

Executive Summary

Recent focus on health literacy and providing health information that is readable, understandable and easy to act on provided the basis for this fellowship. Healthcare professionals recognize that people living with stroke, need more than medical treatment; they need support in mastering and sustaining the complex self-management behaviours necessary to enable them to live as healthily as possible (Heisler, 2006). Education and support contributes to health by equipping people with knowledge and skills that help provide a sense of control and mastery over life circumstances.

Research has shown that providing appropriate education and support to stroke survivors and their caregiver has the potential to reduce hospital readmissions, reduce the risk of recurrent stroke, and decrease patient sense of frustration. It can increase satisfaction with care, by improving their coping skills and personal health practices. To highlight the focus of this fellowship on attaining a higher level of understanding of the perceived needs and expertise in meeting the needs of those affected by stroke this paper lays out the learning process. What do stroke survivors and their families' feel is appropriate? Do their perceived needs differ from what we as healthcare providers think stroke survivors need to know? How can we provide the information in ways that promote self-efficacy through mastering self-management?

To aid in achieving this goal specific learning objectives were chosen to engage in a vision that will enable healthcare professionals to better support people in successfully managing their health and transitions along the care continuum, starting in the acute care setting. Many different stakeholders have perspectives and information about the experience of people with stroke, their families, and caregivers. They have ideas about what could be changed to improve the acute care experience, influence self-management skills, and improve transitions throughout

the care continuum. The process that is summarized in this document was intended to stimulate action based on a new level of understanding gained through appreciating those perspectives.

A learning plan with specific goals and objectives was used to guide the process throughout this fellowship. The objectives of this learning plan were well defined and promoted significant gains in knowledge and expertise in several areas:

- The first step of this fellowship involved learning the process for submitting an application for ethics review. Approval was granted through Queen's University.
- Comprehensive literature reviews and annotated bibliographies were completed covering several key topics that facilitated a higher level of understanding and insight;
 - The challenges and barriers to quality of life identified by stroke survivors and their families;
 - The implications of low health literacy on patient understanding and health outcomes as it pertains to the stroke population;
 - The evidence supporting the application of processes and methods used to determine readability of documents produced for educational purposes in the healthcare setting.
- Scripted interviews and surveys were conducted pre and post implementation of those affected by stroke and acute care healthcare professionals. This helped to gain first-hand knowledge and understanding of survivor and family perceptions. Information gathered was grouped into common themes and was used to inform the content and format of the educational resources and make revisions as needed. Ongoing consultation with these stakeholders allowed for continuous development of insight, understanding and expertise surrounding these perceptions.

- The Precede-Proceed planning model was used to guide the learning, development, and evaluation process throughout the fellowship. It is a participatory process that makes assumptions about promotion of health and involves all stakeholders from the beginning of the process and throughout the project. Gaining understanding into the change process should focus initially on the desired outcome and this model was an excellent fit for this fellowship initiative. Having never worked with a planning model, this was initially a daunting process. However, it proved to be an excellent choice to provide structure within which to plan, implement and evaluate this intervention. This model left latitude for adapting the design of the intervention using the knowledge and insight gained through stakeholder participation throughout the entire process.
- A patient and family guide entitled “Partners in Stroke Recovery” was developed as part of a participatory process that included patients and their families, patient experience advisors, an outstanding mentoring team, an interprofessional team of stroke experts, and the application of the above mentioned learning. This guide was designed using expertise gained in the principles of health literacy and readability. It has undergone revisions based on feedback from stakeholders and will be distributed to a wider group with continued evaluation and revisions as required.
- The public affairs department at Kingston General Hospital (KGH) was involved in the process to ensure that the guide was developed in a design format consistent with KGH branding including logos, fonts and colours. This process facilitated a learning opportunity that had not been anticipated.
- The framework for a Peer Visiting Support Program was developed (framework can be found in the enclosed report) with input from the stakeholders listed above.

Development of the education plan for volunteers and volunteer recruitment is ongoing in collaboration with the interprofessional stroke team and the volunteer program at Kingston General Hospital (KGH). Recruitment of someone that is already part of the volunteer team at KGH to participate in building and developing this program is the first step, with ongoing recruitment planned for the early spring of 2014. The perceptions of these volunteers will allow me to continue to build on learning achieved during this fellowship.

To sustain and build on the learning and expertise, which began during this fellowship, I have been asked to participate on a committee that has been charged with redesigning the corporate educational brochures and pamphlets currently in use at KGH. This group has interprofessional membership including patient experience advisors. I have also been asked to present the data and insights collected during the fellowship to the annual neurosciences best practice workshop scheduled in early March 2014. There is work ongoing to develop the Medicine Program tactics for quality improvement for the next fiscal year. I have been asked to participate by leading a tactic aimed at improving how we connect with, engage and empower our patients and their families to truly become active members of the healthcare team. The first step in the process is effective communication that meets everyone's needs and literacy levels.