Overview of Project 2010-2015

On May 31, 2010, a project team based at Lakehead University’s Centre for Education and Research on Aging and Health (CERAH) was awarded a five-year, $1.825 million Canadian Institutes of Health Research (CIHR) Aboriginal Health Intervention Grant dedicated to improving palliative care services in First Nations communities. The project is lead by Principal Investigators Dr. Mary Lou Kelley, Lakehead University, and Dr. Kevin Brazil, McMaster University.

The four First Nations communities involved in this project include Fort William First Nation, Naotkamegwanning First Nation, and Six Nations of the Grand River Territory, located in Ontario and Peguis First Nation, Manitoba. Letters of commitment were received from over 30 regional, provincial and national partners.

The research is guided by a four phase conceptual model for developing community capacity to provide palliative care and will employ participatory action research. Through this research, First Nations health care providers will be empowered and supported to be catalysts for community change in developing local palliative care programs.

The overall goal of this research is to improve end-of-life care in First Nations communities through developing palliative care programs and creating a culturally appropriate theory of change to guide palliative care program and policy development nationally. Lessons learned from this project have the potential for application to other First Nations communities also in need of developing local palliative care services.

This research project is a collaborative effort by four First Nations communities, a team of researchers and Aboriginal health organizations, who have committed to work together for five years while developing palliative care services and knowledge within their communities.
Introduction to the Project Team

The project team consists of representatives from the four First Nations communities, eight researchers from across Canada and research staff.

First Nations Communities Representatives:
- Maxine Ranville, Naotkamegwaning First Nation
- Karen Bannon and Luanne Maki, Fort William FN
- Lori Monture and Ruby Miller, Six Nations of the Grand River Territory
- Jeroline Smith, Peguis First Nation
- Marcella Kudaka, Dilico Anishinabek Family Care
- Jocelyne Goretzki, Kenora Chiefs Advisory

Research Team:
- Dr. Mary Lou Kelley, (PI) Lakehead University
- Dr. Kevin Brazil, (PI) McMaster University
- Dr. Mary Hampton, University of Regina
- Gaye Hanson, Hanson and Associates
- Mae Katt, CRA-NHR, Lakehead University
- Dr. Bruce Minore, CRA-NHR, Lakehead University
- Valerie O’Brien, McMaster University
- Holly Prince, CERAH, Lakehead University

Research Staff:
- Holly Prince, Aboriginal Project Manager
- Thomas Grinnell, Aboriginal Community Facilitator
- Audra Taillefer, Aboriginal Community Facilitator
- Tracy Sinclair, Aboriginal Community Facilitator
- Melody Wawia, Aboriginal Research Assistant
- Robert Sleeper, Aboriginal Graduate Student Trainee

Project Launch

The project received funding on June 1, 2010. From June to September, activities focused on planning, hiring and project organization.

On September 27 - 29, 2010 there was a launch of the project held in Thunder Bay, Ontario which included all of the researchers and members from the First Nations communities.

During this time, a media event took place at Lakehead University in the Agora moderated by Dr. Ian Newhouse, Director of the Centre for Education and Research on Aging & Health (CERAH). Invited speakers included Chief Peter Collins from Fort William First Nation, Dr. Brian Stevenson, President of Lakehead University and Dr. Rui Wang, Vice-President of Research at Lakehead University.

Following the media event, the Project Management Committee met for two-days, which included the research team and community representatives. This meeting focused on community engagement and networking opportunities, as well as provided a forum for the committee to discuss the hopes and visions for the project. In addition, data collection tools and research protocols were discussed, along with communication strategies.

An appreciation luncheon was also held which recognized individuals and organizations that provided previous support and dedication to the project. This included representatives from funding agencies, training facilitators, students, and research assistant who contributed to the project.

Back row (L-R): Bruce Minore, Valerie O’Brien, Lori Monture
Middle row: Jeroline Smith, Mary Hampton, Karen Bannon, Luanne Maki, Gaye Hanson, Holly Prince
Front row: Mary Lou Kelley, Marcella Kudaka, Jocelyne Goretzki, Doris Bear, Darlene Copenace, Kevin Brazil

Left to Right: Chief Peter Collins, Dr. Brian Stevenson, Dr. Mary Lou Kelley, Holly Prince, Dr. Rui Wang, Dr. Kevin Brazil, Dr. Ian Newhouse
Community Engagement

Following the project launch, community engagement activities began with the establishment of local Project Advisory Committees. Each community has developed these committees responsible for ensuring local control of the project and overseeing all work done, including data collection, analysis and dissemination activities.

Aboriginal Community Facilitators were hired in consultation with the Project Advisory Committees to lead local implementation of the project. The facilitators will be responsible for collecting all of the data for the needs assessment and environmental scan, which involves surveys, interviews, and focus groups. They will also assist in organizing and facilitating community interventions, such as educational events, resource development and policy and procedures.

Community Launches occurred in three of the four communities so far. These launches were open to the community and provided individuals with an opportunity to learn more about the project and to get to know the research team. These were organized by the project advisory committees with the assistance of the facilitators.

Needs Assessment and Environmental Scan

A needs assessment and environmental scan is occurring in each community. The local Project Advisory Committees have provided community specific direction and feedback on research tools and identified the key informants in the communities.

Data are being collected by the Community Facilitators from surveys, focus groups and interviews with Elders, community members, health care providers and members of leadership. In addition, the Community Facilitators are also documenting the history of palliative care in each community by creating a timeline. Data collection started in January 2011 and is expected to be completed by spring 2012.

The results will be delivered back to the Project Advisory Committees and communities. Based on the results from the needs assessment and environmental scan, health care workers and community members in each community will choose a series of clinical, educational or administrative interventions to build their local capacity. Each intervention will be implemented and evaluated for its contribution to developing palliative care programs.

The Project Advisory Committees will work with the research team to decide in what forums to disseminate the research and how the research results will reach a larger audience, including other First Nations communities across Canada.
Collaborators Involvement

For the proposal submission, letters of commitment were received from over 30 regional, provincial and national partners. The letters outlined organizations and individuals contribution to the project which included:

- Providing consultation services
- Participating in research meetings
- Assistance with the delivery and development of education programs
- Advocating for palliative care resources in First Nations communities
- Creating linkages to regional health and social service resources,
- Disseminating project findings through organizational membership and knowledge translation/transfer to health care policy and decision makers
- Providing access to office space/equipment

The first phase of the project focuses on conducting the needs assessment and environmental scan. Once complete, the project advisory committees will then focus on interventions to address the recommendations. At this time, the collaborators support and guidance will be instrumental in assisting the communities in developing their palliative care programs.

In the fall of 2011, a videoconference will be scheduled and all collaborators will be invited to attend. At this time, the communities and research team will provide an update on the activities and the progress of the research.

Conference Presentations

The research team and First Nations community representatives are currently sharing the information from the project at the following conferences.

- Ontario Palliative Care Association, Annual Hospice Palliative Care Conference, April 10-12, Toronto, Ontario. Poster presentation.
- Canadian Hospice Palliative Care Association: Navigating Safe Pathways to Quality Hospice Palliative Care. September 8-11, 2011, St. John’s, Newfoundland. Workshop and poster presentation.
- Canadian Home Care Association 2011 Summit, October 24-26, Niagara Falls, Ontario. Oral and poster presentation.

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