A case study of journey mapping to create a palliative care pathway for Naotkamegwanning First Nation:

An analysis and lessons learned using participatory action research

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A case study of journey mapping to design a palliative care pathway for Naotkamegwanning First Nation:

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Thesis Abstract

Background

There is little known about how to conduct an effective journey mapping process to design a care pathway for First Nations community members who would benefit by having access to local, community-based palliative care programs. This research analyzed a unique journey mapping process that was developed and implemented collaboratively by a Leadership Team of community members in Naotkamegwanning First Nation in Northwestern Ontario, and the members of an EOLFN Research Team based at Lakehead University. The purpose of the journey mapping process was to create the care pathway to guide providing integrated palliative home care for community members who choose to die at home. This thesis analyzes that journey mapping process and offers lessons learned and promising practices that may be applicable for use in other First Nations communities.

This thesis research was nested within a five-year (2010-2015) participatory action research (PAR) project entitled “Improving End-of-Life Care in First Nations (EOLFN) Communities: Generating a Theory to Guide Program Policy and Development” (Principal Investigator: Dr. Mary Lou Kelley). The EOLFN project was funded by the Canadian Institutes of Health Research (CIHR) and was conducted with four First Nations community partners: Naotkamegwanning First Nation, Fort William First Nation, Peguis First Nation and Six Nations of the Grand River Territory. The overall goal of the EOLFN project was to improve the end-of-life care in these four First Nations communities through developing community-based palliative care programs and creating a culturally appropriate theory of change to guide palliative care program and policy development nationally.

Thesis aim

The aim of this thesis is developing and implementing the journey mapping process in Naotkamegwanning, which was one of approximately twenty community-led interventions that were created and implemented throughout the five years of the EOLFN research.

The research questions guiding this thesis are:

1. How effective was the journey mapping process to create the care pathway for integrated palliative home care for Naotkamegwanning community members who choose to die at home?
2. What learnings and promising practices have emerged from this case study that can inform development of an EOLFN workbook tool on journey mapping for use by other First Nations communities?

Methods

This thesis research employs an instrumental case study design, embraces an Indigenous paradigm as its theoretical perspective, and a participatory action research methodology. Qualitative data in the form of researchers' field notes, observations, photos, workshop summary reports and video recordings were collected during the four journey mapping workshops (2013-2014); these existing data were analyzed for this thesis as secondary data sources. After the completion of the four journey mapping workshops, primary data collection for the thesis included a focus group with community members and an online survey with health care providers who were external to the community (e.g. hospital, home care providers, health access centre staff) but provided services in Naotkamegwanning.

Analysis

The focus group data were analyzed first to ground the analysis in the voice of the community. For the community member focus group, an inductive approach was utilized to analyze the data. Using a verbatim transcript, the analysis was done in three stages (1) line-by-

line analysis of the transcript to identify all the ideas expressed during the focus group, (2) grouping similar ideas into themes and subthemes, and (3) organizing the themes to address the research questions. Finally, the qualitative findings from the focus group were visually displayed in a figure, and elaborated in the thesis with quotes to support the themes identified.

The existing data were analyzed next, using the themes generated from the focus group analysis as an evaluation framework, an approach embedded within the PAR methodology. In addition, a guide for analysis of existing data was created based on the research questions by hypothesizing evaluation metrics with my supervisor and these questions were also used in examine the data. Using these two analysis strategies created confidence that all relevant information had been extracted pertaining to the thesis research. This process intended to ensure no ideas, themes, or categories relevant to the research questions were overlooked. I continued to meet with my thesis supervisor on a regular basis to ensure rigour.

Finally, the online survey data were analyzed. These data included numerical data collected using rating scales that were analyzed using descriptive statistics and summarized in tables and open-ended questions to capture participants' opinions about the journey mapping experience. The qualitative data from the open-ended questions were grouped and three over-arching themes were identified and summarized.

Findings

The qualitative findings from the focus group produced a perched eagle figure called "Conducting effective palliative care journey mapping: Learnings and promising practices" and included a grounding theme and four overarching themes. The grounding theme "Journey mapping must be founded in the community's vision for change" emphasized that the community must perceive and articulate expected benefits for its members before undertaking

the journey mapping process to create the palliative care pathway. Supporting the foundational theme are the core ethical concepts of conducting journey mapping in First Nation's communities: "building trusting relationships" and "honouring community control." The first overarching theme, journey mapping requires community planning, identified the importance of community support and awareness to ensure the community's readiness for journey mapping. The second overarching theme, journey mapping requires time commitment, described the lessons learned related to time and identified that journey mapping could not be completed without stakeholder contribution and follow through. The third overarching theme, journey mapping requires that communication is respectful of the community's beliefs, revealed that journey mapping workshops must be conducted in a culturally relevant format that is familiar to the community. The fourth overarching theme, journey mapping develops a culturally appropriate care pathway, established the importance of Elder guidance throughout the journey mapping process and that the journey mapping workshops ultimately resulted in a care pathway that is respectful of the individual's wishes, values and beliefs.

The quantitative findings from the survey included rating scale statements related to the overall journey mapping experience. Respondents rated statements in four categories, including: service delivery, relationship building, the journey mapping workshop process, and recommendation of future journey mapping. Overall results from the rating scale were very positive and there was a high level of agreement on most items amongst respondents that journey mapping was an effective in developing a palliative care pathway.

The qualitative findings from the survey included three overarching themes. The first theme to emerge was that the journey mapping workshops increased communication and established partnerships between community members and health care providers. The second

theme to emerge was that the journey mapping workshops were a time commitment. The third theme to emerge, and key takeaway from the survey was that all respondents agreed that journey mapping is an effective tool to create the care pathway.

Conclusion

The journey mapping workshops developed an innovative and effective process for Naotkamegwanning First Nation to create their palliative care pathway. The promising practices and lessons learned from this research can be used to guide other First Nation's communities and participating stakeholders in creating a culturally appropriate care pathway.

Co-Authorship Statement

I hereby declare that I am the sole author of this thesis.

I have worked as a Research Assistant and Graduate Student Trainee on the "Improving end-of-life care in First Nations communities" research project for the last five years. This thesis research is nested within that overall project, and utilizes previously collected data which I have independently analyzed.

In all cases, the key ideas in this thesis, composition, data collection and analysis, were performed by the author with the supervision of Dr. Mary Lou Kelley, Lakehead University, Professor Emeritus, School of Social Work and the thesis committee members Dr. Elaine Wiersma Lakehead University, Department of Health Sciences and Dr. Chris Mushquash, Lakehead University, Department of Psychology and Northern Ontario School of Medicine.

I understand that my thesis may be made electronically available to the public.

I certify that, with the above qualifications, this thesis, and the research to which it refers, is the product of my own work.

Acknowledgements

Miigwetch to the Elders, leadership team and community members of Naotkamegwanning First Nation for participating in this research. This thesis would not have been possible without the stories you shared and the time your community dedicated to the journey mapping process. Miigwetch to Ms. Maxine Crow, Naotkamegwanning Home and Community Care Coordinator and Mrs. Wilma Sletmoen for your significant contributions to this research. Miigwetch to the Lakehead University Elder in Residence, Elder Gerry Martin.

I would like to thank the participants and working group partners, health care and social service providers that took part in the journey mapping workshops. Thank you for your time and passionate insights and contributions to this research.

Words cannot express the gratitude and appreciation I have for Dr. Mary Lou Kelley, my thesis supervisor, gerontology professor, professional supervisor, and mentor. It has been a pleasure to learn from and be mentored by a leader in the field of palliative care. Over the years you have provided numerous opportunities for me to learn and build new skills as both an employee and student. I feel truly blessed to have met you. Thank you so much Dr. Kelley for your time, guidance, encouragement and patience.

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I wish to thank my thesis committee members from Lakehead University, Dr. Elaine Wiersma and Dr. Chris Mushquash, and my external reviewer from Queen’s University, Dr. Heather Castleden for agreeing to participate, contribute and be a part of this endeavour. Your expertise and thorough feedback have been invaluable.

To my husband, Trevor, parents, Dan and Camy, in-laws Lee and Diana, dog, Kora, Paul and Peg Podemski, closet girlfriends Melissa Skoglund and Melissa Gaslin, and all of my friends and family: thank you for believing in me. Thank you for your patience and support. I have missed you all tremendously!

Dedication

This work is dedicated to:

My grandmother, Lucille Antoinette Chiovitte (nee: Anderson) 1919-1998.

Everyone deserves the choice to die at home.

I wish you would have died at home like you told us you wanted to.

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Chapter one: Introduction

Aboriginal[1] Canadians are aging and those 65 years old[2] and older are expected to grow from 5.9% of the total Aboriginal population in 2011 to between 15.4% and 16.2% by 2036 (Statistics Canada, 2011c)[3,4]. Median age of Aboriginal Canadians will increase from 27.7 years in 2011 to between 34.7 and 36.6 years in 2036 (Statistics Canada, 2011c)[3,4]. While the life expectancy of Aboriginal Canadians has increased, it remains approximately seven years less than non-Aboriginal Canadians (Health Council of Canada, 2013). When compared to non-Aboriginal Canadians, heart disease is 1.5 times higher, type 2 diabetes is 3-5 times higher and tuberculosis infection rates are 8-11 times higher (Statistics Canada, 2006). Many Aboriginal people are living with and dying from chronic health conditions without access to palliative care despite excellent evidence from medical research that people with advanced chronic disease in the last year of life benefit by receiving palliative care (Carstairs, 2010; Fitzsimons et al., 2007).

Palliative care definition

This thesis utilizes the term "palliative care" as defined by the World Health Organization (WHO):

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable

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[1] The descendants of the original inhabitants of North America. The Canadian *Constitution* recognizes three groups of Aboriginal people — Indians, Métis and Inuit. These are three separate peoples with unique heritages, languages, cultural practices and spiritual beliefs (Government of Canada. Aboriginal Affairs and Northern Development Canada, 2012).

[2] This statistic refers to Aboriginal persons 65 and over, however Health Canada (1998) defines Aboriginal seniors as those 55 years and older due to the health inequalities and prevalence of chronic and life limiting disease they face.

[3] The Aboriginal identity variable used in these projections includes those that self-identified as: registered Indian, non-status Indian, Métis, Inuit, other Aboriginal people, and non-Aboriginal people (Statistics Canada, 2011a).

[4] The projections from 2011 to 2036 vary depending on fertility, ethnic mobility and internal migration. (Statistics Canada, 2011c).

> assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

According to the WHO (2015), palliative care:

> provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death. Palliative care integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible until death, and also offers a support system to help the family cope during the patient's illness and in their own bereavement. In addition palliative care uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. Palliative care will enhance quality of life, and may also positively influence the course of illness, and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications. (http://www.who.int/cancer/palliative/definition/en/).

In the last decade, the concentration and understanding of palliative care has shifted from focus on end-of-life care and cancer care, or 'what to do when there is nothing else we can do', to being appropriate at the time of diagnosis with a chronic, life-limiting illness (EOLFN Research Team, 2015; A. S. Kelley & Meier, 2010). Palliative care should be an option available in any healthcare setting, and be offered as the person's needs develop; rather than urgently when the person is in a health crisis (World Health Organization Regional Office for Europe, 2004). An integrated approach to palliative care – one that is offered at the time of, or early in the diagnosis of a chronic, life-limiting condition and throughout the illness trajectory, improves quality of life and reduces suffering (Aiken et al., 2006; Bakitas et al., 2009; Canadian

Hospice Palliative Care Association, 2014; Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Temel et al., 2010)

Currently, many health care providers, citizens and researchers across Canada are uniting to advocate for a national Pan-Canadian palliative care strategy ("Pan-Canadian Palliative and End-of-life Care Strategy," 2014) that would include offering palliative care in First Nations communities for those who wish to receive it. The Ontario Ministry of Health and Long Term Care has endorsed a Declaration of Partnership and Commitment to Action to implement high quality palliative care across Ontario regardless of where people live and has implemented regional palliative care networks that are expected to provide care to people in First Nations communities (Quality Hospice Palliative Care Coalition of Ontario, 2011). The need to develop access to palliative care for all Canadians is felt to be especially urgent now as the federal and provincial governments are developing legislative frameworks to implement Physician Assisted Dying by June 7, 2016. Ensuring Canadians access to medical support to end their life in the absence of guaranteeing them access to quality palliative care, fuels a moral and policy debate.

It is well documented that many First Nations[5] people want the opportunity to die comfortably in their home communities (EOLFN Research Team, 2013a, 2013b, 2013c, 2013d; Habjan, Prince, & Kelley, 2012; Hotson, Macdonald, & Martin, 2004) surrounded by family and friends in a culturally safe manner; however jurisdictional issues and barriers to home care services (Hotson et al., 2004) often lead to hospital transfers and hospital deaths. This results in First Nations people being uprooted from their home communities to receive care in urban

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[5] According to the Government of Canada, Aboriginal Affairs and Northern Development Canada (2012), First Nation is a term that came into common usage in the 1970s to replace the word "Indian," which some people found offensive. Although the term First Nation is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian peoples in Canada, both Status and non-Status. Some Indian peoples have also adopted the term "First Nation" to replace the word "band" in the name of their community (Government of Canada. Aboriginal Affairs and Northern Development Canada, 2012). In this thesis, the terms First Nations peoples is used to describe the community members involved in this research as a collective group.

centres (Gorospe, 2006; Kitzes & Berger, 2004), creating cultural, linguistic and logistical barriers (Habjan et al., 2012). Patients and family members are faced with lengthy travel times with possible relocation to receive care, or in order to be near their loved one's side. Localized, community-driven palliative care programs would better respect the culture, traditions, and languages of First Nations seniors, their family members, and caregivers (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000; Habjan et al., 2012; Hotson et al., 2004). In addition, access to quality community-based palliative care programs could reduce health care costs and system burdens by decreasing the number of unnecessary hospital admissions, hospital days and frequency of emergency department visits (Paz-Ruiz, Gomez-Batiste, Espinosa, Porta-Sales, & Esperalba, 2009).

Chapter two: Literature review

Aboriginal health status and barriers to accessing provincial/territorial health services

The long lasting effects of the residential school system, which attempted to assimilate Aboriginal people into mainstream Canada (Richmond & Ross, 2009) has continued to impact Aboriginal Canadians. Consequences included loss of culture and traditions and increased racism against Aboriginal Canadians. Further impacts are an unbalanced distribution of resources, power, freedom and control, thus influencing health and socio-economic status (Adelson, 2005). The high level of chronic disease amongst First Nations people is related to inadequate housing, lack of employment opportunities and other social determinants of health in First Nations communities (Adelson, 2005; Kant, Vertinsky, Zheng, & Smith, 2013; Mikkonen & Raphael, 2010; Richmond & Ross, 2009).

Many Aboriginal Canadians are also faced with barriers in accessing provincial or territorial health care across their lifespan. According to Habjan, Prince & Kelley (2012) these barriers can be grouped into four categories: (1) barriers related to geography and availability of services; (2) economic barriers; (3) systemic barriers; and (4) barriers related to the specific needs of the Aboriginal population. These may include, but are not limited to, geography, location, infrastructure, jurisdictional issues, language, population, poverty, lack of education, and lack health care of coverage. Living in remote and rural areas contributes to an inability to access health care due to infrastructure issues, transportation issues, long wait times, or lack of access to health care providers or specialists. Lack of education can be associated with failure to seek treatment early in an illness trajectory, or economic insecurity may result in an inability to pay for prescriptions or continue with treatments that are uninsured. Unfamiliarity with the health care system may also result in an inability to navigate the system and apply for necessary financial assistance for uninsured health benefits.

Provision of health services to people living in First Nations Communities

Due to treaty agreements, the federal government, rather than the provincial government, is responsible for providing health care services on-reserve. However, First Nations and Inuit Health Branch (FNIHB) does not fund palliative care as an essential service that is part of localized First Nations and Inuit Home and Community Care (FNIHCC) programs (Hotson et al., 2004; Prince & Kelley, 2010). Thus access to community-based care and services for people with advanced chronic or terminal disease are limited, and provincial services are not consistently available.

FNIHCC was established and funded by Health Canada in 1999 as a response to the urgent home care needs in First Nations communities (Health Canada, 2004) and may include nursing care, personal, home support, and in-home respite care (Forbes & Edge, 2009; Health Canada, 2011). FNIHCC programs are funded Monday to Friday during the daytime, and they are not funded to provide services during nights and weekends. FNIHCC often cannot support clients who require palliative care on nights and weekends due to limited funding and staffing (Health Council of Canada, 2013). Lack of access to palliative care in the community often results in transfers to hospital, located in urban centres, removing the clients from their home community and culture. While reliable data on how many Aboriginal people die in hospital of an expected death in Northwestern Ontario could not be retrieved, anecdotal evidence suggests this is very common.

In 2010, a Joint Working Group (JWG) on Continuing Care Policy Development for First Nations and Inuit was established. The JWG recognized that:

> Jurisdictional issues resulted in a lack of responsiveness to the needs of First Nation communities, significant gaps in services to these communities, and a lack of long-term planning and development of services. Any attempts to address these issues within the current policy context have had limited success (Nova Scotia Aboriginal Home Care Steering Committee, 2010).

The most significant costs to the Canadian health care system at the end-of-life are in-patient hospitalizations (Dumont et al., 2009; Fassbender, Fainsinger, Carson, & Finegan, 2009). According to the Ontario Association of Community Care Access Centres, et al. (2010) a 10% shift of patients who require palliative care from an acute care setting to a home care setting results in $9 million in savings. The report estimated that the cost of providing palliative care services in the home was approximately $4,700 per client (which included non-palliative services), compared to approximately $19,000 per client in an acute care setting.

While the existing literature gives a range of health care system costs, it is based on traditional off-reserve home care services, and has primarily been done in urban centres. Aboriginal Canadians deserve access to the same care offered to all Canadians, yet jurisdictional and funding issues continue to cause barriers to First Nations communities seeking to establish local palliative care programs.

Journey mapping and value stream mapping as a strategy for quality improvement in health services

The focus of this thesis, journey mapping to create a palliative care pathway for Naotkamegwanning First Nation, includes adaptation of the concepts "customer journey mapping" and "value stream mapping" which originated in the marketing and manufacturing industries, respectively. For the purposes of this research, the term client is used similarly to the term customer as described later in this section by Rother and Shook (1999).

Previous use of the term "journey map" or "journey mapping" have been linked to a customer experiences for marketing purposes. According to Richardson (2010):

> A customer journey map is a very simple idea: a diagram that illustrates the steps your customer(s) go through in engaging with your company, whether it be a product, an online experience, retail experience, or a service, or any combination. The more touchpoints you have, the more complicated—but necessary—such a map becomes.

The goal of customer journey mapping is to create a framework that is rooted in data-driven research and visually represented by different phases, that improves the overall experience of the customer, understands how customers are interacting at various touchpoints, and identifies areas for improvement (Lord, 2013).

Graphical depictions of processes, such as flow charts, were first introduced in the manufacturing industry over a century ago (Baudin, 2013). In the book "*Installing Efficiency Methods*" (Knoeppel, 1915), illustrates a diagram of the routing process in a manufacturing plant, and the nature and use of methods and forms in a factory. The process is represented graphically from start to finish with circles and lines identifying the various departments and steps involved in the manufacturing process. Over a century later, these pictorial algorithms have evolved from simple process flow diagrams to the multiple industry buzz term "value stream map."

The Toyota Production System (TPS) coined the phrase "material and information flow analysis" which is the way engineers illustrate both current and future states to establish flow, eliminate waste (muda), and add value (Rother & Shook, 1999). The lean implementation practices of the TPS have established three flows in manufacturing; the flow of: (1) material, (2) information and (3) people/process (Rother & Shook, 1999).

In their book *Learning to See: Value Stream Mapping to Add Value and Eliminate Muda* (1999), TPS employees Shook & Rother introduce the term “value stream” as:

> all the actions (both value added and non-value added) currently required to bring a product through the main flows essential to every product: (1) the production flow from raw material into the arms of the customers, and (2) the design flow from concept to launch. Taking a value stream perspective means working on the big picture, not just individual processes; and improving the whole, not just optimizing the parts (p. 3).

Since the introduction of the value stream map in 1999, it has developed from a manufacturing based model to a tool used in a variety of clinical and patient care settings. The aim is to improve quality and efficiency of health services by making a service “lean” – a term commonly used in value stream mapping. Much attention has been given to identifying the current state of how patients flow through particular health care settings or departments and how unnecessary steps in the process (waste) can be eliminated, often with health care utilization management goals such as, providing better patient care, seeing an increased number of patients per day, and reducing costs.

Many of the stakeholders involved in the journey mapping workshops, such as Community Care Access Centres and hospitals have embraced value stream mapping in their organizations. The EOLFN project adopted the value stream mapping approach in hopes of engaging the stakeholders in a familiar and accepted process of quality improvement. The Naotkamegwanning needs assessment had indicated that the regional provider organizations did not understand what health services were available in the community, what the gaps in service were, and how their own service could be integrated without duplication.

Researching from an Indigenous paradigm

This research adopts an Indigenous paradigm. When embarking in research utilizing an Indigenous paradigm, a researcher must first consider four overarching aspects of paradigms in general. These include: (1) ontology, (2) epistemology, (3) research methodology, and, (4) axiology (Wilson, 2001). While an Indigenous perspective can be embedded into dominant, Eurocentric research paradigms -- such as positivist, post positivist, constructivist, and critical theorist -- until a researcher moves beyond Indigenous perspective to Indigenous paradigm, the researcher cannot truly adopt an Indigenous methodology (Wilson, 2001, 2008). According to Wilson (2001), “Indigenous research needs to reflect Indigenous contexts and world views: that is, they must come from an Indigenous paradigm rather than an Indigenous perspective” (p. 176).

Exploring ontology from a theoretical lens, requires that the researcher “embrace multiple realities” (Cresswell, 2013, p. 20) and ask themselves “what is real?” (Wilson, 2008). To unite ontological beliefs and realities with epistemology, the researcher must understand that what they think about reality is influenced by what they deem as real (Wilson, 2008).

These methodologies lend themselves to political histories among researchers and Indigenous people. According to Kovach (2009), the political challenges are two-fold: A qualitative researcher must first find and use a research approach that is not uprooting, and is justified to “Indigenous standards on research so as to honour the tribal worldview” (p. 29). “The second challenge” Kovach contends, is the “undeniable” (p. 29):

> "There is a fundamental epistemological difference between Western and Indigenous thought, and this difference causes philosophical, ideological, and methodological conflicts for Indigenous researchers" (p. 29).

Mi'kmaw Elder Albert Marshall suggests a two-eyed seeing approach that incorporates Indigenous and Western ways of knowing and marrying the strengths from each by using from both eyes (Bartlett, Marshall, & Marshall, 2012). Bartlett et al. (2012, p. 4) suggest the following eight criteria for weaving Indigenous knowledge and mainstream science.

1. Acknowledge that we need each other and must engage in a co-learning journey.
2. Be guided by Two-Eyed Seeing.
3. View "science" in an inclusive way.
4. Do things (rather than "just talk") in a creative, grow forward way.
5. Become able to put our values and actions and knowledges in front of us, like an object, for examination and discussion.
6. Use Visuals.
7. Weave back and forth between our worldviews.
8. Develop an advisory council of willing, knowledgeable stakeholders, drawing upon individuals both from within the educational institution(s)and within Aboriginal communities.

To incorporate Indigenous ways of knowing into a research methodology, a researcher must move beyond the scope of the aforementioned research paradigms and focus on relational accountability, while simultaneously being guided by appropriate axiology (Wilson, 2001). Denzin & Lincoln (2011), acknowledge that axiology be "part of the basic foundational philosophical dimensions of paradigm proposal" (p. 116). The following principles, identified by Atkinson (2001), which I have incorporated as a guide throughout my thesis research, signify both ethical responsibility and cultural sensitivity by the researcher, and support the worldviews of Indigenous people (Atkinson, 2001; Wilson, 2008).

- Aboriginal people themselves approve the research and the research methods;
- A knowledge and consideration of community and the diversity and unique nature that each individual brings to the community;
- Ways of relating and acting within community with an understanding of the principles of reciprocity and responsibility;
- A non-intrusive observation, or quietly aware watching;
- A deep listening and hearing with more than ears;
- A reflective non-judgemental consideration of what is being seen and heard;
- Having learnt from the listening a purposeful plan to act with actions informed by learning, wisdom, and acquired knowledge;
- Responsibility to act with fidelity in relationship to what has been heard, observed, and learnt;
- An awareness and connection between logic of mind and the feelings of heart;
- Listening and observing the self as well as in relationship to others;
- Acknowledgement that the researcher brings to the research his or her subjective self. (p. 10)

Acknowledgement of subjective self. In terms of my background, I am a mid-aged non-Indigenous American of Scandinavian and Italian descent who became a permanent resident of Canada in 2014. I have lived in Thunder Bay, Ontario since November 2010 with my Canadian husband and rescue dog, Kora. I grew up in the northern Minnesotan city of Duluth with my mom and her boyfriend, who has raised me since I was 11 months old; I call him my dad. My parents, were both only 19 when I was born, and being so young with a baby created additional financial challenges. Outdoor activities, such as camping, fishing, motor sports and skiing have always been a big part of my life thanks to my dad, Dan. My biological father died of a liver infection when he was approximately 40 years of age, and my only memories of him were that he had severe substance abuse issues.

My grandma Lucille, who was a child during the Great Depression and shaped my persona based on the difficult times she experienced because she was a second mom to me while my young parents were busy “making a living.” My mom worked in front-line health care, and my dad was a maintenance man, but their wages weren’t enough to get us by. We received welfare and food stamps, and I received free meals at school. One Saturday a month, grandma and I went to the neighbourhood church, and stood in line to receive government-provided commodities such butter, processed cheese and evaporated milk.

My socioeconomic status as a child shaped who I have become today because I have continued to pursue education as a means of providing myself with a better financial situation than I grew up with. I was the first in my family to receive a university degree, though it came at a hefty financial price tag, and I still have yet to pay back my student loans and interest.

As a Canadian immigrant, I have been constantly absorbing Canadian culture and traditions for the past six years. I have learned to navigate and understand the Canadian health care system as a person that needs to access it and as a Research Assistant and student that must comprehend the complexities of it. I have learned the history and social determinants of health that affect Indigenous Peoples of Canada, yet it is impossible for me to fully understand their experiences. The stories I have been told from the First Nation’s communities participating in the EOLFN research, combined with the support of my thesis supervisor, Dr. Mary Lou Kelley, has inspired this thesis journey.

During my experience as an EOLFN Research Assistant for five years, I have listened to the stories and experiences related to death and dying from numerous First Nations community members involved in the EOLFN research project. During that time, I was involved in the Naotkamegwanning journey mapping research for three years, as both a Research Assistant and Graduate Student Trainee working on my thesis and conducting literature reviews, I believe I am qualified to accurately tell the journey mapping story to create the palliative care pathway for Naotkamegwanning community members that want the option to die at home.

When my grandpa was diagnosed with cancer his final wish was to “die at home.” I was only 19, but towards the end, I recall a hospital bed in the living room and various health care workers tending to him and the IV. My grandma was 70 and tending to his needs around the clock with little help, but she was always healthy and a hard-worker. Shortly after my grandpa died in April 1998, my grandma had a stroke and went to the hospital and then a “nursing home.” Every time I visited her, she said over and over that she wanted to go home. She started to regain function, and my mom and some of her siblings saw to it that she returned home. Looking back, I realize that she had cognitive issues following the stroke and was never the same. She had another stroke and the hospital to nursing home scenario was repeated, but this time she never left. My precious, healthy, strong grandma died exactly where she begged not to, so I dedicate this research to my grandma, Naotkamegwanning community members and any residents in a community that want the choice to die comfortably in their home.

My former work experience has helped prepare me for this thesis research as well. I have worked in the health care system since 2005 and a variety of research administration roles since 2008. My previous work experience has included lean process training and application to create clinical efficiencies and improved health outcomes at both a family medicine residency clinic and a hospital. I have also worked in clinical trial participant recruitment, including medical devices and pharmaceuticals. From 2010-2016 I was a Research Assistant on two five-year qualitative research grants (Principal Investigator: Dr. Mary Lou Kelley) to improve the quality of life for people dying and long-term care homes and the EOLFN project.

I acknowledge the influence of these personal and professional experiences in my work as a researcher. They shaped the knowledge, values and skills I bring to the work. I have continually practiced self-reflection and discussed my understanding with members of the research team, research partners and Elders on an ongoing basis in my effort to best represent the lived experience of all of the research participants.

Wilson (2001) argues that an Indigenous paradigm stems from the belief that knowledge is relational rather than an individual entity: “it is not the realities in and of themselves that are important, it is the relationship that I share with the reality. It is not necessarily an object that is important, it is my relationship with that object that becomes important” (p. 177). To analogize this relationship, and shed light on Indigenous paradigm, Wilson cites the translation of sofa as an object, which in Cree means “someplace where you sit.” Here it becomes obvious that the relationship with the sofa is described rather than the item as a thing or object.

The sofa analogy sparked a reflection to my days as a Clinical Research Assistant. At that time, researchers and research staff identified research participants as ‘subjects.’ Use of the term subjects identifies the participants as “being acted upon” or subjugated, and includes dominance associated with those involved in conducting the research; other than dominance, the relationship is not described. When thinking of this relationship from a PAR approach and Indigenous paradigm, the term research partner is more appropriate, and it eliminates the dominant terminology and articulates the relationship as a partnership based on choice. Thus, the participants and investigators, or partners, are choosing to work together towards common research goals.

Indigenous research methods must be community-oriented and be grounded in the roots of the communities in which the research is taking place (Smith, 2012). Culturally appropriate and traditional ways of exchanging information include sharing circles and storytelling. For this research culturally appropriate methods were used. Observations during the journey mapping workshops were quiet and non-obtrusive. I documented field notes and observations that included non-verbal communication from the participants, and emerging stories and narratives from them. The focus group was conducted in a culturally safe, convenient setting and was facilitated in a semi-structured manner similar to a sharing circle.

Cresswell (2013) suggests, when engaging in field work:

> …where the participants live and work – these are important contexts for understanding what the participants are saying. The longer researchers stay in the "field" or get to know the participants, the more they 'know what they know' from firsthand information.

PAR, which stems from a critical theory paradigm, focuses on social change and positions itself well within the axiological beliefs of Indigenous people (Wilson, 2001). According to Brazil (2012), a PAR approach "serves to deconstruct the Western research paradigm and is inclusive toward an Indigenous understanding of knowledge."

Reflexivity

Positionality. To "position" myself within this research I have openly communicated my role as an EOLFN Research Assistant, EOLFN Graduate Student Trainee, and Health Sciences Graduate Student responsible for writing a thesis. In the section that follows, I will communicate my background as a middle-aged adult with lived experiences.

As a Research Assistant that worked closely with the First Nations communities involved in the EOLFN project, my experience has been that storytelling is an important and effective way to communicate. That being said, my intention in the findings chapter of this thesis will be to tell the journey mapping story respecting the voices of the Naotkamegwanning community members providing it.

Narrative perspectives. My approach to this research is in both first and third person, because of the various roles I have. There is the student researcher 'I' that has been involved in the journey mapping process for nearly three years, the Research Assistant 'I" that has worked on the EOLFN project and along with the community for over five years, and the middle-aged female adult 'I' that must explore the varying subjectivities of my life experiences (Sheldon & Sargeant, 2007). I will disclose the different paradigms I bring to this research, be self-aware of my preconceived assumptions, biases, and belief systems (Strauss & Corbin, 2008) and how my background might inform my interpretation of the data during analysis (Cresswell, 2013). To ensure transparency, from commencement of the research through to dissemination, I will also disclose what I have to gain from the study.

Public health and palliative care

Palliative care as a public health issue was introduced over 25 years ago in a report by the WHO, entitled "Cancer pain relief and palliative care." The report recommended to countries that they implement national policies on cancer pain relief and that palliative care include a series of guiding principles as their foundation. The report also acknowledged that cancer pain and symptom management have been inadequately treated, thus resulting in a "neglected public health problem" (World Health Organization, 1990).

According to Stjernsward, Foley, & Ferris (2007):

> Public Health Strategy (PHS) offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population. For public health strategies to be effective, they must be incorporated by

> governments into all levels of their health care systems and owned by the community. (p. 486).

The public health approach to palliative care moves away from the traditional service delivery approach, where care is delivered within professional services, and focuses on community development, relying on the community as the basis of the care (Abel et al., 2013; Kellehear, 2005). Abel et al. (2013) suggest a new model that builds on the public health approach to palliative care and focuses on community-based care provided by family and health care providers in the clients home rather than in an institution. The model suggests focusing on policy change and an increased service provision so that quality end-of-life care can be provided in the community (Abel et al., 2013). This approach is appropriate for First Nations communities because it moves away from the Western, institution-based model and focuses on increased service provision allowing clients to receive care in their home communities where end-of-life traditions and ceremonies can be embraced.

Historically, the public health discipline has focused on large scale health promotion strategies to reduce mortalities and morbidities and improve the overall health of a society on a population level (Sallnow, Kumar, & Kellehear, 2012). However, an individual’s genetic predisposition and the social determinants of health must also be considered in any public health strategies that are initiated, including when they are targeted for First Nations communities.

Public health policy makers must consider community capacity development models and understand that by building palliative care capacity at the community level and partnering with the external health care providers and agencies, First Nations clients are able to receive individualized care that fits with their cultural beliefs and traditions, supporting quality of life as they approach the end of their life. In a community-based setting, family members and the dying client are supported by friends, neighbours and volunteers during their final days and family is supported after their loss in a culturally safe manner. It is important to note that everyone in the community is either directly or indirectly affected by the ill person's death (Cohen & Deliens, 2012). In fact, Cohen & Deliens (2012) argue the unfortunate circumstance that "the manner in which people die and the quality of dying has blatantly been neglected as a priority of public health, partly because death and dying, in all its aspects, have rather been regarded as antonymous to health and a failure of health care" (Cohen & Deliens, 2012).

