



Waterloo Wellington Aboriginal Palliative Care Needs Assessment

Final Report
April 2014

Hospice of Waterloo Region

298 Lawrence Avenue Kitchener, Ontario N2M 1Y4

Phone: (519) 743-4114

Fax: (519) 743-7021

E-mail: hospice@hospicewaterloo.ca

Judy Nairn, Executive Director

Irena Razanas, Director of Programs and Clinical Services

Barb Wilson MSW, Project Coordinator

Mary Ann Nawagesic, MSW Intern, Ojibway

Elders Advisory Group

Andrea Misquadis, Ojibway

Elaine Garner, Ojibway

Gale Cyr, Algonquin, French

Jean Becker, Innu, Inuit, English

Hospice of Waterloo Region wishes to acknowledge the support of Waterloo Wellington Local Health Integration Network (WWLHIN).



The views expressed in this report do not necessarily reflect the views of Waterloo Wellington Local Health Integration Network and the Government of Ontario

Contents

Executive Summary	4
Elder’s Advisory Group Recommendations	5
Major Findings	7
Recommendations	7
Conclusion.....	9
Project Background	11
Language.....	12
Demographic Profile	13
Methodology.....	15
Goal of Research	17
Determinants of Health.....	19
Wholistic World View	22
Trends Influencing Aboriginal Palliative Care.....	23
Findings/Themes	25
Role of Elders/Access to Elders	26
Education.....	27
Hospital Care/Home Care/Hospice Care	28
Increased Support for Family, Caregivers and Community	31
Access to a Blend of Western Medical Care and Wholistic Traditional Medicine.....	33
Building Relationships	35
Aboriginal Leadership in Palliative Care Services	36
Aboriginal-Specific Palliative Care Guidelines and Protocols.....	37
Aboriginal Health Navigation Team.....	38
Building Community Capacity	38
Acknowledging and Addressing the Impact of Colonization	42
WWLHIN Aboriginal Initiatives	43
Implementing the Recommendations	45
Cultural Safety/Cultural Competency	47
Conclusion	52
Appendix 1: Project Participants	1
Appendix 2: In the Words of the Participants	55
Appendix 3: Survey	61
Bibliography	65

Acknowledgements

Hospice of Waterloo Region wishes to thank the project participants and all those whose support and contributions were vital to the project and the final report. Chi Miigwech to the Elders, caregivers and community members who shared their stories, experiences, insights and ideas about palliative/end of life care for the Waterloo Wellington Aboriginal community. Without the participation of the local Aboriginal community, this project, the report and the recommendations could not have been as informed, relevant or meaningful. We acknowledge that this research was conducted on the traditional land of the Haudenosaunee, Anishnabeg and the Neutral people.

Deep gratitude and heartfelt appreciation are extended to the Elders who supported and guided this project. Andrea Misquadis, Elaine Garner, Gale Cyr, and Jean Becker were the members of the Elders Advisory group. These women generously shared their wisdom, insights, knowledge, support and wonderful sense of humour throughout the project. A special thank you to Lois MacDonald and Dr. Kim Kenney who met individually, attended Circles, and generously shared their wisdom, and support. We were humbled by the participation, kindness, patience, wisdom, and insightful contributions of the Aboriginal community in Waterloo Wellington and their willingness to risk participating in yet another research project about Aboriginal people in Canada.

We wish to recognize Hospice Wellington for the time they sat with us and the use of their space to hold one of the Talking Circles. Chi Miigwech to Mary Ann Nawagesic, a MSW practicum student with Hospice, and to Laurie Minor, Michelle (Margo) Lee, Akiesha Absolon-Winchester and JoAnne Absolon for their invaluable assistance and support.

HWR with its partner Hospice Wellington, is honoured to have had the opportunity to work with the Indigenous community throughout this needs assessment. HWR understands the requirement that Aboriginal knowledge inform, direct and become inherent in Aboriginal health initiatives generally and in end of life care services specifically.

From this point forward this document reflects the voices and messages of the Elders Advisory Committee and the participants from the local Aboriginal communities.

**Humankind has not woven the web of life.
We are but one thread within it.
Whatever we do to the web, we do to ourselves.
All things are bound together.
All things connect.**

- Chief Seattle, 1854

Executive Summary

Introduction

This report presents the findings of a palliative care needs analysis for the Waterloo Wellington Aboriginal community. Hospice of Waterloo Region (HWR) received one time funding from the Waterloo Wellington Local Health Integration Network (WWLHIN) to identify gaps in current palliative care for the local Aboriginal community; to document what palliative care means for the local urban Aboriginal community; to develop recommendations for a model for the integration of effective culturally appropriate palliative care service within the local palliative care system; and, to develop recommendations to the Waterloo Wellington Integrated Hospice Palliative Care Program. Those who participated in this project were motivated and engaged in considering palliative care needs for the local Aboriginal community. Chi Miigwech to the participants who shared rich stories, experiences and insights focused on palliative care with a mix of grief, loss, pain, and humour.

This project represents the beginning of the conversation about Aboriginal palliative care in Waterloo Wellington. The report highlights barriers, challenges and the vision the Aboriginal community has for palliative care supports and services for its members. The stories, experiences, and insights shared and collected in this project should be understood as a snapshot of perspectives that may be helpful in developing best practices, services and a model for providing end of life care for the Aboriginal communities. Far more time needs to be given to and invested in conversations and relationships with Aboriginal people in order to develop meaningful, respectful and culturally relevant end of life care services and supports.

This project faced the unique experience of understanding the palliative care needs of off-reserve urban Indigenous people. To date, much of the work and research addressing Aboriginal end of life models have focused on on-reserve Aboriginal populations. This project created an opportunity for a coming together of the diverse urban Indigenous population in Waterloo Wellington. It was repeatedly identified by participants that a positive outcome of participating in this project was the opportunity to gather with and connect to other Aboriginal people living in their communities.

