

# **NORTHWESTERN ONTARIO PALLIATIVE CARE NEEDS ASSESSMENT PROJECT**

## **Progress Report**

Prepared for:  
NWO End-of-Life Care Network Annual General Meeting  
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In 2006, Northwestern Ontario's End-of-Life Care Network had identified a need to assess the communities in Northwestern Ontario regarding their needs for palliative care services, available resources, and health care providers' educational needs. On behalf of the NWO End-of-Life Network, Centre for Education and Research on Aging and Health (CERAH) at Lakehead University proposed to conduct the community palliative care needs assessment project, and to this end, the proposal for the financial assistance was submitted to the Ontario Ministry of Health and Long-Term Care. In spring 2007, the funding to carry out the *Northwestern Ontario Palliative Care Needs Assessment Project* was received.

This regional project was divided into two parts: (1) palliative care environmental scan; and (2) palliative care educational needs assessment. The purpose of the *environmental scan* was to gather comprehensive information regarding the palliative care services being delivered in Northwestern Ontario. The purpose of the *educational needs assessment* was to gather information to be used to prepare relevant curriculum that is tailored to the needs of palliative care providers as a group, and specific to each discipline. Educating the health human resource workforce about delivering palliative care is key in achieving the goal of allowing people to die at home while receiving quality care for themselves and their families. Understanding educational needs is especially critical in rural and remote communities because little is known about the educational needs of health care providers in these areas.

### **(1) Environmental Scan**

The palliative care environmental scan addressed the following questions:

1. In a given year, how many deaths occur in each community?
2. What are the causes of death?
3. Where are the deaths occurring (i.e. acute care setting, home, long-term care facility)?
4. What kind of palliative care services are available in a community?
5. In a given year, how many people have received palliative care?
6. What disciplines are providing palliative care in a community (i.e. physician, nurse, social worker, personal support worker, and volunteer)?

These questions will be answered with secondary data collected from: Statistics Canada; the Canadian Institute of Health Information; Northwestern Ontario Community Care Access Centre; the Ministry of Health and Long-Term Care; and the Office of the Registrar General - Vital Statistics. Reports from both the 2001 and 2006 Census will also be used.

To date, data pertaining to questions 4, 5 and 6 has been received and analyzed. CERAH is currently waiting to receive secondary data from the Office of the Registrar General (ORG), pertaining to questions 1, 2 and 3. Although the appropriate applications were filed to receive this secondary data over six months ago, new processes and regulations being implemented at the ORG have delayed data extraction to date. The Data Services Coordinator also cited unexpected resource issues as an explanation for the latest delay. The expected date of extraction is during the month of May 2008, after which the data will be analyzed and submitted in the final report to the End-of-Life Care Network.

## (2) Education Needs Assessment

A unique methodological approach was undertaken in order to assess the educational needs of rural palliative care providers across disciplines, as well as the specific needs within disciplines. The educational needs assessment assessed sixteen communities throughout the Northwestern Ontario region. Communities included:

- Armstrong
- Atikokan
- Dryden
- Emo
- Fort Frances
- Greenstone
- Ignace
- Kenora
- Manitouwadge
- Marathon
- Nipigon
- Rainy River
- Red Lake
- Sioux Lookout
- Terrace Bay
- Thunder Bay

The educational needs assessment addressed the following questions:

1. What are the educational needs unique to each discipline that provides palliative and end of life care in Northwestern Ontario (i.e. physicians, nurses, social workers, personal support workers, and volunteers)?
2. What educational needs are shared amongst the disciplines that provide front line palliative and end of life care?

Quantitative and qualitative data was collected through surveys and interviews in each community. Initially, sampling was done using a key informant approach to qualitative research. This approach used data collection to obtain an expert opinion from eight palliative care providers. The goal of the key informant interviews was to determine the gaps in discipline knowledge, and thus the discipline educational needs. The palliative care providers used as key informants were:

1. Physician
2. Registered Nurse – acute care setting
3. Registered Nurse – long-term care facility
4. Registered Nurse – home care
5. Social Worker
6. Personal Support Worker – community care
7. Personal Support Worker – long-term care (i.e. Health Care Aid)
8. Hospice Volunteer

The key informants were individuals who are actively working in the palliative care field, and were identified as palliative care experts in their discipline. The key informants were interviewed in depth regarding their knowledge, understanding, and perception of the discipline

specific competencies<sup>1</sup>. The Canadian Hospice Palliative Care Association's 'Square of Care' and was used as a framework for the interview questions. The goal of the key informant interviews was to determine the gaps in discipline knowledge, and thus the discipline educational needs, providing a base to form the educational needs assessment survey.