From a public health perspective, common genetic predispositions for chronic conditions such as, cancers, diabetes, cardiovascular disease, mental health and asthma (World Health Organization, 2014) along with poor living conditions and communicable disease must also be considered as an underlying issue and social inequality in First Nations communities. That being said, Mikkonen & Raphael (2010) argue that the social determinants of health are shaped by public policy decisions and have more of an influence on health than an individual person's genetic predisposition.

Summary

An analysis of existing literature provided a solid foundation for investigating journey mapping as a strategy for designing a care pathway for Naotkamegwanning First Nation. Exploration of Aboriginal health status and the social determinants of health affecting Aboriginal Canadians identified geographic, socioeconomic and technological barriers to accessing provincial and territorial health services. The provision of health services identified several jurisdictional issues for people living in First Nations Communities. A historical review of the literature related to both journey mapping and value stream mapping, provided a foundation and strategy for approaching these jurisdictional issues and leveraging relationships with external health care providers.

Examination of the literature on researching from an Indigenous paradigm provided the basis for me to self-disclose and acknowledge that I, as a non-Indigenous Canadian immigrant, bring my subjective self to the research. The Indigenous paradigm provided an appropriate foundation to investigate this case study using a participatory action research methodology.

The public health approach to palliative care proved as an emerging strategy that is suitable for the community-based approach to care in First Nations communities. This strategy calls upon public health policy makers to consider community capacity development models and increase the palliative care service provision in First Nation's communities.

Chapter three: Background to the thesis research

Improving end-of-life care in First Nations (EOLFN) communities research project

This thesis research was nested within a five-year (2010-2015) participatory action research project entitled "Improving End-of-Life Care in First Nations (EOLFN) Communities: Generating a Theory to Guide Program Policy and Development." The EOLFN project was funded by the Canadian Institutes of Health Research (CIHR) and was conducted with four First Nations community partners: Naotkamegwanning First Nation, Fort William First Nation, Peguis First Nation and Six Nations of the Grand River Territory. This thesis case study will focus on the Ojibway community of Naotkamegwanning First Nation, also known as Whitefish Bay, which is located in the Lake of the Woods region of Northwestern Ontario in the Treaty 3 territory.

The overall goal of the EOLFN project was to improve the end-of-life care in these four 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. The six specific research objectives of the EOLFN project were to: (1) document Indigenous understandings of palliative and end-of-life care as a foundation for developing palliative care programs, (2) generate a culturally appropriate theory of change in First Nations communities based on a 4-phase model of community capacity development, (3) create an evidence-based tool kit of strategies and interventions to implement palliative care programs in First Nations communities, (4) empower First Nations health care providers to be catalysts for community change in developing palliative care and supportive policy frameworks, (5) improve the capacity within First Nation communities by developing palliative care teams and programs, and strengthening linkages to regional palliative care resources, and (6) develop knowledge and skills in participatory action research (PAR) methodology for First Nations community members, Graduate Students and health professional trainees. The development and implementation of the journey mapping was one of approximately twenty-five strategies and interventions implemented in and by the four First Nations communities.

The EOLFN research project followed the principles of Ownership, Control, Access and Possession (OCAP®[6]), which are sanctioned by the First Nations Information Governance Committee and the First Nations Regional Longitudinal Health Survey, to ensure self-determination in all research concerning First Nations people (First Nations Centre, 2007).

PAR is the methodology that guided the EOLFN research project and the thesis research. The knowledge in the EOLFN research was co-created by the researchers and participants and included regular member checking and dissemination to all of the stakeholders and participants. The PAR approach was appropriate because it recognized the expertise of First Nations community members and promoted integration of community values and traditions into the palliative care programs that were developed at the grassroots level (S. Kemmis & R. McTaggart, 2005). The ongoing cycle of PAR included each First Nations community partner identifying a problem or issue related to developing palliative care, taking action to address it, and reflecting on the experience and outcome. Change was created through an incremental process of tackling more and more of the problems or needs identified by the participants and building on growing achievements. This ongoing cycle of PAR integrated evaluation within the research process throughout the five year EOLFN research project.

Conceptually, the EOLFN research was guided by the five-phase community capacity development model "Process of Palliative Care Program Development" as shown in Figure 1.

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[6] OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). For more information on OCAP®, please visit: www.FNIGC.ca/OCAP.

Figure 1. Process of Palliative Care Program Development

The model, developed by the First Nations participants and EOLFN researchers, includes five phases involved in developing a local palliative care program (EOLFN Research Team, 2015, p. 12). As described in the Developing Palliative Care Programs in First Nations Communities: A Workbook (2015): the phases are: (1) grounding the program in community values and principles, (2) having community readiness, (3) experiencing a catalyst, (4) creating the palliative care program, and, (5) growing the palliative care program.

Beginning at the bottom, each phase needs to build on the phase below; however, work in each phase is continuous and ongoing. The rate of progress varies. Communities can move forward or backward in the phases depending on unique circumstances within each community. This thesis occurred in phase four of the capacity development model because the community had completed much of the developmental work during the first two years of the EOLFN project.

In a First Nations community context, the theoretical framework starts with "Grounding the development in community values and principles." The model recognizes that values and principles of the individual, family, community and culture vary and that each First Nations community is unique.

Phase two, "Having community readiness for palliative care," is where the metaphor of tree roots symbolizes the starting point and foundation of the palliative care program. There are six characteristics that influence community readiness for developing the community's local palliative care program: (1) local leadership, (2) vision for change at the community level, (3) empowerment, (4) health services, (5) collaboration, and, (6) community infrastructure.

At phase three, a community catalyst, either a person or event, occurs and generates motivation for a desired change in the current approach to palliative care. In the EOLFN project, a local health care provider was the catalyst leading the change and creation of the palliative care program. In the EOLFN research, this health care provider was referred to the Community Lead and liaised between the community and EOLFN Research Team. The Community Lead engaged community members to assemble a Project Advisory Committee. A Project Advisory Committee was developed in each community to ensure local control and lead the implementation of the EOLFN research project with the help of a paid Community Lead hired by the Project Advisory Committee and paid by the research grant. The Project Advisory Committee was also responsible for ensuring that the EOLFN research project addressed the needs of the community and was respectful of the culture.

After this catalyst occurs, phase four begins. The Project Advisory Committee and the Community Lead began "Creating the palliative care program." This involved conducting a palliative care needs assessment with Elders, community members, and internal and external health care and social service providers. The needs assessment results and recommendations provided guidance to the Project Advisory Committee so they could focus and prioritize the development of their palliative care programs specific to their identified community needs, and form a Leadership Team to undertake implementation of the palliative care initiatives.

The Leadership Team included the Community Lead, Community Facilitator, members of the Project Advisory Committee, Elders, community members, and other representatives that are dedicated to creating the palliative care program and moving it forward. The Leadership Team in Naotkamegwanning selected journey mapping to design the palliative care pathway as one of their top priorities in creating their palliative care program.

During phase five, the Leadership Team focused on "Growing the palliative care program" by extending beyond the community. At this point, the palliative care program includes internal and external health care and social service providers, Elders, community members, and family members and leadership that continue to drive the process of change. The new palliative care team, with the support of the Leadership Team, grows the palliative care program by strengthening community relationships, building external linkages, providing care, promoting education, and advocating for individuals and families. The journey mapping process engaged these providers and community members in designing the palliative care pathway to best meet the needs of the client.

Naotkamegwanning Community Needs Assessment Results.

Based on the needs assessment data collected from community members, the majority of residents in Naotkamegwanning First Nation would prefer to die at home if services and community supports were available and adequate (EOLFN Research Team, 2013b). Having the option to die at home allows access to family and friends as well as to cultural and spiritual resources. The recommendations from the needs assessment were formulated with the intent to provide people a choice to die at home in the community by creating improved access to high quality, culturally appropriate palliative care services at home. At the time of the needs assessment in 2012, many residents of Naotkamegwanning First Nation did not feel they had the choice to die at home. Over the last several years, all of the community members who were very sick with a progressive chronic or terminal illness and had received Home and Community Care died in the hospital, even though many would have wished to stay at home for care. End of life hospitalizations typically lasted the last three or four weeks of life.

The key recommendations of the needs assessment were:

1. Continue to support the development of a culturally relevant palliative care program in the community that incorporates cultural practices, traditions, teachings, and

education related to death, dying, palliative care, access to and available services, and eligibility requirements;

2. Continue to support the local palliative care team in their efforts to identify and address unmet community palliative care needs, by advocating for required resources and solutions within the community and externally; and,
3. Provide cultural competency education to non-Aboriginal external health care providers who provide care to the residents of Naotkamegwanning First Nation.

Additional recommendations for practice, policy, and education were also provided as a means to move forward with the development and formalization of the community's palliative care program and to improve quality and access to palliative care (EOLFN Research Team, 2013b).

This thesis research arose directly out of Naotkamegwanning's recommendations for practice, which were:

1. To further develop the palliative care program in a manner that is community designed and driven, culturally relevant, embedded with values and encourages the participation of family, community members, volunteers, and external community partners who can support their work;
2. To integrate the palliative care program and services into existing community health services at the primary care level and incorporate the needs of clients of all ages with a wide range of chronic, progressive and life limiting diseases;
3. To organize case conferences for all Naotkamegwanning clients who would benefit by palliative care to improve communication and clarify accountability for service delivery to avoid misunderstandings and conflict. It was recommended that the case

conferences include family members, members of the palliative care program, Naotkamegwanning health care providers and members from external health services where relevant (e.g. Community Care Access Centres, cancer centres, palliative care teams); and

4. To respect that the circle of care in First Nations communities may include many people. It was recommended that the informed consent processes, that guide the sharing of information used in the palliative care program, be revised to ensure the consent processes proactively invite the client to identify all family and community members who may attend case conferences and have access to personal health information.

Following the needs assessment recommendations, the Naotkamegwanning Leadership Team prioritized the initiatives to undertake as they began establishing their palliative care program. One initiative selected as a priority intervention was to create the care pathway for a Naotkamegwanning client in need of palliative care. This thesis analyzes the journey mapping process and the lessons learned from that initiative.

Chapter four: Case study description

Journey mapping introduction

As part of the intervention phase of the EOLFN research project, a series of four journey mapping workshops were conducted with Naotkamegwanning First Nation community members, internal and external health care and social service providers and the EOLFN Research Team. Going forward in this thesis, these participants are defined as the stakeholder working group, or stakeholders. There were two key stakeholders from the Leadership Team that guided the journey mapping process; the Community Lead and the EOLFN Community Consultant. The Community Lead was also the Home and Community Care Program Coordinator. The participants involved in the journey mapping workshops are described in Table 1.

Table 1. Overview of journey mapping participants

Team name/Title	**Member(s)/description**
Stakeholder Working Group	All participants involved in the journey mapping workshops In this thesis, the term Stakeholder Working Group will be used to refer to the collective group of journey mapping workshop participants.
Naotkamegwanning Clinical Team	Internal and external health care providers that provide palliative care in the community.
Naotkamegwanning Leadership Team	Elders, knowledge carriers, Chief and Council, the Community Lead, the Community Consultant, and internal health care providers that provide palliative care in the community.
Home and Community Care Program Coordinator (EOLFN Community Lead)	The Community Lead was also the Naotkamegwanning Home and Community Care Program Coordinator (EOLFN Community Lead). Going forward in this thesis, the Community Lead is identified as the Home and Community Care Program Coordinator (EOLFN Community Lead).
EOLFN Community Consultant	Due to the multiple roles the Home and Community Care Program Coordinator (EOLFN Community Lead) held and her heavy workload, the EOLFN project hired a Community Consultant to assist her with the development of the community's palliative care program. The EOLFN Community Consultant was a retired registered nurse that had previous palliative care program development experience in rural and First Nations communities in Northwestern Ontario, including Naotkamegwanning.
EOLFN Research Team	The EOLFN Research Team members that were directly involved in the journey mapping workshops included the Principal Investigator (M.L. Kelley), Project Manager (H. Prince), Interim Project Manager (J. Marcella), Research Coordinator (M. Wawia), and me in dual roles as a Research Assistant and Graduate Student Trainee.

Journey mapping, in the context of this thesis, refers to a process to improve the coordination and integration of care for clients in First Nations communities as they access services from multiple programs and health care providers. It is done using a workshop format that brings together internal and external health care providers, Elders, and community leadership. It involves in-depth discussion of how First Nation community members transition through the health care system as they approach end of life, and identifies obstacles and solutions to improve service integration. (EOLFN Research Team, 2015)

The outcome of the journey mapping process is a care pathway. First Nations palliative care pathway, or path of care, refers to a diagram or map that outlines the expected care for clients who would benefit by receiving palliative care, including the appropriate timeframes for different phases of palliative care. The care pathway is created by a group of involved care providers during a series of journey mapping workshops in order to become a resource that will guide care for individuals progressing through their care and treatment. The care pathway focuses on providing clients the best palliative care and most positive outcomes as they move between different health care providers and organizations. (EOLFN Research Team, 2015).

The Wiisokotaatiwin Program is what the Naotkamegwanning Leadership Team chose to call their local palliative care program as opposed to using the term Palliative Care Program. The Ojibway word “Wiisokotaatiwin”, as described by the community members, means “taking care of each other” and signifies “doing what we’ve always done, back in the day.” Wiisokotaatiwin was selected because the word palliative is not culturally acceptable in Naotkamegwanning and it is not culturally appropriate to plan for or discuss death.

Journey mapping workshops

Planning for journey mapping began in June of 2013 and four journey mapping workshops were conducted from August 2013 – October 2014. From October – December 2014 a work plan was developed to implement the developed palliative care pathway. A timeline document, including a summary of the journey mapping workshops including dates, times, and a photograph of each location is outlined in Figure 2. The timeline also indicates the work that the community members of Naotkamegwanning completed between the workshops in order to prepare for the next workshop.

Naotkamegwanning journey mapping workshops timeline

June 2013 – December 2014

Jun. – Aug. 2013
Planning for journey mapping begins

Aug. 2013 – Jan. 2014
Leadership team develops the Wiisokotaatiwin program's mission and vision and begins creating the program guidelines booklet.

Feb. – Jul. 2014
The leadership team identifies the nine stages in the palliative care pathway.

Aug. – Sep. 2014
Community submits "Health System Improvement Proposal" (H-SIP) to the NW LHIN and receives funding for a pilot project to address the gaps in service delivery, equipment and education to implement the Wiisokotaatiwin Program.

Oct. – Dec. 2014
Work plan is developed and agreed to with stakeholders

August 2013
Half day workshop
Naotkamegwanning Health Access Centre
Naotkamegwanning First Nation
Journey mapping workshop #1
Initial engagement of stakeholder partners
Presented the results of the community needs assessment
Announced the new palliative care program name: Wiisokotaatiwin (taking care of each other)
Established commitment from the stakeholders to move the care path intervention forward

February 2014
Two-day workshop
Best Western Lakeside Inn
Kenora, Ontario
Journey mapping workshop #2
Introduced lean concepts and value stream mapping
Six sigma black belt consultant facilitated the workshop
Lean terminology was not culturally appropriate and was abandoned, shifted to an open discussion that embraced a two-eyed seeing perspective
Discussed in detail the gaps and barriers in establishing the palliative care pathway
Identified communication breakdowns and strategies for improvement
Created a list of service providers involved in the future state
Composed report and recommended next steps were provided to the stakeholders

August 2014
Half day workshop
Lake of the Woods District Hospital
Kenora, Ontario
Journey mapping workshop #3
Introduced the nine stages in the palliative care pathway
Worked through stages one through five building upon what was identified in previous workshops
Identified the outstanding gaps, barriers and challenges in implementing the care pathway
Created an action plan and agreed upon next steps

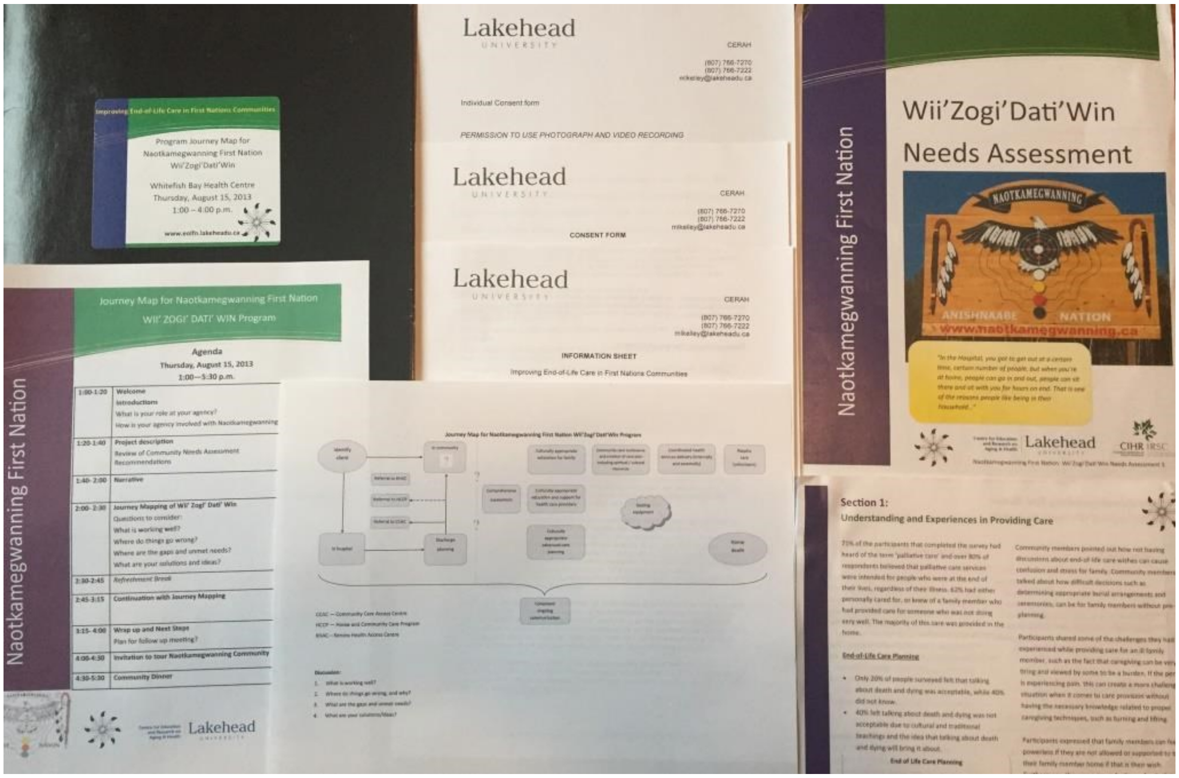
October 2014
Two day workshop
Waasegiizhig Nanaandawe'Iyewigamig Health Access Centre
Kenora, Ontario
Journey mapping workshop #4
Worked through stages six through nine which were internal to the community and culturally focused, dealing with the time before and following death
Discussed LHIN funding and ideas for implementing the palliative care pathway
Created the care pathway "circle" diagram and labeled it the "Wiisokotaatiwin Program Palliative Care Pathway"
Identified next steps for the leadership team in moving the care pathway forward to implementation

Figure 2. Naotkamegwanning journey mapping workshops timeline

The overall goals of the four workshops were to: (1) discuss the journey for Naotkamegwanning community members when they are dying and require palliative care, (2) depict both graphically and textually the current state and desired state of the care pathway, (3) identify areas for improving communication and service integration amongst health care and social service providers for the residents of Naotkamegwanning First Nation, (4) create dialogue about how a resident of Naotkamegwanning First Nation (client) is identified as one that would benefit by palliative care, and (5) how the client transitions through the health care system during this journey, including what potential obstacles they experience during their journey.

Each workshop was carefully planned by the Community Lead and research team. In preparing for the journey mapping workshops, I was responsible for creating the agenda electronically, formatting and preparing handouts, transporting supplies and equipment, securing a venue, arranging catering, and coordinating travel for the EOLFN Research Team.

A typical workshop packet consisted of a folder with an agenda, consent forms, an information letter, and handouts, such as a care path diagram and the community needs assessment, as shown in Figure 3 below.



Improving End-of-Life Care in First Nations Communities

Program Journey Map for
Naotkamegwanning First Nation
Wii'Zogi'Dati'Win

Whitefish Bay Health Centre
Thursday, August 15, 2013
1:00 – 4:00 p.m.

www.eolfn.lakeheadu.ca

Naotkamegwanning First Nation

Journey Map for Naotkamegwanning First Nation
WII' ZOGI' DATI' WIN Program

Agenda
Thursday, August 15, 2013
1:00—5:30 p.m.

1:00-1:20	**Welcome** **Introductions** What is your role at your agency? How is your agency involved with Naotkamegwanning
1:20-1:40	**Project description** Review of Community Needs Assessment Recommendations
1:40- 2:00	**Narrative**
2:00- 2:30	**Journey Mapping of Wii' Zogi' Dati' Win** Questions to consider: What is working well? Where do things go wrong? Where are the gaps and unmet needs? What are your solutions and ideas?
2:30-2:45	*Refreshment Break*
2:45-3:15	**Continuation with Journey Mapping**
3:15- 4:00	**Wrap up and Next Steps** Plan for follow up meeting?
4:00-4:30	**Invitation to tour Naotkamegwanning Community**
4:30-5:30	**Community Dinner**

Lakehead
UNIVERSITY

CERAH

(807) 766-7270
(807) 766-7222
mkelley@lakeheadu.ca

Individual Consent form

PERMISSION TO USE PHOTOGRAPH AND VIDEO RECORDING

Lakehead
UNIVERSITY

CERAH

(807) 766-7270
(807) 766-7222
mkelley@lakeheadu.ca

CONSENT FORM

Lakehead
UNIVERSITY

CERAH

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mkelley@lakeheadu.ca

INFORMATION SHEET

Improving End-of-Life Care in First Nations Communities

Journey Map for Naotkamegwanning First Nation Wii'Zogi'Dati'Win Program

Naotkamegwanning First Nation

Wii'Zogi'Dati'Win
Needs Assessment

Section 1:
Understanding and Experiences in Providing Care

Figure 3. Journey Mapping Workshop Packet Sample

Typical journey mapping workshop supplies included a large roll of paper, different colour post-it notes, markers, and tape. Equipment included audio recorders, batteries, a laptop, a projector, and an extension cord.

In the following section, I will describe the steps involved in the journey mapping process. Within the community, there were social, cultural, spiritual traditions in place, but the community lacked access to medical care delivered in a way that is integrated with their social, cultural, and spiritual traditions. Embarking on this series of workshops united the community members, internal and external health care and social service providers, and the EOLFN

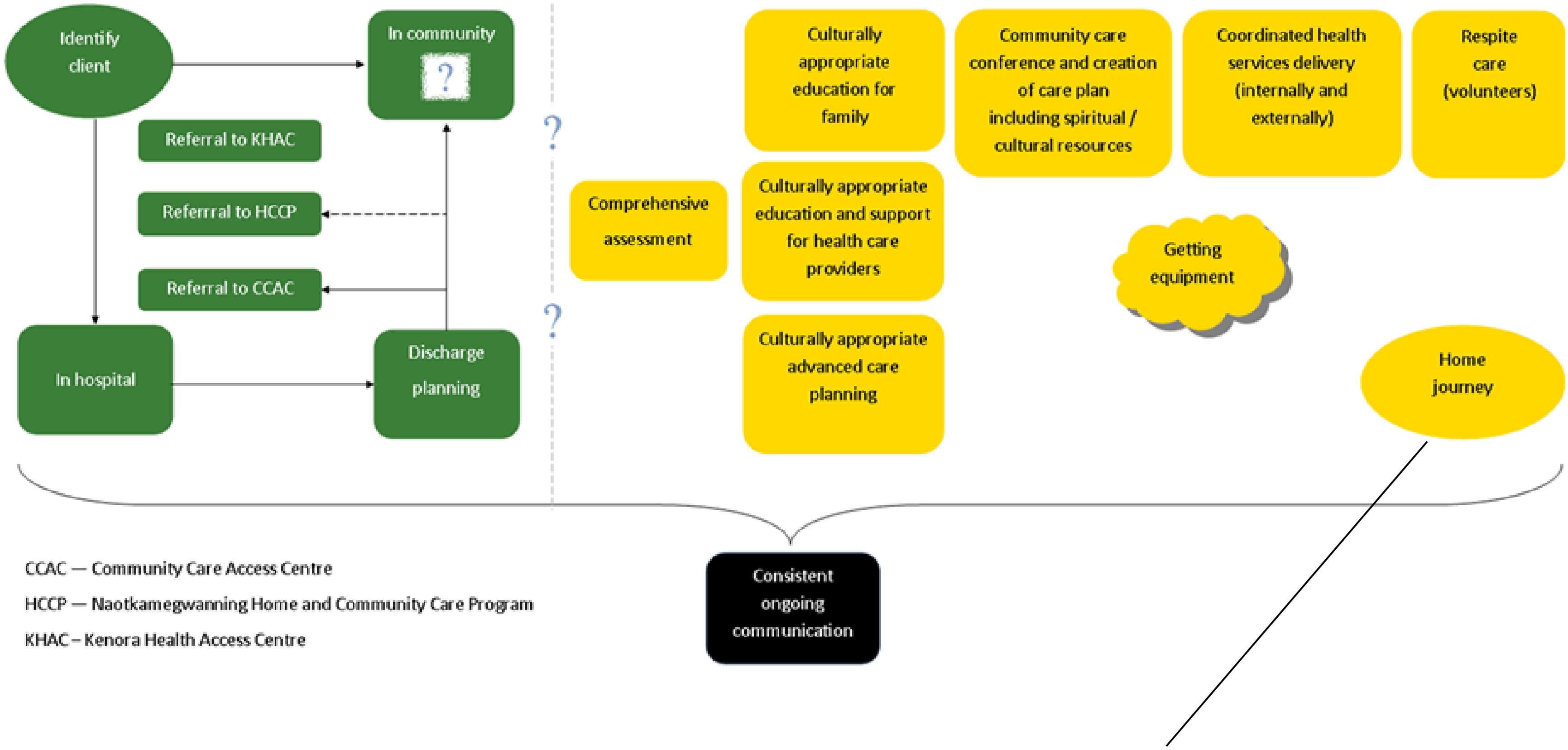
Research Team to collaboratively create a care pathway for clients in Naotkamegwanning First Nation who require palliative care.

Workshop one: Introducing the journey mapping process and engaging stakeholders.

Workshop one was held in Naotkamegwanning First Nation at the Community Health Centre in August of 2013. The journey mapping workshop was in the afternoon following a morning session in which the Principal Investigator and Project Coordinator shared the results of the needs assessment with the community members. During the afternoon, the first journey mapping workshop took place, which will be described in detail in the following paragraphs. The day ended with a traditional feast that allowed for some networking amongst participants.

For the afternoon journey mapping session, 14 participants attended, including: the Home and Community Care Program Coordinator (EOLFN Community Lead), the Community Consultant, community home care nurses, a visiting community physician (based in Kenora), a Discharge Planner and Palliative Care Nurse from a Regional Hospital, a Nurse Manager from the Community Care Access Center, a Nurse Consultant with St. Joseph's Hospital Telemedicine program, a Nurse Practitioner from Waasegiizhig Nanaandawe'Iyewigamig Health Access Centre (WNHAC), and three members of the EOLFN Research Team, i.e. the Principal Investigator, Project Coordinator, and me in my role as a Research Assistant.

The workshop was facilitated by the Principal Investigator. Based on the needs assessment data, the EOLFN Research Team created a diagram of the "current state" of the client experience and the desired "future state" as shown in Figure 4.



Note: Home journey is referring to an in-home death.

Figure 4. A comparison of the key processes in the path of care for a Naotkamegwanning community member: Current and future state

My role in this workshop as a Research Assistant was to document meeting minutes, including observations and field notes, and then draft a final report. The final report, once approved by the EOLFN Research Team, was sent via email to all participants that attended the workshop.

As indicated above, participants received “A framework of the key processes in the path of care for a Naotkamegwanning community member” (see Figure 4) as a hand out and engaged in dialogue regarding the current state. The dialogue was intended to introduce the journey mapping process by beginning to identify areas for improving communication and service integration amongst health care and social service providers for the residents of Naotkamegwanning First Nation. In addition, the intention was to begin discussions about how a client who would benefit by palliative care is identified, how they transition through the health care system during this journey, and what potential obstacles they may experience during their journey. The comparison of the current state (green bubbles) and desired future state (yellow bubbles) as outlined in ***Figure 4*** provided the context and a starting place for the journey mapping process.

In the current state (the state that existed in the community in August 2013), clients were identified when they were in a medical crisis and they were transferred to hospital for assessment. Discharge planning did not systematically include a referral to the community based health care services and information needed for follow up was not provided. Communication barriers existed between health care providers internal and external to the community, and coordination of care was poor. There were no care conferences held in the community.

The discussion in the August 2013 journey mapping workshop focused on how to move from the current state to future state and where this process would be changed so that clients could be identified, assessed and cared for in the community rather than requiring a hospital visit to initiate palliative care services.

The future state would allow for a home death to be supported if the client chose one. At the time of this workshop, there had been no expected deaths in the community for at least the previous four years according to the Home and Community Care Program. All expected deaths took place in the hospital.

Workshop one accomplished bringing together community members, internal and external health care and service providers and the EOLFN Research Team for the first time. In addition, commitment to the journey mapping process from the stakeholders was established and the group began to identify areas for improving communication and service integration amongst one another to improve the experience for the residents of Naotkamegwanning First Nation.

At the end workshop one, the stakeholders committed to attending future journey mapping workshops and understood the purpose of the journey mapping workshops was to create a palliative care pathway. Because workshop one informed the current state, stakeholders were aware that future workshops would focus on how to move from the current state to future state and where the current processes needed to be changed so that clients could be identified, assessed and cared for in the community rather than requiring a hospital visit to initiate palliative care services.

Workshop two: Value stream mapping.

Workshop two took place at the Best Western Lakeside Inn and Conference Centre in Kenora in February 2014. The workshop was two days and included breakfast and lunch, allowing for some ‘off-the-clock’ networking amongst participants.

A total of 17 participants attended, including: two Elders, the Home and Community Care Program Coordinator (EOLFN Community Lead), the Naotkamegwanning Health Director, a member of the Band Council, the Community Consultant, community nurses, a community doctor, a Discharge Planner and Palliative Care Nurse from the District Hospital, a Nurse Manager from the Community Care Access Center, a Nurse Practitioner from the Aboriginal Health Access Centre and three members of the EOLFN Research Team, including myself; the Principal Investigator, Project Coordinator, and me in my role as a Research Assistant and Graduate Student Trainee (as of September 2013).

The workshop was facilitated by a six sigma black belt from the Toronto-based Leading Edge Group which specializes in lean, six sigma, and process management. Employing someone specialized in lean was recommended by managers in the regional home care agency as value stream mapping was being used extensively in health care to improve system efficiency and effectiveness. Thus, using this process would be credible with regional health care providers.

A selection committee involving the Principal Investigator, the Naotkamegwanning Home and Community Care Program Coordinator (EOLFN Community Lead), a manager from the regional home care agency familiar with lean, and the EOLFN Research Project Manager was formed to choose a facilitator. Two candidates were interviewed via telephone and one was chosen to provide facilitation and consulting services for this workshop. This particular consultant was chosen unanimously as she had expertise in conducting value stream mapping (VSM) workshops nationally.

The goals of the two day workshop were discussed as a stakeholder working group with the participants, and a series of six goals were established. The goals included, (1) create a plan, (2) implement it, (3) document the outcomes, (4) evaluate the process, (5) demonstrate lived experiences in the community, and (6) bring the findings forward to the NWLHIN. A "desired future state" flow chart diagram, as shown in Figure 5 was created following this workshop. This figure was an elaboration of Figure 4 introduced in workshop one.

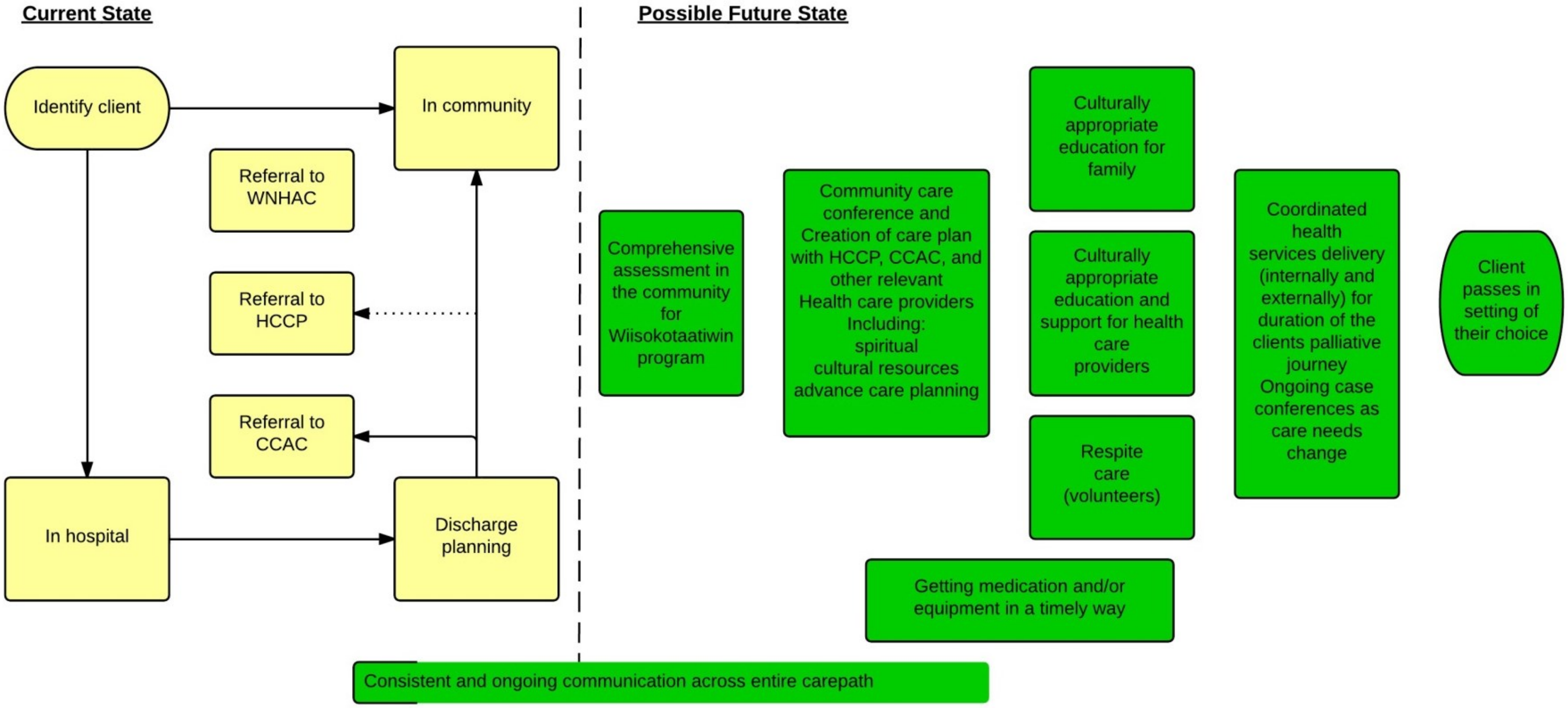


Figure 5. Current and Potential Future State

It was quickly determined by non-verbal communication and lack of participation by community members that this workshop facilitation style and the VSM terminology being used was unfamiliar. Half way through day one of the two-day workshop, the Principal Investigator began to co-facilitate the workshop and introduce a less formal style. At this point progress in discussing the desired future state ensued.