This coming together of the local Aboriginal communities combined with development of a solid foundation through innovative and Aboriginal driven palliative care services and supports will aid in increasing positive palliative care services for the local Aboriginal community. Funders' support of off-reserve urban programming and services that are culturally respectful and reflect the unique needs, priorities and interests of the local Indigenous community will help to establish essential Aboriginal resources, supports and services. Participants repeatedly highlighted that palliative and end of life care cannot be

considered separately from broader health care services noting that palliative care must be understood as being part of the larger health care system.

It is hoped that this needs assessment will help to strengthen relationships between WWLHIN, local healthcare and palliative care service providers and the local Aboriginal community, and inform and deepen understanding of the needs and service delivery considerations specific to Aboriginal palliative care.

Methodology

This five month research project applied an Indigenous Methodology approach to exploring palliative care service needs for Waterloo Wellington Aboriginal people. The project involved 87 people in four Circles with a total of 53 Aboriginal participants and 34 individual conversations with 20 members of the Aboriginal community and 14 non-Indigenous palliative care providers including nurses, a doctor, a social worker, a volunteer, and hospice staff in Waterloo and Wellington. Local Aboriginal protocol was respected in the individual meetings and the Talking Circles.

Elder's Advisory Group Recommendations

The Elder's Advisory group highlighted key themes and recommendations they believe are significant to the development of palliative and end of life care for the Waterloo Wellington Indigenous community.

It is the recommendation of the Elder's Advisory group that the results of this research not be used primarily to fund mainstream training and initiatives designed to provide services to Aboriginal people. Instead, they want to see the implementation of the recommendations identified in this report to be guided and developed by the Aboriginal community; to be of, for, and by Aboriginal people. The Elders want a commitment to support the leadership of the local Aboriginal community in determining and developing the supports and services provided to urban Aboriginal people.

The Elders recommend that WWLHIN establish strong representation from the Aboriginal community to provide direction at provincial and local levels to guide Aboriginal health initiatives in Waterloo Wellington. They strongly recommend that WWLHIN establish a local Aboriginal Advisory group.

The Elders highlight that any Aboriginal health services must provide care across the life span, from birth to death and describe a vision of an Aboriginal health and wellness tailored to provide care to meet the specific and wholistic care needs of the Aboriginal community, including physical, mental, emotional and spiritual care and provide access to Aboriginal Traditional Medicine as well as mainstream medical care. The Elder's Advisory group identified the need to create infrastructure and designated space for Aboriginal health, as well as making space across all services and locations within the local health and palliative care services for Aboriginal culturally safe and appropriate health care. Any space and the

people providing wholistic Aboriginal health care would be a resource to the entire community, including health care providers practicing in Waterloo Wellington.

The Elder's Advisory group recommends the establishment of additional resources for palliative home care services and supports, ensuring that Aboriginal people living with a life-threatening illness remain in their home for as long as possible. The required supports and services must include financial, social, emotional, spiritual and cultural resources for Indigenous people wishing to be at home and if possible die at home.

The Elders highlighted the need for WWLHIN to continue providing funding and ongoing commitment to develop palliative care to the Aboriginal community. They identified that future funding opportunities to develop Indigenous palliative care must involve the Aboriginal community to identify, design and deliver new initiatives.

There is a strong belief that programming for the Indigenous people in Waterloo Wellington need to be developed of, by, and for the Indigenous community. It was stated that this does not mean the Aboriginal community will not work with mainstream organizations and services, rather that they need to have control and make the decisions about who and how they involve community partners and resources in the development of initiatives for Aboriginal people.

An Aboriginal health navigation system was recommended as a priority by the Advisory group who note the need for processes and systems in the health care system to advocate, guide, educate, support and respond to the unique health care and palliative care needs currently faced by the urban Aboriginal community. This would provide cultural support and resources to individuals and families involved in the health care system and receiving palliative care, facilitate access to Elders, Traditional Medicine and Healers, help work with hospital staff to arrange ceremony, advocate for culturally informed care, and refer to grief and bereavement support that understands intergenerational trauma and complex grief and bereavement. An Aboriginal health navigation program would advocate for the best possible range of options for families with the lowest possible number of barriers and challenges. Such a program could support health and palliative care providers to learn more about Aboriginal culture and understand what culturally safe care involves, and increase ability to interact more effectively with Aboriginal clients. The Elders expressed their belief that Aboriginal health navigation would be connected to the Aboriginal community agencies.

Increased funding and educational support for Aboriginal people to enter health care professions, including Personal Support Workers (PSW's), nursing, doctors, nurse practitioners, occupational therapists, etc. is seen as a priority by the Elders. This would include increased funding for health profession training opportunities for Aboriginal people, combined with increased support and encouragement for Aboriginal youth to pursue health education and training, thereby increasing the numbers of Aboriginal professional caregivers available to provide health care, including palliative care.

Major Findings

It is evident that with the growing urban Aboriginal population, culturally respectful and appropriate palliative care and end of life care models must be developed for urban centres.

