

*Educating for
Sustainable Well-
Being: Concepts,
Issues, and
Perspectives*



The Daily Lived
Experience:
Neurological
Conditions

Dr. K. Roger, FSS
November 24, 2012

The daily lived experience of neurological decline:

- What do we know about it –
- What do we see in our world around us -
- How do we support those living with it –
- What are our values and attitudes around health-

Types of conditions

- ALS, PD, AD, HD, MS, Stroke, ABI, Tourette's
- Episodic (symptoms/trajectory)
- Long term / not fatal / no cure
- Can run in families
- Can be more prevalent in some regions
- Lack of understanding and research

Neurological Health Charities of Canada (NHCC)

<http://www.mybrainmatters.ca/en>

Mission

To improve the quality of life for all persons with chronic brain conditions, and their caregivers, by: elevating brain health to the top of government agendas; increasing awareness and influencing government decision makers regarding brain health; and, ensuring that research, prevention, treatments and supports for those living with chronic brain conditions are universally accessible and fully funded.

Three Year Study (2007-10)

- Funded:
 - UM start-up grant; URGP
- What: communication and decision-making
- Who:
 - PD and MS



2007-08

PHASE I:

Community based consultations (3)

2009

PHASE II:

Interviews (16) (individual, support, professional)

2010

PHASE III:

Follow-up interviews (8) and focus groups (2)

Findings

- Lack of data being collected in organizations
- Health care fragmented around the city
- Health care professionals act as experts and gate keepers, family NB

- Mgt of time – flex time and energy
- Spouses did not see self as ‘caregivers’
- Personal history, experience, likes and dislikes NB – not medicalized
- Impact of research on individuals



LINC study: 2010-13

2009 National Population Health Study of Neurological Conditions:

- Minister of Health and National Health Charities of Canada (important coalition)
- 15 studies – 15M

‘Everyday Experience of Living with and Managing a Neurological Condition’

- Manitoba, Dalhousie, Queen’s

LINC Study

- Phase I: quantitative population-based survey collected information on available resources, impact of conditions on participation and perceived health status. Administered to 3000 people with any neurological condition over 18 years old living anywhere in Canada.

LINC

- Phase II: cohort study, 300 volunteers 24 to 64 years from Phase 1. Monthly basis over a 10-month period.
- Phase III: multiple perspective case study (MPCS) 18 individuals, 12 adult participants and 6 parents. Each focal participant nominated 4 supporters.

Potential for data use

- Participation at work, school and home
- Youth and parents, adults
- Across seasons
- Across conditions
- Across age groups and gender
- 90 Interviews
- 1500 surveys (x4)

EMERGING CONCEPTS



1. Lack of general knowledge and awareness about social impact
2. Lack of professional knowledge across neurological conditions, and between professionals
3. Lack of knowledge by employers
4. Participation depends on being able to be an 'active agent of change' yourself
5. Social support invaluable: coping and resilience

LINC study website:

<http://occupationaltherapy.dal.ca/The%20LINC%20Study/>

Spirituality

Identity and 'suffering'

Methods paper

Penner, L., & Roger, K. (2013). How individuals affected by neurological illnesses maintain selfhood while negotiating care: Implications for health care providers, in print, *Communication and Medicine*.

Roger, K., & Medved, M. (2010). Living with Parkinson's disease: managing identity together, *International Journal of Qualitative Studies on Health and Well-being*, Issue May/June, 5(2), 1-8.

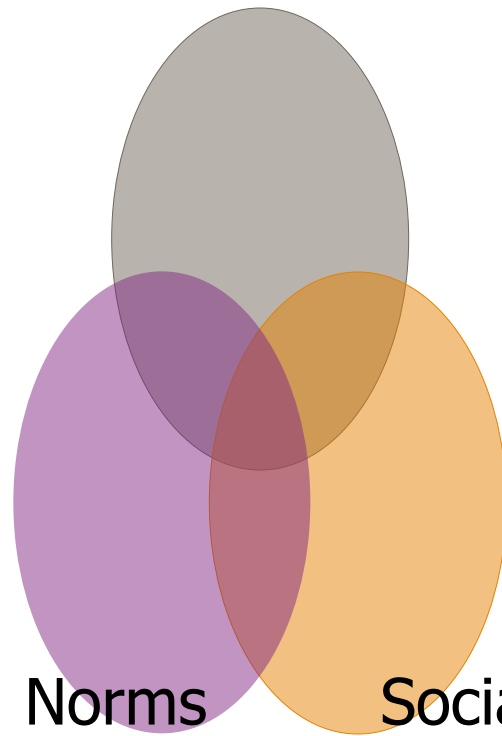
Roger, K., Mary-Quigley, L., & Medved, M. (2010). Perceptions of health care communications of formal and informal care providers and persons with Parkinson's disease and Multiple Sclerosis, *Journal in Healthcare Communication*, 3(2), 124-137.

Roger, K., & Penner, L. (2010). Diving for water: Methodological considerations, *International Journal of Qualitative Methods*, 10(1), 1-13.



Vision and Role for Community?

Autonomy and Family



Social Values and Norms

Social and Medical:
Programs, Research and Policy

Recommendations

1. Training for general public, professionals, employers
2. Programs and services that serve the needs of folks with neurological conditions
3. Respite for family

What do we want to see, as a community, when we look in the mirror?

It takes a village.....

