

Communicative Access Measures for Stroke – Submission

Reducing communication barriers to ensure promotion of patients' rights to have information presented in a way that it can be understood and the right to participate fully in decision-making is consistent with policies in the USA, Canada, UK and Australia. For example, the Joint Commission (the organization responsible for hospital accreditation in the US) now includes communicative access and health literacy within its standards. Such practices are also in line with the World Health Organization's definition of health:

“Health is the ability to live life to its full potential. For many people with disabilities, the realization of that ability is dependent on factors in society. When a person in a wheelchair finds it difficult to enter into her office building because it does not provide ramps or elevators, the ICF identifies the focus of the intervention: it is the building that should be modified and not the person who should be forced to find a different place of work” (Brundtland, 2002).

However, the literature and anecdotal experience suggest that in current practice, even within patient-centered approaches, patients/clients with stroke and communication difficulties e.g. aphasia, do not enjoy equal access to service. For example, within health care facilities patients with communication difficulties are often not included in day to day decisions such as choosing menus or major decisions such as choice of surgery, therapy goals or discharge plans.

This poster session will describe a project that was initially motivated by a demonstration project (Simmons-Mackie et al., 2007) designed to increase communicative access to information and decision making in health care targeting a “systems” level of health care via a multi-faceted, team-based intervention. The initiative provided insights into factors that facilitated or impeded communicative access in 3 types of health care settings. The researchers concluded that targeting systems level change appeared to be a useful approach to improving access to health care information and decision making for people with aphasia. However, one limitation of the project was the lack of an appropriate tool to quantitatively capture changes in communicative access. Administrators and policy-makers, as well as other stakeholders, typically find quantitative representation of changes to be most convincing. We felt that addressing the need for a quantitative measure of communication access in health, and particularly stroke care, would be both practical and useful. Thus, the current project was conceived to address the following objectives:

- To develop and evaluate a user-friendly questionnaire designed to measure communicative access to information and decision-making within health care systems from the perspective of the frontline health care providers
- To develop and evaluate a user-friendly, pictographic measure of communicative access to information and decision-making from the perspective of the client/patient with a language barrier such as aphasia

- To involve relevant stakeholders in the development and evaluation process from the beginning in line with Knowledge Transfer and Exchange (KTE) principles
- To trial questionnaires and obtain feedback from a variety of potential users from the continuum of health care services, and finally,
- To test the sensitivity of the health service provider's questionnaires in a pre-/post-intervention study by piloting the questionnaire before and after an intervention designed to improve access to information and decision-making.

An additional objective was added post hoc as we found it necessary to develop a separate questionnaire on policy to be completed by system administrators.

The result was the development and trialing of 3 questionnaires including 1) an internal evaluation tool for administrators to assess policies and procedure compliance with communicative access standards, 2) a tool for front line staff to report their perspectives on communicative access within a facility or program, and 3) a pictographic questionnaire for clients/patients with aphasia designed to assess the accessibility of services from the clients perspective. Questions on all tools are answered using Likert-Types scales or yes/no responses. Development of the tools involved multiple focus groups of experts in the field of aphasia and communicative access who gave input throughout the development process. In addition, all three questionnaires were trialled at a geriatric and long-term care rehabilitation hospital, and preliminary pre-/post-testing was completed at a Low Tolerance Long Duration (LTLT) program within a skilled nursing facility delivering complex continuing care.

The poster presentation will provide examples of the content for each of the measures, as well as results of qualitative and quantitative evaluations from focus groups, trials, and pre-/post-testing. The poster will also describe next steps for establishing the validity and reliability of the questionnaires and creation of online access to the questionnaires. The web-based administration option will facilitate rapid evaluation and cross institution comparisons. The ultimate aim of the project is to provide methods for promoting communicative access in health care and to support quality improvements in care for people with aphasia.