Identified Gaps in Palliative Care for Aboriginal People Living in Waterloo Wellington:

- Gaps in awareness about end of life care information, resources, and services exists within the Aboriginal community.
- Gaps in access to and utilization of Aboriginal Elders and Healers in palliative care services.
- Challenges and barriers exist for practicing Traditional Medicine and ceremony in hospital settings. Traditional Medicine refers to any ceremony, substance, process, teaching, song, story or symbol that helps to restore balance in human beings and their communities.
- Gaps in financial, spiritual, emotional, cultural and social supports available for family, caregivers and the Aboriginal community receiving palliative care.
- Gaps in culturally informed, and appropriate grief, loss and bereavement supports for Aboriginal people
- Gaps in access to a blend of Western medical care and wholistic Traditional Medicine.
- Lack of culturally relevant information and services focused on end of life care for Aboriginal individuals and families making it difficult for health care providers and their Aboriginal patients to have meaningful dialogue on palliative care and to make care plans that consider and respect cultural values and beliefs.
- Gaps in training and opportunities to heighten awareness of culturally safe and competent care for health care providers involved in palliative care
- Gaps in awareness on the part of health and palliative care providers of the impact of historical and present day colonization factors experienced by Aboriginal people, and how these factors greatly influence end of life, grief and bereavement.

Recommendations

- Develop an information palliative care toolkit by and for the Aboriginal community. The toolkit would include information, resources, services, and supports for families, caregivers and community members involved in palliative and end of life care and bereavement.
- Develop protocol and procedures to define and support the role of Elders in the provision of palliative care support in hospitals and community.

- Develop and implement protocol and procedures to reduce challenges and barriers that currently exist for practicing Traditional Medicine and ceremony in hospital settings.
- Develop an end of life care model that includes an Aboriginal health navigation program ensuring the greatest possible range of options to Aboriginal families with the lowest possible number of barriers and challenges.
- Establish financial and human resources for emotional, social, physical, cultural, and spiritual support for Aboriginal patients, family, caregivers and the Aboriginal community involved in end of life care and bereavement support.
- Develop culturally appropriate resources, information and services focused on palliative care for Aboriginal individuals and families that will enable health care providers and their Aboriginal patients to have meaningful dialogue about palliative care plans that take into account and respect cultural values and beliefs
- Develop Aboriginal specific, culturally safe, and respectful grief, loss and bereavement supports for the Aboriginal community.
- Develop training, protocol, and collaboration between mainstream health care providers and Elders, Healers and community leaders to facilitate access to a blend of Western medical care and Wholistic Traditional Medicine
- Develop and deliver training by the Aboriginal community to increase capacity of mainstream health care providers to provide culturally safe and appropriate palliative care to Aboriginal people. Ensure training addresses the impact of historical and present day colonization faced by Aboriginal people.

The Elders and the project participants highlighted that Aboriginal people require culturally safe and appropriate care, including palliative care providers that understand the importance of family and community roles, the cultural values and beliefs, and the role of Elders, Traditional Medicines and Healers and ceremony. The need for wholistic health care that understands the spiritual, mental, emotional and physical aspects of each person, and sees all of these as having equal value and strengths was repeatedly identified. Participants highlighted that when mainstream health care focuses on only the physical aspects of illness and palliative care, and understands this as having priority over the other parts of the person, this is not helpful care to many Aboriginal people.

Participants recommend the need for grief and bereavement support that is culturally informed, respectful and safe. It was highlighted that within the Aboriginal community, many individuals have experienced multiple and often traumatic deaths. A significant gap and a great need was identified for professionally supported grief, bereavement and healing to address complicated, complex, and cumulative personal, family and community grief and intergenerational trauma and loss for the Aboriginal community.

A theme that was repeated throughout the individual and Circle meetings was a clear preference by participants towards the term cultural safety over cultural competence. The

National Aboriginal Health Organization (NAHO) (2009) describes cultural competence as “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations.” The NAHO (2009) suggests cultural safety within Aboriginal health care means the health care provider can “communicate competently with the patient in that patient’s social, political, linguistic, economic, and spiritual realm”. They go on to state that “cultural safety analyzes power imbalances, institutional discrimination, colonization, and colonial relationships as they apply to health care and health education”. An absence of cultural safety would involve any “action that diminishes, demeans, or disempowers the cultural identity and well-being of an individual,” (NAHO, 2009). Providing culturally safe care requires training and education, self-reflection, and the courage to change one’s thinking and behavior.

Conclusion

This project involved 87 participants in total including four Talking Circles with 53 Aboriginal participants and 30 individual conversations with 20 members of the Aboriginal community and 14 non-Indigenous palliative care providers including nurses, a doctor, a social worker, a volunteer, and hospice staff in Waterloo and Wellington (appendix 1). Participants highlighted the value of being engaged in this project and the opportunity to gather together to talk about palliative and end of life care for the Aboriginal community.

This needs assessment looked specifically at palliative care needs and recommendations for the urban, off-reserve Indigenous population residing in Waterloo Wellington, highlighting barriers, challenges and the vision the Aboriginal community has for palliative care for its members. The stories, experiences, and insights shared and collected in this project are intended to guide development of best practices, services and a model for providing end of life care in the local Aboriginal communities.

- All participants identified the importance of building end of life and health care services for Aboriginal people living in Waterloo Wellington through wholistic Indigenous knowledge and practice.
- Participants identified the challenges faced by urban Aboriginal people due to the lack of services and supports that integrate culture or have culturally relevant aspects including wholistic care, Elders and spiritual ceremonies.
- It is recommended that WWLHIN establish an Aboriginal Advisory group for the local LHIN to ensure Aboriginal representation in health care decisions that impact Aboriginal people in Waterloo Wellington. Collaboration is occurring among the local Aboriginal agencies and services to formulate a plan to work together to strengthen health care for local Aboriginal people. A decision was made at the monthly Ogiima

meeting, a gathering of local Aboriginal service providers, to support White Owl Native Ancestry Association as the local Aboriginal agency to work with WWLHIN to explore future funding opportunities. In order to implement the recommendations of this needs assessment, it will be essential to secure funding to continue the work that has begun with this process.

