STROKE REDESIGN COMMUNITY ENGAGEMENT

COASTAL COMMUNITY OF CARE

OCTOBER 2014

BACKGROUND

Vancouver Coastal Health (VCH) and Providence Healthcare (PHC) are currently undergoing a regional stroke system redesign initiative. The aim is to design an integrated and coordinated system of care for stroke patients within VCH/PHC to increase access to stroke services and resources across the continuum of care. The Coastal Community of Care (North Shore, Sea to Sky, Sunshine Coast, Powell River and Central Coast) wanted to incorporate patient and family input into the redesign process. The Heart & Stroke Foundation partnered in this engagement, interested in learning more about stroke survivors' experiences integrating back into their home communities.

COMMUNITY ENGAGEMENT PROCESS

Five focus groups were planned for stroke survivors and their caregivers throughout the Coastal Community of Care. The sessions were promoted using local media and through key stakeholders. In total, 25 stroke survivors and 20 caregivers attended. An online survey was also created and publicized, with 15 respondents. Email feedback was provided by 2 people and no one responded to the offer of a phone interview.

Location	Stroke Survivors	Caregivers	Survey /email	Total
Whistler	2	2	0	4
Squamish	0	0	0	0
Sechelt	7	6	6	19
Powell River	11	10	8	29
North Shore	5	2	2	9
Other	N/A	N/A	1	1
TOTAL	**25**	**20**	**17**	**62**

Table 1: Engagement participants, by community

WHAT WE ASKED PARTICIPANTS

- What worked in your care journey?
- What could have been better?
- What services are missing from your home community – related to prevention, rehabilitation, monitoring or specialists?
- Given that treatment in Vancouver or North Vancouver might provide optimal care, would you be willing to travel? Why or why not? What would need to be in place to facilitate this?
- How open are you to telephone or video-conference care?

LIMITATIONS

Limited funding prohibited running a focus group on the Central Coast. An online survey as well as an invitation to arrange phone interviews, both publicized through local media and key stakeholders, failed to attract any participants in this region. Our assumption is that stroke journeys for people living in Bella Bella, Bella Coola, or the surrounding area, would be quite unique and we therefore will not apply the findings presented here to the Central Coast. Instead, we will continue to explore other opportunities for localized engagement.

Additionally, low focus group turnout in Whistler and no turnout in Squamish suggests that feedback from these communities, while valuable and insightful, are not necessarily representative of the typical stroke experience in the Sea to Sky region.

SUMMARY OF FINDINGS – OVERALL & BY COMMUNITY

Overall

1. Generally, patients and families were pleased with their emergency and in-hospital care, particularly from the advanced and comprehensive stroke centers (e.g. Lion's Gate and Vancouver General hospitals).
2. There is a need for more rehabilitation services in rural areas, particularly for speech therapy.
3. The further patients live from Vancouver, the less willing and/or able they are to travel to access optimal care, especially outpatient rehabilitation and specialists, and the more open they are to receiving care via telephone and video conferencing (see page 8 for more details).
4. There are common perceptions that the quality of stroke care differs from site to site and that accessing the best care often involves a "fight".

North Vancouver

- Desire for more services, for instance more physiotherapy sessions while in the hospital and longer stays in in-patient rehabilitation wards or facilities
- Excellent community-based, stroke-specific rehabilitation programming (e.g. pool based programs and Stroke Recovery group)
- Some concerns related to poor communication between VCH staff and patients and/or caregivers while in-hospital

Whistler

- Need for more rehabilitation and support services in the community, including specifically for younger stroke survivors
- Willing to travel to Vancouver for services, even though at times it is risky travelling in poor weather
- Very pleased with ambulance response and emergency transfers
- Good experiences as an in-patient at GF Strong and the with support received from North Vancouver Stroke Recovery Group (there is no local recovery group)

"There is no OT available in Whistler so we needed to get into the group in North Vancouver. They didn't want to open it to someone living so far away, so we had a fight getting in. And then made sure we made it every session – twice a week often driving through crazy weather – to prove that we deserved to be eligible." **– Caregiver, Whistler**

