

Stroke and Aphasia in Canada - Submission

As is the case in many areas of the world, aphasia treatment is far from being a priority within the Canadian healthcare system. This poster represents one part of a larger initiative planned to begin addressing the challenges of aphasia intervention and developing aphasia research capacity in Canada by aligning with the stroke community. While the presentation will focus on the Canadian experience in the area of stroke and aphasia, we hope to stimulate an international exchange of views.

Stroke care in Canada has become increasingly evidence-based over the past decade with groundbreaking work in Ontario gradually moving to a national level. Stroke best practice guidelines put out by the Canadian Stroke Network every two years are beginning to form the basis for stroke decision-making in Canada and are now referenced internationally. In terms of both an enabling infrastructure and funding opportunities, it makes sense to align aphasia with stroke; however, aphasia is only minimally represented in these guidelines. Similarly, a review of the presence of aphasia research presentations and/or articles at stroke conferences, and in stroke journals, provides additional evidence that aphasia is underrepresented in the general stroke arena. For example, the Canadian Stroke Network recently hosted the second annual Stroke Congress in 2011 drawing over 1000 stroke researchers, frontline practitioners and administrators from all over Canada and internationally. However, other than a pre-conference course on decreasing language barriers to stroke care and a few isolated posters presented by students in areas such as health policy, there was a dearth of speech-language pathology presentations on aphasia.

Preliminary discussion with selected stroke leaders in Canada helped identify reasons for the seemingly disparate agendas for aphasia and stroke, and development of a plan for remedying the situation. This presentation will describe our thinking on the most effective way to integrate aphasia into stroke best practice in Canada as well as actions and results to date

The challenges identified include the following:

1. Stroke thought leaders have difficulty articulating what aphasia treatment is.
2. Existing research evidence in favor of aphasia treatment has not been widely disseminated beyond our own field. For example, we tend to publish efficacy research and evidence guidelines largely within our own journals. Research evidence is not always meaningful to the broader stroke community. For example, stroke leaders have suggested that much of our research addresses “micro” outcomes; the relevance to functional reintegration into family and community is not clear
3. Exceptions include research evidence presented within the broader framework of neuroplasticity principles (e.g. constraint-induced treatment)

We will share our thoughts on potential first steps including:

1. Use what we have learned about the concept of ‘value’ from health economics and applying it to this situation - looking for solutions to problems *that make sense to our stakeholders* (in this case, the stroke community)
 - a. Highlighting the finding by a health economist (Lam, 2010) that aphasia had the highest negative impact on Quality of Life when compared with other illnesses/diseases including cancer, in the population living in Ontario skilled nursing facilities for complex continuing care
 - b. Highlighting challenges for stroke teams that need to be addressed e.g.
 - i. Difficult to give information and ask questions when the stroke patient has aphasia
 - ii. Difficult to understand what they are trying to say/ask
 - iii. Hard to know if you can ‘rely’ on their responses
 - iv. Negative impact on quality of care/research
 - v. Can be time consuming and not enjoyable
 - c. Demonstrating that we have solutions to address policy challenges and implications for stroke care administrators and managers with regard to the language barriers imposed by aphasia e.g.
 - i. Complying with legislation regarding disability, health equity and quality of healthcare
 - ii. Impact on patient satisfaction
 - iii. Impact on quality of care and potential for diagnostic and other errors
 - iv. Impact on job satisfaction for frontline staff
2. Pay attention to our external environment rather than focusing solely inward where we mostly talk to each other (and even within this, interacting mostly with other researchers rather than also focusing attention on getting our research out to clinicians and policy-makers)
3. In line with the above, apply what we know about Knowledge Transfer and Exchange (KTE) to get information about our research out to the stroke community AND to practicing speech-language pathologists in the area of stroke. Nursing and other rehabilitation professionals should be supporting communication goals as much as is done with areas related to physical and occupational therapy
4. Leverage resources such as the Community of Practice on ‘Aphasia and Communicative Access’ funded by the Ontario Ministry of Health via the Seniors Health Research Transfer Network
5. Use *Living with Aphasia: Framework for Outcome Measurement (A-FROM)* to present a unified approach to aphasia treatment and outcome goals, grounded in the World Health Organization’s ICF, that provides a clear and consistent message regarding what we do.
6. Develop a template for evidence-based Best Practice Guidelines across the stroke care pathway that takes into account what we do know and what is relevant to the stroke community e.g.
 - a. Systematic reviews of experimental research in our field
 - b. High level qualitative research in our field
 - c. Clinical expertise

- d. Perspectives of people with aphasia and/or families on how problems should/could be addressed
- e. Latest neuroplasticity research in the area of stroke

The ultimate goals of this initiative are to have aphasia be an integral part of the Canadian Best Practice stroke guidelines at every stage of the stroke care pathway and to have the concept of 'Communicative Access' be included in the section on resources applicable across the continuum of stroke care. This presentation will outline these goals, plans to achieve them and progress to date.