- Individual Aboriginal beliefs and values need to be understood and explored within a respectful, trusting, compassionate and open relationship between the palliative care providers and those receiving care. There is tremendous resiliency and strength among the local Aboriginal people, and an investment and commitment to building Aboriginal community and culture in Waterloo Wellington
- Combining Aboriginal wisdom and wholistic healing with mainstream resources and knowledge has the potential to create strong and effective services and supports that will ultimately benefit all residents of Waterloo Wellington.
- Ongoing funding and commitment from WWLHIN is critical to ensure the findings from this needs assessment are implemented by the local Aboriginal community. The community requires Aboriginal end of life and health care providers to deliver service built on mental, emotional, physical and spiritual resources.

“If we don’t follow through, people will still not be able to get the passing that they deserve. I think this is a good start as long as it continues, as long as it can become a catalyst of movement.”

Male participant

Project Background

Over the two years prior to undertaking this project, Hospice of Waterloo Region (HWR) had developed a relationship with Wilfrid Laurier University's (WLU) Master of Social Work (MSW) Aboriginal Field of Study (AFS), providing practicum opportunities for students in the program. While doing a practicum for my MSW AFS (Wilfrid Laurier University) with HWR, I had the opportunity to sit with four Elders and begin to learn more about end of life care needs within the Aboriginal community. This research project was informed by and developed, in part, as an outcome of these discussions and an Elders Circle with HWR.

During my practicum, these four Elders guided and taught me to follow protocol, to listen more than I spoke, to be present so that I could truly hear the stories being shared with me, to be more patient, to be an ally, and so much more. Jean Becker, Gale Cyr, Elaine Garner, and Andrea Misquadis shared rich teachings about Aboriginal people, culture, and end of life care. Both HWR and myself deeply appreciate the insight, wisdom and moments of laughter and humour these four Elders shared while gently, yet firmly guiding us in our learning, Chi Miigwech.

One-time funding was provided by the Waterloo Wellington Local Health Integration Network (WWLHIN) to HWR. The funding was to be used to identify gaps in current palliative care for Aboriginal people in Waterloo Wellington; to document what palliative care means within the Aboriginal culture; to develop recommendations for a model for the integration of effective culturally appropriate palliative care service for the palliative care system in Waterloo Wellington; and to develop recommendations to the Waterloo Wellington Integrated Hospice Palliative Care Program.

Agency Profile – Hospice of Waterloo Region

For the past 20 years, HWR has been providing emotional, psychosocial, and practical support to individuals living with a life threatening illness and their caregivers and family. Services are provided in the home, hospital, and long term care settings by specially trained volunteers and professional staff. All services are provided free of charge. HWR's current focus is education and community outreach services. There are no residential beds on site. HWR is committed to providing care focused on hope, dignity and choice, on life and living each day, emotional support and compassionate presence that is sensitive to personal, cultural and religious preferences.

Project Coordinator's Profile

I am a non-Aboriginal woman who has worked in the Waterloo Wellington community for about 23 years. My experience in Aboriginal palliative care was limited prior to my MSW practicum and my involvement in the MSW Aboriginal Field of Study program. I bring an interest in end of life care and have volunteered with end of life care organizations.

I am grateful for the opportunity to work with HWR and the local Aboriginal community to examine palliative care needs for the local Indigenous community. Throughout this needs assessment I was conscious of the need to follow protocol, to be respectful, and to be inclusive of community members, while not burdening individuals with research-related requests and expectations. Early in this research project I sat with an Aboriginal woman who shared some advice; she suggested that those working with Aboriginal people must be authentic, present, respectful, and honest. I hope that I was able to bring her advice to my work with the local Aboriginal people. I appreciate the opportunity to sit in circle, have tea, and talk with the amazing participants involved in this research project.

Language

Canada's Constitution recognizes three categories of Aboriginal people: First Nations, Inuit, and Metis. In this report the term Aboriginal and Indigenous are used interchangeably to refer to First Nations, Inuit, and Metis people when the information does not differentiate between the three groups, and to refer to the diverse groups of Aboriginal people within Canada. The term wholisitc is used throughout this report. By spelling word as wholisitc the intention is to express the wholism and interconnectedness of all things as reflected in Aboriginal understanding and worldview. Wholism acknowledges the whole; the body, mind, heart, and spirit; and the four directions; and, past, present, and future. We intend no disrespect in any spelling we have used.

Demographic Profile

The Aboriginal community in Waterloo Wellington is comprised of a richly diverse group of people gathered from the north, south, east and west reaches of Canada. There is no single “Aboriginal” culture in Canada, Ontario, or Waterloo Wellington. In the individual meetings and the talking circles there were people who self-identified as Anishinaabe, Cree, Ojibway, Chippewa, Algonquin, Blackfoot, Inuit, Innu, Haudenosaunee, Iroquois, Mohawk, Oneida, Seneca, Cherokee, Metis, and Mi'kmaq, and not all participants identified.

The Aboriginal Community in Waterloo Wellington

Statistics vary greatly from one source to the next, making it difficult to say with certainty what the Aboriginal population of Waterloo Wellington actually is. An article appearing in the Record July 5, 2012 reported 15,000-17,000 Aboriginal people living in the Waterloo Region. Statistics Canada reports that in Kitchener/Waterloo and Cambridge there are 12,895 people of North American Origin, 9,750 First Nation people, 3,015 Metis and 375 Inuit people (www.12.statcan.gc.ca). Based on the Aboriginal Peoples Survey 2006, there were 9,990 Aboriginal people living in Waterloo Wellington: 70% First Nations, 29% Metis, and 1.8% Inuit. Few of the local Aboriginal population (15%), had lived in the area their whole lives. There are many factors contributing to the uncertainty of the Aboriginal population including reluctance, fear, and caution of some Aboriginal people to identify in surveys and censuses; the tendency to move between urban settings and reserve; and, shared housing, homelessness or transient housing. Members from the Waterloo Wellington Aboriginal community believe the population to be much larger than what is reflected in any of the current statistics. While the Aboriginal population is relatively small compared to the overall population of Waterloo Wellington, Aboriginal Affairs and Northern Development has identified the Aboriginal population as the fastest growing segment of the Canadian population.

