

# LAND ACKNOWLEDGEMENT

Nova Scotia Health is located in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People, and we acknowledge them as the past, present, and future caretakers of this land.

May this acknowledgment demonstrate a commitment to working to dismantle ongoing legacies of oppression and inequities and recognize the current and future contributions of Indigenous communities in Nova Scotia.



## Disclaimer

The goal of the ABI Journal club is to foster skills of research critique, promote interprofessional interaction and encourage the inclusion of evidence-based practice.

Please join us in creating a safe and approachable learning environment.

Please note that although presenters may have an interest in the article that is presented, they may not necessarily be an expert in that field.

This event is for your learning only. Please do not distribute slides or recordings. Recordings can be distributed by Journal Club organizers only.



# ATTENDANCE

If you are participating as a group, please enter the names of everyone in attendance in the chat.

Thank you!





## ABI JOURNAL CLUB

**Understanding the priorities in life beyond the first year after stroke: Qualitative findings and non-participant observations of stroke survivors and service providers**

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Nova Scotia  
**ABINETWORK**

# Understanding the priorities in life beyond the first year after stroke: Qualitative findings and non-participant observations of stroke survivors and service providers

## Why I chose this Article

- Focuses on the unmet needs of person with ABI, 1-5 years post injury and how one's quality of life is directly impacted when needs go unmet.
- Utilizing the evidence to support the benefit of supporting person with Stroke longer term through a weekly social/support group with skilled facilitation.

## **Why Researchers want to explore this further**

- Unmet health needs directly associated with a lower quality of life in stroke survivors.
- There is little research into the Survivor's and health professional perceptions of their long term needs post-injury
- From the perspective of the Survivor and the health care professional, What are the long term priorities of the person's who have had a Stoke.
- This will inform developing appropriate services to assist survivor's in leading satisfying post-stroke life.

## **Why Explore this Issue (Historical)**

- A systematic review of 19 survey studies showed that survivors had a high prevalence of long-term unmet needs
- 74% having at least one unmet need
- median of two to five unmet needs per survivor
- 32 quantitative studies found a high prevalence of survivors with unmet needs, ranging from 15% to 98%. (the highest being 2 years post stroke)
- unmet needs in the areas of physical function, mental health, leisure exercise, and return to work were identified

## Why Explore this Issue (Historical)

- 32 quantitative studies revealed that post-stroke communication challenges persisted for many years
  - Survivors identified a need for assistance in communicating with others outside of their homes,
  - creating meaningful roles,
  - maintaining support networks
  - moving forward with a sense of control
- younger survivors are complex. Their self-growth is interrupted.
- need support to internalize stroke into their lives in order to make a better adjustment



## **AIM of the Study**

- 1) To understand stroke survivors' priorities in life beyond one year after stroke !
  - goals to attain
  - activities that they perceived as meaningful or comfortable to perform
  - persons whom they would like to maintain relationships and socially connected
- 2) What activities do survivors usually seek to satisfy their priorities/goals.
- 3). The results will inform future development of appropriate community-based services

## Participants

40 survivors were recruited from a support group and two community based centers.

- 18 years old or above;
- clinically diagnosed with a first-ever/recurrent, ischemic/hemorrhagic stroke;
- discharged to home after their recent stroke for at least one year;
- had a Montreal Cognitive Assessment score above the second percentile



## Participants-Providers

14 Providers Interviewed

- extensive experience providing community-based services
  - four volunteer groups
  - two non-profit making non-government organizations
  - one government-funded centre.

## **Limitations**

- survivors were limited to those without severe aphasia or hearing problems.
- nursing and social work, no other health professions were represented among our provider participants.

## **METHODS- Study Design**

- individual interviews with stroke survivors
- observation of the survivors' typical day (patterns of daily activities) and how these activities satisfied their life priorities.
- Interviews with providers
- Based on the providers' perceptions, they sought to learn more about the survivors' long-term life priorities.
- The study followed the Consolidated Criteria for Reporting Qualitative Research

## Data Collection-Survivors

- trained research assistant (RA)
- face-to-face interview
- A semi-structured interview guide was developed based on the literature
  - life priorities
  - short-term and/or long-term personal or life goals,
  - activities that they perceived as meaningful or comfortable to perform,
  - people whom they would like to maintain relationships and social connections with,
  - activities that they did to achieve these life priorities.