Stakeholders participated in an interactive session in which they placed sticky notes on long pieces of paper taped to the wall under various categories such as community strengths and weaknesses, barriers and facilitators, collaboration and partnerships, and resources and services, as shown in Figure 6 and Figure 7.

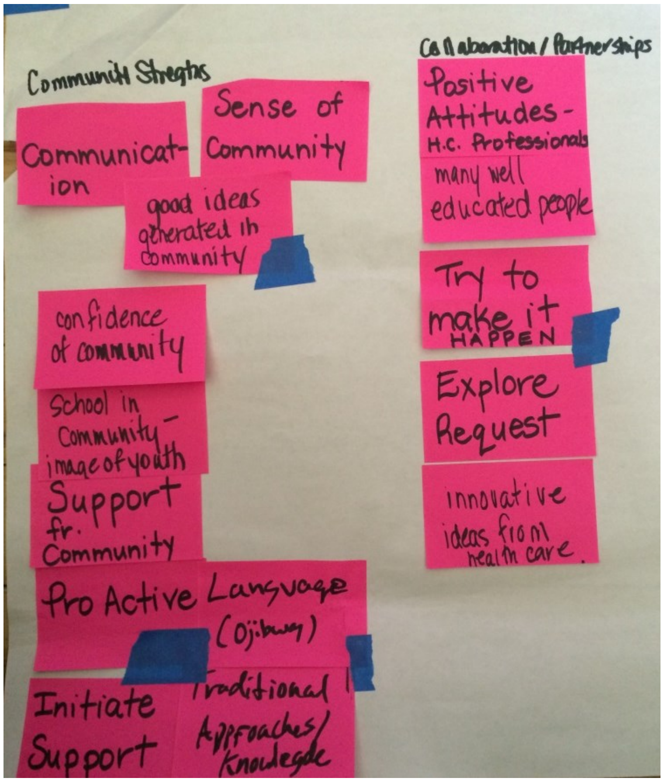


Figure 6. Workshop #2 interactive session: Community strengths

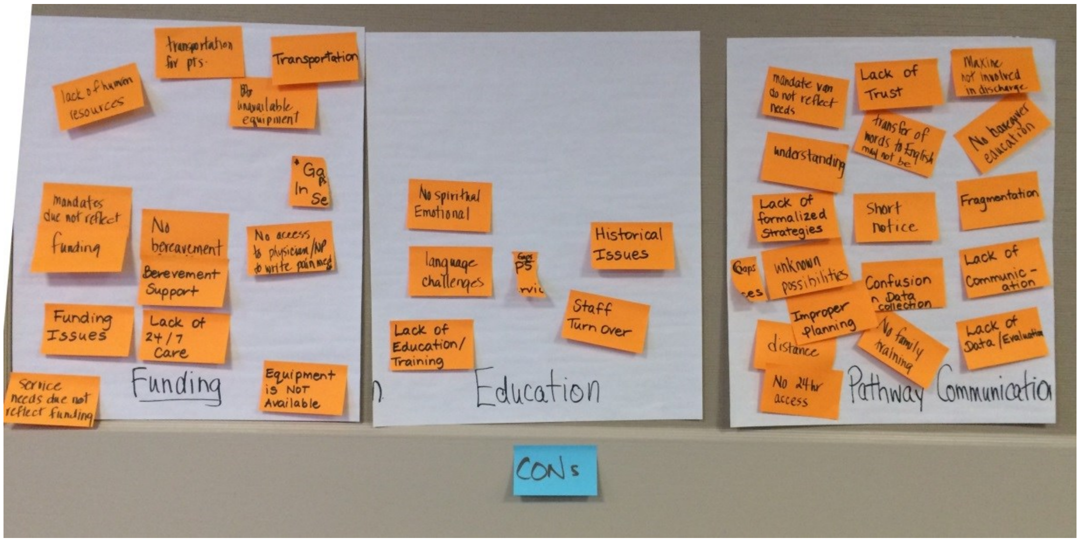


Figure 7. Workshop #2 interactive session: Community barriers

On day two, the stakeholder working group began to map out the desired future state, resulting in a flowchart diagram of the various touch points involved in the desired future state of the care pathway. Day two concluded with stakeholders brainstorming about the services that may be required for clients to receive quality palliative care in the community. The group created a list of 57 services and the current providers, if any, of the listed services, as shown in Table 2.

Table 2. List of palliative care services and providers

No.	Service Required	Current Provider	Proposed Provider	Reason for Recommended Change	Strategy: how to deliver on recommendation
1	Emergency Financial Assistance	Band Office Leadership			
2	Occupational Therapy	Regional home care agency			
3	Physiotherapy	Regional home care agency			
4	Nutritionist	Regional home care agency			
5	Speech/Language Pathologist	Regional home care agency			
6	Mobility/Accesibility	Regional home care agency Band Housing Manager Community Homecare			
7	Social Work	Regional home care agency Aboriginal health access centre			
8	Foot Care	Chirpodist Aboriginal health access centre Medical Clinic(s) PSW Private providers			
9	Family	Community			
10	Traditional Healer	Community Health Services Individual Families Aboriginal health access centre			
11	PSW	Community Homecare			
12	Home Support (external house)	Community Homecare LTC			
13	Client Family Assessmnt	Community Homecare Community Care Conference Stakeholders			
14	Housekeeping	Community Homecare/LTC			
15	Nursing	Community Regional home care agency Nurse Practioner			
16	Volunteer	Community/Family Friends Ontario Works High School Students			
17	Physician	Medical doctors Specialists - Winnipeg or Thunderbay or Kenora Aboriginal health access centre			
18	Groceries shopping and delivery	Aboriginal health access centre			
19	Child Care	Family and Friends Provincial Works Programs Daycare Headstart Babysitting Course Elders			
20	Respite Care	Family and Friends Long Term Care homes			
21	Translater	Family decision Elder Support Program Local hospitals			
22	Funeral Services	Family preference - Kenora area			
23	Lawyer	Family preference private			
24	Spiritual Support	Family Community Traditional Roman Catholic Sioux Narrows Mormon Kenora Mennonite Sioux Narrows			

Due to lack of time, the three columns on the left of the table that address the topics of proposed provider, reason for recommended change, and strategy on how to deliver the recommended change involved were not completed. The task of completing this table was passed along to the Leadership and Clinical Teams that had been formed in Naotkamegwanning for consideration in moving forward with the future state.

My role as a Research Assistant and Graduate Student Trainee was to document meeting minutes, including observations and field notes, and then create a final report. The final report was approved by the EOLFN Research Team and sent via email to all participants that attended the workshop.

In addition, the Leading Edge consultant also provided a report to the EOLFN Research Team. This report included an overview of VSM and key concepts, barriers and facilitators that occurred during the workshop, a series of diagrams related to the current and future state, as well as a list of potential providers and their potential roles in the desired future state. The report concluded with a list of recommendations for next steps in moving forward with the desired future state.

Workshop two reunited existing stakeholders and introduced new stakeholders that were not present in workshop one, creating a more robust group of community members, internal and external health care and service providers and EOLFN Research Team members. The list of palliative care services and providers was identified by participants as useful for moving ahead. In addition, the hospital shared their palliative care assessment forms with the group, which provided ideas on how to adjust the in-home assessment form used by Home and Community Care.

Workshop three: Finalizing the care path and next steps.

Workshop three took place at the Lake of the Woods District Hospital in Kenora in August 2014 and via Ontario Telemedicine Network (OTN) to include distance participants from Thunder Bay. Remote participation by OTN was a unique component of this workshop. The workshop was a half-day in the afternoon.

A total of 20 participants attended, so I have listed them in Table 3 below.

Table 3. Workshop Three Attendees

Role	**Organization/Agency name**
Elder	Naotkamegwanning First Nation Leadership Team
Home and Community Care Program Coordinator (EOLFN Community Lead)	Naotkamegwanning Home and Community Care Program and EOLFN Research Team
Health Director	Naotkamegwanning Home and Community Care Program
Member with health portfolio	Naotkamegwanning Chief and Council
Community Health Representative	Naotkamegwanning Home and Community Care Program
EOLFN Community Consultant	EOLFN Research Team
Community Nurse Manager	Community Nursing Provider (FNIHB) (professional nursing agency providing services in the community)
Telemedicine Nurse	Regional Telemedicine program from hospice unit in Thunder Bay hospital
Palliative Care and telemedicine Manager	Regional Health Sciences Centre & Cancer Centre in Thunder Bay
Aboriginal Patient Navigator	Regional Health Sciences Centre/Cancer Centre in Thunder Bay
Discharge Planner	District Hospital in Kenora
Palliative Care Nurse	District Hospital in Kenora
Director	Regional Community Care Access Center in Thunder Bay
Program Director	Aboriginal Health Access Centre (AHAC) Kenora
Nurse Advisor with the Home and Community Care Portfolio	First Nations Inuit Health Branch (FNIHB), northern Ontario
Principal Investigator	EOLFN Research Team
Interim Project Manager	EOLFN Research Team
Research Coordinator	EOLFN Research Team
Research Assistant and Graduate Student Trainee (me)	EOLFN Research Team

The workshop was facilitated by the Principal Investigator, the Community Consultant, and the Home and Community Care Program Coordinator (EOLFN Community Lead) from Naotkamegwanning. My role as a Research Assistant and Graduate Student Trainee was to document meeting minutes, including observations and field notes, and then create a work plan of follow up actions for the key stakeholders.

The goals of the workshop were to bring partners together, discuss and agree upon next steps and share the high level care path, as shown in Figure 8.

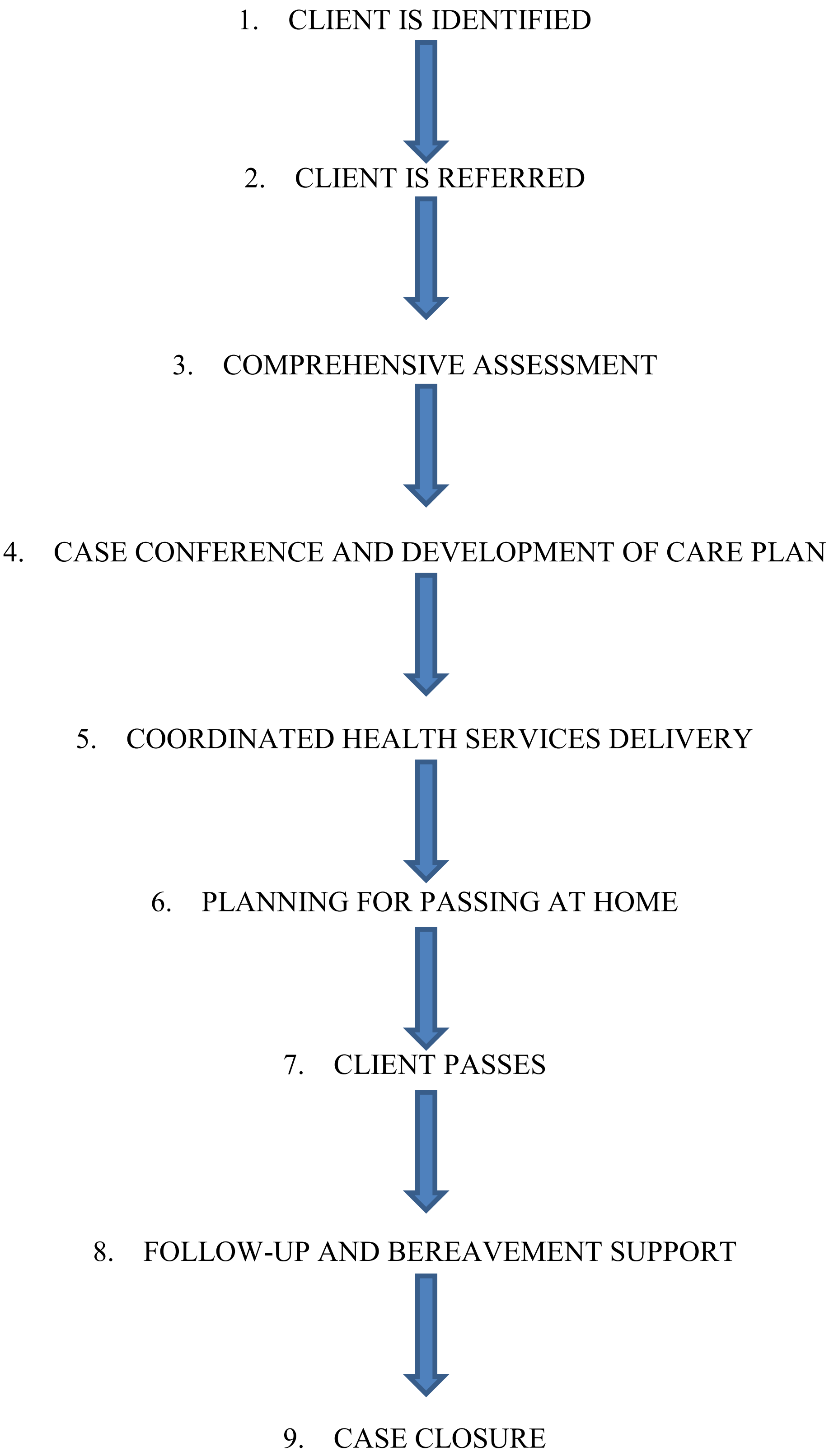


Figure 8. Nine stage care path flowchart

Workshop three contributed to creation of the care pathway in that it reunited the stakeholders to introduce the care path flowchart and discuss and agree upon next steps. The linear care path (Figure 8) had been developed by the Home and Community Care Program Coordinator (EOLFN Community Lead), the Community Consultant, and the EOLFN Research Team based on the previous workshops and needed to be validated by the other stakeholders. In addition, the roles and activities of each organization at each step needed to be detailed and discussed so that a clear plan of who was responsible, timing of care, and how activities should be coordinated, could be solidified. This included individuals taking responsibility for identified tasks and committing to be accountable for the progress. For example, the Home and Community Care Program Coordinator (EOLFN Community Lead) and Community Consultant partnered with a regional discharge planner to revise the process so that the Home and Community Care Program was informed in advance so that equipment and services could be arranged prior to the client being to discharged. In addition, the Home and Community Care Program Coordinator (EOLFN Community Lead) and Community Consultant also worked with the community's professional nursing agency and a nurse from a regional hospital to revise the palliative care assessment form so questions were similar in the community and hospital, but not duplicated. It was during these exchanges that the stakeholders began to learn about, and understand one another's roles.

It was during workshop three that the community informed the external partners that they would be involved in stages one through five of the care pathway only. Stages six through nine would be private to the community and be these stages would be discussed internally with the leadership team.

Workshop four: Including cultural components in the care path.

Workshop four took place at Waasegiizhig Nanaandawe'Iyewigamig Health Access Centre (WNHAC) in Kenora in October 2014 as part of the community's Leadership Team meeting. The workshop was held over two days with nine members of the Leadership Team. I also attended the meeting with prior approval from the Leadership Team. There were no external health care providers at this meeting as the focus was on the internal community roles and activities.

The workshop was facilitated by the Community Consultant. My role as a Research Assistant and Graduate Student Trainee was to assist the Leadership Team with creation of the care path. The Leadership Team's administrative assistant was present to document meeting minutes and recorded the dialogue on an audio recorder. At times, I assisted the Community Consultant with facilitation. I also documented field notes and observations and took photographs.

The goal of the workshop was to review what had been done over the previous year with all of the stakeholders and ensure cultural components, beliefs and traditions were incorporated into all of the stages of the care path. Of the nine stages involved in the care path, the Leadership Team identified stages 6-9 as private to the community, thus they wanted to discuss the details of these stages only within the Leadership Team, not involving the entire stakeholder working group. As a team, the Leadership Team created Figure 9 called "The Nine Stage Wiisokotaatiwin Program Care Path."

Figure 9. The Nine Stage Wiisokotaatiwin Program Care Path

Workshop four contributed to the lessons learned in creation of the care pathway in that it was private to the community involving only members of the Leadership Team, the Community Consultant and me as a Graduate Student. There were no external health care providers at this meeting as the focus was on the internal community roles and activities. It was during this workshop that the care pathway evolved from a linear process to a circular diagram.

Following the fourth journey mapping workshop, the stakeholder work plan was completed by me, the Community Consultant and the Home and Community Care Program Coordinator (EOLFN Community Lead) based on the workshop minutes. It was then reviewed and approved by the EOLFN Research Team, and sent via email to key stakeholders from the stakeholder working group. The details of each organization's role and their tasks were discussed in series of teleconferences over a couple of months, facilitated by the Principal Investigator, Project Manager, and Community Consultant. My role during these teleconferences was to take minutes and update the work plan. Finalizing the detailed work plan was a critical step in making the role of each organization specific and clear in order to implement the new care pathway for clients. It also allowed each organization to see how their role integrated with the roles of others in the overall care plan.

Purpose and rational for this research

This particular journey mapping intervention, conducted in Naotkamegwanning First Nation, was nested within the five-year PAR research project that aimed to improve the quality and access to palliative care in First Nations communities. Based on the results of the Naotkamegwanning needs assessment, there was an expressed wish by people living in the community to receive palliative care at home and have the option to die at home. Thus, the EOLFN Research Team created and implemented the series of four journey mapping workshops, as described in the previous section. Analyzing the lessons learned during the unique journey mapping intervention, which was conducted collaboratively by the Naotkamegwanning Leadership Team and the EOLFN Research Team from 2013-2014, is the focus of my thesis research.

Chapter five: Methodology

Study purpose and research questions

In conjunction with a participatory action research study, the primary purpose of this thesis research was to analyze the journey mapping process undertaken in Naotkamegwanning to create a care pathway that would support community members who choose to die at home. The desired outcome was to share the lessons learned and provide recommendations for palliative care journey mapping in First Nations communities for the future.

The research questions guiding this thesis are:

1. How effective was the journey mapping process to create the care pathway for integrated palliative home care for Naotkamegwanning community members who choose to die at home?
2. What learnings and promising practices have emerged from this case study that can inform development of an EOLFN workbook tool on journey mapping for use by other First Nations communities?

More specifically, this research will describe the importance of each of the roles involved in the journey mapping workshops and the contributions of the stakeholder working group. It will analyze how the four journey mapping workshops contributed to creating the care pathway by exploring the facilitators and barriers, learnings and promising practices, and key catalysts. Findings emerged from my analysis of primary and secondary data collected over two years.

Ethical considerations in Indigenous health research

This research was guided by the principles of OCAP® (Ownership, Control, Access and Possession), outlined in Table 4 below, which are sanctioned by the First Nations Information Governance Committee (2016). These principles aim to ensure self-determination in all research concerning First Nations people.

Table 4. Definitions and principles of ownership, control access and possession (OCAP®)[7]

Ownership	Refers to the relationship of a First Nations community to its cultural knowledge, data and information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.
Control	The aspirations and rights of First Nations Peoples to maintain and regain control of all aspects of their lives and institutions extend to research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.
Access	First Nations Peoples must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
Possession	While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breech or misuse. This is particularly important when trust is lacking between the owner and possessor.
From: Snarch, B. (2004). Ownership, Control, Access, and Possession (OCAP®) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities. *Journal of Aboriginal Health*, 1(1): 80–95. Also in Brazil, K. (2012).	

Design

As discussed, this thesis was nested within the EOLFN research project. The overall EOLFN project utilized a comparative case study design (of four communities), adopted community capacity development as its theoretical perspective, and a PAR methodology. This

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[7] OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). For more information on OCAP®, please visit: www.FNIGC.ca/OCAP.

thesis research focused on one First Nation Community in the EOLFN project, Naotkamegwanning First Nation, and one intervention that the community undertook, journey mapping to design a palliative care pathway. The cyclical process of PAR (Lewin, 1946; McTaggart, 1997), namely, planning, acting, observing, and reflecting, were integrated into the overall EOLFN research. This allowed me to focus my thesis research on the relevant cycles of PAR, so I could study how things were done, why they were done the way they were, what changed along the way, and what, if anything could have been done differently.

I used an instrumental case study design (Stake, 1998), embraced an Indigenous paradigm as the theoretical perspective, and a PAR methodology (Kemmis & McTaggart, 2005). Consistent with case study design and the principles of PAR, a variety of data and data collection methods were used such as field notes and observations of the workshops, document review, a community focus group, and an external stakeholder online survey. In each case, a form of data collection was chosen that was most appropriate to the goal, context and participants.

In an instrumental case study, as described by Stake (1998):

> A particular case is examined to provide insight into an issue or refinement of theory. The case is of secondary interest; it plays a supportive role, facilitating our understanding of something else. The case is often looked at in depth, its contents scrutinized, its ordinary activities detailed, but because this helps us pursue the external interest. The case may be seen as typical of other case or not (p. 88).

In this thesis research, the case that was analyzed is defined as the entire journey mapping process in Naotkamegwanning and the activities that took place to create the care pathway.

To study the case, multiple forms of data were analyzed. Existing qualitative data in the form of researchers' field notes, observations, photos, documents (meeting minutes and summary reports) and video recordings were collected during the four journey mapping workshops. After the completion of the four journey mapping workshops, primary data collection for the thesis included a focus group with community members which intended to capture participants' perceptions of the outcomes of the journey mapping process, and an online survey with the EOLFN Research Team and health care providers who were external to the community but provided services in Naotkamegwanning.

A focus group with community members and an on-line survey with the EOLFN Research Team and were selected as the appropriate methods for data collection based on acceptability of the method to the participants, the size of each participant group, and to achieve the highest participation or response rates from each group.

The community had a Leadership Team meeting scheduled as a two-day retreat in April of 2015, at which time the EOLFN Project Manager contacted the Home and Community Care Coordinator/Community Lead to ask if it was appropriate to conduct a focus group about the journey mapping experience during the retreat. The Home and Community Care Coordinator/Community Lead agreed that it would be an appropriate for me to come to the Leadership Team retreat during that time and conduct a focus group The Leadership Team membership was no more than ten, so the conducting a focus group was also appropriate for the size group. In addition, some of the community members that were involved in the focus group did not have computer or internet access, were not tech savvy, or they did not read English; therefore an on-line survey was not appropriate. Furthermore, the EOLFN research team had learned during the community needs assessment, that when conducting paper survey data collection in the community required continued presence in the community, going door-to-door, which was not feasible.

An on-line survey was selected as the most appropriate method for the EOLFN research team and the external health care providers because it was often difficult to get the entire group together based on varying schedules and locations. An on-line survey gave the participants the opportunity to respond at their convenience, leave the survey and finish it later, not have to travel, and it was less time consuming for them.

Embedded throughout this research, are the principles of the Indigenous paradigm outlined by Atkinson (2001) as discussed earlier in the literature review chapter. Each of these principles ensure that I conducted my research in an ethically responsible and culturally safe manner, while respecting Indigenous ways of knowing (Atkinson, 2001; Wilson, 2008). Additional ethical considerations are discussed later in the Research Ethics Board and Ethics Procedures section.

Understanding the community context of the journey mapping

Stake (1998) indicates the importance of describing the setting in which the case occurs so that the findings can be understood and their applicability can be assessed in other contexts. This includes the physical setting and the socio-cultural influencers on the case. (Stake, 1998).

The community context for this research is the Ojibway community of Naotkamegwanning First Nation (also known as Whitefish Bay), which is located in the Lake of the Woods region of Northwestern Ontario in the Treaty 3 territory, as shown by Google Maps (2014) in Figure 10 below.

Figure 10. Naotkamegwanning First Nation (Whitefish Bay) Map

(https://www.google.ca/maps/place/Naotkamegwanning+First+Nation+%28Whitefish+Bay+First+Nation%29/@49.2210023,-91.681051,8z/data=!4m2!3m1!1s0x52bdced49415d4c5:0xd4d72b9a6706301f)

The community has year-round road access and an ice road in the winter. The nearest urban center, the town of Kenora, has a population of approximately 15,348 (Statistics Canada, 2011b), and is 96 kilometers to the north. Of the l,208 registered band members, 712 live on-reserve and 496 live outside of the community.

Naotkamegwanning community members take pride in keeping their Anishinaabe cultural practices, beliefs, and traditions strong. Many of the people continue a connection with the land and maintain a lifestyle that includes fishing, hunting and harvesting of wild rice. Nearly half of the residents are able to speak Ojibway and the importance of passing on teachings, language and cultural practices are evident in their delivery of programs and services within the community (EOLFN Research Team, 2012).

Naotkamegwanning has a number of community-based programs and services that are focused on culture such as, a Head Start program through grade 12 schooling, an Elders Centre for supportive housing, a health centre offering clinical care, a medical service with ambulatory and paramedic services, and a women's shelter. Treaty #3 Police Services and Family Services also have offices within the community. In addition, there is a traditional roundhouse and pow wow grounds in the community (EOLFN Research Team, 2012).

As of 2013, approximately 5% or 36 members are seniors over 65 years of age. In terms of the aging and health of Naotkamegwanning's residents, the leadership and service providers are responsive to the changing needs of the Elders. The role of the family to offer support for their Elder is encouraged. In 2007, the integration of the Long Term Care Program and the Home and Community Care Program created the current Community Care Program. Approximately thirty personal support workers, home makers and nurses are employed by the program, mostly part-time. Although there is fluctuation in the caseload, staff care for about forty clients a month who are mostly Elders. This integrated model of care for Elders and people living with disabilities is a single point of access and customized care plans for those requiring service within their homes or in the Elders Centre. Most people receiving support live independently in their own homes. Elders are a vital source of information and guidance on the many programs, services and governance within Naotkamegwanning First Nation (EOLFN Research Team, 2012).

The Naotkamegwanning Home and Community Care Program and staff are the drivers of change within the community to create a palliative care program, including undertaking the journey mapping process. In particular, the Home and Community Care Program Coordinator (EOLFN Community Lead) Maxine Crow has provided leadership throughout the journey mapping process. She chairs a community Leadership Team of six people that include Elders, a member of the Band Council, and other community service providers (EOLFN Research Team, 2012).

The regional context of the journey mapping.

The North West region of Ontario, commonly referred to as Northwestern Ontario, includes the Districts of Thunder Bay, Rainy River, and Kenora. Within the North West region, the North West Local Health Integration Network (NWLHIN) is responsible for overseeing the integration and coordination of local health services to make it easier for clients to access necessary care (Ontario Local Health Integration Network, 2014). In addition, the NWLHIN is responsible for allocating funding for the following health services in Northwestern Ontario: hospitals, Community Care Access Centres, long-term care homes, community support service organizations, community health centres, and community mental health and addictions agencies.

Please see Figure 11 for the NWLHIN catchment area (Ontario Local Health Integration Network, 2011).

Figure 11. NWLHIN catchment area map

(Ontario Local Health Integration Network, 2011)

According to the NWLHIN website (2014), there are several rural and remote small towns and First Nations communities spread throughout the region. In fact, the NWLHIN has the largest proportion of Indigenous Peoples (19.2%) of all Ontario LHINs (Ontario Local Health Integration Network, 2011). Due to the geographic spread of these towns and communities, there are many challenges in planning, delivering and accessing health services (Ontario Local Health Integration Network, 2011). Within the Kenora District, Naotkamegwanning residents have access to the following provincial health services: Lake of the Woods District Hospital, Waasegiizhig Nanaandawe'Iyewigamig Health Access Centre (WNHAC), and the Northwest Community Care Access Center (NWCCAC).

Participant recruitment and inclusion criteria

Participants for the journey mapping have been engaged in the EOLFN project since August 2013 and at that time consented to be part of this case study. Consistent with Creswell (2013), three considerations were employed in the initial participant recruitment and inclusion criteria process: (1) selection of sampling strategy, (2) participants in the sample, and (3) sample size (Cresswell, 2013).

Purposeful sampling was selected, because the purpose of the thesis research is to understand what happened during the creation of the care pathway, determine if the journey mapping process has been effective in creating the care pathway, and recommend promising practices to other First Nations communities. Therefore, all stakeholders that participated in the journey mapping workshops were appropriate participants in this thesis research. This included Naotkamegwanning Elders, community members, the EOLFN Research Team, internal health care providers, and external health care providers who work in regional health services that provide health care to residents of Naotkamegwanning.

Of the four journey mapping workshops, attendance varied from 13 to 24 attendees. All participants received an information letter and provided signed consent to participate in the EOLFN research project. At the end of the final workshop, participants were verbally invited to participate in a follow-up data collection for my thesis in the form of a focus group for community members and on-line survey for health care providers and EOLFN Research Team members. The overall consensus of workshop participants was that they would like to participate in the follow-up data collection process. This led to a sample size of n=26 participants for this thesis research.

Focus group participants.

In April 2015, Naotkamegwanning community members (n=12) were invited to participate in a semi-structured focus group at the time and location convenient to the participants.

Please see Appendix A for the focus group information letter, Appendix B for the focus group guide and Appendix C for the Lakehead University Research Ethics Board (REB) approval letter.

Survey participants.

From June – August 2015, internal and external health care providers (n=13) and the EOLFN Research Team (n=3) were invited to complete an online survey that included 14 rating scale questions and nine open-ended questions.

Additional details regarding the focus group and survey analysis and findings are in sections and chapters that follow, respectively.

Research Ethics Board and ethics procedures.

This research fell under the auspices of the larger EOLFN project, which was originally approved by the Lakehead University REB in 2010. Naotkamegwanning has no research ethics board, however, willingness to participate in the overall EOLFN project was initially sought in 2005 before the project began from the Chief and Council of Naotkamegwanning, the Elders and community members. At that time, the Elders and community members agreed to be part of the palliative care project, its interventions and sub-studies, which includes this thesis research. Furthermore, prior to or during the journey mapping workshops, all potential participants received a verbal explanation of the overall study and an EOLFN information letter that is attached in Appendix D. Participants all provided free, prior and informed consent with signature as part of the EOLFN project. Please see Appendix E for the EOLFN informed consent form.

The majority of the data included in this thesis were collected during the four journey mapping workshops and community member focus group. I was employed as an EOLFN research administrative assistant in 2010 and have been covered by the EOLFN REB approval since 2011. I participated in the journey mapping data collection as both a Research Assistant and Graduate Student Trainee from 2013-2015. Specifically, for this thesis, additional new data were collected through an on-line survey to supplement the existing data. The community chose to have the raw research data stored and managed at Lakehead University by the EOLFN research team because they do not have a local REB an do not have the local capacity to maintain it.

Following the approval of my thesis proposal, a “Request for Amendment to a Project Approved by the Research Ethics Board” form was submitted to the Lakehead University REB electronically through the REB ROMEO research portal system. The purpose of the amendment form was to conduct an on-line survey with internal and external health care providers and the EOLFN Research Team and analyze all existing data pertaining to the journey mapping process. The amendment included: (1) the study background and purpose, (2) survey participant information email body text, (3) a copy of the on-line survey, and, (4) my Tri-council Policy Statement Training (TCPS) certificate (completed December 13, 2012 and attached in Appendix F). Prior to the submission of the amendment, it was reviewed and approved by the EOLFN Principal Investigator and Project Manager. The approval letter was sent via email, as Lakehead University REB amendment approvals are now paperless. Please see Appendix G for the approval and email correspondence regarding the paperless approval process.

For five years, all electronic data, including the focus group audio recording, has been, and will continue to be stored in two places; on a password protected laptop and on an encrypted external hard drive kept in a locked filing cabinet, located in a locked office on site at Lakehead University – Centre for Education and Research on Aging & Health (CERAH).

Data collection

Summary of previously collected data.

Most of the data that were used in this case study were existing and collected from August 2013 through April 2015 as part of the EOLFN project. Previously collected data included written documents, field notes of direct observations and all materials prior to, during, and following the series of four journey mapping workshops. Preparatory data that related to planning and preparing for the journey mapping sessions included: meeting agendas, email correspondence, invitee lists and participant packets. Data obtained during the workshops included: field notes, observations, meeting minutes, care pathway diagrams, and photographs.

Post workshop data included: workshop reports and recommendations, an OTN videotape, a community member focus group and audio recording.

In my role as an EOLFN Research Assistant, I was the responsible for collecting the majority of this data. The existing data used for the thesis were summarized in Table 5 below prior to beginning my analysis.

