itself my significantly impair an individual's ability to articulate clearly or make rational decisions. It would seem to be much more efficient to provide primary care and helpline professionals more insight into the language and terminology that the public is likely to use in order to translate that into the technical diagnostic language they use professionally. Additionally, CMPA recently published a study (CMPA, *Originally published September 2015 P1504-4-E)* highlighting the need for non-emergency professionals to have more thorough risk management strategies that embody better familiarity with stroke types and leverage their patient's medical history.

In additional to potential for misdiagnosis, there is a pervasive sense that survivors are either not believed or not listened to. Perhaps the most glaring example of a combination of advocacy and the need to be believed is the documentation that one survivor created. Within a three ring binder is a compilation that captures every phone call, appointment schedule and conversation that the survivor and her family with medical staff – and which continues to this day.

Impossible Consent

Stroke is a very scary event for survivors and family members alike. The medical aspects of stroke are typically not understood by lay people and yet they may be asked to listen to treatment options and then agree with a path that medical staff are recommending. This can add more uncertainty to an already stressful situation and the "permission" granted is more an acknowledgement that medical staff have a plan than an indication of true understanding or real choice.

On the ward

The experience on the ward may be very different for survivors and family. Some of the survivors that we spoke to have little memory of the first days after they have been admitted to hospital.
A huge benefit of this type of study is the ability of the survivor/family unit to get a more complete view of the stroke event and the follow up that occurred. We found that, even 3 or more years on, survivors and family may not have taken the time or not had the opportunity to fill in the gaps in the event and follow-on treatment - particularly in the acute treatment ward. "I would be interested in hearing what my family member, my husband has to remember, because it will give me the insight that I don't have."
In particular, survivors and their family members often don't have a chance to discuss and share their memories and feelings with each other for a long time after the event.

I think you talked about finding it out? Do you want to tell about Donna's and Andy's example when she interviewed him? Other stories?

The time in the ward(s) was also the first experience for which family came to recognize that they had to advocate and act on the survivors behalf. "If I had not been sitting there and went to the nurses station and said something is definitely wrong how long would it have been before somebody checked on her" and "how important it is to have someone there like as much as possible." expresses the fear that there needs to be an advocate next to the patient at all times in order to ensure that they are not ignored and that there is a clear understanding of the medical situation.

For caregivers there is a constant struggle to gain information and understanding of the survivor's condition in a form that is understood by the family member.

"(I) wanted more information from various places", "so I wanted to know and see everything" and " (I) Needed computer connectivity for work and information gathering"

Once it is established that the survivor has a caregiver, the healthcare system depends heavily on that caregiver individual or individuals to understand the survivor's condition and potential decisions that have to be made.

Given that family members consider that it is extremely important to be at the bedside is much as possible we wondered about the challenges that must be faced by family members that cannot be there or who cannot comprehend. Representation is exacerbated if the survivor and family are from out of town. For survivors who are able to work remotely there is almost total dependence on local family or friends for such things as housing; particularly when the survivor is on the cheap ward.

Procedures and treatments are not always explained in a ways that are understandable to survivors or family. Staff may state what is happening for the survivor or family but may not ensure that it is understood. "I know the nurses God love them, they can barely keep up and I don't know how they do it" is acknowledgement that the staff are very busy, but there was also frustration that "I think the communication things would've been kind of good to confirm that (I) understood what they were saying".

"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". Understanding what the survivors and families should or shouldn't do in terms of activity or exercise was a source of concern particularly when survivors are in the acute ward. Survivors spoke of hiding activities from the medical staff because they were not sure if it was allowed or recommended "they said to do 2 word puzzles …I was burning through 100 a day".

“the people in the other beds - are you getting better than they are ?” was an expression that there was no apparent mechanism to help survivors or family determine or measure the progress that the survivor is making other than to see how they're doing relative to the other survivors. Procedures and treatments are not always explained in a way that's understandable. “I know the nurses God love them, they can barely keep up and I don't know how they do it” is acknowledgement that the staff are very busy

Over and Out

“this place reacts to emergencies, once you’re past all that they sort of lose interest” In this respect, stroke is similar to many other conditions. Once the acute event has been resolved to a level that is satisfactory to the medical specialists, the survivor is sent off with little continuity in the treatment. Some participants expressed frustration that once released from the cute and recovery wards, they were left to fend for themselves. This is particularly true of survivors that had direct family support. The healthcare system provides assistance and guidance for those that lack support but there is a significant burden placed on family to organize and comprehend the complexity of the post-stroke rehabilitation, benefits and regulations.

The frustration is extremely high with survivors who outwardly appear to be fully recovered but may have residual effects from stroke that are invisible to friends, co-workers or even the healthcare system. A request for supplemental assistance can create a huge internal conflict for survivors. The survivor is struggling to build self confidence through positive expressions that they are improving, but there is a sense that the support system requires survivors and family to emphasize a lack of progress.

Opportunities

Broader messaging and education with respect to identifying stroke and encouragement to get to the ED even if in doubt

Some facilities to handle of out town family

Advocate or facilitator that can act on behalf of survivors without direct family

A navigation service to help family support find the correct paths through the complexities of after-care

Passport provided via multiple media formats

Stroke education and information in video or other formats that could be consumed on mobile devices while on the ward

Are there additional tasks that INSIPRES volunteers can perform for survivors (advocacy, getting questions answered, etc)

Blame and remorse

the survivors we spoke to, for the most part, wanted to convey that there was nothing in their lifestyle that you could blame the stroke on. There is a real sense that they are trying to establish that they are not to blame for this. In the

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