Sunshine Coast	• Expressed an urgent need for more rehabilitation services, particularly for speech therapy • Strong perception that there is a lack of clinical stroke expertise, as well as clinical and rehabilitation support for survivors, as compared to Vancouver • Willing to travel to the city for optimal care but also facing significant barriers and stress related to associated time and expenses • With some initial reluctance, open to using telephone and video conferencing in certain circumstances (see page 9 for details) • Shared feeling of being "lost" in the system and a desire for support in navigating through the stroke recovery journey ***"My father really needs emotional support, counselling. His whole life stopped with this stroke, it has been devastating. But he still can't communicate because we don't have any speech therapy. How can he talk, how can he process what happened, if he can't actually speak. He is totally isolated without language."*** **– Caregiver, Sechelt**
Powell River	• Expressed an urgent need for more rehabilitation services – with priority given to speech therapy, closely followed by hand therapy and physiotherapy in the hospital's hydrotherapy pool • Overall, very pleased with emergency, hospital-based care received in Vancouver but upset by the significant contrast to the support available in their home community • Very limited willingness and/or ability to travel to the city for optimal care (other than emergency or in-patient care) due to significant time and expense associated with the two-ferry trip • More willing and/or able to access services on Vancouver Island, which is only one ferry away, than in Vancouver • High interest in "joining" Island Health Authority • Open to, and even excited about, using telephone and video conferencing or any strategy that reduces travel to Vancouver • Stroke Recovery group is very active and acts "as a lifeline", especially to stroke survivors without family in the community • Desire from Stroke Recovery group to re-establish a formal communication channel with Powell River hospital to more easily communicate with and support stroke survivors ***"The structure and routine at GF Strong worked so well for me, I saw so much progress. Coming back home, with absolutely no services or support was totally devastating. I felt hopeless."*** **– Stroke survivor, Powell River**

KEY THEMES – ACROSS COMMUNITIES

WHAT WORKED WELL?

1. Overall, Outstanding Care

- "Superb" and "exceptional" care throughout stroke journey
- Repeated sharing of positive experiences with emergency and in-patient care, particularly at Lion's Gate (LGH), Vancouver General (VGH), Holy Family, and GF Strong
- Full routine and comprehensive approach to rehabilitation at GF Strong
- Some reference to outpatient rehabilitation and speedy intake at emergency room at LGH
- Overall very high level of satisfaction with BC Ambulance

"I had excellent, committed, caring staff on the ward at Lions Gate. It really felt like they were advocating for my best care."
– Stroke survivor, North Shore

2. Bringing Resources and Rehabilitation Services to Rural Communities

- Access to CT scan and tissue plasminogen activator (t-PA) in home community
- Specialists frequent visits to Whistler (not necessarily stroke related)
- GF Strong organized for patient to be able to receive limited private rehab after returning to Whistler
- Access to in-hospital hydro-therapy pool and hand-focused physical therapy in Powell River (PR) – both have since been cancelled

3. Communication Between Communities of Care

- LGH rehabilitation clinicians initiated weekly telephone conversations with patients in PR, provided rehab "homework", and connected to Stroke Recovery Association Coordinator
- Holy Family connected with Occupational Therapist in PR before discharging patient

4. Patient-Centered Care

- Joint meetings with families, clients and all clinicians working with the patient
- Social worker booking meeting directly with caregiver
- Responsiveness of leadership to patient issues (e.g. Physiotherapy Manager)
- Being able to make one's own decision to stop driving

5. Support to Stay at Home

- Two visits a day from homecare
- Support to make sure house is wheelchair accessible
- Training on what to do if you fall down at home alone

6. Community and Family-Based Support

- BC Stroke Recovery Association groups (for survivors and caregivers) are tremendously important – both as an emotional, social support system and as a rehabilitation service provider. In PR they fundraise to provide weekly visit by physiotherapist from Vancouver Island.
- Online support, such as Luminosity and smart phone applications to support cognitive functioning and communication

- Community able to raise money for CT machine and hydro-therapy pool in PR
- Stroke-specific programming at community centers (e.g. pool programs)
- Having an advocate – usually a family member – "the squeaky wheel gets the grease"
- Finding routines and support in the community to remain active and social
- HandiDART, for those living within a service area

WHAT COULD BE IMPROVED?