Table 5. Existing data analyzed for this thesis

Date(s)	Length	Participants	Location	Facilitator	Format	Workshop focus	Data analyzed
August 15, 2013	½ day (4 hours)	n=14 Community members, EOLFN Research Team, internal and external health care providers (HCP)	Naotkamegwanning First Nation	Principal Investigator	Face-to-face workshop	Journey mapping (current state)	Preparatory meeting minutes, participant list, agenda, HCP forms, workshop meeting minutes, observations and field notes, photos, process flow charts, final report
February 5-6, 2014	2 days (14 hours)	n=17 Community members, EOLFN Research Team, internal and external HCP	Best Western Lakeside Inn Conference Centre, Kenora	Outside consultant	Face-to-face workshop	Value stream mapping (began future state)	Preparatory meeting minutes, participant list, agenda, HCP forms, workshop meeting minutes, observations and field notes, photos, process flow charts, final report
August 6, 2014	½ day (3 hours)	n=20 Community members, EOLFN Research Team, internal and external HCP	District Hospital, Kenora	Principal Investigator and Community Consultant	Face-to-face workshop and webinar	Journey mapping (future state/planning of details)	Preparatory meeting minutes, participant list, agenda, workshop meeting minutes, observations and field notes, webinar video, process flow charts
October 1-2, 2014	2 days (11 hours)	n=9 Project advisory committee and community members and EOLFN Research Team	Aboriginal Health Access Centre (AHAC) Kenora	Community Consultant	Face-to-face workshop	Validation of concepts from previous meetings; creation of care pathway	Participant list, agenda, workshop meeting minutes, observations and field notes, photos, audio recordings, process flow charts, care path diagram
April 16, 2015	90 minutes	n=8 Focus group with Naotkamegwanning project advisory committee	Best Western Lakeside Inn Conference Centre, Kenora	EOLFN Research assistant (Jessica Koski)	Face-to-face focus group	PAR (See focus information letter and group guide)	Focus group transcript; field note and observations.

Focus group with community members.

On April 16, 2015, I conducted a semi-structured focus group using a focus group guide with open-ended questions. The focus group guide was developed by me and my thesis supervisor based on previous data from the needs assessment related to the community's barriers and challenges as identified by the community and health care providers. Development of the focus group guide also involved reviewing the objectives of the journey mapping workshops and the priorities identified by the Leadership Team.

A total of eight participants attended the focus group (not including me), seven of which are Naotkamegwanning community members. The eighth participant was the EOLFN Community Consultant who was hired to support and assist the Home and Community Care Program Coordinator (EOLFN Community Lead) in Naotkamegwanning. The focus group was conducted as part of a two-day retreat that involved the Leadership Team.

At the start of the focus group, I read the information letter to the participants and presented each participant with a copy. During the presentation of the information letter, it was openly noted to the participants that due to the nature of a focus group format, anonymity of focus group participants could not be guaranteed, however all focus group data would be de-identified. I asked the participants if they had any questions or concerns, and no one did, so I proceeded with the consent process. Because all of the focus group participants had already participated in the overall EOLFN project and signed consent, they were asked to verbally reaffirm their consent prior to the focus group. The consent process was not audio recorded because I wanted to reaffirm consent to participate prior to introducing the recorder. Each participant was not asked to state their name and that they consent. For example, a positive head nod or remaining present in the focus group meeting room was considered acceptable consent to continue with the focus group questions.

The reason to go about the consent process in this way, was based on the Canadian Institutes of Health Research (2005) Guidelines for Health Research involving Aboriginal People. According to these guidelines:

> Written consent is not always appropriate. For most people in our society, a signed statement is the normal evidence of consent. However, for some groups or individuals, a verbal agreement, perhaps with a handshake, is evidence of trust, and a request for a signature may imply distrust. In some types of research, oral consent may be preferable (http://www.cihr-irsc.gc.ca/e/29134.html).

Once everyone provided consent, I introduced the audio recorders and asked the participants if they were comfortable with the discussion being recorded. I made sure everyone understood that the data collected will be used by the overall EOLFN research and my thesis research in a de-identified manner, and that only the EOLFN Research Team would have access to the audio recording and data. It was noted that this is a safe environment for participants and the Home and Community Care Program Coordinator (EOLFN Community Lead) was there to support them with questions and/or translation, and they participants can decline participation at any time.

I sought to answer the open-ended questions listed in the focus group guide. These questions were designed to explore the experience of community members in relation to answering the overarching research questions. When necessary, I used probing techniques, to obtain additional information, but I did use probing in a way that would not lead participants or be intimidating to them.

On-line survey with health care providers and EOLFN Research Team members.

External health care providers and the EOLFN Research Team were sent an email that included a description of the research embedded in the body of the email (see in Appendix H). The email asked them to read the information letter information letter (see Appendix I) and participate in a 15-minute online survey (see in Appendix J). At the bottom of the email, there was a link that led the participants to an online SurveyMonkey® survey. The first page of the survey was the study information letter which concluded by asking for their consent. After reading the information letter, the first question participants were asked was: "I give consent to participate in this study." If the participant chose "yes", they continued through the survey. If the participant selected "no", the structural logic ended the survey.

The on-line survey questions were developed by me with guidance from my thesis supervisor based on the focus group guide and previous data from the needs assessment related to the community's barriers and challenges. Similar to the focus group guide, development of the survey questions also involved reviewing the objectives of the journey mapping workshops and the priorities identified by the Leadership Team.

The format of the on-line survey combined a rating scale with 14 statements and nine questions with open-ended free-text fields. The scale portion of the survey sought to document respondents' perceptions of the journey mapping including the process and benefits for communication, collaboration and care delivery. The open-ended questions in the survey sought information related to the most and least beneficial aspects of the journey mapping workshops, what could have improved the workshops, and if participants would recommend similar workshops to other First Nation's communities.

Data analysis

The data analysis strategy for this research had two components: analysis of the qualitative data and analysis of the survey data. Findings from both were compared for similarities and differences to see if the data from different sources and stakeholders triangulated or whether there were divergences.

For the qualitative data analysis, the focus group data was inductively analyzed first. These data best captured the voice of the community members related to the research questions. Generating the themes from the community perspective sensitized me to the Naotkamegwanning participants' perspective and provided a culturally respectful lens from which I could analyze the existing data that had been collected during the journey mapping workshops. The existing journey mapping workshop data were analyzed next using an analysis guide created for that purpose. Patton's Qualitative Checklist was also used to guide the qualitative data analysis process to ensure the qualitative findings were clear, credible, and addressed the research questions (Patton, 2003). The survey data from the external providers from health care organizations were analyzed separately and the process is described later in this section.

Focus group transcription and analysis.

An inductive approach (MacPherson & McKie, 2010) was used to analyze and code the focus group data that was collected in April 2015. First, I transcribed the focus group verbatim from the audio recording. Then I printed the focus group transcript and validated it by reading the print-out while simultaneously playing the audio recording to ensure word-for-word accuracy. Next, I made the changes electronically and reprinted the transcript. I read the transcript in its entirety three times over the course of five days before I began coding to ensure my familiarity with the data (MacPherson & McKie, 2010). At that point, following transcribing, validating, and reading, I became immersed in the focus group data. I was conscious that the impressions I formed were consistent with the context of the data set (Hatch, 2002). Once I became immersed in the data, I began memoing and key themes were highlighted and colour-coded. I was then ready to begin a three-part inductive analysis process that included (1) line-by-line analysis of the transcript to identify the ideas represented during the focus group, (2) grouping the ideas into themes and subthemes, and (3) organizing the themes to address the research questions (Thorne, Kirkham, & O'Flynn-Magee, 2004).

The themes identified were reviewed with my supervisor at which time we created a large visual diagram on the wall which mapped out the themes, with journey mapping at the center. My supervisor and I were able to review and modify the themes during the creation of the diagram to better reflect the data, more effectively address the research questions and more clearly provide a structure to tell the story of the journey mapping experience. Should there have been a disagreement on the coding structure, a member of the thesis committee would have been asked to review the theme(s) and decide on the appropriate code; however, there was consensus on the coding.

In the end, a foundational theme that grounded the analysis, two core ethical concepts, four overarching themes, and seven subthemes emerged to answer the research questions from the perspective of the community. To support these themes and tell the story of the journey mapping process, narrative quotes with significant meaning(s) were extracted. To ensure anonymity, titles were used to identify the participants.

Consistent with APA (6th ed.), quotation marks were omitted for quotes of 40 words or more. Direct quotes have been italicized to indicate the quote is verbatim. Field notes are in plain font because they are not direct quotes; they were summarized and documented by me.

Both direct quotes and field notes have been formatted in indented free-standing blocks (American Psychological Association, 2010).

To improve the clarity of meaning in data extracted from the focus group for my quotes, I did edit the participant's verbatim statements as described in the next paragraph. Before editing, I carefully reflected on the content and context of the quote so that I could accurately interpret the intent of the speaker. I am confident that the intent and thoughts communicated by the participants were not misrepresented or changed as a result of the editing process.

In the quotes presented in the findings, the removal of unnecessary words, such as non-lexical conversation sounds (uh, um, mhm, uh-huh, hmm) or repeated words (yeah, yeah) are represented by ellipses appearing in square brackets. For example: […]. Free standing ellipses, represented by three consecutive periods: …, were used to indicate the speaker is pausing to think about something. Throughout the narrative quotes, parentheses were used to provide supplementary information that was not communicated verbally, such as: *(emphasized).* The word "emphasized" appears in parentheses to indicate to the reader that the previous word or statement was emphasized. Additionally, parentheses were used to provide supplementary information to the reader that was communicated visually only to those present in the room. This refers to information that was not explicitly stated aloud by the original source, such as: *(points to community member).* In this example, the additional information in parentheses provides contextual clarity for the reader.

Analysis of existing workshop data.

After the thematic structure of the results were created inductively from my community focus group analysis, these themes were then used as a sensitizing framework to guide the analysis of the pre-existing workshop data (described in Table 5). To organize these data, I inventoried it and organized it by workshop sequence (one through four) and date. Within each workshop folder there were three categories: (1) preparatory workshop documents, (2) post workshop data, including meeting minutes, observations, field notes, and reports, and, (3) other data, including photographs and an OTN video.

To analyze and code the existing data, the themes generated from the focus group analysis were used as a sensitizing framework to guide the analysis. In addition, an additional guide for analysis of the existing data (see Table 6) was created based on the research questions by hypothesizing evaluation metrics with my supervisor (Patton, 2003) and these questions were also used to examine the data. Using these two analysis guides created confidence that all relevant information had been extracted pertaining to the thesis research. This process intended to ensure no ideas, themes, or categories relevant to the research questions were overlooked. I continued to meet with my thesis supervisor on a regular basis to ensure rigour.

Table 6. Guide for analysis of existing data

How effective was the Naotkamegwanning journey mapping process to create the care pathway for integrated home palliative care for Naotkamegwanning community members who choose to die at home?
What learnings and promising practices have emerged from this case study that can inform development of an EOLFN toolkit on journey mapping for other First Nations communities?
What was the role or contribution of the various stakeholders/participants in the journey mapping process?
How did each stakeholder role contribute to the journey mapping process? • How did Naotkamegwanning leadership and clinical teams contribute to the journey mapping process? • How did the Home and Community Care Program Coordinator (EOLFN Community Lead) contribute to the journey mapping process? • How did the Community Consultant contribute to the journey mapping process? • How did the EOLFN Research Team contribute to the journey mapping process? • How did Naotkamegwanning leadership and clinical teams contribute to the journey mapping process? • How did other stakeholders contribute?
How did each one of the four journey mapping workshops contribute to creating the care pathway?
What were the facilitators and barriers in the journey mapping process? This includes contextual issues such as time, attendance, etc.
What were the key catalysts during the journey mapping workshops?
How did the workshops contribute to system integration? For example facilitating communication, collaboration, knowledge of services
How could the journey mapping process be improved in future?
What is the unfinished business in the journey mapping process?
What was the most significant change that resulted from the journey mapping and creation of the care pathway?
What process of palliative care journey mapping in FN communities is recommended for the future?
Was the concept of two-eyed seeing evident in the data? If so, how?
Is there anything else in these data that is interesting, important or relevant to the research questions?

Survey analysis.

The survey data were transferred from SurveyMonkey into Microsoft Excel. Quantitative data were summarized in tables and the responses to the open-ended questions were analyzed line-by-line to capture participants' opinions about the journey mapping experience. The qualitative data from the open-ended questions were then grouped and three over-arching themes were identified and summarized.

Rigour

PAR research, to be rigorous, must be guided and controlled by the participants, and lead to actions that benefit them. Because creation of the care pathway was grounded in the findings of the community needs assessment and the journey mapping process was led by the Naotkamegwanning community, this thesis has respected the fundamental principles of PAR. The lessons learned and promising practices that have been identified through this thesis research provide practical outcomes that will benefit Naotkamegwanning and other First Nations communities that choose to conduct journey mapping in the future.

To ensure rigour, this research utilized the "Eight 'Big-Tent' Criteria for Excellent Qualitative Research" as identified by (Tracy, 2010). These include: (1) a worthy topic, (2) rich rigor, (3) sincerity, (4) credibility, (5) resonance, (6) significant contribution, (7) ethics, and (8) meaningful coherence.

Each of the aforementioned criteria has been incorporated into my thesis research. For example, as discussed in the background, there are gaps in the literature in relation to journey mapping to create a palliative care pathway in First Nations communities; therefore, the topic is worthy, relevant, and timely. Furthermore, this research has meaningful coherence because it uses methods and procedures that are appropriate to the research purposes and it meaningfully connects the literature with the research questions and the lived experience of the participants.

In addition, the study is rich in rigour because I was immersed in the research setting and had ongoing relationships with the participants for over two years while collecting data with the community and partners. I have incorporated mixed-methods into the data collection process so that the most suitable method of data collection and analysis was used in each situation. I have also ensured sincerity by self-disclosing my values, biases, and personal background, and ensured transparency in the research methods. As discussed in the ethics section, this research incorporates a well-rounded ethical plan. The research will ensure exiting ethics in that a final bound copy will be provided to the Naotkamegwanning community members.

In the sections that follow, I have demonstrated that the remaining criteria have been incorporated. For example, to ensure credibility, the findings are rich in detail and supported by participant quotes. By creating a culturally relevant figure to display the qualitative findings, the research outcomes have been presented in a way that will best resonate with First Nations community participants. In addition, the research provided a significant contribution to gaps in literature related to journey mapping to create a palliative care pathway in First Nations communities, and how the journey mapping process could be conducted in the future.

Triangulation.

To ensure the data were comprehensive and robust, methodological triangulation (Cresswell, 2013) was incorporated in this thesis research. Methodological triangulation was achieved because more than one data set was collected from a variety of participants in different ways (Strauss & Corbin, 2008). In embracing a PAR methodology (Kemmis & McTaggart,

2005) various data were collected, including a focus group, observations and field notes, a survey, meeting minutes and workshop reports .

Prior to analysis, I reviewed various arguments related to triangulation. My use of triangulation in this research was not to evoke a univocal truth, but more so as a means to identify differing accounts from community members and health care providers (Angen, 2000). As discussed in the next chapter, the findings from the focus group, survey and existing data were consistent for the most part and saturation in the data was achieved. When saturation was achieved, it provided a strong source of rigour and resulted in reliable findings. By incorporating triangulation, I was also able to identify where community members and health care providers' viewpoints varied. I felt that by considering triangulation in this way, I would be best able to analyze the effectiveness of journey mapping to create the palliative care pathway and identify lessons learned and promising practices.

Member checking.

Following the completion of analysis, member checking (Cresswell, 2013) was conducted to validate the qualitative themes that arose and ensure the voice of the community was accurately interpreted. The Home and Community Care Program Coordinator (EOLFN Community Lead) and the Community Consultant vetted the findings because they were key informants and participated in all of the journey mapping workshops and the focus group. I met with each individually via teleconference to summarize the qualitative findings and asked for their input. Both the Home and Community Care Program Coordinator (EOLFN Community Lead) and the Community Consultant agreed that the findings were an accurate interpretation. In the findings chapter, I introduce a perched eagle figure that I designed to represent the qualitative findings. Both key informants felt the eagle is a thoughtful and appropriate way to represent the findings.

At the end of the teleconference with the Home and Community Care Program Coordinator (EOLFN Community Lead), I made arrangements to hand deliver a final bound copy of this thesis, upon its completion and approval, for distribution to the Leadership Team. The Home and Community Care Program Coordinator (EOLFN Community Lead) also asked for an electronic copy of the perched eagle figure (discussed in the findings chapter) to share with the Leadership Team and community.

A summary of the findings will be provided to the stakeholders that participated in the journey mapping workshops. In addition, open-access to a free practical guide on journey mapping that incorporates many of the findings of the thesis is already available for use by other First Nations communities at www.eolfn.lakeheadu.ca.

Chapter six: Findings

The detailed findings that are presented in this chapter support that all participants, Naotkamegwanning community members and external health care providers, perceived the journey mapping process as effective to create a new palliative care pathway. Having the care pathway developed helped to integrate the services of internal and external health care providers with the community's cultural practices. The journey mapping process was seen as contributing to improved client care in Naotkamegwanning.

However, equally important, there were many learning and promising practices that emerged from the data during the case study research. The Naotkamegwanning community members, the external health care providers and the EOLFN Research Team members all made suggestions for improving the process for use by other First Nations communities. Consistent with the PAR methodology, ongoing changes were implemented over the two years of the journey mapping based on feedback received from participants. There were regular project meetings that allowed for reflection by the EOLFN Research Team and community members about improvements. The final journey mapping guide, created by the EOLFN Research Team as part of the project workbook, incorporated many of learnings and promising practices presented in this thesis research.

Within this chapter, the findings are divided into two sections: (1) findings from analysis of the qualitative data, which include community member focus group findings, meeting minutes, workshop reports, field notes and an OTN workshop video, and, (2) findings from external partner surveys that include both numerical data from rating scales and qualitative data from open-ended questions.

Findings from the qualitative data analysis:

The themes generated from analyzing the qualitative data are displayed visually, a practice which is common among qualitative researchers. Data display helps in the presentation of inferences and conclusions and offers a ways of organizing, summarizing, simplifying, or transforming data (Verdinelli & Scagnoli, 2013). For this thesis research, I sought to tell the story of the Naotkamegwanning journey mapping experience by displaying the data in a symbolic, meaningful way.

The findings are visually represented in Figure 12 titled “Conducting Palliative Care Journey Mapping: Lessons Learned and Promising Practices” which incorporates an eagle perched atop a pine tree. The journey mapping figure adopts the perched eagle as a grounding metaphor to infer that the journey mapping process must be founded in the community’s vision for change. The pine tree represents the EOLFN project’s overall approach based on the principles of PAR and community capacity development. Supporting the foundational theme and infusing up through the pine tree’s branches are the core ethical concepts of conducting journey mapping in First Nation’s communities: “building trusting relationships” and “honouring community control.” At the center of the eagle’s body is the core organizing concept, “Naotkamegwanning palliative care journey mapping.” A thematic map extending from the core out into the body identifies four major themes (closest to the center) and five subthemes that extend outwards into the wingspan. These themes and subthemes represent the lessons learned and promising practices I interpreted from the data.

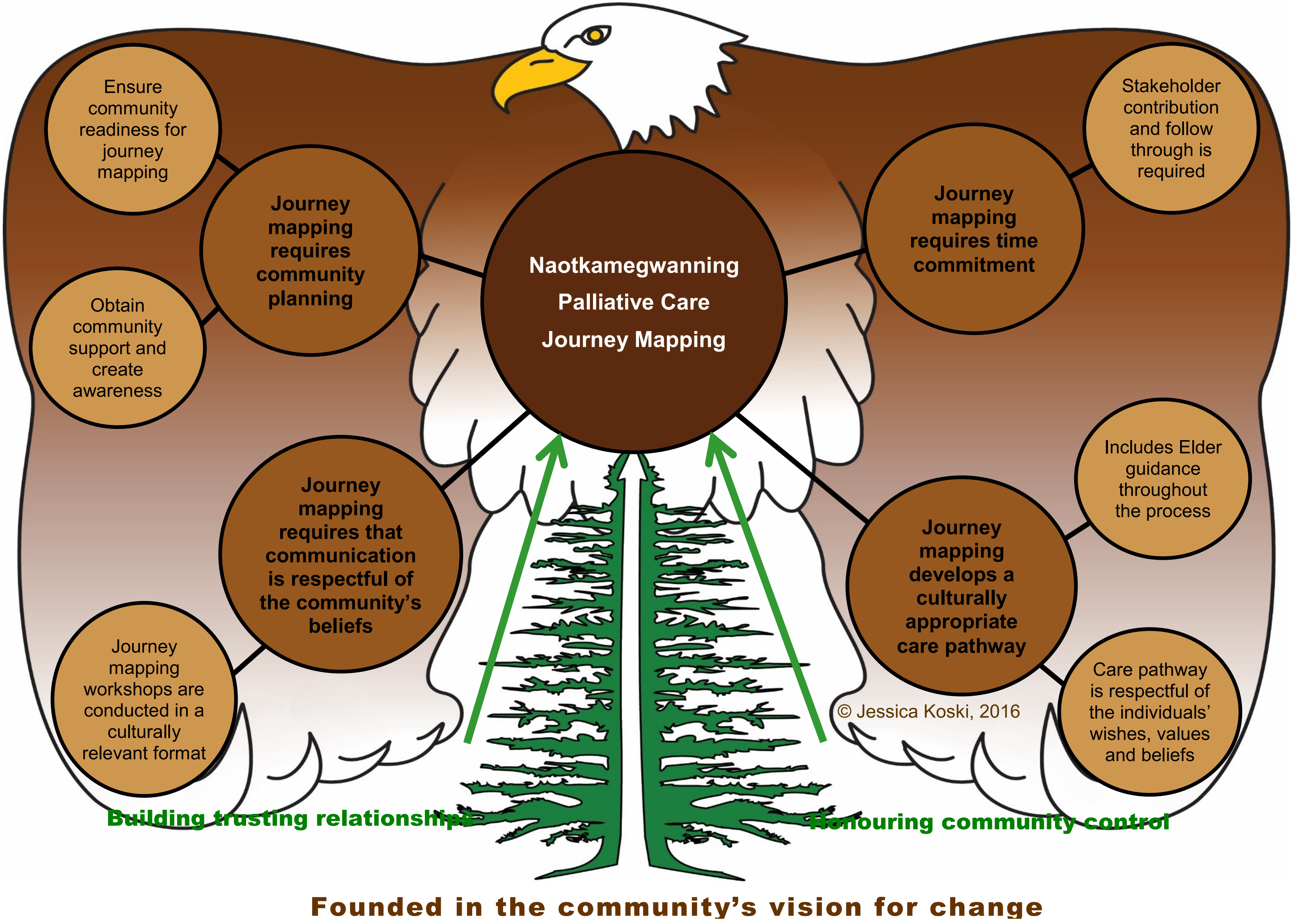

Figure 12. Conducting effective palliative care journey mapping: Learnings and promising practices

The idea to represent the data within the body of an eagle came to me because it is symbolic to the Naotkamegwanning First Nation community and appears in the community's logo. I was also inspired by the visual model used by the EOLFN project, "Process of Palliative Care Program Development" (Figure 1), which is discussed in the Introduction chapter. I feel that my figure is an evolution of the EOLFN model, incorporating the tree image. Throughout the EOLFN research, the Community Leads and Community Facilitators shared stories about the importance of the eagle. As one member of the Advisory Committee, Six Nations of the Grand River Territory explained:

> The pine tree symbolizes the tree of peace. The branches provide protection and the white roots spread in the four directions of the earth. The eagle on top is a spiritual being that warns of impending danger and is a symbol of strength. The eagle watches over all and is a connection to the Creator (EOLFN Research Team, 2015, p. 5).

This quote resonated with me, and provided the inspiration for me to draw the eagle and represent the findings in a unique way. I envisioned the eagle soaring high, close to the Creator. It has the ability to see past, present and future, which is similar to the approach taken during the journey mapping workshops when creating the care path. Community members shared stories from their past experiences, and those examples were used to create the current (present) state which provided the basis for creating the desired (future) state of care. While the themes within the wingspan of the eagle encapsulate all the qualitative themes identified in this research, there is unoccupied space. The space that remains is intentional as it allows room for future research and development of this figure.

Prior to finalizing use of the perched eagle in the journey mapping figure as a representation of the findings, I met with the Lakehead University Elder in Residence, Elder Martin. I offered him tobacco wrapped in red broad cloth, introduced myself, this thesis research, and the eagle figure I drew. I asked Elder Martin if it was appropriate to use the eagle to represent my findings, and he said that it was. He agreed with the description of the eagle's ability to see past, present, and future, explained its relationship with the Creator, and importance in Ojibway culture.

As shown in the journey mapping figure, the qualitative data are grounded by the foundational theme "Journey mapping must be founded in the community's vision for change." . Supporting the foundational theme and infusing up through the pine tree's branches are the core ethical concepts of conducting journey mapping in First Nation's communities: "building trusting relationships" and "honouring community control." There were four major overarching themes that emerged during the analysis phase. These overarching themes include: (1) journey mapping requires community planning, (2) journey mapping requires time commitment, (3) journey mapping requires that communication is respectful of the community's beliefs, and (4) journey mapping develops a culturally appropriate care pathway. From these overarching themes, several sub-themes also emerged which are supported by direct quotes from the focus group participants or field notes. In the sections that follow, each of these themes and subthemes are elaborated and supported by field notes and quotes from my research. Collectively, the themes and subthemes address the research questions as they illustrate the perceived effectiveness of the journey mapping and incorporate the lessons learned and promising practices for future use in First Nations communities.

In the case study chapter, I described each of the four journey mapping workshops in detail and provided an overview of the stakeholders involved in the journey mapping process. In this chapter, I summarize how each journey mapping workshop contributed to the overall creation of the care pathway and describe in detail each stakeholder's contribution during the journey mapping process. Each workshop was analyzed for its contribution to improving system integration, including the barriers and facilitators, key catalysts, and key learnings and promising practices in creating the care pathway. The domains, such as locations, attendees, and allocated time were analyzed as well.

Foundational theme: Journey mapping must be founded in the community's vision for change.

The data supported the idea that the journey mapping process must be founded in the community's own vision for change. The theme, "Journey mapping must be founded in the community's vision for change" is therefore the grounding theme in this thesis analysis. It emphasizes that the community must perceive and articulate expected benefits for its own members before undertaking the journey mapping process to create the palliative care pathway. This idea of grounding every action in community values and principles is also consistent with the community capacity development model "Process of Palliative Care Program Development" that guided all of the strategies to help build community capacity in palliative care.

For Naotkamegwanning, the expected benefits to community members became evident when the following stories were shared at a journey mapping workshop. During this workshop, a community member who was also a local health care provider (HCP) was asked to provide her perspective on why journey mapping is important for the community members and what she hoped they would achieve. She told the following story that she had obtained permission from a client of the Home and Community Care program to share in the research. I documented her story in the following field note:

> The client is frail and elderly with adult children that work, so the client has been transported around to their children's homes, in town (Kenora) and in the community (a

> 120 km distance) because they work. The Home and Community Care Program has done its best to support the client Monday through Friday, 9:00 a.m. to 5:00 p.m., but that is not very helpful to the family. If someone could provide after-hours care and go stay with the client in the client's home, that would be more beneficial to everyone.
>
> [Community member HCP; Journey mapping workshop #3; Field note]

The community HCP shared three more examples that illustrate the motivation for the journey mapping (below). The first indicates that keeping clients at home for as long as possible is valued by the client, family and community even if the final outcome is a hospital death. The second is an example of a community member that could have benefited from local palliative care services but was unnecessarily transferred to hospital at the end of their life. The third expresses her desire to develop a local palliative care program and her belief that dying at home in a rural area is possible.

> There was one client in the past that wanted to pass at home, and they tried their best to make the client's wishes come true, but with different policies and mandates, the client died in the hospital. They were able to keep the client in the community as long as possible, so that was a good thing. [Community member; Journey mapping workshop #3; Field note]

> There was another client that recently passed. At the service the visiting physician whispered to me, '(name of client) could have passed at home; that client should have passed at home.' The community HCP was not sure at the time why the physician said that, and indicated that follow-up would be necessary to determine why the client went to the hospital at the end of life. The HCP reflected that often the family panics when their

> loved one approaches death, but it could also be due to inadequate services in the community, or other reasons. [Community member; Journey mapping workshop #3; Field note]

> *"I know it [home death] is possible".* The community member shared that they have heard success stories – one in particular about a rural man with cancer, and he was able to get a hospital bed and had various care providers coming into the house, and he was able to pass at home. "*So if it can happen, why can't it in Whitefish [Naotkamegwanning]? Why is it so difficult for that to happen in our community?"* the community member asked. [Community member; Journey mapping workshop #3, Field note from OTN video]

A member of the EOLFN Research Team added the following comments related to why clients should have a choice to die at home:

> *Last year four clients in Naotkamegwanning passed away, all in the hospital, and this year three clients from Naotkamegwanning passed away, all in the hospital; I am not saying that all of the people wanted to die at home, but some of them did want to die at home, and that wasn't a possible option. In other words, 100% of clients in Naotkamegwanning First Nation die in the hospital. The whole goal is to make it [home death] a possible choice. The federal government is trying to implement a national palliative care strategy, the goal of which is people have a choice.* [Research team member; Journey mapping workshop #3; OTN video]

To summarize the importance of the foundational theme, the journey mapping to create a palliative care pathway was motivated by community members' vision for change. Journey mapping was not viewed as a standalone process or isolated event. Consistent with the community capacity development model (Figure 1) the events described in the field notes were catalysts for change that lead to the creation of a community vision, and that vision guided the entire journey mapping process. For Naotkamegwanning First Nation, the vision for change was that community members wanted the option to receive palliative care at home in their community so that it was grounded in their culture and traditions. They know this vision is possible to achieve if adequate supports (after-hours care, community-based services and funding) are in place. Community members saw the journey mapping as one strategy to achieve their vision.

Core ethical concepts of conducting journey mapping Naotkamegwanning First Nation

Building upon the foundational theme, two core ethical concepts were identified in the data: (1) building trusting relationships, and (2) honouring community control. These ethical concepts infuse up through the branches of the pine tree and are prerequisites prior to conducting journey mapping.

Building trusting relationships

As identified and summarized from the three workshop meeting minutes that involved external health care providers, each journey mapping workshop began with an introduction by the workshop facilitator that emphasized the importance of focusing on the community needs during the journey mapping sessions. This introduction was then followed by a story from one or more community members as to why journey mapping and creation of the care pathway was important for their community. The workshop facilitator then invited all workshop stakeholders to introduce themselves. Following introductions, ground rules were set and goals and expectations were discussed as a group.

These relationship building activities were documented in the following excerpt from the workshop meeting minutes.

Ground rules were established:

- Consider the two-eyed seeing concepts
- Silence phones/take calls outside
- One speaker at a time
- Stick to start/end times and take breaks

Our goals are to:

- Create a plan,
- Implement it,
- Document the outcomes,
- Evaluate the process,
- Demonstrate lived experiences in the community, and
- Bring the results/outcomes/findings forward to LHIN

Expectations were discussed:

- Focus on the community; listen to and hear the needs of the community
- Build relationships in the community
- Be aware roles may stretch
- Develop a recommendation model

[Journey mapping workshop #2; meeting minutes]

These activities began to build relationships between community members and health care providers, however, community members expressed they had felt intimidated by the external health care providers. The following quotes provide evidence:

Another journey mapping session that we had was at the hospital. Maybe you [Elders] want to talk about that 'cuz uh, I again, I can sense (laughs) something from you guys [Elders] at that time. [Community member; Focus group]

I guess it's just, for me it was just the people (external health care providers) that were there. Nothing bad, it was just their intimidation, I guess. They're just, we know they're *really smart people, and ya know, what do I have to offer kind of thing (laughs).* [Elder; Focus group]

The ideas expressed in the previous conversation alluded to communication challenges associated with professionals and the long lasting effects of colonization which resulted in a sense of disempowerment. Two Elders also mentioned that at times they felt they weren't listened to. These ideas contradict the findings from the survey of external health care providers, in which 100% of respondents felt the "*voice of the community members was respected and the views of the community members were incorporated. Most felt that their own voice was also heard in the workshops."* Therefore the lesson learned for future journey mapping is that building trusting relationships is essential.

Because the community had been working with the research team two years prior to conducting the journey mapping workshops, a trusting relationship between the community and research team was already in place. Abandoning the value stream mapping strategy in Workshop #2 and instead adopting a more culturally appropriate story telling approach as previously described also strengthened the trust. When the value stream mapping format and terminology was abandoned, it became the turning point of the workshop.

Honouring community control

Prior to engaging in journey mapping workshops, individuals external to the community – both researchers and health care providers- must ensure community control is honoured. The overall EOLFN project, which embraced a PAR methodology, community capacity development and the principles of OCAP®, ensured full community involvement and honoured the community's control. This was evident by the role of the Leadership Team that was established in the community and by the community. The Leadership Team provided local control and guidance of the research being conducted in the community and determined who would be included in the journey mapping. The community maintained copies of all of the project reports and summaries, however, they chose to have the raw research data stored and managed at Lakehead University by the EOLFN research team. All the primary and secondary data used in this thesis are being stored consistent with the Lakehead University Research Ethics Board policies as described in the research ethics section of this thesis.

The importance of this ethical concept became evident during the value stream mapping workshop (journey mapping workshop #2) when it was identified that the value stream mapping approach was not resonating with community members and a storytelling approach was adopted instead. It was at that time community members requested that no typed notes be taken during the discussion while they shared cultural practices and traditions related to the end of life. However, it was agreed upon that I could draw a diagram during this time as long as traditional practices were not included. The following field note demonstrates evidence of this respect of community control.

> The majority of the discussion for day two is found in the attached care path diagrams. At the request of the community laptops were put away and notes were not taken during this discussion, rather an open group dialogue was preferred. I drew out a high-level flowchart of the process being discussed, but I did not document any traditional practices that were discussed. [Field note; Journey mapping workshop #2]

The remainder of this section describes the four major themes that are included in the journey mapping figure and the six subthemes and support them.

Theme one: Journey mapping requires community planning.

The first major theme to emerge from the qualitative data was that journey mapping requires community planning. The community learned that the journey mapping process required substantial preplanning to undertake the overall process. Additional preparatory planning was needed prior to each of the journey mapping workshops. Planning needed to include community-based planning and engaging people and organizations outside of the community. Planning needed to be led by the Project Advisory Committee, the Leadership Team and Community Lead and/or Community Facilitator.