In the second stage of data collection, at least three palliative care providers from each community, serving as representatives of their discipline, were asked to complete a survey. The surveys were comprised of demographic questions, educational needs questions and education format questions. The educational needs questions were derived from the results of the key informant interviews; they were primarily discipline specific, with some ranging across disciplines. As a result, five different surveys were created for five different disciplines, with most educational needs questions being unique. The demographic and education format portions of the survey were the same for all disciplines.

Two hundred participants were recruited by personal letter of invitation, sent to palliative care providers from a variety of disciplines (physicians, nurses, social workers, personal support workers and volunteers), working in communities in Northwestern Ontario. The mailing list was created using the CERAH data file which includes the addresses of the majority of palliative care providers in the region. Input from the project advisors was also sought to ensure at least three palliative care providers were identified in each community.

The participants were directed to an online survey with a personal entrance code. The participants also had the option to complete the survey over the phone in an interview format with the research assistant. The participants were asked to complete the survey within one week of receiving the instructions. The researchers followed up by telephone two times with participants who had not returned the consent form.

A total of 46 palliative care providers completed the survey. Thus the response rate was approximately 23 percent. Tables 1 and 2 below depict the participant population by community and by discipline respectively.

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<sup>1</sup> The physician, nurse, and social worker competencies are based on the norms of practice in palliative care. The physician competencies are part of the undergraduate medicine palliative and end-of-life care curriculum guide, approved by the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC). The nurse competencies, both general and specific, are approved by the Canadian Associations of Schools of Nursing. The social worker competencies reflect various areas of practice; they are approved by the National Delphi Consensus Study. Personal support workers do not have professional competencies outlined in the literature; therefore, their role as outlined in the Pan-Canadian Gold Standard for Palliative Home Care was used to develop the interview questions for the key informant in this discipline. Furthermore, there are no competencies outlined in the literature for hospice volunteers at the present time. The project coordinator conducted an in depth interview with the administrator of Hospice Northwest, Thunder Bay, Ontario, who actively trains the organization's volunteers. This interview was used to define the role of hospice volunteers, which were in turn used in the key informant interview, instead of competencies.

Table 1: Palliative Care Education Needs Assessment Participants by Community

<b>Community</b>	<b>Total # of Participants</b>
Armstrong	1
Atikokan	5
Dryden	5
Emo	2
Fort Frances	2
Greenstone	1
Ignace	0
Kenora	3
Manitouwadge	0
Marathon	1
Nipigon	0
Rainy River	3
Red Lake	3
Sioux Lookout	2
Terrace Bay	2
Thunder Bay	16
<b>Total</b>	<b>46</b>

Table 2: Palliative Care Education Needs Assessment Participants by Discipline

<b>Discipline</b>	<b>Total # of Participants</b>
Health Care Aid	3
Hospice Volunteer	7
Nurse	19
Personal Support Worker	4
Physician	8
Social Worker	5
<b>Total</b>	<b>46</b>

The survey data will be thoroughly analyzed in SPSS to identify the palliative care educational needs in Northwestern Ontario. Comparisons will be made between disciplines, and within disciplines between rural and urban settings. The analysis will include descriptive statistics and frequency measures on the numerical data obtained from the survey. Additionally, all open ended questions will be qualitatively analyzed using thematic network techniques, consistent with accepted principles found in the literature.

To date, much of the education needs assessment data has been analyzed. However, a comprehensive summary of the key findings remains in progress.

A complete report detailing the Northwestern Ontario Palliative Care Needs Assessment project, in its entirety, will be given and presented to the EOL Care Education Standing Committee on June 2, 2008.