Ontario’s Aboriginal Population

There are almost 300,000 Aboriginal people (First Nations, Métis and Inuit) living in Ontario. According to the 2006 Census, the total population of Aboriginal people in Ontario rose from 188,315 in 2001 to 242,495 in 2006 – an increase of 29 per cent. However, it is important to note that there were seven First Nations that did not participate in the 2006 Census, and three others were incompletely enumerated. Based on information from Indian and Northern Affairs Canada (INAC), the estimated population of these 10 communities was about 54,000. When INAC’s information is included, the total estimated population of Aboriginal people in Ontario is 296,495 (Ministry Of Aboriginal Affairs, Quick Facts).

In the Profile of Aboriginal Peoples in Ontario, the Attorney General identifies that there are 13 distinct groups of First Nation peoples in Ontario with their own languages, customs, and territories. The Profile of Aboriginal Peoples in Ontario identifies the Nations as the

Algonquin, Mississauga, Ojibway, Cree, Odawa, Pottowatomi, Delaware, and the Haudenosaunee (Mohawk, Onondaga, Onoyota'a:ka, Cayuga, Tuscarora, and Seneca). According to the Metis Nation of Ontario there are about 15,000 Métis people in Ontario.

- ❖ The Aboriginal population in Ontario grew by 28.8% between 2001-2006. By comparison, the non-Aboriginal population in Ontario grew by about 6.6% from 2001 to 2006.
- ❖ 2% of the total population of Ontario residents are Aboriginal people.
- ❖ 1 in 3 First Nations people live on-reserve in Ontario.
- ❖ The Chiefs in Ontario identify 133 First Nations in Ontario, 127 of which are recognized by the Indian Act.
- ❖ According to the 2006 Census, 62 per cent of Aboriginal people in Ontario, or 150,565 people, live in urban areas.

(Ministry of Aboriginal Affairs, Quick Facts,
<http://www.aboriginalaffairs.gov.on.ca/english/services/datasheets/Aboriginal.pdf>)

Aboriginal People in Canada

According to the 2011 census, Aboriginal peoples in Canada totaled 1,400,685, or 4.3% of the national population, spread over 600 recognized First Nations governments and bands with distinctive cultures, languages, art, and music, (TD Economics, 2013). There are more than 65 distinct dialects within the Aboriginal language groups in Canada (*Statistics Canada*, 2009). It is important to not generalize or make assumptions about Aboriginal people; just as any two Canadians of European decent may have little in common, any two Canadian Aboriginal people may not carry the same experiences, values, beliefs, and teachings. In the course of this project we sat with participants who carry Traditional teachings, others who carry Christian teachings, and others still who carry both Traditional and Christian teachings. Baskin (2011) makes the point:

“one area of diversity among Indigenous peoples is being on a continuum in terms of knowing about and practicing our knowledges and world views. At one end of the continuum are those who have a deep understanding of our knowledge and live the practices every day. At the other end are those who have never had the opportunity to learn about their culture and worldview due to the effects of colonization [...] There is a range of understanding and experiences between these two positions,” (p. 15-16).

Several of the participants we met with during the course of this project highlighted the point that it is important that health care providers not make any assumptions about the

values, beliefs and practices of the Aboriginal people they work with, noting it is better to ask than to make inaccurate assumptions.

Methodology

This five month research project applied Indigenous Research Methodology to exploring palliative care service needs for Aboriginal people living in Waterloo Wellington. As a non-Aboriginal community agency, HWR and the researcher had to consider both our own worldviews and those of the Aboriginal community in order to work in a good way and avoid doing harm. Applying Indigenous Research methodology helped to guide a process that honoured and respected Aboriginal ways of knowing, being, and doing.

Hospice was committed to ensuring Aboriginal control over this research, which was accomplished by having Aboriginal people in decision making positions each step of the project from development through to the final report. This took the form of an Elder's Advisory group, Aboriginal Circle facilitators, Aboriginal key informants including four Talking Circles (53 Aboriginal participants) and 34 individual conversations with members of the Aboriginal community (20) and non-Indigenous palliative care providers (14) including nurses, a doctor, a social worker, a volunteer, and hospice staff in Waterloo and Wellington.

HWR actively worked to begin conversations, build relationships and engage participants from the Aboriginal community in the research processes. HWR held a commitment to conduct this project in a manner that included an understanding of reciprocity and accountability. HWR recognized its responsibility to take direction and guidance from the Aboriginal community and to build relationship through conversation. Indigenous research requires a commitment to listening to learn, it demands the research honour what is shared and learned during the process; it relies on Elders as key informants; it includes a decolonizing perspective and framework; it asks the researchers to locate themselves; and it involves self-awareness, and being aware of oneself in relation to others. HWR endeavored to be guided in this project by these components of Indigenous Research Methodology. We used methods of collecting information that were congruent with Aboriginal ways, including the oral tradition by sharing conversation, listening to stories, Talking Circles, and honouring story telling as a means of teaching and sharing information. HWR approached this research as an ally and worked together with the Aboriginal community towards a shared goal.

In applying Indigenous methodology, HWR was mindful of both the non-Aboriginal and the Aboriginal worldview. Hospice needed to be respectful and accountable to the Aboriginal community we were working with, and to ultimately contribute to increased space within the health sector for Aboriginal knowledge and ways of being. A significant factor in undertaking the Aboriginal Palliative Care Needs Assessment involved HWR's awareness of not being

the expert in Aboriginal palliative care and not taking centre stage when working with the Aboriginal community. The Aboriginal community was understood to be the expert of their palliative care needs and to be the leaders in determining the process applied to the project and the recommendations developed. There was also the understanding that HWR and the Aboriginal community were holders of knowledge and could collaborate in the development of knowledge about palliative care needs for the urban Aboriginal population. When HWR undertook this endeavour, a commitment was made to produce authentic results with the goal of not oppressing or misrepresenting Aboriginal people and culture.