1. Rehabilitation & Support Services

- Increased access to speech therapy in home communities was repeatedly identified as the most critical and urgent need of stroke survivors and a key barrier to all other aspects of recovery
- Increased access to physiotherapy, mental health services, home support and driver's rehabilitation in home community
- There is a drastic contrast between services and support in comprehensive/advanced stroke centers and home communities
- One physiotherapy session per week for eight weeks is too limited – need more sessions each week, over a longer time period
- Increase number of daily in-hospital physiotherapy sessions and allow for longer stays
- Additional support to deal with comprehension related impairment
- Support tailored specifically for young stroke survivors

> ***"We can get home support and home adaptations, we can connect with others who have similar experiences but we cannot access the rehabilitation services needed. This is a huge problem for stroke survivors."***
> **– Stroke survivor, Powell River**

- More relevant resource list and recommendations from Occupational Therapist

Patient experiences:

- Feeling as though they are being "kicked out" of in-patient care too early
- At Holy Family, being made to choose between which body parts to rehabilitate – hands or legs – perception that there was not enough staff to work on both
- Initially told they were ineligible for rehabilitation sessions at Lion's Gate due to living in Whistler. After successfully "fighting" to be accepted they often drove in dangerous conditions to in order to "prove" they, and others from Whistler, should be eligible.
- Occupational Therapist's recommendation for most appropriate equipment was not as helpful or up-to-date as outside source
- Too many barriers – including high fees – to using hydrotherapy pool in Powell River (PR)
- Cancellation of hand-focused rehabilitation class in PR – Stroke Recovery Association found a volunteer to run group who is now leaving the community

2. Level of Stroke-Related Training and Expertise

- Perception of low level or lack of stroke expertise in rural communities
- Need for more stroke-specific training for rehabilitation therapists in home communities and for generalists in all care settings
- Patients who are also paying for private rehabilitation, or coming from a comprehensive stroke center, see a significant variance in expertise

Patient Experiences:

- Private experience with neuro-based physiotherapy and focus on movement rather than strength building, was significantly more helpful than VCH physiotherapy
- Told at Holy Family that patient had "plateaued" but then in private, neuro-focused care immediately saw further improvements
- In emergency room, doctor "insisted it was high blood sugar, neglected stroke protocol and sent me home"
- Two CT scans were done "too early", leading to incorrect (non-stroke) diagnosis
- Initial diagnosis in Powell River was a brain tumour, stroke only identified upon arrival in Vancouver
- Family at St. Mary's were told that their mother was eligible for an "important drug" (t-PA?) and that doctors had been in touch with stroke team in Vancouver to support administration. An IV was actually set up before family was told that drug was not in the hospital pharmacy. Mother died in hospital three days later with family believing she would have lived with the drug.
- Receiving t-PA in Powell River and ten minutes before the "window" closed where drug can be effective, the doctor noticed that IV was not actually dripping

3. Discharge and Transfers

- Provide more notice and better prepare patients and caregivers for discharges and transfers
- Provide more written information – it is difficult to remember everything you are told

"I had three transfers and it felt like I was starting from scratch every time."
– Stroke survivor, Sechelt

- Recovery information focuses on the upcoming months, while people who have strokes are affected for their whole lives. Need to explain long-term recovery and expectations.