Sub-themes emerging from this major theme were to: (1) ensure community readiness for journey mapping, and (2) obtain community support and create awareness.

Ensure community readiness for journey mapping. As documented in multiple field notes, prior to conducting the journey mapping workshops, there was hesitation from some of the Elders on the Leadership Team to actively participate in the project due to cultural teachings that prevent discussing or planning related to death and dying. The Home and Community Care Program Coordinator (EOLFN Community Lead) was also hesitant to draw attention to the research at first because the feeling in the community was that the project led to discussions about death and palliative care. This reluctance resulted in fragmented and insufficient preplanning which negatively impacted the initial workshop. During the focus group community members and Elders identified preplanning activities that would have been beneficial to ensure readiness for the journey mapping workshops. Once the Leadership Team began using the term Wiisokotaatiwin (taking care of each other), they became more actively involved and the journey mapping process progressed more effectively.

Focus group participants agreed that internal community planning is the first step in the journey mapping process. Participants felt "[journey mapping] should have started from [within] the community instead of inviting all our external health care providers first." In the following quote, a focus group participant indicates that the community should have done more preplanning by determining what services were in place prior to inviting external health care providers:

> *…I think that we should've started within our own health services all our, our team, and see what services […] we access, like mental health access or another group of, um, resources, might have another group, you know, we should've sat together and did that.* [Community member; Focus group]

Meeting organization was required to prepare for the four journey mapping workshops. For Naotkamegwanning, EOLFN Research Team members worked side-by-side with the Community Lead to arrange meeting space, catering, handouts, workshop supplies, and coordinate specific dates and times to accommodate the largest number of participants. Planning for the journey mapping workshops included preparatory teleconferences with the Home and Community Care Program Coordinator (EOLFN Community Lead), Community Consultant and members of the EOLFN Research Team, including the Principal Investigator, Project Manager, Project Coordinator and Research Assistant. During these teleconferences we discussed the logistics of the journey mapping workshops, documented actions items, discussed who would do what and made a plan for next steps. Each preparatory teleconference, with the exception of the value stream mapping workshop #2, was one hour. Preparation for the value stream mapping session required a series of three one to two hour teleconferences with the consulting group from Toronto. The first teleconference was a discovery call led by the Principal Investigator and Community Facilitator to introduce the project and community context to the consultant. The second teleconference was led by the consultant and the concepts of lean were discussed. The third teleconference was a group discussion about logistics and we reviewed the proposed agenda for the journey mapping workshop. Following the preparatory teleconferences, any clarifying questions or follow-up on task items were discussed via email exchange.

The following conversation demonstrates an example of the logistics involved in preparing for the journey mapping workshops, and the recommendation that other communities can streamline the journey mapping process based on the lessons learned from Naotkamegwanning's experience:

> *I'm hoping that the toolkit that we create, will kind of, not eliminate that step (extensive planning for the journey mapping), but make it easier for that community…You know, this is what Whitefish did, we don't want to do it exactly how they did it, but […] we can do this part this way…You know what I mean?* [Community member; Focus group]
>
> "Streamline it." the Community Consultant replied.
>
> *For their own community […] because the journey mapping part of it […] took a lot of time and it took a lot of work to get the people together […] how much people did we have at that first session?...Like um, 20 people, our health care providers…And we had to…make sure that everybody was available for that date, ya know?* [Community member; Focus group]
>
> "And that took planning…" the Community Consultant added.
>
> *And that was, to make everybody available.* [Community member; Focus group]

During the journey mapping process, there were three groups that moved the process forward. Each contributed to the planning for the journey mapping in a unique way. The Leadership Team moved the process along internally within the community by carrying out the recommendations from the workshop reports. The EOLFN Research Team supported the planning for the journey mapping workshops; documented the workshops, and provided workshop reports following the journey mapping. The stakeholder working group, which carried out tasks assigned during the journey mapping workshops.

Obtain community support and create awareness. Focus group participants discussed the Wiisokotaatiwin (palliative care) Program, and the importance of getting community support for palliative care and creating awareness about what is being done. All focus group participants felt it was important to have community support prior to the development of a palliative care program, however participants had varied feelings on how the progress of the program, including journey mapping and development of the care path, should be shared with the entire community. Some participants felt the program should not be shared with the community until it was up and running, while others felt they could have benefited by being informed as the development of the program and care path progressed.

Focus group participants discussed the significance of the community understanding that the Wiisokotaatiwin Program is "what we used to do back in the day for each other" and that it is not planning for death.

The following quote indicates the need for promoting community awareness when the palliative care initiatives were implemented in the community. It illustrates the lack of understanding of some community members:

> *When they ask me about 'what's [the Wiisokotaatiwin] program about?' Like, [EOLFN Community Lead] trying to do…and they're like is [EOLFN Community Lead] talking about death? And I'm just like 'No! [The EOLFN Community Lead is] talking about keeping us home longer.' Because, I, I'm 41. I'm going to be up there in 20 years and I*

> *want to stay home as long as I could, and that's what [the Wiisokotaatiwin] program is starting. That's what I'm trying to explain to them.* [Community member; Focus group]

As one community member explains in the following quote, the Wiisokotaatiwin (palliative care) Program and its related initiatives, such as journey mapping, needed to be described to community members in an appropriate way so that they understand the benefits and purposes.

> *…It's about how we care for that person, because we have home care clients, and we like, go visit them every day, ya know, like every week, and monitor, health monitor and make sure they're ok.*
>
> *…But, with the Wiisokotaatiwin program, it's more compassionate, more, more, there for you, NOT (emphasized) the illness, we're there for you, we're not trying to cure your illness, we're trying to make you as comfortable as possible, and, it's not a failure if you do go in hospital, […] that's still ok, but while you're home, we're going to take care of you the best we can…* [Community member; Focus group]

Another community member added an example related to enhanced home care services in the community made available by the Wiisokotaatiwin program pilot funding from the NW LHIN:

> *For me, it's like if somebody says I'm ill, I, don't wanna be in hospital, I wanna be home, you know, it's like, ok we can do that, we have the money (pilot funding) now, we have the resources, we have the, like the staff, we have respite care, like if your family needs a break we'll have somebody there for your, so that you can, your, your caregivers can go out shopping for you while somebody takes care of you, and is trained and understands the program, knows how to take care of you and, and then your family will be at, at ease,*

> *they won't have to worry they don't have to be stressed, you know, you're loved one will be taken care of, like how YOU (emphasized) take care of your loved one. So it's just, um it's not palliative care to me, I always say it's not about death and dying, it's about how you provide that care to that person. That's, I, I always try to explain it the best I can. Palliative just DESCRIBES (emphasized) the care.* [Community member; Focus group]

This community member shared story from another community member who had heard about the program, and how that community member feels about palliative care:

> *And this one [community member] shared with me, um, the [community member] said my mum doesn't want to go hospital, we don't want her to go to hospital, so I'm going to take care of her like she took care of me. So that's kind of how I, I like to think of it too.* [Community member; Focus group]

The community member continued with an additional story related to community awareness:

> *As [Wiisokotaatiwin program] employees, and that's how I wanna like, kind of not be the family, but be that support for the family, because the family and the caregivers need that help too. Like you (points to Elder) and the other family members who are taking care of these other, [...] people that we've felt that needed these enhanced services. So this Wiisokotaatiwin is not just taking care of that individual, it's taking care of the family.* [Community member; Focus group]

Once community members and Elders from the Leadership Team understood the program in familiar terms, they became more actively involved in the Wiisokotaatiwin Program development and started talking about it within the community which created awareness. This was valuable because communication about the Wiisokotaatiwin Program and the journey mapping initiative was done face-to-face, by word of mouth, in familiar and appropriate terms.

Theme two: Journey mapping requires time commitment.

Evidence related to journey mapping requires commitment was emphasized in focus group data, field notes, observations, and meeting minutes. The sub-theme of this major theme was: stakeholder contribution and follow through is required.

Focus group participants stressed that "the journey mapping process takes time and other communities should be aware of that." Participants spoke to the fact it takes time to figure out who should be involved, develop a stakeholder working group, schedule workshops at times convenient to everyone, and prepare for the workshops. In term of developing the palliative care pathway, participants said, it takes time to understand other organizations' internal protocols. They also said it takes time for the external partners to discuss the activities of the stakeholder working group internally within their organizations with management and carry out the tasks assigned during the journey mapping workshops. It is important for the stakeholders involved in journey mapping workshops to be aware of the required commitment. In Naotkamegwanning the process took two years.

As demonstrated in the following quote, one community member spoke to the lessons learned related to the time commitment associated with journey mapping:

> *…And we only slotted one afternoon, we thought we were going to have it complete that afternoon, and then we found that, that wasn't realistic (laughs) because we had the doctors there, we had CCAC there, we had everybody there, but then everybody started giving their input and it kinda, we realized that it wasn't going to take an afternoon and that's when we booked that other one […] for the two days.* [Community member; Focus group]

When focus group participants were asked what they would change about the journey mapping process, the length of time the journey mapping took was identified as a something the community members would change. One community member said "Put it in two days, not two years…"

As the care path was developed during the journey mapping workshops, questions arose that often required the stakeholders to review their internal protocols before providing an answer. This took time to do and the community learned that journey mapping could not be done in one workshop. The following quote provides evidence to these concepts:

> *I mean we could sure do it a lot quicker, […], 'cuz you know we had a hard time trying to figure out how best to get those partners, […] that's one thing I think that um, we learned, it does take time, I mean […] ya know, we, uh, wouldn't have to scramble like we did, it doesn't need to take what we did, but […] some of those things you can't just do in two days because you can make the plan, but all those people have to go back to their own organization, back to their own community and find out… Here's an example: There's an issue about maybe if someone is on narcotics, like storing those drugs in the house, what are we going to do to solve that because lots of families don't want to have narcotics in the house, it's not necessarily safe…ya have to have periodic meetings so that people have time in the middle to go back to their own organization and their own places of work and make sure that the place of work is able to accommodate, what we'd really like to, do you know what I mean?* [Community consultant; Focus group]

Findings from the focus group were supported by data from my field notes and the workshop meeting minutes. Time was identified as an issue during the journey mapping workshops in two distinct ways: (1) lack of time during the journey mapping workshops, and (2) the length of time required to complete the journey mapping workshops, create and implement the care pathway.

During the journey mapping workshops, it took considerable time to discuss each of the nine stages of the care pathway and various possible scenarios that the client might experience during their progression through the care pathway. Facilitators needed to follow the workshop agendas and allocate strict time limits for discussion on each topic. Sometimes when the stakeholder working group was gaining momentum or making progress on a certain aspect of the care pathway, we would run out of time for that topic and need to move on. In other cases, there were times when certain paths could not be complete, because it required a member of the stakeholder working group follow-up within their organization on protocols, policies, or procedures. Follow-up via teleconferences or email was then required to make additional progress. That being said, time was utilized most productively when the stakeholder working group was face-to-face.

Time in regards to duration to complete the care pathway was also a barrier, in that the entire process took over two years from the first journey mapping workshop to the time that the care pathway was implemented in the community with clients requiring palliative care. While this was a barrier identified by both community members and health care providers, there were several processes and procedures that needed to be worked through by the clinical team in order to complete the care pathway and prepare for its implementation. For example, there were several versions of a comprehensive client assessment form being used to determine the client's needs and it was desired to have one common form if possible. The hospital had its version, the community nursing providers had their version, and the Home and Community Care Program had their version. This is one example involving the clinical team having to work out an agreed upon process before moving forward with an additional journey mapping workshop or implementation of the care pathway.

The contribution of each workshop is summarized in Table 7 below.

Table 7. Journey mapping workshops 1- 4: Contribution to the lessons learned in creation of the care pathway

Workshop One **Introducing the journey mapping process and engaging stakeholders**	**Workshop Two** **Value stream mapping**	**Workshop Three** **Finalizing the care path and next steps**	**Workshop Four** **Including cultural components in the care path**
Focused on bringing together community members, internal and external health care and service providers and the research team for the first time. Commitment to the journey mapping process from the stakeholders was established and the group began to identify areas for improving communication and service integration among themselves that would improve the experience for the residents of Naotkamegwanning First Nation. Stakeholders committed to attending future journey mapping workshops and understood the goal of the journey mapping workshops was to create a palliative care pathway.	Reunited existing stakeholders and introduced new stakeholders that were not present in workshop one, creating a more robust group of community members, internal and external health care and service providers and research team members. The value stream mapping format and terminology was attempted and then abandoned. Implementing the philosophy of the two-eyed seeing approach (Iwama, Marshall, Marshall, & Bartlett, 2009) was introduced as a way to integrate the expectations of both the community and health care providers.	Reunited the stakeholders and introduced the care path flowchart, discussed and agreed upon next steps. The linear care path developed based on previous workshops was validated by the other stakeholders. The roles and activities of each stakeholder at each stage of the care pathway was discussed in detail and documented. The community informed the external partners that they would not be involved in stages six through nine because those steps are private to the community. It was determined that the next steps for the stakeholders would involve follow-up teleconferences to review a work plan in order to implement the care path.	Workshop four was private to the community involving only members of the leadership team, the community consultant and me as a graduate student. There were no external health care providers at this meeting as the focus was on the internal community roles and activities. The care pathway evolved from a linear process to a circular diagram identified as the nine stage Wiisokotaatiwin Program care pathway. A draft of stages six through nine was created and documented during this workshop.

Stakeholder contribution and follow through is required

Data from my field notes, observations and the workshop meeting minutes supported the subtheme that stakeholder commitment is essential in the journey mapping process. The following findings relate to the contribution and follow through of the stakeholders involved in the journey mapping workshops.

The role of the stakeholders in the journey mapping process was to meet face-to-face, provide background on their role or position within the community, external agency, or member of the EOLFN Research Team and establish rapport to form a stakeholder working group.

Stakeholders that participated in the journey mapping were individuals that represented the following organizations or groups: Naotkamegwanning Home and Community Care Program, Naotkamegwanning Leadership Team members, First Nations Inuit Health Branch nursing provider agency (professional nursing agency), District Hospital, Regional Community Care Access Centre, Aboriginal Health Access Centre, Regional Hospital – Telemedicine Nurse Hospice Palliative Care, Home and Community Care Program First Nations and Inuit Health Branch – Ontario Region – Health Canada, Regional Health Sciences Centre, Regional Cancer Centre, a community doctor and three members of the EOLFN Research Team, which included the Principal Investigator (my thesis supervisor), the Research Coordinator and me in my roles as a Research Assistant and Graduate Student Trainee.

The contribution of the stakeholders consisted of: attending the journey mapping workshops, discussing and working through the gaps and barriers to create a desired state of care (palliative care pathway), providing clarity to the mandates of their organization/agency, introducing the journey mapping process within their organization/agency, and creating a palliative care pathway for Naotkamegwanning First Nation. Stakeholders have been identified in Table 8 by team name or title, members and description, and their activities and tasks.

Table 8. Journey mapping participants

Team name/Title	Member(s)/description	Activities/tasks
Stakeholder Working Group	All participants involved in the journey mapping workshops	The stakeholder working group was responsible for attending and actively participating in the journey mapping workshops, doing assigned homework and bringing the results back to the group, and introducing the work being done within their organizations. This group was formed in August 2013 and remained in place through the completion of the journey mapping workshops in October 2014.
Naotkamegwanning Clinical Team	Internal and external health care providers that provide palliative care in the community	After the nine stages in the care pathway were created, the Clinical Team was formed. The Clinical Team created and documented protocols related to the palliative care pathway that were identified during the journey mapping workshops and based on a work plan[8]. Some of the protocols developed were: revised palliative care assessment forms; improved communication via the in-home chart; a step-by-step process for case conferencing; inclusion of the circle of care during creation of the care plan, and coordination of grief and bereavement services for care givers and families after the client has died. This group was formed in November 2014 after the journey mapping workshops were complete.
Naotkamegwanning Leadership Team	Elders, knowledge carriers, Chief and Council, the Home and Community Care Program Coordinator (EOLFN Community Lead), the Community Facilitator, the	Oversaw the progression of the journey mapping and ensured local control was maintained throughout the process. Each of the three journey mapping workshops that were conducted with the external partners required prior preparation by members of the leadership team. The leadership team ensured that tasks assigned to the clinical team were accomplished and followed-up on when necessary.

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[8] At the end of workshop four, in my role as a Research Assistant, I worked with the Home and Community Care Program Coordinator (EOLFN Community Lead) and Community Consultant to create a work plan that guided the tasks necessary for each stakeholder organization/agency. This was a very time consuming process that took three people 20 hours to complete. Once the work plan was finalized a series of clinical team teleconferences were arranged and facilitated by the EOLFN principal investigator and Project Manager, that included me, the Home and Community Care Program Coordinator (EOLFN Community Lead), Community Consultant and specific stakeholder organizations/agencies. The goal of the teleconferences was achieved because the external stakeholders committed to the tasks in the work plan which allowed for implementation of the palliative care pathway that was created.

Team name/Title	Member(s)/description	Activities/tasks
	Community Consultant, and internal health care providers that provide palliative care in the community	
Home and Community Care Program Coordinator (EOLFN Community Lead)	The Community Lead was also the Community Facilitator and the Naotkamegwanning Home and Community Care Program Coordinator (EOLFN Community Lead)	In this thesis the Community Lead is identified as the: Home and Community Care Program Coordinator (EOLFN Community Lead) The Home and Community Care Program Coordinator (EOLFN Community Lead) liaised between the stakeholder working group, the leadership team, the clinical team, the EOLFN Research Team and the Home and Community Care Program to ensure the journey mapping workshops and palliative care pathway were consistent with the goals of the leadership team and community. Prior to each journey mapping workshop, the Home and Community Care Program Coordinator (EOLFN Community Lead) would work with the EOLFN Research Team and Community Consultant via teleconference to discuss the agenda and handouts, ensure the appropriate stakeholders were invited, coordinate logistics, and determine necessary supplies. The Home and Community Care Program Coordinator (EOLFN Community Lead) would then survey the stakeholders to determine a date and time for the workshop and communicate the date and time when most stakeholders were available to attend the workshop back to the EOLFN Research Team. Once a location had been secured, the Community Lead would communicate that to the stakeholder working group. The Home and Community Care Program Coordinator (EOLFN Community Lead) co-facilitated or facilitated each of the journey mapping workshops with the exception of the value stream mapping session. Following the introductions in the journey mapping workshops, the Home and Community Care Program Coordinator (EOLFN Community Lead) would share why journey mapping to create the palliative care pathway is important to the community and invite community members to share stories about their family members' experiences. Following each of the journey mapping workshops, the Home and Community Care Program Coordinator (EOLFN Community Lead) worked with the Community Consultant

Team name/Title	Member(s)/description	Activities/tasks
		and Leadership Team to prioritize and complete the tasks that were identified in the journey mapping workshops.
Community Consultant	Due to the multiple roles and heavy workload of the Home and Community Care Program Coordinator (EOLFN Community Lead) held, the EOLFN project hired a Community Consultant to assist the Community Lead with the development of the Wiisokotaatiwin Program. The Community Consultant is a retired registered nurse that had previous program development experience in rural and remote Northwestern Ontario communities.	The contribution of the Community Consultant was to provide assistance and support to the Community Lead in implementing the palliative care path which was necessary to establish the Wiisokotaatawin Program Provide expertise related to rural and remote palliative care program development. The Community Consultant attended all leadership team meetings in the community and teleconferences with the EOLFN Research Team to prepare for the journey mapping workshops. The Community Consultant contributed her previous expertise as an RN and experience in program development to assist in guiding the community and Leadership Team between journey mapping workshops.
EOLFN Research Team	The EOLFN Research Team involved in the journey mapping workshops included the Principal Investigator, Project Manager, Interim Project Manager, Research Coordinator, and myself in dual roles as a Research Assistant and Graduate Student Trainee.	Prior to each journey mapping workshop, preparation teleconferences would be held with the EOLFN Research Team, the Community Lead and the Community Consultant. During the teleconferences we created the workshop agenda, determined appropriate handouts for the workshop packets, ensured the appropriate stakeholders were invited to the workshop, discussed possible workshop dates and locations, and determined necessary workshop supplies. In my role as a Research Assistant, I was responsible for taking meeting minutes during these preparatory teleconferences.
Members of the EOLFN Research Team that attended the workshops in person are described in detail below. This section describes the EOLFN Research Team members' role during the workshop only and does not include the preplanning or post workshop activities which have already been described.		

Team name/Title	Member(s)/description	Activities/tasks
EOLFN Research Team	Principal Investigator	During the journey mapping workshops, the contribution of the Principal Investigator was to lead and oversee the research activities, including co-facilitation of the workshops. In the three workshops that involved external stakeholders, the Principal Investigator introduced the EOLFN project, read the information letter (when there were new attendees) and asked new participants for their consent. In addition, the Principal Investigator provided an update on the progress since the previous workshop to the stakeholder working group.
EOLFN Research Team	Research Coordinator	During the journey mapping workshops, the contribution of the Project Coordinator was to prepare and present updates to the stakeholder working group on the overall progress of EOLFN project, assist the Principal Investigator in obtaining signed consent forms, and track time during the workshops to assist the workshop facilitator(s) with progression through the agenda. She also assisted the facilitators by observing participants' relational dynamics and identified any issues with engagement or lack of understanding so they could be brought to the facilitator's attention and addressed.
EOLFN Research Team	Research Assistant	During the journey mapping workshops, my role as a Research Assistant was to take meeting minutes, record attendance, take pictures and document observations and field notes.

Theme three: Journey mapping requires that communication is respectful of the community's beliefs.

Focus group participants from Naotkamegwanning indicated that culturally appropriate communication that was respectful of the community's beliefs was very important and therefore should be incorporated throughout the journey mapping process. The importance of communication was evident from my observations and field notes. The issue of language, finding the right words to use, was the focus of much discussion during the focus group and during the journey mapping. It was a major role for the Home and Community Care Program Coordinator (EOLFN Community Lead) to explain the concept of palliative care in a culturally appropriate way. The sub-theme of this major theme was that it requires journey mapping workshops are conducted in a culturally relevant format.

Focus group participants agreed that it is not in their culture to plan or talk about death. Use of the word palliative is not acceptable to the Elders and there is no translation in the Ojibway language for the term palliative. The Naotkamegwanning Leadership Team chose the Ojibway word "Wiisokotaatiwin" as the name of the community's palliative care program. The community describes "Wiisokotaatiwin" as "taking care of each other." Focus group participants agreed that other words (not palliative) should be used at all times.

The following conversation between an Elder and a community member HCP during the focus group provides supporting evidence that use of the word palliative was not culturally acceptable:

> *I think this is one of thee, uh, the fear of the warriors, especially Anishanabe when you talk about death. You don't talk about death, not a little bit… There's a word that you can find, that you're gonna be taking care of, you're gonna be looked after… There's a*

> *way that you can find without using that word. And it's, uh, real appropriate to Anishanabe people.* [Elder; Focus group]
>
> *That's why we tried […] why in the beginning we said we don't use that term, palliative, so in the beginning we changed it to Wiisokotaatiwin.* [Community member; Focus group]

One Elder acknowledged an increased understanding about the meaning of palliative care based on personal experience. The following quote provides insight:

> *Yeah. Just gotta […] change it over in your mind. What it's all about and, and uh, I'm looking after my mother, she's 86, and uh, I'm understanding just working with her, taking care of her, I'm starting to understand it more. Especially yesterday when I panicked, I wasn't home to give her supper and her medication, and (the Home and Community Care Coordinator) already had somebody there to do that, so um, that was really GOOD (emphasized). So we've always been careful about using that word. [Elder; Focus group]*

The following conversation provides additional evidence about how the community thinks of palliative care, and that community members have been careful about the terminology:

> *And, […] it's about making life as comfortable and as good for that person […] as it can be. The way that they and their family choose.* [Community consultant; Focus group]
>
> *Yeah, but I think we've all, we've been really careful about that since we, well since I've been involved.* [Elder; Focus group]

Focus group participants acknowledged how difficult the topic of death and palliative care were to discuss. As documented in my field notes, when one participant mentioned their struggles with these topics, the entire focus group nodded in agreement and several participants said “yes” or “mhm” to confirm they concurred. One Elder added the importance of understanding the program and what it’s about:

> *About using that word, I think, I kind of struggled with it, I was kind of, ‘oh, I don’t know’, and then you (points to community member) would explain it again, then I would… ‘ok, that’s what it’s about.’ You explained it really well that one time in Whitefish. I think that’s what changed my mind about it ‘cuz I was kind of thinking, uh, I’ve always had this, uh, of stepping down from the leadership team, or from the program because of what I understood about it, again and I was only thinking palliative care.* [Elder; Focus group]

The following field note also provides clarity on the way that one community member thinks about the time when a person decides to come home from the hospital, or stay at home.

> The community member stated “we are not talking about end-of-life, we are talking about the moment when they decide they want to come home.” [Community member; Journey mapping workshop #4; Field note]

Focus group participants shared that in their culture, they are taught not to prepare for the worst, meaning they are taught not to prepare for death.

Some participants felt planning for one’s death or discussing death and dying are culturally taboo, and some community members believe it can be detrimental. Evidence of this perception is demonstrated in the following quote:

> *…The reason why I say that ‘cuz we were doing all this planning and speaking about all, all this stuff what could happen, or what, ya know, bad stuff…and in the meanwhile there’s like, a bunch of funerals happening. And we should have just been more mindful of what we were doing, at the same time, and had that guidance that whole time. So,*

> *that's kind of, you know, 'cuz this is real hard stuff to talk about and deal with.*
>
> [Community member; Focus group]

Journey mapping workshops are conducted in a culturally relevant format

The language and approach used in the workshops to discuss the client journey and create the care pathway also needed to be culturally relevant. The importance of this was evident during workshop #2. A Toronto-based, Lean Sigma Black Belt facilitated workshop #2. This workshop facilitator used value stream mapping terminology and lean-based concepts that were unfamiliar to Naotkamegwanning community members, such as SIPOC: suppliers, inputs, process, outputs, customers, and current state, future state, micro and macro steps, push and pull, flow, and establishing the value stream. Community members disengaged from the workshop process gradually over the day. As identified earlier, focus group participants indicated that community members shut down and value stream mapping simply did not work.

The following field note identifies the challenges encountered during the value stream mapping workshop:

> It was evident early in the process that the value stream mapping tool was not the correct tool to extract the necessary information. The process of mapping out detail and speaking/planning for death was not synonymous with First Nation culture. While we had a room of attendees eager and available to participate, another series of tools needed to be utilized to draw out the required information.
>
> The approach was then changed [for day two] to reflect more of an open discussion that integrated the expectations of both the community and the health care providers. Health care professionals and representatives from the community both had the opportunity for

> input into the discussion. Specific facilitated exercises were used to pull information from the team. [Field note; Journey mapping workshop# 2]

To an Elder, the value stream mapping style workshop and facilitation style seemed hurried. This is demonstrated in the following quote:

> *Yeah, it was really fast that first day, like we had all that stuff on the wall like bang, bang, bang. Ya didn't have time for it to soak in. Ya know?* [Elder; Focus group]

According to one community member, *"...I found that you guys (Elders) shut, you kind of shut down and you kind of, the way that it was being facilitated that day, it didn't, it wasn't familiar to us."*

This idea was also supported with the following field note:

> During the break a EOLFN Research Team member was outside chatting with the Elders. The EOLFN Research Team member asked them how they felt the session was going, mentioning they were quiet and not participating. The Elders said that the words being used and facilitation style are not familiar. One Elder felt overwhelmed. [Field note; Journey mapping workshop #2]

Focus group participants felt that communication in the workshops was difficult periodically for various reasons. While some participants felt they weren't listened to at times, others felt intimidated by the external health care providers. In addition, participants discussed that communication was challenging when unfamiliar terminology was used, such as that included in the value stream mapping workshop.

The following conversation demonstrates that Elders disengaged during the value stream mapping workshops:

> *Do you remember how, like that (value stream mapping session) went for you guys (Elders)? What your thoughts and feelings about that session? Because I was saying, like that morning, we could sense like you guys weren't too involved, you guys seemed kind of, I don't know how to say it…* [Community member; Focus group]

"I was overwhelmed." an Elder replied.

> *But then in the afternoon…or the next day, it was more workshop-like. So you could talk more freely. When you guys started to open up and share.* [Community member; Focus group]

> *That's when we had [the doctor] in there…and that's probably why we shut down (laughs).* [Elder; Focus group]

Focus group participants established that the value stream mapping session, simply "didn't work."

> *I think we learned from that one (value stream mapping) that […] that facilitator, that whole process with Toronto just didn't work very well. Did it? When we just sort of worked, um either just leadership team or with the care providers and just kind of used common sense, it just seemed to go better, I think, from my point of view.* [Community Consultant; Focus group]

The journey mapping workshops were impacted by community events and cultural practices. Focus group participants discussed how events that took place in the community affected the entire community. For example, prior to the second journey mapping session, which was a two-day workshop, there was a death in the community. This is documented below:

> There was also a death in the community a couple of days ago, and the community members said they felt preoccupied, but they did not want to cancel this two-day workshop. [Field note; Journey mapping workshop# 2]

Workshop participants wondered whether or not the Elders would request cancelling the workshop out of respect for the deceased, however they did not. The impact of the death was also discussed in the focus group, and participants indicated that even though it was a hard time, they still made progress with the creation of the care path. The struggle community members experienced is illustrated in the conversation below:

> *Oh, I was just going to say, I think if I remember too, um, there had, someone had passed that…* [Research team member; Focus group]
>
> *It was kind of hard.* [Community member; Focus group]
>
> *Yeah, yeah.* [Multiple participants agreeing; Focus group]
>
> *It was a tough time.* [Research team member; Focus group]
>
> *Yeah. Right.* [Elder; Focus group]
>
> *Yeah, it was really hard that time.* [Community member; Focus group]
>
> *So I guess we went through stuff like that that with still getting somewhere.* [Elder; Focus group]

Community members also preferred conducting the journey mapping through face-to-face meetings as compared to teleconferences. They found teleconferences and video conferences challenging and they appreciated that relationships developed better in face to face meeting.

> *I think the good thing that came out of that journey mapping is that we got to see people face-to-face, rather than by phone, and ya know, we put a name to the face and kinda got*

> *to meet people and these people came, got to see our community.* [Community member; Focus group]

> *I think even in between there we had these um, telephone conferences and video conferences…So we had little mini, mini ones in between. And I think for me, that was too hard because there were bits and pieces and we had to put it all together, ya know? So that's, that process I didn't enjoy at all (laughs). It took a lot of time and, a, a lot of work just getting it organized. Those sessions, I didn't like at all.* [Community member; Focus group]

In terms of lessons learned, participants discussed alternate approaches to value stream mapping and identified traditional ways of discussing information, such as the use of a sharing circle. This idea is supported by the following quote:

> *Yeah, yeah. I just think sitting around and just having discussion, I think that's what worked. More from then, you guys [points to Elders] were giving more input.* [Community member; Focus group]

Theme four: Journey mapping develops a culturally appropriate care pathway.

The Leadership Team wanted to ensure that the care pathway created through the journey mapping was culturally appropriate. Throughout the first three journey mapping workshops that included external health care providers, stakeholders created a nine stage palliative care pathway, shown earlier in Figure 9. The activities of each stage were detailed in a large spreadsheet, including what person or organization was responsible.

Focus group participants discussed the importance of respecting the community's culture and traditions. The focus group participants indicated that the external health care providers, whose role was recognized as important in the care of the dying person during stages 1- 6 did not need to be included when discussing cultural and traditional practices that were used at end of life (stages 6-9). For the fourth and final workshop, community members met privately to ensure culture and traditions were incorporated throughout all stages one through nine, with emphasis on stages six through nine.

Sub-themes of this major theme are: (1) journey mapping includes Elder guidance throughout the process, and (2) the care pathway is respectful of the individual's wishes, values and beliefs.

Journey mapping includes Elder guidance throughout the process

Both Elders and community members agreed that guidance from Elders should be sought continuously throughout the journey mapping process. Elder guidance is important to the community because the topics discussed throughout the journey mapping process are difficult. As identified in the subtheme "ensure community readiness for journey mapping" the community learned that there was hesitation in the beginning from some of the Elders and the Home and Community Care Program Coordinator (EOLFN Community Lead) related to the research topic due to cultural teachings about death and dying; therefore Elder guidance was not sought throughout the entire journey mapping process.

As one participant ruminated, planning to have an Elder present at each journey mapping workshop would have provided guidance and leadership throughout the journey mapping process. This idea is evidenced by the following quote:

> *The last meetings we've had, we've never had an Elder speak and set our mind straight of the goal, and what not to think bad and what, what to think good, and then by smudging and having an Elder speak that puts our mind where it should be, in the right place.* [Community member; Focus group]

Participants spoke about the inclusion of Elders several times, stating they get into work mode, get busy and forget to seek Elder guidance. The following conversation between an Elder and community member supports this idea:

> *I think me, and I'll speak for myself and I think maybe like because I'm still learning about our culture and our traditions, it's… maybe I should have seeked more advice from Elders on how to proceed with these kind of meetings, and our journey mapping, because I think me, I was too in, um, not work mode, but (laughs) how do you say it?* [Community member; Focus group]
>
> *Concentrating on this (journey mapping).* [Elder; Focus group]
>
> *I was so much concentrating on this and getting it DONE (emphasized). So I think I should have sought more advice.* [Community member; Focus group]

Another Elder added:

> *Yeah, I think, I think we should've had one (Elder) at every, every meeting that would've been, that, I think that's an important part of what we're doing.* [Elder; Focus group]

One community member added the following comments to support Elder involvement in the journey mapping process:

> *And, ya know we kind of talk lightly about it sometimes. And we gotta realize that, ya know, it's not in our culture to, to plan like this. So that's why, you know, I feel more comfortable when we do have an Elder around, ya know because it kind of keeps us all in check. And, I mean it makes us mindful of everything. So, that's one thing I think would make, ya know, smoother meetings and stuff. Especially regarding, the stuff, the work we're doing.* [Community member; Focus group]

Elders added to the discussion that it is important for everyone to remind each other that an Elder should be present because sometimes even the Elders forget about the necessity of the presence.