This research involved Aboriginal community consultation on the research topic, in decision making, and participation throughout the research process. This project worked with the principles of partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect (Jacklin & Kinoshameg, 2008). The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2010) highlights that research involving Aboriginal peoples must be built on respectful relationships and to encourage collaboration and engagement between researchers and participants. Throughout this process, care was taken to engage in relationship building and adherence to Aboriginal protocol. Reciprocity was a valued and important element of this project. In recognition and exchange for the time and information participants shared with HWR during this project, they were offered tobacco and monetary honouraria.

It was understood and appreciated that engagement and involvement of the local urban Aboriginal community was essential to ensure relevancy, community support, community knowledge, capacity building and sustainability of any initiatives that grow out of this project. Time was given to sitting with, listening to stories, having tea, and building trust and relationship with the members of the Aboriginal community who participated in this project.

The research included a review of literature related to Aboriginal palliative care with an emphasis on Canada. While the literature on Indigenous palliative care in Canada is not extensive, consideration of Aboriginal end of life care challenges has increased in more recent publications. Much of the existing literature that was found focused on rural, remote and on-reserve Aboriginal communities in Canada. Far less information was available about urban and off-reserve Aboriginal palliative care.

Four Talking Circles (53 participants) and 34 individual conversations with members of the Aboriginal community (20) and non-Indigenous palliative care providers (14) were arranged to gather stories, experiences, insights and thoughts about end of life care services for local Aboriginal people. One Talking Circle was held in Guelph at Hospice Wellington and three Circles were held in Kitchener at HWR. Interviews were held with individuals living in Wellington County and Waterloo Region. All participants self-selected to participate in the research, based on having experiences and/or thoughts and insights about providing care to a loved one living with a life threatening illness. The participants' stories, experiences

and ideas (appendix 2) shared in Talking Circles, individual meetings, and in surveys (appendix 3), provided invaluable information to begin to identify existing barriers to culturally safe and respectful end-of-life care for Aboriginal people, and to highlight recommendation and actions.

In keeping with Indigenous methodology the draft version of the report was distributed to the Aboriginal research participants to ensure the recommendations accurately reflected the community's perceptions. Feedback on the draft report was received by email, phone conversation, in writing, in group and individual meetings. Each person who participated in this research, as well as the local Aboriginal organizations and mainstream health and palliative care service agencies received a copy of the final report.

Goal of Research

The goal for this research project was to identify the strengths, challenges, and gaps within the current palliative/end of life care service for local Aboriginal. To accomplish this it was important to create an opportunity for Aboriginal voices and stories to be heard on palliative care for urban Aboriginal people. Recommendations address the areas participants identified as needing to be strengthened and improved to better meet the Aboriginal community's needs, values, and priorities from the community's perspective.

Recommendations were developed for palliative care services and for culturally safe and appropriate practices to guide palliative care and policy development for the Aboriginal community.

The Wall Quilt

Participants created and crafted squares in memory of loved ones at end of life. A co-created quilted wall piece was designed to represent 'partnerships' with all those involved in the building of relationships and development of a vision for future palliative care services of, by and for the Aboriginal community in Waterloo Wellington. The wall quilt is a representation of the stories, experiences, and insights shared in the process of this project.

Determinants of Health

Viewing Palliative Care, End of Life and Health from a Wholistic Perspective

Participants in Circle and individual meetings spoke of the need for services and supports for Aboriginal people to be provided from a wholistic perspective and model. Participants repeatedly made the point that end of life care cannot be viewed in isolation; rather, it needs to be viewed in context of an individual's whole life. One Elder shared that end of life must be viewed and understood within the context of the seven stages of life. Another participant said that health care providers working with Aboriginal people, including those providing end of life care, need to have an understanding of the social determinants of health, the impacts of colonialism, and the realities of Aboriginal people living in Canada. Another Elder said that what a person's life has been like will strongly influence what their death and dying will be like and that it is hard to have a good death if one has not had a good quality of life.

Impacts of Colonization on Health and End of Life Care

“The determinants of health for First Nations people in urban settings, and Aboriginal peoples more widely, cannot be understood in isolation of the backdrop of colonial relations that continue to shape access to health care, health care experiences, and health outcomes. Persistent disparities in health and social status are thus entrenched in the history of relations between Aboriginal peoples’ and the nation-state [... resulting in] the cumulative effects of poverty, violence, despair and intergenerational trauma [... which are] manifestations of the complex interplay of historical, social, political, and economic impacts of colonialism,”
(Browne, McDonald, & Elliott, 2009, p. 25).

Castleden, Crooks, Sloan Morgan, Schuurman, Hanlon, and InterTribal Health Authority (2009) identify that while Aboriginal people in Canada represent many distinct cultures they do share a common history involving the colonial experiences of marginalization, exploitation, and maltreatment. Aboriginal people also share significant health inequalities relative to the non-Aboriginal Canadian population. This can be attributed to a great extent to colonization. Colonial ideologies continue to impact Aboriginal communities because these continue to be the ideologies that inform current policy and services to Aboriginal families, health, social programming, justice, education, research, and ways of life (Haigh, 2012.)

Many Aboriginal people embrace a concept of wholistic health that views health as including not only physical well-being, but also mental, emotional and spiritual wellbeing. Poor health and palliative care must be understood in the context of the full range of social determinants of health including socioeconomic circumstances, poverty, poor housing, etc.,

as well as determinants related to colonial history, including violence and intergenerational effects (Sutherland & Freel, 2013).