Patient Experiences:

- Wife went to visit with husband in hospital and was told he was being discharged, felt unprepared to bring him home as he was unable to move or talk. She had to "fight" to have him stay in hospital and he ended up being there for another two weeks.
- Went to pick husband up for discharge and he was "totally out of it" - highly medicated on sleep medication that he never had to take again
- Multiple patients not warned about very common post-stroke seizures, which then caught them off guard at home
- After transfer from Vancouver General to Lion's Gate "I felt like they did not have my basic information"

4. Listening to and Communicating with Families and Patients

- More on-going and consistent communication and relationship-building with patient and family
- More meetings with patient, family and all involved clinicians
- Someone to help patients navigate the system, including the transition back into home community

"You need someone to walk the journey with you, we had a social worker in palliative care, which was great, but lost him once my husband got better – after that we just felt lost."
– Care Giver, Sechelt

- Online information does not always work – desire to talk to real people – especially given elderly stroke population

  Patient Experiences:

- Family felt excluded as they overheard discussions being made about mother in open concept emergency room, with no follow-up communication to them
- After weeks of caregiver being on the floor every day, still didn't know clinicians names or even that there was a "head nurse"
- During home visit, Occupational Therapist was not listening to where patient wanted to live (e.g. upstairs versus downstairs)

5. Pessimistic Prognosis and Language

- Repeated, highly emotional sharing about how prognosis is communicated to patients and families as well as confusion about why there is not more room for hope and optimism in this critical moment

  Patient Experiences:

- Father was put into palliative care, family told to "stop hoping", hospital stopped feeding patient "real food" – family continued to feed him and hope. Then legs moved within two weeks and "doctors began to pay more attention". Patient is now significantly recovered.
- 25-year-old stroke survivor initially placed in palliative care before showing signs of improvement and being moved to GF Strong. Now significantly recovered.

"I don't like the term "plateau" - there has to always be hope of improvement and something to work towards"
- Caregiver, Sechelt

- Husband told that his wife has a 30% chance of survival and to "take her home to die", over five years ago

6. Perceptions about Varying Quality of Care and "Fighting" for Care

- Awareness that quality of care and health outcomes are dependent on where you receive care
- Stroke survivors who have strong and resourceful advocates more likely to access optimal care
- General confusion about admission criteria into GF Strong
- Elderly feel they have to "fight" for care and are being denied care due to their age
- Inequality in service provision between urban and rural communities

  Patient Experiences:

- Patients who are accepted into GF Strong or Holy Family feel lucky, others frustrated about being "denied"
- After having a stroke in the U.S. the patient's neurosurgeon – based on his understanding of where she would receive the best care – would not release her unless it was into GF Strong
- Patient told she was ineligible for GF Strong because she lives on the Sunshine Coast
- After initially being denied admission within VCH, patient wrote their MLA and was admitted into VGH within 3 days
- "I felt a lack of interest in my condition, possibly due to my age of 89 years"

7. Post-Stroke Transportation

- Extremely difficult to lose the ability to drive in rural communities where public transportation is already limited
- HandiDART service area is limited – does not extend to those living outside of the community borders
- Remaining active and connected to community is critical to survivor's overall recovery and mental health but requires huge time commitment from caregivers
- Often significant hills, impossible to get to bus stops in wheel chairs
- Poor process and communication around drivers licence being revoked

8. In-Hospital Fall Prevention and Food

Patient Experiences:

- After a dose of morphine and without locking the bed or removing the chair from his bedside, patient fell on his head and shoulder trying to go to the bathroom
- Patient slipped in the hospital and broke her hip, the day before going to be discharged. This significantly set back her recovery.
- Kitchen was locked with nurse having to open it every time the family needed access, the hospital food was "awful", and cafeteria closed at 6 pm

LOOKING TO THE FUTURE

1. Travelling for Optimal Care

Across communities, compromise and stress were associated with any discussion on travelling to Vancouver or North Vancouver for care. However, participants were more willing to travel for optimal care if:

- It is for emergency or in-patient care (although many stroke survivors from Whistler and the Sunshine Coast were travelling for weekly out-patient care as well)
- They believe travel will lead to better health outcomes
- Travel does not require more than one ferry ride
- When appointment scheduling allows for same-day return travel (e.g. from the Sunshine Coast, ideal appointment time is 11 am)
- When appointment is with a specialist and limited to 3-4 times a year
- When they have the personal means to support travel – such as family member to drive them, free accommodation and/or family in Vancouver, and the finances to allow for family to take time off work and travel with them.