> *We always have to remind each other about this stuff because even an Elder-in-training (laughs), ya know, sometimes I forget. You're so busy day-to-day stuff. Just have to remind each other (audible sigh).* [Elder; Focus group]

In addition, Elders and community members agreed that arranging for a traditional opening is important.

The importance of this practice is supported by the following quote:

> *Yeah, I think every meeting we should have had a traditional opening, because that is such an important part of what we're doing, even at the hospital, even if we had to do it outside, I think, or even at home, before we left.* [Elder; Focus group]

One of the journey mapping workshops took place in a meeting room at Lake of the Woods District hospital. As described by the Elder in the previous quote, the importance of traditional opening is so meaningful, they would have done it outside, or at home in the community prior to leaving for the workshop.

The care pathway is respectful of the individual's wishes, values and beliefs

During the journey mapping, the community members developed detailed guidelines and protocols regarding the behaviours of each group of health care providers. Guidelines were created for each stage in the care pathway (Figure 9). These guidelines and protocols outlined what needed to be done, what health care providers were involved and how they would work together and with the clients and the families.

These guidelines were developed with the caveat that each client's situation and experience is unique. The guidelines emphasized that health care providers and care givers must be aware the guidelines are just that, a guide that needed to be individualized. Those providing care must be aware that deviation from the guidelines may be necessary so that each client's individual care experience is respectful of their unique wishes, values and beliefs. These wishes values and beliefs need to be incorporated into day to day care. That includes offering traditional healing practices if they are requested.

Throughout the journey mapping process, the community members felt it was difficult to get their cultural view of the person acknowledged and valued by the external health care providers. This is due, in part, to very different perspectives. The following quote discusses the perceived difficulty uniting the Western healthcare model that focuses on applying science-based best practices and Indigenous ways of knowing and caring:

> *If you recall, we identified nine steps in the care plan. The first five steps involved our health care professionals, so that's where they were giving all their input, and then, so I think that's where we kind of felt, um, how do you say it, where we weren't listened to, I*

> *guess, you can say, but then in those five steps we could have given more of our cultural input. Right? But here we do this, and we're like, we could have, I guess trying to, trying to incorporate that into their health, um, into their care. And then the steps six through nine, that's where we, we completed those steps where it involved us at the community.* [Community member; Focus group]

In addition, one Elder spoke about lack of understanding and negative perceptions associated with the traditional ways of healing outside of the community:

> *I been trying to push out […] traditional ways for people to understand, like we don't even get funding for traditional healing, so we just do it anyway because […] the traditional way works, but as long as you try to sell that to the, either the government, or […] anybody, they don't want to see that it's […] reliable tool to healing for Anishinaabe people, […] ya know? They don't want to understand that, ya know […] and I've been stressing […] all the time, every time I talk to a group of people, I stress my traditional, my understanding, because I know it works for me as an Anishinaabe person, but other people, they just don't want to see that... Like some of the doctors are starting to understand it […], they'll try to just, uh, understand the ways of the Anishinaabe people, ya know, but when ya try and sell this kind of thing to a, a government, it's just don't want to see it. ...It really works for us as Anishinaabe people, but it's always a problem though, that no one understand us, ya know? They think we're nuts as Elders, that uh, ya know, they think we're losing our minds, but it's not, it works. Last night I was telling [points to Elder] there was a whole bunch of us that went to the sweat lodge last night, and we're healing people that are really sick, you know, and uh so, it works.* [Elder; Focus group]

The Elder continued discussing the lack of understanding about traditional healing and the challenges with the government and health care providers accepting the value of traditional ways. As expressed in the following quote, the Elder believes doctors in the Western health care system try to supress the disease, while the traditional healers in the community try to cure the person.

> *I always talk about my [family member] and I don't know what kind of disease that [family member] went through, ya know and don't really understand the disease, but as soon as the Elders got together, the disease… This kind of things eh that they don't want to understand, and this is what we should involve the program, really strong traditional, but how do you sell that, because as soon as the government (inaudible word) says they're not going to fund it because it's not, it's not their way, it's not what they have in mind like the doctors, but what they have in their minds, the way they're healing, ya know. So, so we believe in healing but the doctors, doctors wants to kinda just lower down, like I mean, supress it, but the sickness is always there. As soon as you stop taking, that person, it comes up again, but Anishinaabe, when they start healing, they know what they're looking for something, that person should be cured. And that's one of the problems, the problems that we have, so how do you sell that to the government, eh.*
> [Elder; Focus group]

Summary of qualitative findings

The lessons learned from the qualitative findings were identified and elaborated in these findings. At the outset, journey mapping must be founded in the community's vision for change. Journey mapping also requires community planning which involves ensuring the community's readiness for journey mapping, and then obtaining community support, followed by creating awareness. Journey mapping is a time commitment that involves face-to-face meetings on a regular basis. Stakeholder commitment to journey mapping workshops and involvement in creation of the care pathway is essential. Communication should be respectful of the community's beliefs, as death and dying are not discussed and palliative care is not a familiar term in the Ojibway language. Journey mapping workshops should be in a format that is culturally relevant and familiar; Western models, such as value stream mapping are not recommended. Naotkamegwanning journey mapping was effective in creating a nine stage, culturally appropriate care pathway, and Elder guidance is recommended throughout the journey mapping process. Health care providers and care givers must tailor each client's experience through the care pathway to their individual wishes, values, and beliefs.

Findings from the survey data

After completion of the journey mapping, the survey was sent to 16 members of the stakeholder working group who were considered external to the community; 13 external health care providers and 3 members of the EOLFN Research Team. Of the 16 surveys that were sent out, there were 9 respondents, resulting in a 56.25% response rate. Respondents completed 24 questions: 14 rating scale questions and 10 open-ended questions. In this chapter, the survey findings are displayed in two sections: (1) quantitative results of 14 rating scale questions, summarized in a table and, (2) qualitative results of 9 open-ended questions, summarized by grouping the responses, identifying themes, and a narrative interpretation.

Quantitative survey findings: Responses to rating scale statements.

Survey participants rated 14 statements related to the overall journey mapping experience on a rating scale of 0-4 that included the following response options: don’t know, strongly disagree, disagree, agree, and strongly agree (see Table 9). An even point scale of 1-4 was selected for responses, and “don’t know” received the score of zero. The neutral option of “neither agree, nor disagree” was deliberately not included to intentionally obtain a forced-choice response, because a neutral response has the tendency to be a “catch all” category.

Table 9. Quantitative survey rating scale scores

Don’t know (DK)	**Strongly disagree (SD)**	**Disagree (D)**	**Agree (A)**	**Strongly agree (SA)**
0	1	2	3	4

Dichotomization by grouping disagree and strongly disagree, and agree and strongly agree was utilized to summarize the data because the data set is small. All nine respondents rated each statement 1 through 14 except for question nine in which one respondent did not provide a rating. None (0%) of the survey respondents selected strongly disagree for any statement 1 through 14. The results for each rating scale statement is summarized in Table 10 below.

Table 10. Quantitative survey rating scale summary

#	Statement	Don't know	Disagree	Agree	Response Count
1	The Naotkamegwanning journey mapping workshops helped me look at my work in a different way than before.	1 11%	1 11%	7 78%	9 100%
2	The Naotkamegwanning journey mapping workshops helped me better understand the roles of the other care providers involved.	0 0%	1 11%	8 89%	9 100%
3	The Naotkamegwanning journey mapping workshops helped me better understand the policies and procedures (mandates) of the other organizations involved.	0 0%	0 0%	9 100%	9 100%
4	The Naotkamegwanning journey mapping workshops identified gaps and problems in service delivery.	0 0%	0 0%	9 100%	9 100%
5	The Naotkamegwanning journey mapping workshops identified new strategies to improve communication, coordination and integration of care delivery.	0 0%	1 11%	8 89%	9 100%
6	The Naotkamegwanning journey mapping workshops helped me better understand the needs and preferences of clients in Naotkamegwanning.	0 0%	1 11%	8 89%	9 100%
7	The Naotkamegwanning journey mapping workshops generated commitment to solve service delivery issues for residents of Naotkamegwanning.	0 0%	1 11%	8 89%	9 100%

#	Statement	Don't know	Disagree	Agree	Response Count
8	The Naotkamegwanning journey mapping workshops will help to improve care delivery for Naotkamegwanning residents who are in the last year of life.	1 11%	1 11%	7 78%	9 100%
9	I feel like my voice was heard in the Naotkamegwanning journey mapping workshops.	1 12.5%	0 0%	7 87.5%	8 100%
10	I feel like the voice of the community members was respected during the Naotkamegwanning journey mapping workshops.	0 0%	0 0%	9 100%	9 100%
11	I feel like the views of the community members were incorporated during the Naotkamegwanning journey mapping workshops.	0 0%	0 0%	9 100%	9 100%
12	I feel external health care providers and community members now better understand each other.	1 11%	1 11%	7 78%	9 100%
13	The Naotkamegwanning journey mapping process was effective to create a care pathway for palliative care.	0 0%	0 0%	9 100%	9 100%
14	I recommend that other First Nations communities do a journey mapping exercise to improve palliative care in their community.	0 0%	0 0%	9 100%	9 100%

Summary of Table 10.

Overall the results of the rating scale were very positive and there was a high level of agreement on most items amongst respondents.

Service delivery related outcomes.

All (100%) of the respondents agreed that conducting the journey mapping had the following benefits: *helped me better understand the policies and procedures (mandates) of the other organizations involved; identified gaps and problems in service delivery and was effective to create a care pathway for palliative care.* Further, most agreed or strongly agreed that the workshops: *identified new strategies to improve communication, coordination and integration of care delivery; generated commitment to solve service delivery issues for residents of Naotkamegwanning; will help to improve care delivery for Naotkamegwanning residents who are in the last year of life.*

Relationship building outcomes.

Most respondents agreed that: *external health care providers and community members now better understand each other; better understand the needs and preferences of clients in Naotkamegwanning; better understand the roles of the other care providers involved; and look at their work in a different way than before.*

Journey mapping workshop process.

Regarding the process of conducting the workshops, all (100%) of the respondents agreed that the *voice of the community members was respected and the views of the community members were incorporated. Most felt that their own voice was also heard in the workshops.*

This finding is elaborated upon further in the discussion because it contradicts the qualitative findings from the focus group participants (community members), who stated they felt at times they were not listened to.

Future journey mapping.

All (100%) of the respondents *recommend that other First Nations communities do a journey mapping exercise to improve palliative care in their community.*

Qualitative survey findings: Responses to open-ended questions.

Survey participants were asked ten open ended questions including one "additional comments" field. Participants were given the option to skip open-ended questions or leave them blank and still progress through the survey. This option was given because not all of the open-ended questions applied to each participant in the stakeholder working group (e.g. EOLFN Research Team members). The majority of the questions were answered by all nine participants, with the exception of "additional comments." At most, three of the nine participants skipped any given question. Therefore, there was a large amount of qualitative data.

For analysis, each response to the open-ended questions were summarized and three main overarching themes were identified. The themes are: (1) journey mapping increased communication and established partnerships, (2) journey mapping was a time commitment, and, (3) journey mapping is recommended to create a care pathway.

Journey mapping increased communication and established partnerships.

Survey respondents indicated that the journey mapping workshops led to in increased communication and established partnerships amongst community members, and internal and external health care providers.

When asked what the most significant change or outcome of the journey mapping was, respondents indicated that increased communication between the community and health care providers was achieved. One respondent indicated stated there was an "increased awareness of the need to facilitate (help promote) communication between organizations and the community."

When asked what the facilitators (catalysts) to the journey mapping workshops were, respondents indicated that the use of Ontario Telemedicine Network (OTN) technology increased communication between the participants from Naotkamegwanning/Kenora and those in Thunder Bay during the third workshop which took place at Lake of the Woods District Hospital in Kenora. While some members of the stakeholder working group from Thunder Bay attended this workshop in person, the majority of the members were unable to attend in person due to travel time and cost.

When asked if the journey mapping workshops gave new ideas about how to improve care for residents of Naotkamegwanning, one health care provider indicated that "the communication binder [in-home chart] did prove to be very helpful in home." During the journey mapping workshops, an in-home chart was identified as a need for clients on the Wiisokotaatiwin Program. As a result of the implementation of the in-home chart, communication within the circle of care was increased.

When asked the most valuable aspects of participating in the journey mapping workshops, respondents indicated it was getting community members and providers together face-to-face, establishing new partnerships, and learning each other's roles and organizational mandates. As one respondent expressed:

> [The most valuable aspect of participating in the journey mapping was] *meeting the community members and learning the intricacies of service provision in the area, as well as learning how providers can work together in more coordinated care to deliver services in rural First Nations communities.* [External partner survey respondent]

When asked what the crucial future steps to improve palliative care in Naotkamegwanning are, respondents said continued communication and collaboration between the community and the external health care providers is necessary. One respondent said that engaging policy makers would advance the changes that have taken place.

Journey mapping was a time commitment.

When asked what the barriers were during the journey mapping workshops, all respondents identified time as a barrier, but the respondent's description of why time was a barrier was defined in various ways. Survey respondents expressed that journey mapping was a time commitment, stating that the duration from start to finish was too lengthy, and the time between workshops (six months) needed to be reduced. One respondent commented "the length of time to complete the workshops was a barrier" indicating the overall process took too long from start to finish (two years). Alternatively, two other respondents commented "we could have used more time" suggesting more time was needed during the actual workshops to discuss and work through processes, especially when issues, gaps and barriers were identified. According to one respondent, "it took such a long time between workshops" however in another respondent's opinion, "it took time to help everyone see what the process required of them." Respondents also stated that the timing of workshops should be arranged to better accommodate external stakeholder attendance. Additionally, one respondent commented that the least valuable aspect of participating in the journey mapping workshops was the value stream mapping session (workshop #2) because it "was a waste of time."

Indirect comments related to time were the use of OTN in the third workshop as a method of increased participation for members of the stakeholder working group located in Thunder Bay. There were six participants that attended via OTN that otherwise would not have been able to participate due to the distance and travel time[9]. Adding to this idea was the various locations of the journey mapping workshops, which were strategically selected for the convenience of the stakeholder working group. One respondent stated:

> *I think the combination of locations of the workshops was a facilitator – it was important to have the first one in the community with outside care providers travelling to the community in order to show respect for the community, and to ensure external providers who were going to make decisions and recommendations about care had actually seen the community, but I think having the last couple in Kenora ensured a better attendance by external providers, and was less distracting for community members, they were away from their jobs and other responsibilities in the community.*
>
> [Survey respondent]

When asked how effective the journey mapping workshops were in creating a care pathway for Naotkamegwanning clients in need of palliative care, respondents stated the goals (creation of a care pathway) were achieved.

When asked what suggestions they had for First Nations communities conducting journey mapping workshops in the future, there were comments related to reducing the amount of time in the workshop by "having the current state mapped out [in advance]" suggesting that this could be done internally within the community prior to bringing in external health care providers, allowing more time to focus on the future state. One respondent said "I think the overall process was excellent and [other First Nations communities] could replicate it more quickly and effectively" suggesting the lessons we learned would abbreviate the process in the future.

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[9] Thunder Bay, ON to Kenora, ON is approximately 490 km and takes about 5-1/2 hours to drive (11 hours round trip), depending on the time of year and road conditions/construction. Drive time combined with a half-day meeting usually requires an overnight stay in Kenora.

Journey mapping is recommended to create a care pathway.

Survey respondents agreed they would recommend journey mapping to create a care pathway for First Nations community members that could benefit by palliative care. Survey respondents also had suggestions on how to improve the journey mapping process for future use.

When asked what the most significant change or outcome of the journey mapping was, one respondent indicated that “a care path was actually developed which will benefit the community, and we had the opportunity to study the process and make recommendations on the process for other communities.”

When asked the question “How effective were the journey mapping workshops in creating a care pathway for Naotkamegwanning clients in need of palliative care?” the majority of respondents stated the journey mapping workshops were “very effective” in creating the care pathway. Some respondents offered additional comments stating that “we floundered a bit with process, but I think the key in creating the care pathway is to get all the players together and committed, and the workshops certainly accomplished that.” Another respondent stated that “we needed to change the facilitation strategy to better engage the community members more quickly.”

Survey respondents agreed that the value stream mapping process used in workshop #2 was not successful, nor was the facilitation style. Value stream mapping was identified as both a barrier and the least valuable aspect of participating in the journey mapping workshops. Respondents felt that value stream mapping disengaged community members and was intimidating to them. They also felt that a “fancy process” was not needed, and one respondent indicated to “keep it [journey mapping] simple.”

When asked what the barriers during the journey mapping workshops were, one respondent indicated that:

> "the facilitation process of the February 2014 workshop [value stream mapping] was a barrier because the value stream mapping process we tried to use was just not suited to our task, and it was confusing and intimidating for community members."

When asked what the least valuable aspect of participating in the journey mapping workshops were, one respondent said "the facilitator from Toronto" and another respondent built upon this idea stating "[the least valuable aspect of participating in the journey mapping workshops was] the frustration of attending the [value stream mapping] workshop, where we had excellent attendance by care providers and community members, but couldn't make the process work."

Respondents suggested that the Home and Community Care Program Coordinator (EOLFN Community Lead) facilitate or co-facilitate the workshops. One respondent appreciated the facilitation style of the Principal Investigator and stated "[the Principal Investigator's] pointed questions and excellent information drawing techniques were key to moving the session along."

When asked what suggestions they had for First Nations communities that conduct journey mapping workshops in the future, one respondent summarizes, by stating:

> "*I would strongly recommend journey mapping workshops as the most effective way of developing a care path, which for all intents and purposes, is the [palliative care] program; you need a good facilitator for the workshops who understands health care and the community, but no need for processes – keep it simple: 'what happens now?' 'What do we want to happen?' 'What do we need to do to make that happen?*"

Summary of survey findings

Overall, the key findings were consistent in both sets of data collected in the survey.

The first theme to emerge from the open-ended questions, was that the journey mapping workshops increased communication and established partnerships between community members and health care providers. Survey respondents also agreed with the rating scale statements that they felt the voices and views of community members were respected and heard.

The second theme to emerge from the open-ended questions, was that the journey mapping workshops were a time commitment. One of the most time consuming components of the journey mapping workshops was working through each of the nine stages in the care pathway. In order to work through the care pathway, health care providers and community members needed to understand one another's policies and procedures to identify gaps and problems in service delivery. While time consuming, the responses to the rating scale indicated that as a result of the journey mapping workshops, health care providers better understand each other's mandates, and that gaps and problems in service delivery were identified during the journey mapping workshops.

The third theme to emerge, and key takeaway from the survey was that all respondents agreed that journey mapping is an effective tool to create the care pathway. This was a theme identified from the open-ended questions and a rating scale statement that 100% of respondents agreed with.

Chapter 7: Discussion

This chapter begins with discussion on the most significant findings related to the research questions posed in this thesis. Discussion of the effectiveness of journey mapping is followed by additional discussion on the learnings and promising practices that emerged. The chapter concludes with an exploration of the thesis findings relative to previous research, study limitations, and implications for policy, practice, and future research.

Most significant findings

The key finding from this thesis research is that the Elders, community members, internal and external health care providers and members of the EOLFN Research Team, who were the stakeholders involved in the Naotkamegwanning journey mapping workshops, all recommended journey mapping as an effective process to create a palliative care pathway for First Nations communities. Over a period of two years in Naotkamegwanning, by implementing the principles of PAR, an effective methodology for conducting journey mapping gradually evolved. These emerging learnings and promising practices have been documented and analyzed for this thesis research.

The findings of this thesis research have already contributed to the creation of a published guide entitled “Conducting journey mapping to create a palliative care pathway for First Nations communities: A step by step guide”. Based on the experience in Naotkamegwanning, the Guide was developed for use by First Nations communities that wish to conduct journey mapping. This guide is included as part of the “Developing Palliative Care Programs in First Nations Communities: A Workbook” (EOLFN Research Team, 2015) which is a primary outcome of the EOLFN project. Other First Nations communities have reported to the EOLFN project that they are using the lessons learned in Naotkamegwanning and customizing the journey mapping guide for their own community. The role of the EOLFN research team to support their process, in the future, can thus be accomplished by using the Workbook and Guide as resources.

Findings also indicated that journey mapping works best as part of a longer term community capacity development process. Consistent with the perched eagle (see Figure 12), journey mapping must be founded in the community's vision for change and be guided by the ethical principles of building community relationships and honouring the choices of the community. It was led from within Naotkamegwanning by the Home and Community Care Program Coordinator (EOLFN Community Lead) and required Elder support and community support to be successful. The journey mapping workshops should also begin after a foundation for implementing a palliative care program has been established. Consistent with the Process of Palliative Care Program Development model (see Figure 1), Naotkamegwanning did substantial preplanning and implemented many preparatory activities prior to the workshops, including a community needs assessment, to prepare the community members.

Building community capacity is a slow incremental process and this is why the care pathway ultimately took two years to complete. Initially, there was not enough Elder and community support for journey mapping. However, when the term Wiisokotaatiwin began being used (as opposed to palliative care or dying), Elders and community members started to understand the vision and goal of the work being done and became more engaged. Strong internal community leadership was key. The need to change terminology to be culturally and community- appropriate was one of the issues identified during the journey mapping process and rectified.

Discussion of lessons learned and promising practices

Contribution of stakeholders was essential

Face-to-face stakeholder commitment for long term involvement was essential in the journey mapping process and creation of the palliative care pathway. Planning by the leadership team determined which stakeholders were most relevant to include in journey mapping before the very first workshop. All stakeholders invited were involved in providing services to people living in Naotkamegwanning and were personally motivated to improve quality of service. There was a high level of retention of the stakeholders over the two-year period, with only a few unavoidable changes due to retirement, illness or maternity leave. Face-to-face meetings were always more productive than telephone, telemedicine or email communication.

Related to stakeholders' involvement, another lesson learned was that external health care providers needed support from their organization's management to participate in the journey mapping workshops. Participation required a major commitment of time and sometimes travel or telemedicine costs. One participant, a nurse from a regional hospital, was so passionate about how telemedicine could contribute to palliative care in Naotkamegwanning that she drove her own car from Thunder Bay to Naotkamegwanning to participate in the first journey mapping workshop. There were thus organizational costs for her time or travel to the journey mapping workshops, so she needed the support and approval from her management to receive reimbursement for costs incurred.

Each stakeholder had an important role in the journey mapping workshops and they were all essential for moving forward the process and creation of that care pathway. To implement the care pathway and provide services to the community members in the proposed new way, stakeholder commitment needed to continue after the journey mapping workshops were complete.

Value stream mapping is not recommended

The standard value stream mapping approach as commonly used in quality improvement in health services in Ontario did not enhance the journey mapping experience or facilitate the creation of the palliative care pathway. In fact, this approach was a barrier. Therefore, it is not recommended for use in other First Nations communities. Applying the guiding principles of the Indigenous paradigm (Atkinson, 2001) is more appropriate.

The value steam mapping workshop facilitation style and lean terminology was introduced because it is familiar to most health care providers and a key tool used in their own settings. However, the approach proved unfamiliar to community members and did not resonate with them. During the value stream mapping session, community members' non-verbal body language provided cues that they were not engaged and they did not participate in discussion. As a result, the value stream mapping format and lean terminology were discontinued the day it was introduced and the workshop format was revamped to a story telling exchange with terminology that all stakeholders were familiar with. The workshop facilitator also sat down beside the Elders to hear their wishes and concerns rather than continuing to stand for her presentation or completion of process diagrams on the wall.

This new format was more consistent with the guiding principles of the Indigenous paradigm (Atkinson, 2001) and it was well accepted by the external health care providers. Using the experience of Journey Mapping Workshop #2, Table 11 below provides some examples of how the guiding principles were implemented during the journey mapping workshop experience.

Table 11. Guiding principles and examples of their use during journey mapping workshop #2

Guiding principle (Atkinson, 2001)	**Example from journey mapping workshop #2 (Value stream mapping)**
Ways of relating and acting within community with an understanding of the principles of reciprocity and responsibility	The workshop facilitator discussed the ground rules at the beginning of the workshop, thus all stakeholders participated in establishing these ground rules which ensured that they were respectful for all participants involved.
A deep listening and hearing with more than ears	The EOLFN Research Team members observed non-verbal communication cues, such as lack of engagement, from community members and Elders. During the morning coffee break on the first day of workshop #2, the Research Coordinator approached the Elders gathering outside to explore why they weren't participating. They stated that the facilitation style was unfamiliar. Knowing this, the value stream mapping format and terminology was abandoned following the break.
A reflective non-judgemental consideration of what is being seen and heard;	During the journey mapping process, several gaps and barriers were identified. Because of the relationships and trust built during the face to face meeting, the stakeholder working group functioned by problem-solving these issues together. There was no hostility or defensiveness.
Having learnt from the listening a purposeful plan to act with actions informed by learning, wisdom, and acquired knowledge;	After the value stream mapping format was abandoned, Elders and community members became more actively involved and good progress on creating the care pathway was made. All of those present made a commitment to continue to work together to complete the palliative care pathway. At the end of the workshop (#2), an action plan for next steps was documented and reviewed with the stakeholders. After the workshop a workshop report was created and distributed to all the stakeholders.

Workshop facilitators and all participants must remain culturally aware, be responsive and continually monitor the audience

Workshop facilitators played a key role during the journey mapping workshops because they must be aware of what the audience is telling them, in particular, non-verbally. The lesson learned is that the facilitator must be aware of cues such as no eye contact, folded arms and other cues that result in lack of participation. These cues also vary culturally between First Nations participants and external health care professionals. As discussed in the last section, during workshop #2, First Nations community members and Elders disengaged and did not participate until the format of the workshop was abandoned and revised. Further, the focus group findings indicated that community members felt intimidated and that at times they weren't listened to. Yet, the health care providers did not perceive this; they perceived that the community voice was heard.

The differing expectations and opinions between community members and health care providers is a lesson learned for future facilitation and stakeholders. The facilitator and other stakeholders must all work to ensure that everyone gets a chance to participate and that all stakeholders are listened to. Where possible, the facilitator should be a First Nations person or co-facilitators can include one member of the community and one external person.

When necessary, the workshop facilitator should invite Elders or community members by asking "what do you think?" to facilitate participation. Having a cultural guide such as an elder in the workshop to consult and support also assists the facilitator. This promising practice ensures that all voices are heard and avoids disempowerment.

Journey mapping improved communication, improved service integration and enhanced services

One of the most significant barriers to service integration and care delivery related to communication problems between organizations and providers (e.g. use of consent forms, documentation lacking or not shared). During the journey mapping workshops, stakeholders collaborated on many initiatives for improving communication. The improved collaboration and improved communication translated into better service integration and enhanced services for the clients.

According to the survey data and workshop reports, the three main contributions to improving system integration were: (1) review of, and improvement to the discharge planning process, (2) review of, and improvement to the in-home chart, and, (3) addition of a tablet for the use of the Ontario Telemedicine Network (OTN) in the community. Each of these is elaborated below.

Revised and improved the discharge planning process. Prior to the journey mapping workshops, discharge planning between the hospitals[10] and the community lacked effective communication. Often clients requiring enhanced services would be discharged without contacting the Home and Community Care Program Coordinator (EOLFN Community Lead) or during times when the Home and Community Care Program office was closed and did not provide service (evenings, weekends and holidays). This lack of communication resulted in clients being discharged home from hospital without the proper equipment or home care services in place to receive suitable care in their homes. Often, the consequence of the poor discharge planning was that the client returned to the hospital for proper care.

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[10] Naotkamegwanning clients typically seek care at hospitals in Kenora, Thunder Bay, and Winnipeg.

During the journey mapping workshops, the Home and Community Care Program Coordinator (EOLFN Community Lead) and a regional Discharge Planner discussed how the discharge process could be improved. The hospital then better understood the services of the Home and Community Care program and the hours of operation. Together they created a plan for whom to contact when the Home and Community Care Program Coordinator (EOLFN Community Lead) was out-of-the-office (community nurse). This revised and improved the process was then trialed and ultimately adopted once the care pathway was implemented.

In-home chart. As a tool to improve communication among providers, an in-home chart was identified as a need for clients receiving enhanced services as part of the Wiisokotaatiwin Program. This chart is a binder of information that can be left in the client's home so that all health care providers and family members had access to it. Pertinent medical and social information, the care plan and the names and contact information for the health care providers are included in the chart. This chart is commonly used by home care programs providing palliative care in urban Ontario.

During the journey workshops, the stakeholder working group discussed ideas about how the in-home chart could be utilized to increase communication among all members in the client's circle of care. A new process was developed that required home care providers to document any adjustments to the care plan via the in-home chart. The process included a protocol for caregivers and hospital staff to follow if a client is transferred to the hospital. When a client is transferred to the hospital, care givers were instructed to provide the in-home chart to the hospital providers. Hospital providers were instructed to document notes in the chart, whether it be an emergency department visit or an admission. The in-home chart then returned with the client when discharged from hospital.

Use of Ontario Telemedicine Network (OTN) in the community. One of the stakeholders involved in the journey mapping workshops was a regional nurse who shared experiences using OTN for communicating with health care providers in other rural and remote communities in Northwestern Ontario. During the journey mapping workshops, the nurse provided insight on how a tablet and access to OTN could improve community health care providers' communication with health care providers located in urban centres. The EOLFN Research Team then connected the Home and Community Care Program Coordinator (EOLFN Community Lead) with an OTN telemedicine pilot project at the Thunder Bay Reginal Health Sciences Centre that allowed the community to obtain access to the network and participate in training. Telemedicine then became an option for community members, caregivers and family members requiring health care appointments, both during normal business hours and after-hours care. Telemedicine was also used during care conferences in the communities to connect with regional palliative care experts. It should be noted, however, that since OTN is a program of the provincial government and Home and Community Care Program is federal health service, often OTN would not be available in a First Nation community. Naotkamegwanning remains on the pilot program as of this date.

Journey mapping integrated the expectations of the community and the health care providers

The journey mapping process provided an environment (time, place) and strategy for promoting mutual understanding between the community and the external health care providers. During the journey mapping it became clear that two distinct world views and their related expectations existed pertaining to providing and receiving palliative care. Based on the thesis research, I have summarized these in the following Figure 13: Integrating the expectations of both the community and external health care providers.

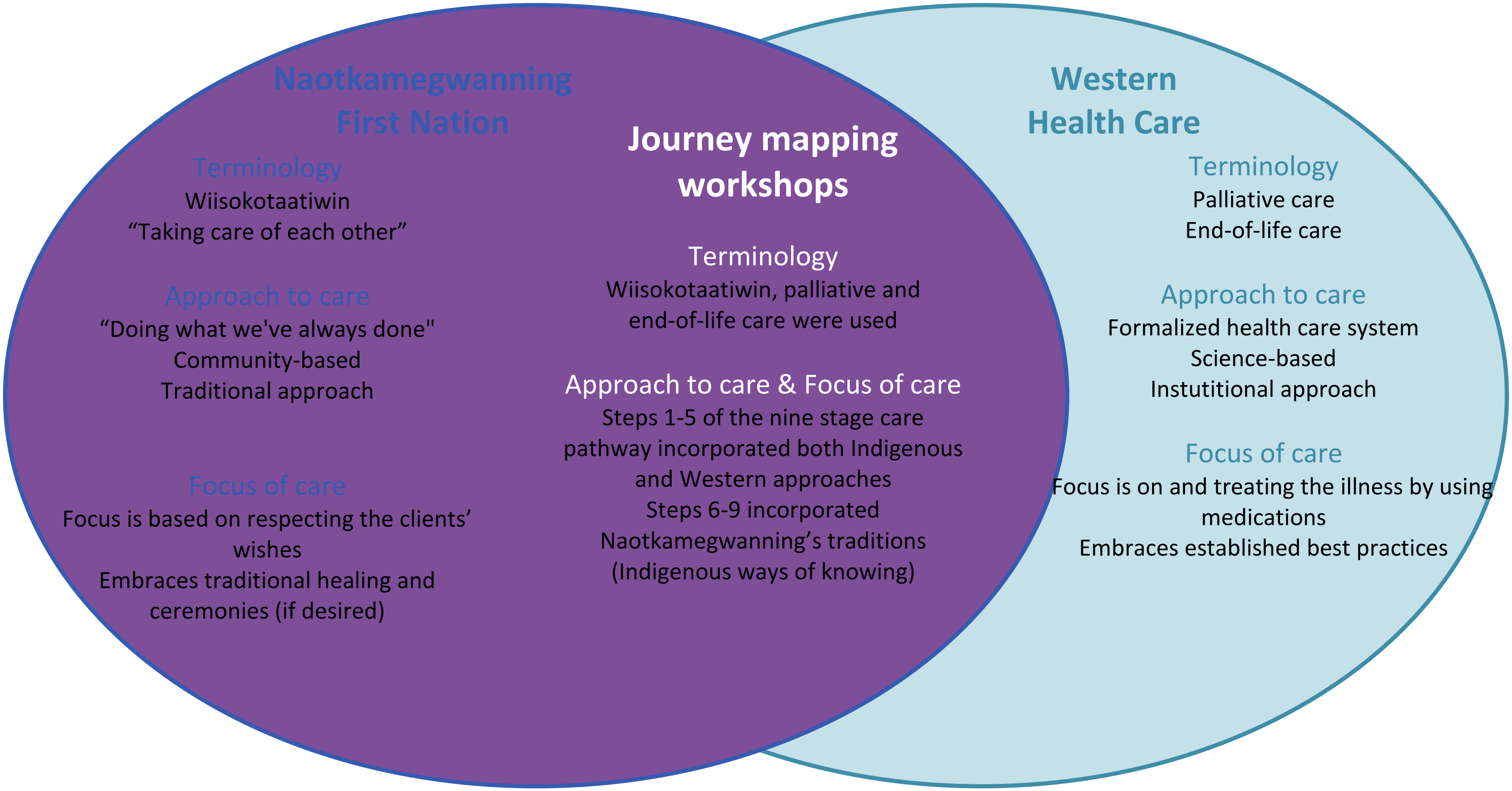

Figure 13. Integrating the expectations of both the community and external health care providers[11]

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[11] This figure was created based on the “Lessons learned for weaving Indigenous knowledge and mainstream science” in Bartlett et al. (2012, p. 4). The idea to represent the information in a Venn diagram came from “Two-eyed seeing: A model for co-advancement” (Canadian Institutes of Health Research, 2011, p. 6) and “Palliative care programs for First Nations communities: Integrating two systems” (EOLFN Research Team, 2015, p. 73).