The National Household Statistics highlight some concerning trends within the Aboriginal population. Aboriginal children aged 14 and under more frequently live in a single parent

“Socioeconomic status (SES) remains a determinant for health and ill-health, with the risks associated with morbidity and mortality for low socioeconomic groups identified by robust and consistent evidence. The poor die younger; have higher disease burden; are less likely to act to prevent disease; and are less likely to present early in the symptomatic phase.

The poorer health outcomes of low socioeconomic groups extend across the lifespan. Understanding the experience of socioeconomic deprivation at the end of the lifespan is consequently important,” (Lewis, DiGiacomo & Currow, 2011p. 106).

household than their non-Aboriginal peers. Almost half of children aged 14 and under in foster care in Canada are Aboriginal. There is greater representation of Aboriginal children living with grandparents or other non-parent relatives than the non-Aboriginal population (TD Economics, 2013). According to MacKinnon (n.d.), 50 percent of status First Nations children in Canada live in poverty as measured by the Low Income Measure (LIM). Correctional Service Canada reports Aboriginal offenders are disproportionately represented at all levels of the criminal justice system; in March 2007, Aboriginal people comprised 17% of federally sentenced offenders, while the general Aboriginal population was only 2.7% of the Canadian adult population (CSC). Hwang (2001) makes the point that Aboriginal people are greatly over-represented among homeless groups in Canada. One in every four off-reserve Aboriginal children live in poor housing conditions, compared to 13% of other children in Canada (Hick, 2007). Rates of poverty for Aboriginal women are double that of non-Aboriginal women, (Townson, 2005). Wilson and MacDonald (2010) report that in 2006 the median income for Aboriginal people was \$18,962 - 30% less than the \$27,097 median income for the rest of Canadians. Aboriginal people experience higher rates of suicide, substance abuse, imprisonment and other social barriers than other people living in Canada (Wilson & MacDonald, 2010). First Nations, Inuit

and Metis seniors have poorer health than non-Aboriginal seniors, with higher rates of chronic diseases and other conditions. The legacy of colonialism has left Aboriginal peoples, particularly elders, ranked among the poorest and most vulnerable of Canadian people (Health Council of Canada, 2013). With the number of older Aboriginal people continuing to grow there will be increasing demand to provide appropriate Aboriginal health care services generally and palliative care specifically (Health Council of Canada, 2013). All

of these realities will form and inform an individual's, and their community's experiences of health, wellness, palliative care and quality of end of life.

The World Health Organization (2008) identified that poverty and ill-health are inevitably linked. The lower an individual's socio-economic status, the worse their health will be. Living in poverty has many aspects, including material deprivation (food, shelter, sanitation, and safe drinking water), social exclusion, lack of education, unemployment, and low income. All of these factors result in reduced opportunities, limited choices, and threats to health (Haines, Heath, & Smith, 2000). These factors will greatly impact end of life experiences.

The Canadian government believed that an effective way to assimilate Aboriginal people into Euro-Western Canada was to remove Aboriginal children from their families and homes and to provide education and training based on the beliefs and values of Euro-Western Canadians. Residential schools were created out of the 1867 Constitution Act. This prevented Indigenous children from learning their own culture and interrupted cultural practices, including ceremonies and languages, resulting in these not being passed on to the next generation.

The Centre for Social Justice identifies that the forced introduction of European culture and values on Aboriginal societies, the placement of Aboriginal people on designated land, the creation of laws, practices and controls to promote assimilation began a cycle of social, physical and spiritual damage to Aboriginal people in Canada. While colonization, racism, oppression and discrimination have had a significant impact on Aboriginal people, the reality of Aboriginal people and traditional cultures in Canada is truly one of resilience, survival and evolution. Aboriginal people in Canada have a long and proud history that includes rich cultural and spiritual traditions. All of these factors must be understood as being relevant to the development of services and supports for Aboriginal people in Canada, including end of life/palliative care services.

My vision I guess is for a time when there's full acceptance of traditional Indigenous practices when they are wanted, if the family is asking. It should not be an oddity. Most of the time people make accommodations. It should not have to be fought for. All these facilities ought to have training about our people and the diversity of our people and the beautiful ceremonies from our diverse cultures. We need to have a place here, this is our country, and we have a lot of little ones." Elder

Wholistic World View

Kathy Absolon (2010) suggests that Indigenous wholistic theory encompasses the spiritual, emotional, mental and physical elements of being, acknowledges the past, present and future, and is earth based drawing on the teachings of Creation. Strand, & Peacock, (2003) discuss a wholistic view as focusing on four areas: "spirituality"-- living according to the belief in the interrelatedness of all things; "mental well-being"-- having clear thoughts; "emotional well-being"-- balancing all emotions, and; "physical well-being"-- attending to the physical self.

A participant made the point that Traditional Healing is wholistic in that it does not focus on symptoms or diseases but rather deals with the total individual. Wholistic healing focuses on all aspects of the person, not just on the illness. Several participants stated that end of life care needs to recognize the whole person. Caron (2006) suggests that Aboriginal Traditional Medicine has its roots in the philosophy of balance. Traditional Medicine refers to any substance, process, teaching, song, story or symbol that helps to restore balance in human beings and their communities. Caron (2006) notes that a disconnection in care occurs when health care providers ask only about the physical aspects of health and wellness. A participant identified that it was important to her that a doctor know what is right about her and not just what is wrong with her. She made the point that she needs her doctor to see her for more than her illness.

Hunter, Logan, Goulet, Barton (2006) identify that those providing health care to Aboriginal people need to interact in authentic ways, with the understanding of the experience of being ill from the perspective of the ill person, including the interconnectedness of the mental, physical, emotional and spiritual realms. An Aboriginal woman shared her belief that a person can die well if they are in a good place in their mind, in their heart and in their spirit, adding that the body is only one part of the whole person.

