Assessing the Needs of Stroke Survivors and Caregivers Post Hospital Discharge on Prince Edward Island

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Background

- Since **2004** Health PEI and the Heart and Stroke Foundation in PEI (HSF|PEI) have partnered in the development and implementation of the **PEI Organized Stroke Care Program**
  - Many components of the *PEI Integrated Stroke Strategy* have been implemented in the areas of public awareness, prevention, hyperacute & acute care and rehabilitation services
  - The final phase, which is focused on community reintegration, will further address remaining gaps

Community Reintegration *…return to mainstream family and active community living…*

Lindsay, et al. (2013).Canadian Best Practice Recommendations for Stroke Care: Chapter 6 Stroke Transitions of Care

Purpose

- To hear from stroke survivors, caregivers and external and internal stakeholders experiences with community reintegration to inform the next steps of the **PEI Organized Stroke Care Program**

Methods

Survivors and Caregivers

- Recruitment methods included a letter mail out, posters, newspaper and public service announcements
- Data was collected from 47 survivors and 46 caregivers through:
  - In person discussion groups using an interview guide (tape recorded and transcribed)
  - Online and paper surveys for survivors and caregivers who could not attend
  - Individual interviews arranged on request

Healthcare Professionals and Community Partners

- Input received using an online survey and a face to face stroke summit

Literature Review

- A literature review was completed to further support and validate findings

Results

Stroke survivors and caregivers across PEI report similar findings to those in published literature and are grouped into **three main areas of needs** differing between **two time periods**:

Time 1:
- Initial transition to home consistently reported as a stressful and challenging time
- Marks the beginning of life after stroke

Time 2:
- Survivor and caregiver needs change over time
- They need to adjust to being home prior to considering returning to community activities

Time 1: Initial Transition to Home

"we are sending him home and that's it they sent him home. He was still totally paralyzed on the right side, he had aphasia, he had some problems cognitively, he had problems physically, he couldn't go use the bathroom himself, so I did all that." – Stroke Caregiver

Time 2: Adjusting to Life After Stroke

"for us to go anywhere I've got my wheelchair, … my walker, everything to take in the van…it's a lot of work. It's a lot of work for him as much as it is for me" – Stroke Survivor

Needs	Challenges	Enablers	Challenges	Enablers
1. Physical support and supervision	1. Learning new skills to care for survivors at home 2. Physical assistance 3. Social isolation	1. Training and mentoring; Check in and follow up 2. Support from family/ friends; Home Care support 3. Visitors	1. Caregiver and stroke survivor strain and adjustment; depression 2. Social isolation	1. Respite - range of flexible options; Day programs; Vacation for caregiver; Home Care; Community supports; Counseling; Peer support 2. Visitors
2. Adaptive equipment and appropriate housing	1. Determining appropriate type and locating equipment/ services 2. Financial strain	1. OT home assessment; Equipment loan out programs; Ambulatory Stroke Rehab Services 2. Financial assistance (timely)	1. Innovative adaptations to participate in desired activities 2. Changing needs overtime and increased comorbidities 3. Potential expenses	1. Creative solutions 2. Education/ Information on how to access Community Care and Long Term Care when required 3. Financial assistance
3. Support for stroke recovery	1. Number of appointments 2. Optimal rehab intensity and self management capacity building; Fatigue 3. Obtaining information	1. Help with transportation; Telestroke-Rehab 2. Ambulatory Stroke Rehab Services; Telestroke-Rehab 3. Single point of contact; Home Care and other support services	1. Transition to community participation and social integration 2. Additional information as needs change 3. Public/ family understanding of stroke and its impact (not all impairments are visible)	1. Ambulatory Stroke Rehab Services; Community Based Programs; Day Programs; Help with transportation; Telestroke-Rehab 2. Someone familiar to call; Ongoing education sessions 3. Education; Community engagement

Conclusion

Stroke survivors and caregivers face a number of challenges returning to their home and community. A greater collaboration between the health system and communities is needed to build a coordinated system of supports and services that optimizes a successful integration and leads to better outcomes.

Next Steps

1. A proposal has been submitted to government to:
   a) Create a Stroke Navigator position to assist stroke survivors and caregivers access supports and services they need.
   b) Create a Respite and Rehab home care program to provide respite while also providing opportunity to practice activities/ skills.
2. Heart and Stroke Foundation in PEI begin discussions with communities to facilitate community capacity to address survivor and caregiver needs

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