In Figure 13, Indigenous and Western views that emerged during the journey mapping process are shown on the left and the right, respectively. In Naotkamegwanning the words “palliative care” and “end-of-life care” are not used; the community replaces these terms by the phrase “taking care of each other” (Wiisokotaatawin). Naotkamegwanning’s approach to health care is “doing what we’ve always done” and is community-driven. The foundation is based on traditional approaches and focuses on the client’s wishes and traditions. The Western approach to health care, alternatively, is founded on formalized health care principles and takes a science-based, institutional approach that focuses on established best practices.

I created the figure “Integrating the expectations of both the community and health care providers” using a Venn diagram format to provide myself with visual context before going into the journey mapping process, and to identify the necessity for a place that creates mutual understanding and bridges each world view. The workshops became a safe space for the participants where the ethical principles of “building trusting relationships” and “honouring community control” were exercised along with the principles of the Indigenous paradigm.

As illustrated in the center of the Venn diagram, it is necessary to “weave back and forth” (Bartlett et al., 2012, p. 4) when referring to terminology, the approach to care, and the focus of care. During the journey mapping workshops, community members discussed their traditions and health care providers discussed organizational protocols. The care pathway incorporated both of these. However, during journey mapping workshop #3, the community members decided that external health care providers would only be involved in discussing stages 1-5 of the care pathway and stages 6-9 would remain private to the community. That was because the role of the health care providers was limited to treatment of the illness and related symptoms and did not include being involved in the culture based approach to providing end-of-life care in the community. Thus external providers they did not need to know about local practices at end of life.

Using journey mapping as a strategy for integrating the expectations of both the community members and the external health care providers is not only consistent with the Indigenous paradigm but also the “Lessons learned for weaving Indigenous knowledge and mainstream science” in (Bartlett et al., 2012). Some examples of the applicability of Bartlett et al. (2012) “Lesson’s learned” criteria to the journey mapping process are identified in the following Table 12.

Table 12. Lessons learned for weaving Indigenous knowledge and mainstream science and examples of their use during the journey mapping process

Criteria (Bartlett et al., 2012)	**Example from journey mapping**
Acknowledge that we need each other and must engage in a co-learning journey	A key lesson learned during the journey mapping process was that stakeholder contribution and follow through was essential. Multiple initiatives to improve communication and collaboration were important to create needed health care improvements based on shared expectations.
Be guided by Two-Eyed Seeing	When the value stream mapping format and terminology were abandoned during journey mapping workshop #2, the two-eyed seeing strategy was suggested by the Principal Investigator as an engagement strategy to bring together Indigenous and Western ways of knowing (Bartlett et al., 2012).
Use visuals	Visual diagrams of the current state (in 2013) and the desired future state were used throughout the journey mapping. The figure of the nine stage care pathway was designed by the community to guide their work in providing palliative care.
Weave back and forth between our worldviews	As illustrated in the Venn diagram and described earlier, it is necessary to weave back and forth when referring to terminology, the approach to care, and the focus of care.
Develop an advisory council of willing, knowledgeable stakeholders, drawing upon individuals both from within the educational institution(s) and within Aboriginal communities	The stakeholder working group that participated in the journey mapping workshops involved community members, Elders, internal and external health care providers, and the EOLFN Research Team based at the Centre for Education and Research for Aging & Health (CERAH) at Lakehead University.

Contribution of findings to literature on palliative care in First Nations communities

In my literature review, no literature could be found that investigated First Nations journey mapping as either a general strategy to improve community health services or as a process to create a palliative care pathway. Therefore, this thesis research can fill a literature gap by providing a case study of using a journey mapping process to create a palliative care pathway for a rural First Nation community in Northwestern Ontario.

This research has also contributed new knowledge that value steam mapping as a quality improvement strategy practiced in urban health organizations may not be effective for use in First Nations communities. Through this research, the goals of value stream mapping to improve quality and effectiveness of services were achieved using a modified process that is more culturally appropriate. This research has led to developing culturally appropriate, promising practices for First Nations communities seeking to create a palliative care pathway using journey mapping.

This research has contributed to creating new concepts and definitions that can advance implementation of First Nations journey mapping to create palliative care pathways in the future. The strategy of creating care pathways could also be employed for improving care for people with other care needs, for example dementia or diabetes. As a result of the EOLFN research and this thesis research two unique definitions have been produced: (1) First Nations journey mapping, and (2) First Nations palliative care pathway. These definitions are provided below.

First Nations journey mapping refers to a process to improve the coordination and integration of care for clients as they access services from multiple programs and health care providers. It is done using a workshop format that brings together internal and external health care providers, Elders, and community leadership. It involves in-depth discussion of how First

Nation community members transition through the health care system as they approach end of life, and identifies obstacles and solutions to improve service integration (EOLFN Research Team, 2015).

First Nations palliative care pathway, or path of care, refers to a diagram or map that outlines the expected care for clients who would benefit by receiving palliative care, including the appropriate timeframes for different phases of palliative care. The care pathway is created by a group of involved care providers during a series of journey mapping workshops in order to become a resource that will guide care for individuals progressing through their care and treatment. The care pathway focuses on providing clients the best palliative care and most positive outcomes as they move between different health care providers and organizations. (EOLFN Research Team, 2015)

Study limitations

This thesis research has provided a number of valuable lessons learned and promising practices related to conducting journey mapping to design a palliative care pathway in a First Nation's community, but they findings cannot be generalized to other communities in Northwestern Ontario, provincially or nationally until additional research has been done. That limitation is inherent in the instrumental case study design which is intended to examine individual case in depth rather than to generate findings with broad generalizability. The goal of the thesis research was in-depth analysis on one case.

The majority of the data analyzed in this thesis were existing data analysis collected over two years by the EOLFN project. This dataset could be considered a limitation because the previously collected data was not collected with my research questions in mind. Thus I was limited by what the data were. However, I did collect some primary data at the end of the journey mapping specific to my thesis. I also had access to participants via telephone or email. No ambiguities or unanswered questions arose during data analysis that needed clarification.

The length of time the journey mapping process took from preplanning before the first workshop to the time focus group and survey data was collected could be considered a limitation because it was a two-year process in total. Fortunately, I was a Research Assistant on the EOLFN project for five years and directly involved in the entire two years of the journey mapping process. During the two years, I attended all of the workshops to participate in data collection. In the focus group and surveys that took place after the workshops were completed, some of the participants expressed difficulty recalling details from the early sessions. However, the workshop data collected during the two years was consistent with the data collected from the focus group and survey. This consistency indicates that saturation was achieved and that the data are reliable.

Implications of findings for policy

As Canada moves towards a national strategy on palliative care, providing palliative care as part of the federal government's First Nations Inuit Health Branch Home and Community Care Programs is a critical need but currently an unrealized reality. Palliative care is not funded as an essential service by the federal government and current funding levels for Home and Community Care are insufficient to provide palliative home care. Creating collaborations and partnerships between the federal and provincial health systems and local First Nations communities are one solution. Federal policy makers must find ways to address the jurisdictional issues that currently exist. In the thesis research, journey mapping facilitated overcoming jurisdictional barriers through creating relationships and collaborations between federal and provincial health services at the local community level. The Ontario region of Home and

Community Care has already implemented a pilot project with approximately 30 First Nations communities to develop palliative care programs and implement journey mapping, using the EOLFN workbook and journey mapping guide (M. L. Kelley, 2016).

The Ontario Ministry of Health and Long Term Care has endorsed a declaration to advance high quality, high value palliative care in Ontario, regardless of where people live (Quality Hospice Palliative Care Coalition of Ontario, 2011). Each of Ontario's fourteen LHINS are now mandated to implement regional palliative care programs that is inclusive of First Nations communities. However, there is no provincial model or additional funding to extend the provision of palliative and end of life care to First Nations communities. Each LHIN in Ontario must address the needs of their population.

The findings from this case study are timely because researchers in Canada and internationally are promoting public health as the new paradigm for health policy related to palliative care. From September 18-20, 2017, Canada will host the 5th International Public Health and Palliative Care Conference in Ottawa, Ontario. The International Public Health and Palliative Care Conference advocates for taking a global, public health approach to palliative care that enhances the quality of life and death for all people (Pallium Canada, 2015). This is an appropriate policy paradigm to address the palliative care needs of First Nations communities as it includes community development as a primary strategy and acknowledges the need to address the social determinants of health. Journey mapping has a potential role to play in implementing a public health approach to palliative care.

Implications for practice

The lessons learned from the Naotkamegwanning journey mapping workshops have provided promising practices that can be used as a foundation in the development of standardized approaches to providing palliative care in First Nations communities regionally, provincially or nationally. For example, the nine stage palliative care pathway that was developed is a promising practice that can be used as a starting point for the desired future state. Additionally, based on the lessons learned from the thesis, value stream mapping should be avoided in First Nations communities.

A Regional Palliative Care Program for Northwestern Ontario has been created with the mandate of implementing the recommendations of the NWLHIN's Regional Palliative Care Plan (North West Local Health Integration Network, 2014). A version of journey mapping presented in this thesis is currently being conducted in the NWLHIN catchment area, which includes First Nations communities and rural and remote communities. Journey mapping is seen by the regional program staff as a valuable strategy to promote system integration at the level of patient experience because it links back to the popularity of value stream mapping with health care providers. It has also been shown to be relevant and effective for use in First Nations communities through this thesis research.

Implications of findings for future research

The findings of this research can now be examined for their relevance and applicability in other First Nations communities in our region, in Ontario and in Canada. Future researchers may explore partnership with one or more First Nations communities in PAR projects focused on palliative care that use journey mapping as a tool to create the palliative care pathway for community members that want the choice to die at home. When engaging in similar research, researchers must partner with leadership in the community, identify a local champion (Community Lead) and establish a leadership team that provides local control and guidance. The community will then identify their vision and with appropriate preparation journey mapping can be undertaken at that time.

Alternatively, First Nation's communities may choose to develop their own palliative care programs using the workbook created by the EOLFN research project entitled "Developing palliative care programs in First Nations communities: A Workbook" (EOLFN Research Team, 2015). Researchers could collaborate with these communities to evaluate the outcomes of their work and evaluate the effectiveness of the workbook and journey mapping guide as a community based tool.

Chapter 8: Conclusion

The purpose of this thesis research was twofold. First, I analyzed the process of journey mapping to create the care pathway for integrated palliative home care for Naotkamegwanning community members who choose to die at home. Journey mapping was perceived to be an effective strategy to create a palliative care pathway by all involved stakeholders. Second, I identified learnings and promising practices that informed the development of an EOLFN workbook tool on journey mapping for use by other First Nations communities. The participatory action research (PAR) methodology was suitable for this case study because evaluation is embedded within the cycle of PAR, and therefore that methodology was appropriate for the purpose of the research.

This thesis research embraced an Indigenous paradigm as its theoretical perspective and the lessons learned and promising practices that resulted from this case study were consistent with the principles of the Indigenous paradigm. The findings produced a perched eagle figure called "Conducting effective palliative care journey mapping: Learnings and promising practices." The perched eagle figure resulted from the qualitative findings and included a grounding theme and four overarching themes.

The grounding theme "Journey mapping must be founded in the community's vision for change" emphasized that the community must perceive and articulate expected benefits for its members before undertaking the journey mapping process to create the palliative care pathway. This idea of grounding every action in community values and principles is also consistent with the community capacity development model "Process of Palliative Care Program Development" that guided all of the strategies to help build community capacity in palliative care. Two ethical principles emerged, which were “building trusting relationships” and “honouring the choices of the community.”

The first overarching theme, journey mapping requires community planning, identified the importance of community support and awareness to ensure the community’s readiness for journey mapping. The second overarching theme, journey mapping requires time commitment, described the lessons learned related to time and identified that journey mapping could not be completed without stakeholder contribution and follow through. The third overarching theme, journey mapping requires that communication is respectful of the community’s beliefs, revealed that journey mapping workshops must be conducted in a culturally relevant format that is familiar to the community. The fourth overarching theme, journey mapping develops a culturally appropriate care pathway, established the importance of Elder guidance throughout the journey mapping process and that the journey mapping workshops ultimately resulted in a care pathway that is respectful of the individual’s wishes, values and beliefs.

The findings from this thesis revealed that journey mapping is a promising practice to help navigate jurisdictional issues between the federal and provincial governments for providing palliative care services in First Nations communities. A shift in Canadian health care policy that includes an infusion of funding to fill the existing service gaps is urgently needed to support capacity development and integrated palliative care as part of local Home and Community Care Programs. Attention to the geographic, socioeconomic and technological barriers faced by First Nations communities in Northwestern Ontario will further support community capacity development.

A public health approach to palliative care is an appropriate policy paradigm to address the palliative care needs of First Nations communities because it includes community development as a primary strategy and acknowledges the need to address the social determinants of health.

Implementing strategies such as journey mapping will support First Nations people to receive palliative care at home if that is their choice. Journey mapping could also further reduce costs and burden to the health care system by allowing First Nations people to receive palliative care services in their home communities and avoid unnecessary transfers to acute care that uproot them and their families from their community and culture.

The journey mapping workshops developed an innovative and effective process for Naotkamegwanning First Nation to create their palliative care pathway. The promising practices and lessons learned from this research can be used to guide other First Nation's communities and participating stakeholders in creating a culturally appropriate care pathway.

Lexicon of terminology discussed in this thesis

Aboriginal peoples: The descendants of the original inhabitants of North America. The Canadian *Constitution* recognizes three groups of Aboriginal people — Indians, Métis and Inuit. These are three separate peoples with unique heritages, languages, cultural practices and spiritual beliefs. (Government of Canada. Aboriginal Affairs and Northern Development Canada, 2012)

First Nation: A term that came into common usage in the 1970s to replace the word "Indian," which some people found offensive. Although the term First Nation is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian peoples in Canada, both Status and non-Status. Some Indian peoples have also adopted the term "First Nation" to replace the word "band" in the name of their community. (Government of Canada. Aboriginal Affairs and Northern Development Canada, 2012)

First Nations palliative care pathway: Refers to a diagram or map that outlines the expected care for clients who would benefit by receiving palliative care, including the appropriate timeframes for different phases of palliative care. The care pathway is created by a group of involved care providers during a series of journey mapping workshops in order to become a resource that will guide care for individuals progressing through their care and treatment. The care pathway focuses on providing clients the best palliative care and most positive outcomes as they move between different health care providers and organizations. (EOLFN Research Team, 2015)

First Nations Journey map: Refers to a process to improve the coordination and integration of care for clients as they access services from multiple programs and health care providers. It is done using a workshop format that brings together internal and external health care providers, Elders, and community leadership. It involves in-depth discussion of how First Nation community members transition through the health care system as they approach end of life, and identifies obstacles and solutions to improve service integration. (EOLFN Research Team, 2015)

Palliative care: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization, 2015)

Participatory action research: Is a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, context-specific and future-oriented (Waterman, Tillen, Dickson, & de Koning, 2001). In participatory action research, the degree of participant involvement varies on a continuum from researchers consulting the community's view (least involvement); to designing the study and then collecting data with the help of the community; to the community working closely with researchers; to total participant control (most involvement) (M. L. Kelley & McKee, 2013; S. Kemmis & R. McTaggart, 2005).

Reserve: Tract of land, the legal title to which is held by the Crown, set apart for the use and benefit of an Indian band. (Government of Canada. Aboriginal Affairs and Northern Development Canada, 2012)

Value stream: all the actions (both value added and non-value added) currently required to bring a product through the main flows essential to every product: (1) the production flow from raw material into the arms of the customers, and (2) the design flow from concept to launch. Taking a value stream perspective means working on the big picture, not just individual processes; and improving the whole, not just optimizing the parts. (Rother & Shook, 1999)

References

Abel, J., Walter, T., Carey, L. B., Rosenberg, j., Noonan, K., Horsfall, D., . . . Morris, D. (2013). Circles of Care: Should community development redefine the practice of palliative care? *BMJ Supportive and Palliative Care, 3*, 383-388. doi:10.1136/bmjspcare-2012-000359

Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health, 96* (Suppl 2), S45-61. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16078555

Aiken, L. S., Butner, J., Lockhart, C. A., Volk-Craft, B. E., Hamilton, G., & Williams, F. G. (2006). Outcome evaluation of a randomized trial of the Phoenix Care intervention: program of case management and coordinated care for the seriously chronically ill. *Journal of Palliative Medicine, 9*(1), 111-126.

American Psychological Association. (2010). *Publication Manual of the American Psychological Association* (6th ed.). Washington, D.C.

Angen, M. J. (2000). Evaluating Interpretive Inquiry: Reviewing the Validity Debate and Opening the Dialogue. *Qualitative Health Research, 10*(3), 378-395.

Atkinson, J. (2001). *Privileging Indigenous Research Methodologies*. Paper presented at the Indigenous Voices Conference, Carins, Queensland.

Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Seville, J., . . . Ahles, T. A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomized controlled trial. *The Journal of the American Medical Association, 302*(7), 741-749.

Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-eyed seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences, 2*(4), 331-340. Retrieved from http://www.integrativescience.ca/uploads/articles/2012-Bartlett-Marshall-Integrative-Science-Two-Eyed-Seeing-JESS.pdf

Baudin, M. (2013). Where do "value stream maps" come from? [Web log article]. Retrieved from http://michelbaudin.com/2013/10/25/where-do-value-stream-maps-come-from/

Brazil, K. (2012). Issues of diversity: participatory action research with Indigenous peoples. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory research in palliative care: Actions and reflections* (First ed., pp. 129-137). Oxford, UK: Oxford University Press.

Canadian Hospice Palliative Care Association. (2014). *The Way Forward: An integrated palliative approach to care*. Retrieved from Ottawa, ON:

Canadian Institutes of Health Research. (2005). Best practices for protecting privacy in health research. Retrieved from http://www.cihr-irsc.gc.ca/e/29134.html

Canadian Institutes of Health Research. (2011). *Aboriginal Peoples' Wellness in Canada: Scaling Up the Knowledge*. Retrieved from Calgary, AB: http://www.integrativescience.ca/uploads/files/2011_Aboriginal_Peoples_Wellness_in_Canada_scaling_up_the_knowledge.pdf

Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. Ottawa, ON: Queens Printer Retrieved from www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf.

Cohen, J., & Deliens, L. (2012). Applying a public health perspective to end-of-life care. In J. Cohen & L. Deliens (Eds.), *A public health perspective on end of life care* (First ed., pp. 3-18). New York, NY: Oxford University Press.

Connor, S. R., Pyenson, B., Fitch, K., Spence, C., & Iwasaki, K. (2007). Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *Journal of Pain and Symptom Management, 33*(3), 238-246.

Cresswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (Third ed.). Thousand Oaks, California: SAGE Publications, Inc.

Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research* (Fourth ed.). Thousand Oaks: SAGE Publications, Inc.

Dumont, S., Jacobs, P., Fassbender, K., Anderson, D., Turcotte, V., & Harel, F. (2009). Costs associated with resource utilization during the palliative phase of care: A Canadian perspective. *Journal of Palliative Medicine, 23*(8), 708-717. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19837702

Ellerby, J. H., McKenzie, J., McKay, S., Gariepy, G. J., & Kaufert, J. M. (2000). Bioethics for clinicians: 18. Aboriginal cultures. *Canadian Medical Association Journal, 163*(7), 845-850. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11033715

EOLFN Research Team. (2012). Improving End-of-Life Care in First Nations Communities. Retrieved from http://eolfn.lakeheadu.ca/the-communities/naotkamegwanning-first-nation

EOLFN Research Team. (2013a). *Fort William First Nation community needs assessment report*. Retrieved from Thunder Bay, ON: http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/FWFN_CommunityReport_Final_July102013.pdf

EOLFN Research Team. (2013b). *Naotkamegwanning First Nation community needs assessment report*. Retrieved from Thunder Bay, ON: http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/NFN_CommunityNeedsAssessment_Report_August2013_wo_RECs.pdf

EOLFN Research Team. (2013c). *Peguis First Nation community needs assessment report*. Retrieved from Thunder Bay, ON: http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/PFN_CommunityReport_Final_Oct2013.pdf

EOLFN Research Team. (2013d). *Six Nations of the Grand River Territory community needs assessment report*. Retrieved from Thunder Bay, ON: http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/SNGRT_CommunityReport_Final_May122013.pdf

EOLFN Research Team. (2015). *Developing palliative care programs in First Nations communities: A workbook*. Retrieved from http://eolfn.lakeheadu.ca/wp-content/uploads/2015/07/Palliative-Care-Workbook-Final-December-17.pdf

Fassbender, K., Fainsinger, R. L., Carson, M., & Finegan, B. A. (2009). Cost trajectories at the end of life: The Canadian experience. *Journal of Pain and Symptom Management, 38*(1), 75-80. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19615630

First Nations Centre. (2007). *OCAP: Ownership, control, access and possession. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations*. Retrieved from Ottawa, ON: National Aboriginal Health Organization: http://www.naho.ca/documents/fnc/english/OCAP.pdf

Fitzsimons, D., Mullan, D., Wilson, J. S., Conway, B., Corcoran, B., Dempster, M., . . . Fogarty, D. (2007). The challenge of patients' unmet palliative care needs in the final stages of chronic illness. . *Palliative Medicine, 21*(4), 313-322.

Forbes, D. A., & Edge, D. S. (2009). Canadian home care policy and practice in rural and remote settings: challenges and solutions. *Journal of Agromedicine, 14*(2), 119-124. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19437267

Google Maps (Cartographer). (2014). Naotkamegwanning First Nation, Pawtik, Ontario [map]. Retrieved from https://www.google.ca/maps/place/Naotkamegwanning+First+Nation+%28Whitefish+Bay+First

+Nation%29/@49.2210023,-91.681051,8z/data=!4m2!3m1!1s0x52bdced49415d4c5:0xd4d72b9a6706301f

Gorospe, E. C. (2006). Establishing palliative care for American Indians as a public health agenda. *Internet Journal of Pain, Symptom Control and Palliative Care, 4*(2). Retrieved from https://ispub.com/IJPSP/4/2/8930

Government of Canada. Aboriginal Affairs and Northern Development Canada. (2012). Aboriginal peoples and communities: Terminology. Retrieved from http://www.aadnc-aandc.gc.ca/eng/1100100014642/1100100014643

Habjan, S., Prince, H., & Kelley, M. L. (2012). Caregiving for elders in first nations communities: Social system perspective on barriers and challenges. *Canadian Journal on Aging, 31*(2), 209-222. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22608239

Hatch, J. A. (2002). *Doing qualitative research in education settings*. Albany, NY: State University of New York Press.

Health Canada. (1998). *Reaching out: A guide to communicating with Aboriginal seniors*. Ottawa, Ontario: Minister of Public Works and Government Services Canada. Retrieved from http://publications.gc.ca/collections/Collection/H88-3-30-2001/pdfs/com/reach_e.pdf.

Health Canada. (2004). *Transfer of health programs to First Nations and Inuit communities. Handbook 1: An introduction to three approaches*. Ottawa, ON: Health Canada Retrieved from http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/fnihb-dgspni/pdf/pubs/agree-accord/2004_trans_handbook-guide_1-eng.pdf.

Health Canada. (2011). *Building quality healthcare*. Ottawa, ON: Health Canada.

Health Council of Canada. (2013). *Canada's most vulnerable: Improving health care for First Nations, Inuit and Metis seniors*. Retrieved from http://www.healthcouncilcanada.ca/content_ab.php?mnu=2&mnu1=48&mnu2=30&mnu3=55.

Hotson, K. E., Macdonald, S. M., & Martin, B. D. (2004). Understanding death and dying in select first nations communities in northern Manitoba: Issues of culture and remote service delivery in palliative care. *International Journal of Circumpolar Health, 63*(1), 25-38. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15139239

Iwama, M., Marshall, M., Marshall, A., & Bartlett, C. (2009). Two-eyed seeing and the language of healing in community-based research. *Canadian Journal of Native Education, 32*(2), 3-23.

Kant, S., Vertinsky, I., Zheng, B., & Smith, P. M. (2013). Social, cultural, and land use determinants of the health and well-being of Aboriginal peoples of Canada: A path analysis. *Journal of Public Health Policy, 34*(3), 462-476. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/23760133

Kellehear, A. (2005). *Compassionate cities: public health and end-of-life care*. London ; New York: Routledge.

Kelley, A. S., & Meier, D. E. (2010). Palliative care: A shifting paradigm. *The New England Journal of Medicine, 363*(8), 781-782. doi:10.1056/NEJMe1004139

Kelley, M. L. (2016, July 10, 2016). [Thesis Discussion Meeting].

Kelley, M. L., & McKee, M. (2013). Capacity development in participatory action research. In J. M. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory research in palliative care: Actions and reflections* (First edition. ed., pp. 40-52). Oxford, UK: Oxford University Press.

Kemmis, & McTaggart. (2005). Participatory Action Research: Communicative Action and the Public Sphere. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research*. London: SAGE Publications.

Kemmis, S., & McTaggart, R. (2005). Participatory action research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (Third ed., pp. 559-603). Thousand Oaks, CA: SAGE.

Kitzes, J., & Berger, L. (2004). End-of-life issues for American Indians/Alaska Natives: Insights from one Indian Health Service area. *Journal of Palliative Medicine, 7*(6), 830-838. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15684850

Knoeppel, C. E. (1915). *Installing efficiency methods*. New York, NY: The Engineering Magazine Company.

Kovach, M. (2009). *Indigenous methodologies: Characteristics, conversations and contexts*. Toronto, ON; Buffalo, NY: University of Toronto Press.

Lewin, K. (1946). Action Research and Minority Issues. *Journal of Social Issues, 2*(4), 34-46.

Lord, J. (2013). A quick guide to customer journey mapping. Retrieved from http://bigdoor.com/blog/2013/11/01/a-quick-guide-to-customer-journey-mapping/

MacPherson, I., & McKie, L. (2010). Qualitative research in programme evaluation. In I. L. Bourgeault, R. Dingwall, & R. G. De Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 454-478). Los Angeles, CA: SAGE.

McTaggart, R. (1997). 16 Tenets of Participatory Action Research. In Y. Wadsworth (Ed.), *Everyday Evaluation on the Run* (Second Edition ed., pp. 128). Melbourne, AUS: Allen & Unwin.

Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. Toronto, ON: York University School of Health Policy and Management.

North West Local Health Integration Network. (2014). *Regional Palliative Care Plan*. Retrieved from Thunder Bay, ON: http://www.sjcg.net/documents/research/projects/nwlhin-rpcp/resources/North%20West%20LHIN%20Regional%20Palliative%20Care%20Plan%20%28English%29.pdf

Nova Scotia Aboriginal Home Care Steering Committee. (2010). *Aboriginal long term care in Nova Scotia: Aboriginal transition fund home care on-reserves project*. Nova Scotia Retrieved from http://novascotia.ca/dhw/ccs/documents/Aboriginal-Long-Term-Care-in-Nova-Scotia.pdf.

Ontario Local Health Integration Network. (2011). *North West Local Health Integration Network (LHIN) Population Health Profile*. Queens Printer for Ontario. Ottawa, ON. Retrieved from http://www.northwestlhin.on.ca/AboutOurLHIN/Our%20Communities.aspx

Ontario Local Health Integration Network. (2014). Our Communities. Retrieved from http://www.northwestlhin.on.ca/AboutOurLHIN/Our%20Communities.aspx

Pallium Canada. (2015). Canada Awarded 2017 International Public Health and Palliative Care Conference! Retrieved from http://pallium.ca/canada-awarded-2017-international-public-health-and-palliative-care-conference/

Pan-Canadian Palliative and End-of-life Care Strategy, M-456, 41st Parliament (2014).

Patton, M. Q. (2003). Qualitative Evaluation Checklist. Retrieved from http://www.wmich.edu/evalctr/archive_checklists/qec.pdf

Paz-Ruiz, S., Gomez-Batiste, X., Espinosa, J., Porta-Sales, J., & Esperalba, J. (2009). The costs and savings of a regional public palliative care program: the Catalan experience at 18 years. *Journal of Pain and Symptom Management, 38*(1), 87-96. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19615632

Prince, H., & Kelley, M. L. (2010). An integrative framework for conducting palliative care research with First Nations communities. *Journal of Palliative Care, 26*(1), 47-53. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/20402186

Quality Hospice Palliative Care Coalition of Ontario. (2011). *Advancing high quality, high value palliative care in Ontario: A declaration of partnership and commitment to action*. Retrieved from http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf

Richardson, A. (2010). Understanding Customer Experience. *Harvard Business Review*. https://hbr.org/2010/10/understanding-customer-experie Retrieved from https://hbr.org/2010/10/understanding-customer-experie

Richmond, C. A., & Ross, N. A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health Place, 15*(2), 403-411. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/18760954

Rother, M., & Shook, J. (1999). *Learing to see: Value stream mapping to add value and eliminate muda* (1.3 ed.). Cambridge, MA: Productivity Press.

Sallnow, L., Kumar, S., & Kellehear, A. (2012). Public health and palliative care: A historical overview. In L. Sallnow, S. Kumar, & A. Kellehear (Eds.), *International perspectives on public health and palliative care*. Abingdon, Oxon: Routledge.

Sheldon, F., & Sargeant, A. (2007). Ethical and practice issues in qualitative research. In J. M. Addington-Hall, E. Bruera, I. J. Higginson, & S. Payne (Eds.), *Research methods in palliative care* (pp. 315). New York, NY: Oxford University Press.

Smith, L. T. (2012). *Decolonizing methodologies: Research and Indigenous peoples* (Vol. Sixth). London, UK: Zed Books.

Snarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health, 1*(1), 80-95.

Stake, R. E. (1998). Case Studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 346). Thousand Oaks, CA: SAGE Publications, Inc.

Statistics Canada. (2006). *Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations, 2006 Census*. Retrieved from http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/p5-eng.cfm.

Statistics Canada. (2011a, November 30, 2015). Concepts: Projections of the Aboriginal population and households in Canada, 2011 to 2036. Retrieved from http://www.statcan.gc.ca/pub/91-552-x/2015001/section04-eng.htm

Statistics Canada. (2011b). *Focus on Geography Series, 2011 Census*. Retrieved from http://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-cma-eng.cfm?LANG=Eng&GK=CMA&GC=598.

Statistics Canada. (2011c). *Table A1: Age structure indicators by Aboriginal identity, Note 1 Canada, 2011 and 2036*. Retrieved from http://www.statcan.gc.ca/pub/91-552-x/2015001/t/tblA1-eng.htm.

Stjernsward, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. *Journal of Pain and Symptom Management, 33*(5), 486-493. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17482035

Strauss, A., & Corbin, J. (2008). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 346). Thousand Oaks, CA: SAGE Publications, Inc.

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine, 363*(8), 733-742.

The First Nations Information Governance Centre. (2016). The First Nations Principles of OCAP®. Retrieved from http://fnigc.ca/ocap.html

The Ontario Association of Community Care Access Centres (OACCAC); The Ontario Federation of Community Mental Health and Addiction Programs (OFCMHAP); The Ontario Hospital Association (OHA). (2010). Ideas and Opportunities for Bending the Health Care Cost Curve: Advice for the Ontario Government. Retrieved from https://www.oha.com/KnowledgeCentre/Library/Documents/Bending%20the%20Health%20Care%20Cost%20Curve%20%28Final%20Report%20-%20April%2013%202010%29.pdf

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 21. Retrieved from https://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf

Tracy, S. J. (2010). Qualitative quality: Eight big-tent criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10).

Verdinelli, S., & Scagnoli, N. I. (2013). Data Display in Qualitative Research. *International Journal of Qualitative Methods, 12*, 359-381. Retrieved from https://www.ideals.illinois.edu/bitstream/handle/2142/45262/FINAL%20VERSION_QUALITATIVE%20DATA%20DISPLAY.pdf?sequence=2

Waterman, H., Tillen, D., Dickson, R., & de Koning, K. (2001). Action research: A systematic review and guidance for assessment. *Health Technology Assessment, 5*(23), iii-157. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11785749

Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education, 25*(2), 175-179. Retrieved from http://scholar.google.ca/scholar_url?url=http://www.researchgate.net/profile/Shawn_Wilson2/publication/234754037_What_Is_an_Indigenous_Research_Methodology/links/0a85e5320f48b8d0a3000000.pdf&hl=en&sa=X&scisig=AAGBfm1285b0KGKgkaZwp6grXC42LtUDjw&nossl=1&oi=scholarr&ei=BCHyVNf1EO2_sQSYg4LoCA&ved=0CBsQgAMoADAA

Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Black Point, NS: Fernwood Publishing.

World Health Organization. Retrieved from http://www.who.int/cancer/palliative/definition/en/

World Health Organization. (1990). Cancer pain relief and palliative care. *Technical report series 804. Geneva: World Health Organization.* Retrieved from http://whqlibdoc.who.int/trs/WHO_TRS_804.pdf

World Health Organization. (2014). Genes and noncommunicable diseases. Retrieved from http://www.who.int/genomics/public/geneticdiseases/en/index3.html

World Health Organization. (2015). WHO Definition of Palliative Care. Retrieved from (http://www.who.int/cancer/palliative/definition/en/)

World Health Organization Regional Office for Europe. (2004). *Palliative care. The solid facts* E. Davies & I. J. Higginson (Eds.), (pp. 32). Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf

Appendices

Appendix A: Focus Group Information Letter (for the current study)

Centre for Education and Research on Aging & Health
t: (807) 766-7274 f: (807) 766-7222
mlkelley@lakeheadu.ca

Wiisokotaatiwin Program Journey Mapping:

Focus Group Participant Information Letter

INFORMATION SHEET

Dear Potential Participant,

As a participant in the journey mapping workshops that took place from August 2013 – October 2014, you are invited to participate in a focus group about your overall experiences with creating a care pathway for Naotkamegwanning clients that are very very sick. The information collected from this focus group will be used to create a journey mapping workshop workbook for other First Nation's communities and become part of a Lakehead University master's thesis entitled "A case study of journey mapping to design a palliative care pathway for Naotkamegwanning First Nation: A qualitative evaluation." The Research Assistant and Graduate Student for this research is Jessica Koski and the Principal Investigator and thesis supervisor is Dr. Mary Lou Kelley, Lakehead University, Thunder Bay, Ontario.