Factors that made participants less willing to travel for optimal care were:

- Cost of ferry, parking, accommodation, and lost income of family members – for some these mean that travel is simply not an option
- Provincial Travel Assistance Program (TAP) only reimburses ferry travel when patient is in the car – families dropping patients off or visiting patients do not get reimbursed

"I went to Holy Family Hospital for rehab and found that it was very difficult and stressful to be away from home and the environment there was overwhelmingly confusing and stressful… They do not have any services close by or anywhere to walk or exercise safely."
– Stroke survivor, Sechelt

- TAP passengers not receiving priority boarding onto ferries
- Travel from Powell River requires two ferries – the schedule is very limited and ferries can be late, cancelled or over capacity if you are not early enough. Connecting two ferry journeys can be very difficult and/or require from 5 hours to an entire day of travel.
- Depending on health and energy level of patient, a day of ferry travel can be prohibitively exhausting
- Powell River patients are significantly more willing to go to Vancouver Island for care – which requires only one ferry – and even to "join" Island Health Authority

2. Care by Telephone and Video Conferencing

Factors that make some patients more willing to receive care via video or telephone are:

- Living in Powell River – while participants on the Sunshine Coast had a number of caveats to receiving video or telephone based care, those in Powell River were immediately open to these options
- Having a local clinician (therapist or physician) and/or family member in the room
- The reason for the appointment – for instance a medication review and other less "hands on" issues
- Having already met with and/or established a relationship with the clinician on the other end
- They are accessing expertise they wouldn't otherwise have access to
- Stroke expert was giving guidance to, and building knowledge base, of local clinician
- They could be at home
- It was winter, making ferry travel even more difficult
- Video preferred over telephone

"Most recently, we received an invitation to attend 6-8 sessions on "Living with Stroke" but we cannot access them as the return travel is at least 9 hours for each session and the expense for ferry travel would be close to $1000. We have the technology to include remote communities like Powell River – why aren't we using it?" – Stroke survivor, Powell River

Factors that make some participants less willing to receive care via video or telephone are:

- Closer proximity to Vancouver and/or the ability and means to travel
- A preference for face-to-face interactions and needing a "full sense of who is there and what is happening"
- Receiving rehabilitation services – where the ability for therapists to see and touch patient is more important

3. Imagining an Ideal System

- Having a consistent person to help patient and family navigate the system and "walk the journey with you"
- Access to stroke specific rehabilitation in home community, including the ability to access infrastructure already in place (e.g. hydrotherapy pool in Powell River) and neuro-rehabilitation
- Dedicated rehabilitation beds in local hospital
- Having a "travelling team of stroke specialists" that regularly visit rural communities
- More in-home care, including occupational therapists and help with basic home care
- More support for caregivers and providing caregivers who want it with basic physio and speech therapy skills

NEXT STEPS

1. Nov 2014 – Summary report will be sent to stakeholders and participants

2. Nov & Dec 2014 – Stroke Redesign team will share findings (in report and/or presentation formats) with regional stroke steering committee and Coastal Stroke Redesign leadership team in order to:

    - identify gaps and priorities for system improvements in rural and urban communities

    - where possible, integrate findings into stroke redesign strategy to support best care from a patient experience perspective

3. Ongoing – Stroke Redesign and Community Engagement teams will continue to explore opportunities and strategies to meaningfully engage stroke survivors and their caregivers on the Central Coast.

4. Spring 2015 – VCH Community Engagement team will follow-up with Stroke Redesign team on what tangible impact this feedback has had. This information will then be shared with engagement participants.

We are deeply grateful to the stroke survivors and their caregivers for taking the time to tell us their stories and share their insights. We were humbled and moved by your strength, spirit and grace. Additional gratitude to the Stroke Recovery Association of BC Coordinators for facilitating this engagement process.

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