## Data Collection-Providers

- An individual interview was conducted
- A semi-structured interview guide was adapted from the guide used for stroke participants
- providers discussed their experiences of designing activities for stroke survivors
- perceptions of the survivors' life priorities and the activities that survivors performed to achieve their priorities
- challenges in improving these current services to better facilitate the survivors' pursuit of their life priorities.

## **Results – Five Themes were Derived**

- Healing the mind to move forward
- Optimizing adaptations and maintenance in physical function,
- Living a safe and cost-effective life
- Returning to work
- Giving back to society



## Healing the Mind -Survivor

- Time (provider)
- Still emotionally vulnerable years after Stroke (provider)
  - Notably, they found emotional vulnerability in nearly all survivors, regardless of age, gender, stroke severity, or duration. It was simply a matter of degree and individual choice whether to show it or not
- Need for flexible psychological support (survivor)
- existing community-based services were inadequate in terms of providing immediate support for chronic survivors(provider and survivor)

## Optimizing adaptations and maintenance in physical function

The **survivor and provider** physical functioning usually plateaued after one year however survivor's goal is to continue to maximize their physical independence over their lifetime.

- Survivor wants more focus on adaptations and maintenance
- The **provider** participants agreed that more home visits conducted by health professionals could be performed to identify problems in post-stroke adaptations (post 1 year)
- Desire for new and professionally-supported services

## **Leading a safe and cost-effective life**

- Developed a sense of what is good for self (survivor)
- Providers identified that the survivor's had become knowledgeable and semi-expert with their diagnosis.
- Barrier-free facilities to improve access in community
- The stroke and provider participants unanimously suggested more public education to promote the rights of people with physical disabilities to be treated fairly
- Looking for one-stop affordable services

## Return to Work

- Addressing financial needs
  - Financial burden after stroke decreased income
  - Spouse become caregiver

### Unresolved barriers to seeking and sustaining employment

- Difficulty finding work
- Physical limitations
- Competing with others without disability

## **Giving Back to Society**

- Survival experiences are an asset to help others
- Barriers to volunteering

## AUTHOR'S CONCLUSIONS

- Stroke Survivors want a life after stroke that is mind healed, optimally adapted and physically functioned, safe, cost-effective, and with the opportunity to return to work and contribute to society in the long run
- Community-based services can be improved so that chronic stroke survivors can receive more at-home, technology-supported psychological intervention, self-management support, barrier-free, one-stop services, and opportunities for employment or volunteering
- More public education to promote a socially inclusive society and collaboration between academic and community organizations



# JOURNAL ARTICLE EVALUATION

1. Could you figure out how to implement the intervention from what they wrote?
2. Did the authors make unrealistic simplifying assumptions?
3. What do you like about the method, implementation, and evaluation, especially with reference to the Acquired Brain Injury content?
4. What don't you like?
5. Can the results be used to solve other problems? How generalizable are the results?



## ACKNOWLEDGEMENT

THANK YOU to those who have assisted in choosing, evaluating, discussing & presenting!

THANK YOU to Annie's Café  
<http://anniesplacecafe.ca/>

THANK YOU to Nova Scotia Health

THANK YOU to the Nova Scotia ABI Network

THANK YOU to the Brain Repair Center





## CONTACT INFORMATION

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## Relevance

- 1) To understand stroke survivors' priorities in life beyond one year after stroke, including the goals to attain, the activities that they perceived as meaningful or comfortable to perform, and the persons whom they would like to maintain relationships and social connections with; and
- 2) 2) To explore the activities that survivors usually performed to satisfy their priorities in life.

## INSERT BACKGROUND/ADDITIONAL INFORMATION

if needed, highlight relevant language, definitions, and topics within the article that are necessary for the viewer to understand the context of the research.



## REFERENCES & RECOMMENDED READING

INSERT CITATION FOR THIS PAPER AND ANY OTHER SOURCES USED TO SUPPORT BACKGROUND UNDERSTANDING.

Altman, R. & Bagley, S. (2012). BMI Journal Club Template.