This focus group is a sub-study of the five-year project titled "*Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development*" which is led by Dr. Mary Lou Kelley and funded by the Canadian Institutes of Health Research.

Your participation in this focus group is voluntary and you refuse to participate in any part of the focus group, decline to answer questions, or discontinue participation at any time during the focus group. The focus group will be audio-taped, and at the beginning, you will be asked for verbal consent because you have already signed a consent to participate in the overall research project. When you are asked for your verbal consent to participate, you may decline to be audio-taped and that will be respected.

It is not anticipated that there are risks to your safety by participating in this focus group, however, because the topic of the research involves the issue of Naotkamegwanning clients that are very, very sick, we recognize that some focus group questions may be of a sensitive and personal nature. Should you have difficulty and require support following the focus group, you be assisted to access support and counselling services. Access to support resources will be organized in advance and appropriate assistance will be identified by the community Project Advisory Committee.

The information that you provide will remain confidential and securely stored at Lakehead University for five years and will be accessed only by the researchers and staff involved in the project. Please note that the confidentiality of focus group participants cannot be fully guaranteed due to the group format. However, all participants are encouraged to respect the privacy of individuals taking part in the group.

The findings from this focus group may be presented at conferences or published in a journal so that others may learn from it, ensuring confidentiality of the participants. In all cases, findings will be reported in non-identifying and summary format, conforming to the guidelines for research ethics at Lakehead University and no individual participants will be identified in published results without their explicit consent. When direct quotes are used in writing to support research findings, only "Naotkamegwanning community member" or "Naotkamegwanning Elder" will be used.

Participants in this focus group will be asked to provide feedback following the analysis to ensure their thoughts have been properly documented. The community will receive a copy of the final thesis, upon its completion.

If I have any questions concerning the project, please feel free to contact: Jessica Koski, Research Assistant and Graduate Student, Master of Health Sciences program, Lakehead University (807) 766-7299 or jkoski@lakeheadu.ca

Dr. Mary Lou Kelley, School of Social Work, Lakehead University at (807) 766-7270 or by e-mail at mlkelley@lakeheadu.ca

Lakehead University Research Ethics Board at (807) 343-8934.

Thank you for your time and consideration.

Jessica Koski, Research Assistant & MHSc (candidate)

Appendix B: Wiisokotaatiwin Program Journey Mapping: Focus group guide

From your perspective:

1. What was the purpose of the journey mapping? Did it meet your expectations?

2. Do you think community members could voice their views during the workshops? Do you feel your voices were heard during the workshops?

3. What were the barriers and facilitators during the journey mapping?

    a. Probes: location, time, facilitation style, participants, etc.

    b. Probe for “stop/start/continue” to revise the protocol

4. Was the journey mapping successful in helping the Naotkamegwanning community?

    a. Please provide examples or details if you can

5. What was the most significant benefit/change for your community members?

    a. Probe: What of all those things discussed was most significant?

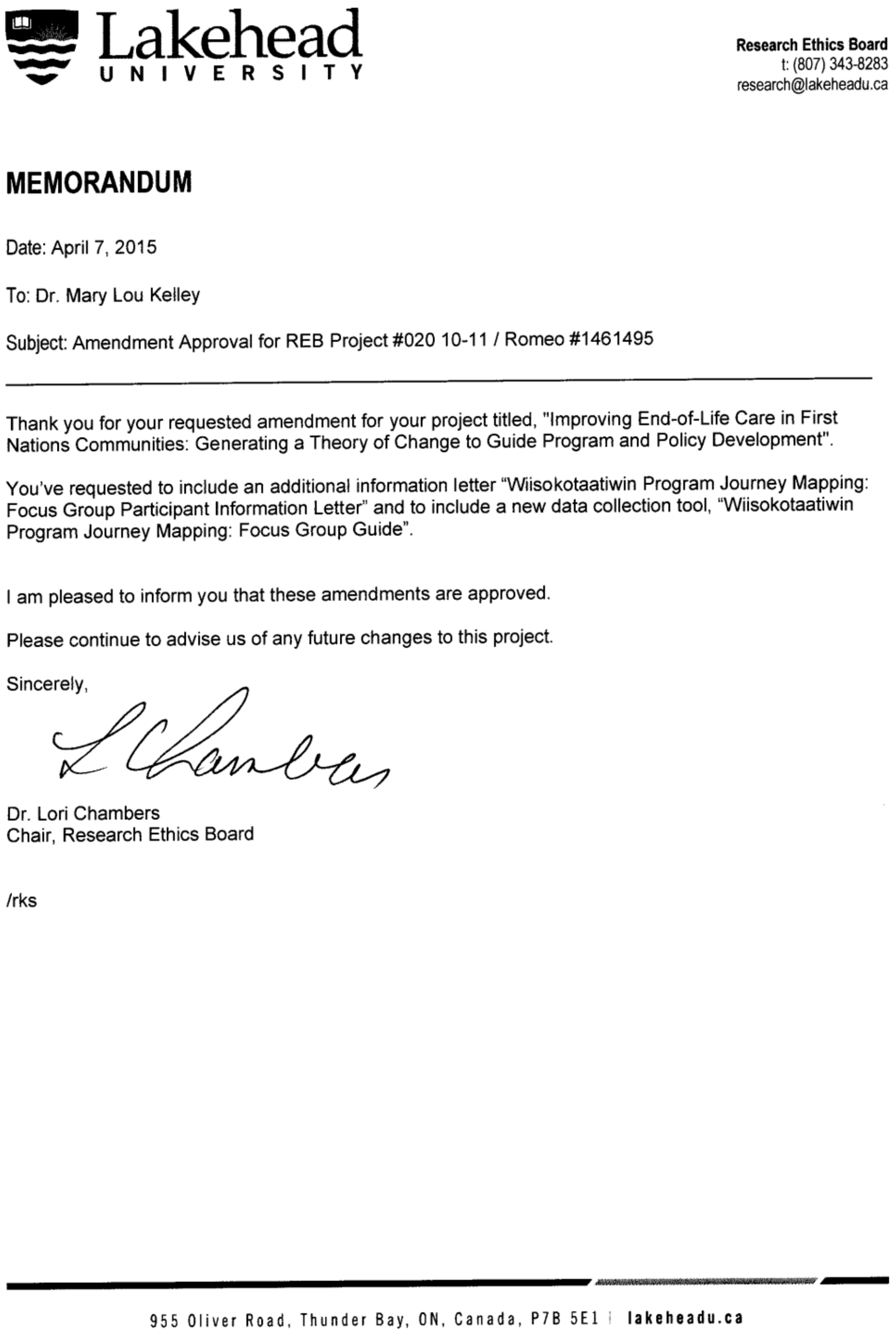
6. Do you think external health care providers and community members now better understand each other?

7. What remains unfinished?

8. Would you recommend other First Nations communities do a journey mapping exercise like you did?

9. Any other comments?

Appendix C: Lakehead REB focus group approval letter



Lakehead
UNIVERSITY

Research Ethics Board
t: (807) 343-8283
research@lakeheadu.ca

MEMORANDUM

Date: April 7, 2015

To: Dr. Mary Lou Kelley

Subject: Amendment Approval for REB Project #020 10-11 / Romeo #1461495

Thank you for your requested amendment for your project titled, "Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development".

You've requested to include an additional information letter "Wiisokotaatiwin Program Journey Mapping: Focus Group Participant Information Letter" and to include a new data collection tool, "Wiisokotaatiwin Program Journey Mapping: Focus Group Guide".

I am pleased to inform you that these amendments are approved.

Please continue to advise us of any future changes to this project.

Sincerely,

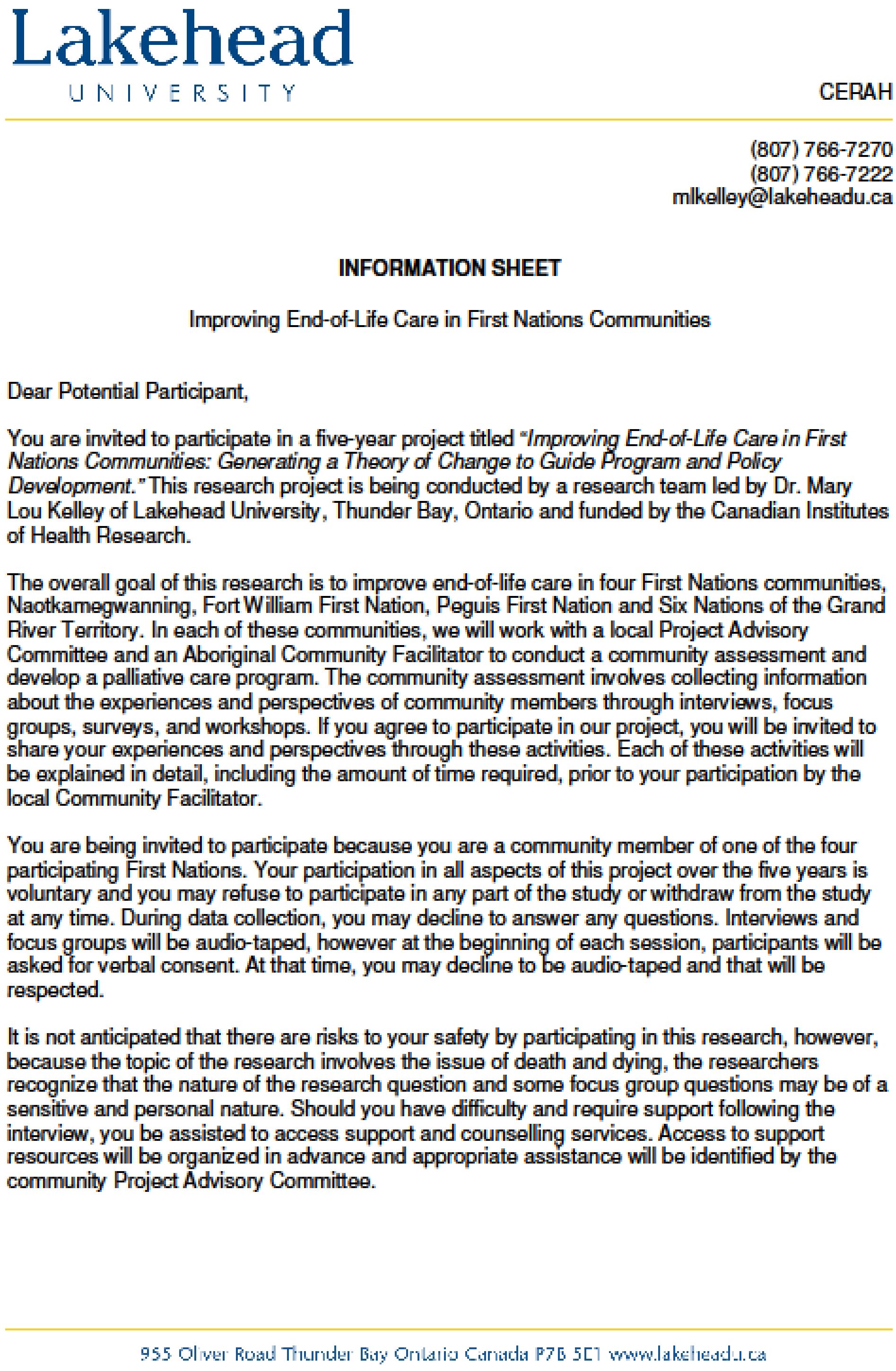
L Chambers

Dr. Lori Chambers
Chair, Research Ethics Board

/rks

955 Oliver Road, Thunder Bay, ON, Canada, P7B 5E1 | **lakeheadu.ca**

Appendix D: Original Information Letter (overall EOLFN project)



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INFORMATION SHEET

Improving End-of-Life Care in First Nations Communities

Dear Potential Participant,

You are invited to participate in a five-year project titled *"Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development."* This research project is being conducted by a research team led by Dr. Mary Lou Kelley of Lakehead University, Thunder Bay, Ontario and funded by the Canadian Institutes of Health Research.

The overall goal of this research is to improve end-of-life care in four First Nations communities, Naotkamegwanning, Fort William First Nation, Peguis First Nation and Six Nations of the Grand River Territory. In each of these communities, we will work with a local Project Advisory Committee and an Aboriginal Community Facilitator to conduct a community assessment and develop a palliative care program. The community assessment involves collecting information about the experiences and perspectives of community members through interviews, focus groups, surveys, and workshops. If you agree to participate in our project, you will be invited to share your experiences and perspectives through these activities. Each of these activities will be explained in detail, including the amount of time required, prior to your participation by the local Community Facilitator.

You are being invited to participate because you are a community member of one of the four participating First Nations. Your participation in all aspects of this project over the five years is voluntary and you may refuse to participate in any part of the study or withdraw from the study at any time. During data collection, you may decline to answer any questions. Interviews and focus groups will be audio-taped, however at the beginning of each session, participants will be asked for verbal consent. At that time, you may decline to be audio-taped and that will be respected.

It is not anticipated that there are risks to your safety by participating in this research, however, because the topic of the research involves the issue of death and dying, the researchers recognize that the nature of the research question and some focus group questions may be of a sensitive and personal nature. Should you have difficulty and require support following the interview, you be assisted to access support and counselling services. Access to support resources will be organized in advance and appropriate assistance will be identified by the community Project Advisory Committee.

The information that you provide will remain confidential and securely stored at Lakehead University for seven years and will be accessed only by the researchers and staff involved in the project. If you are completing a survey, the survey will not be labeled to identify who completed it. Confidentiality of focus group participants cannot be fully guaranteed due to the group format. However, all participants will be encouraged to respect the privacy of individuals taking part in the group.

The findings from this study may be presented at conferences or published in a journal so that others may learn from it, ensuring confidentiality of the participants. In all cases, findings will be reported in non-identifying and summary format, conforming to the guidelines for research ethics at Lakehead University and no individual participants will be identified in published results without their explicit consent.

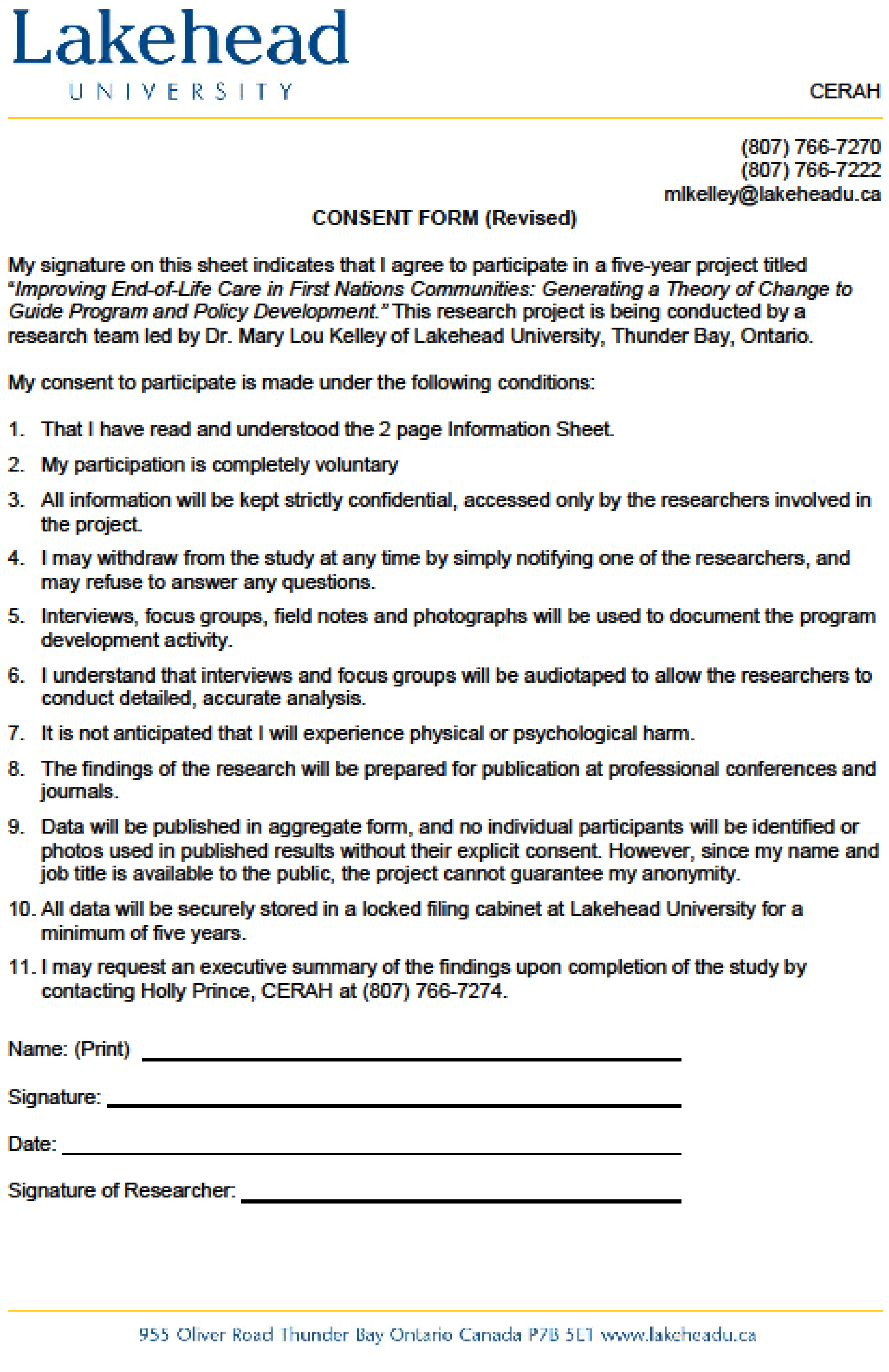
The community will receive a summary of the project, following the completion of the project. You can request an executive summary of the findings upon completion of the study by contacting Holly Prince, Project Manager at hprince@lakeheadu.ca or (807) 766-7274.

If I have any questions concerning the project, please feel free to contact: Dr. Mary Lou Kelley, School of Social Work, Lakehead University at (807) 766-7270 or by e-mail at mlkelley@lakeheadu.ca or the Lakehead University Research Ethics Board at (807) 343-8934.

Thank you for your time and consideration.

Mary Lou Kelley, MSW, PhD
School of Social Work
Lakehead University

Appendix E: Original Informed Consent (overall EOLFN project)



Lakehead
UNIVERSITY

CERAH

(807) 766-7270
(807) 766-7222
mlkelley@lakeheadu.ca

CONSENT FORM (Revised)

My signature on this sheet indicates that I agree to participate in a five-year project titled "*Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development.*" This research project is being conducted by a research team led by Dr. Mary Lou Kelley of Lakehead University, Thunder Bay, Ontario.

My consent to participate is made under the following conditions:

1. That I have read and understood the 2 page Information Sheet.
2. My participation is completely voluntary
3. All information will be kept strictly confidential, accessed only by the researchers involved in the project.
4. I may withdraw from the study at any time by simply notifying one of the researchers, and may refuse to answer any questions.
5. Interviews, focus groups, field notes and photographs will be used to document the program development activity.
6. I understand that interviews and focus groups will be audiotaped to allow the researchers to conduct detailed, accurate analysis.
7. It is not anticipated that I will experience physical or psychological harm.
8. The findings of the research will be prepared for publication at professional conferences and journals.
9. Data will be published in aggregate form, and no individual participants will be identified or photos used in published results without their explicit consent. However, since my name and job title is available to the public, the project cannot guarantee my anonymity.
10. All data will be securely stored in a locked filing cabinet at Lakehead University for a minimum of five years.
11. I may request an executive summary of the findings upon completion of the study by contacting Holly Prince, CERAH at (807) 766-7274.

Name: (Print) ______________________________

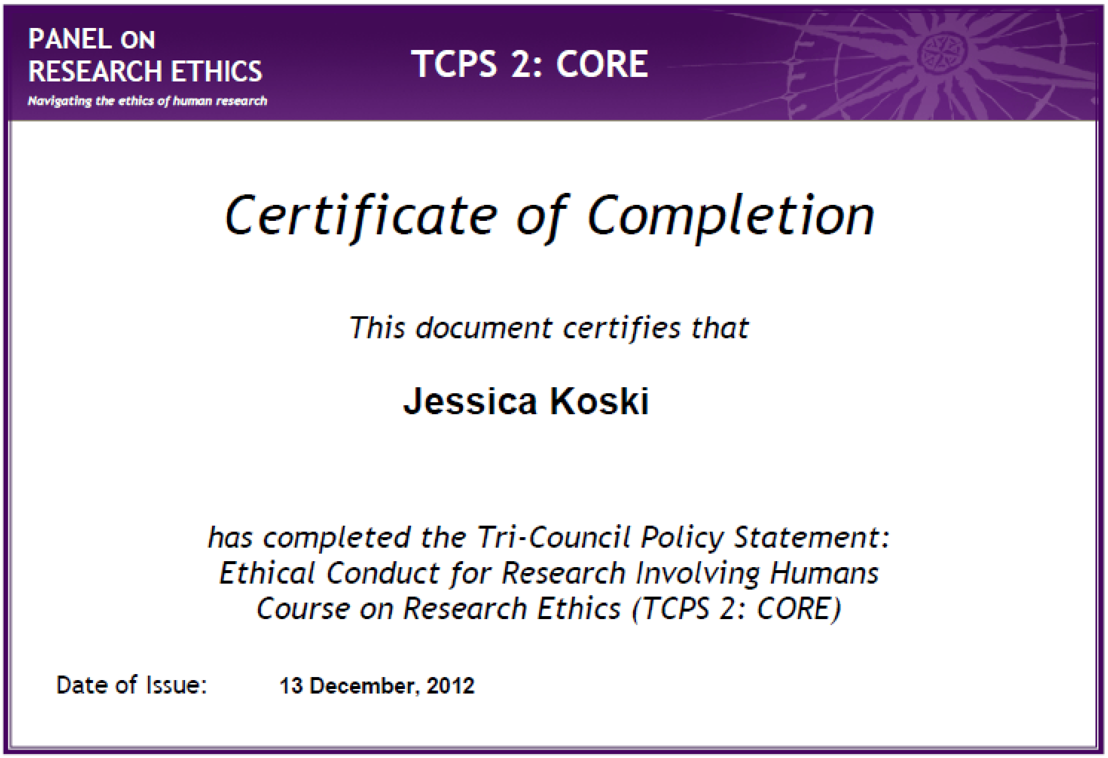
Signature: ______________________________

Date: ______________________________

Signature of Researcher: ______________________________

955 Oliver Road Thunder Bay Ontario Canada P7B 5E1 www.lakeheadu.ca

Appendix F: Student investigator TCPS certificate



PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

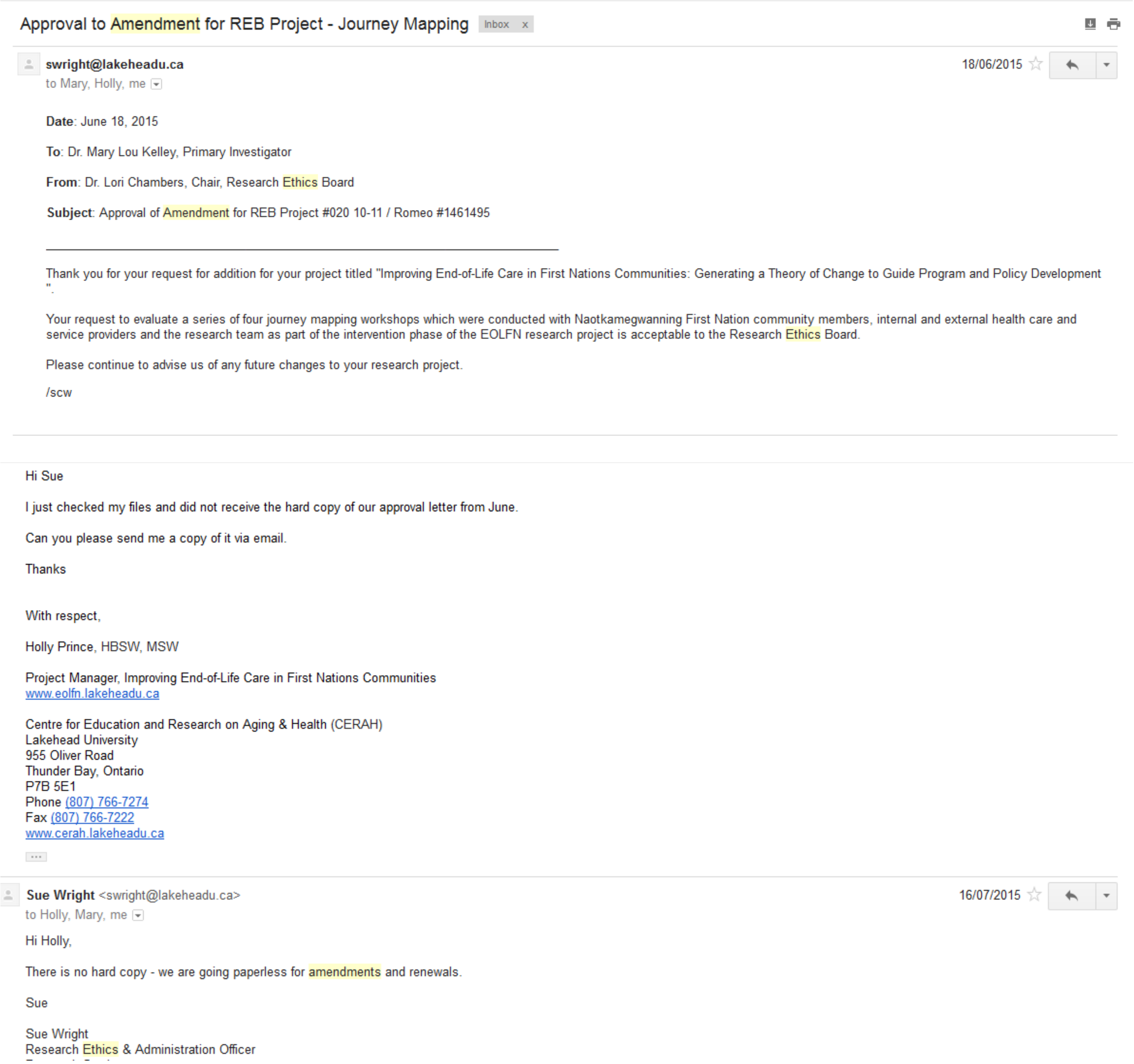
This document certifies that

Jessica Koski

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

Date of Issue: **13 December, 2012**

Appendix G: Lakehead University REB "paperless" approval of thesis



Approval to Amendment for REB Project - Journey Mapping

swright@lakeheadu.ca 18/06/2015
to Mary, Holly, me

Date: June 18, 2015

To: Dr. Mary Lou Kelley, Primary Investigator

From: Dr. Lori Chambers, Chair, Research Ethics Board

Subject: Approval of Amendment for REB Project #020 10-11 / Romeo #1461495

Thank you for your request for addition for your project titled "Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development ".

Your request to evaluate a series of four journey mapping workshops which were conducted with Naotkamegwanning First Nation community members, internal and external health care and service providers and the research team as part of the intervention phase of the EOLFN research project is acceptable to the Research Ethics Board.

Please continue to advise us of any future changes to your research project.

/scw

Hi Sue

I just checked my files and did not receive the hard copy of our approval letter from June.

Can you please send me a copy of it via email.

Thanks

With respect,

Holly Prince, HBSW, MSW

Project Manager, Improving End-of-Life Care in First Nations Communities
www.eolfn.lakeheadu.ca

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www.cerah.lakeheadu.ca

Sue Wright <swright@lakeheadu.ca> 16/07/2015
to Holly, Mary, me

Hi Holly,

There is no hard copy - we are going paperless for amendments and renewals.

Sue

Sue Wright
Research Ethics & Administration Officer

Appendix H: Email body for on-line survey participants

Dear journey map working group participant,

As a participant in the journey mapping workshops that took place from August 2013 – August 2014, you are invited to complete a 15 minute survey about your overall experiences with creating a palliative care pathway for Naotkamegwanning clients. <link to survey>

The information collected from this survey will be used to create a journey mapping workshop workbook for other First Nation's communities and become part of a Lakehead University master's thesis entitled "A case study of journey mapping to design a palliative care pathway for Naotkamegwanning First Nation: A qualitative evaluation." The Research Assistant and Graduate Student for this research is Jessica Koski and the Principal Investigator and thesis supervisor is Dr. Mary Lou Kelley, Lakehead University, Thunder Bay, Ontario.

This research is part of a sub-study of the five-year project titled "*Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development"* which is led by Dr. Mary Lou Kelley and funded by the Canadian Institutes of Health Research.

If I have any questions concerning the project, please feel free to contact: Jessica Koski, Research Assistant Centre for Education and Research on Aging & Health (CERAH) and Graduate Student, Master of Health Sciences program, Lakehead University (807) 766-7299 or jkoski@lakeheadu.ca

Dr. Mary Lou Kelley, School of Social Work, Lakehead University at (807) 766-7270 or by e-mail at mlkelley@lakeheadu.ca

Lakehead University Research Ethics Board at (807) 343-8934.

Appendix I: Survey Participant Information Letter and Consent

The information collected from this survey will be used to create a journey mapping workshop workbook for other First Nation's communities and become part of a Lakehead University master's thesis entitled "A case study of journey mapping to design a palliative care pathway for Naotkamegwanning First Nation: A qualitative evaluation." The Research Assistant and Graduate Student for this research is Jessica Koski and the Principal Investigator and thesis supervisor is Dr. Mary Lou Kelley, Lakehead University, Thunder Bay, Ontario.

This research is part of a sub-study of the five-year project titled "*Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development"* which is led by Dr. Mary Lou Kelley and funded by the Canadian Institutes of Health Research.

Although your responses may be linked to your email address, the information that you provide in this survey will be confidential and de-identified. There are no known safety risks to participate in this survey. The data will be securely stored in a de-identified manor at Lakehead University for five years and only be accessed by the researchers and staff involved in the overall project. You may withdraw at any time and or refuse to answer any question, without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be securely deleted.

The findings from this survey may be presented at conferences or published in a journal so that others may learn from it, ensuring confidentiality of the participants. In all cases, findings will be reported in non-identifying and summary format, conforming to the guidelines for research ethics at Lakehead University and no individual participants will be identified in published results without their explicit consent. When direct quotes are used in writing to support research findings, only "internal/external health care provider" or "social service provider" will be used.

Participants in this survey will be invited to provide feedback following the data analysis to ensure their thoughts have been properly documented. Participants will receive an electronic copy of the final thesis, upon its completion.

If I have any questions concerning the project, please feel free to contact: Jessica Koski, Research Assistant Centre for Education and Research on Aging & Health (CERAH) and Graduate Student, Master of Health Sciences program, Lakehead University (807) 766-7299 or jkoski@lakeheadu.ca

Dr. Mary Lou Kelley, School of Social Work, Lakehead University at (807) 766-7270 or by e-mail at mlkelley@lakeheadu.ca

Lakehead University Research Ethics Board at (807) 343-8934.

I have read the above information letter and consent to participate in this study.

Yes (go to Q1) No (end survey)

Appendix J: External health care provider and research team survey

Your information:

Please indicate which of the following groups you belong to:

- ☐ External heath care provider to Naotkamegwanning
- ☐ Research team

Your opinion:

For the following statements, please select the number that represents your opinion of the journey mapping workshops.

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
The journey mapping workshops helped me look at my work in a different way than before.	1	2	3	4	
The workshops helped me better understand the roles of the other care providers involved.	1	2	3	4	
The workshops helped me better understand the policies and procedures (mandates) of the other organizations involved.	1	2	3	4	
The workshops identified gaps and problems in service delivery.	1	2	3	4	
The workshops identified new strategies to improve communication, coordination and integration of care delivery.	1	2	3	4	
The workshops helped me better understand the needs and preferences of clients in Naotkamegwanning.	1	2	3	4	
The workshops generated commitment to solve service delivery issues for residents of Naotkamegwanning.	1	2	3	4	
The workshops helped improve care delivery for Naotkamegwanning residents who are in the last year of life.	1	2	3	4	
I feel like my voice was heard in the workshops.	1	2	3	4	
I feel like the voice of the community members was respected during the workshops.	1	2	3	4	

I feel like the views of the community members were incorporated during the workshops.	1	2	3	4	
I feel external health care providers and community members now better understand each other.	1	2	3	4	
The journey mapping process was effective to create a care pathway for palliative care in Naotkamegwanning	1	2	3	4	
I recommend other First Nations communities do a journey mapping exercise.	1	2	3	4	

For the following questions, please describe your opinion of the journey mapping workshops.

In your opinion, what was the purpose of the journey mapping?

<free text field>

What were the barriers during the journey mapping?

Things to consider include: location, timing, facilitation style, organization, use of technology, comfort of the environment for expressing views, cultural responsiveness.

Please list the barriers:

<free text field>

What were the facilitators during the journey mapping?

Things to consider include: location, timing, facilitation style, organization, use of technology, comfort of the environment for expressing views, cultural responsiveness.

Please list the facilitators:

<free text field>

Did the workshops give you new ideas about how to improve care for the residents of Naotkamegwanning?

Examples to consider: palliative care education, culturally appropriate care and training.

<free text field>

What was the most significant change or outcome for your organization?

<free text field>

What worked well in the journey mapping workshops?

<free text field>

What did not work well in the journey mapping workshops?

<free text field>

What suggestions do you have for the future?

<free text field>

What remains unfinished?

<free text field>

Additional comments:

<free text field>

Thank you for taking the time to complete this survey.

The results will be shared with you via email in the form of a report.