***We understand who we are -
We know where we came from -
We accept and understand our destiny here on Mother Earth -
We are spirit having a human experience.***

(Ian Anderson Continuing Education Program in End-of-Life Care, Aboriginal Perspectives)

Trends Influencing Aboriginal Palliative Care

Given the number of participants who attended the Talking Circles and individual meetings, it is clear that the issues related to end of life care are important to the Waterloo Wellington Indigenous community.

It is interesting to note that the 14 mainstream health care providers identified they were aware of providing care to between none and up to two Aboriginal individuals or families throughout their practices. This included three local Hospices, community based palliative care services, and hospital palliative care. It is unlikely these palliative care services have in fact provided care to none, one or two Aboriginal families. What is more likely is that Aboriginal people receiving services are not self-identifying or do not have opportunity to provide this information. Additionally, the non-Aboriginal health care providers identified desire to learn more about providing culturally safe care to Aboriginal people, noting that they wanted to feel more competent and capable when providing care to this population.

Several Aboriginal participants noted concern that many Aboriginal people do not access health care early enough for helpful curative or intervention actions to be received. They suggested some of the barriers to accessing care are caused by differences between conventional Western health care and Aboriginal cultural values and beliefs. Other participants suggested a lack of trust and education were reasons some Aboriginal people seek health care late in the progression of disease and may not return for treatment and follow-up.

Colonization, residential schools, and child protection practices along with experiences of racism and marginalization in Canadian society have created significant mistrust by Aboriginal people of mainstream institutions, including the health care system. Additionally, if the care provided is not culturally safe, Aboriginal people may not fully participate in a treatment plan (Health Council of Canada, 2013). Hampton et al (2009) identify key barriers in health care for Aboriginal people as including discriminatory attitudes and lack of respect for unique Aboriginal cultural differences by health care providers, as well as lack of staff training in areas of Indigenous culture and spirituality. These factors are further complicated by differences in Western and Aboriginal cultural understandings of death, dying and grief.

Prince and Kelley (2010) suggest the need for end of life care services for Aboriginal people will continue to increase with the growing numbers of Aboriginal populations. These researchers found cultural values, beliefs, and practices are often not taken into consideration by those offering care to the Aboriginal population. O'Brien (2012) identified appropriate palliative care services for Aboriginal people in Canada as becoming urgent with the number of Aboriginal people 65 and over expected to double between 2001 and 2017.

A theme repeated by participants is the need for service providers to be aware and respectful of the great diversity that exists within Indigenous urban populations in Waterloo Wellington. This diversity reflects the parts of Canada individuals are originally from, the various spiritual beliefs and practices, including Traditional Teachings, Christianity and combinations of these, status and non-status and many other areas of diversity. Participants stated that any end of life care must provide culturally safe and appropriate care to all Aboriginal people.

“The Circle is important to our people. I think that’s what our people want and have been asking for. If anything comes out of this, if we could even provide that, it is good. It is just the circle of life. To do things using our ways and have a happy outlook.” Male participant

Findings/Themes

The participants who met individually and in Talking Circles were given an outline of the purpose of this research. In the Talking Circles and individual meetings, participants were asked to consider, but not limit their responses to these points of interest:

- To develop a definition of what palliative care means within the Waterloo Wellington Aboriginal population
- To identify gaps in current palliative care and the services and supports for the Waterloo Wellington Aboriginal population, and
- To identify a vision and model for palliative care services and supports for Aboriginal people living in Waterloo Wellington.

In addition to the points listed above, several other themes were identified in Circle and individual meetings. The themes identified below represent those that were repeatedly identified throughout the process and will be expanded in the next section of this report.

- Improve access to Elders
- Define the role of Elders in palliative care
- The need for education within the Aboriginal community about palliative care services and supports in Waterloo Wellington
- Challenges and barriers exist for practicing Traditional Medicine and ceremony within hospital care settings.
- Increase support for family, caregivers and the Aboriginal community involved in providing palliative care to a loved one, including financial, spiritual, cultural and social supports.
- Positive experiences within Hospice palliative care services were identified by participants.
- Improve access to a blend of Western medical care and wholistic Traditional Medicine
- Increase training and awareness of culturally safe and appropriate support to Aboriginal people in health care settings and service providers.
- Importance of local Aboriginal community involvement and control of any palliative care projects for the Aboriginal community
- Need for development of Aboriginal-specific palliative care guidelines and protocols in Waterloo Wellington
- Increase capacity to deliver Aboriginal end of life services for both the Aboriginal community and for mainstream health care providers
- Palliative care and bereavement support for the Aboriginal community must acknowledge and be informed by an understanding of the impact of colonization, both historical and present day

Role of Elders/Access to Elders

Elders are individuals that have gained the respect of the community for their wisdom, philosophy on life, cultural knowledge, and ceremonies.

They provide a foundation of knowledge and experience and teach balance in emotions, behavior, thinking and spirituality. Elders are Aboriginal people who have gifts for working with community members, helping to maintain the wholistic health and wellbeing of the individual and the community. Elders strive to teach by example, walking and talking in a good way. The sharing of their wisdom and guidance is healing.

- Participants identified that it can be difficult to access Elders in the community. It was noted that this is particularly true for Aboriginal people who are newer to the community.
- Visiting Elders for hospitals need to be treated in the same way other chaplains, Spiritual care providers, and religious leaders are. It was recommended that Elders be reimbursed for the costs of providing spiritual care in the same way other spiritual care providers are.
- Participants highlighted need for greater recognition and understanding of the role of Aboriginal Elders and Healers in mainstream health care, including awareness that “medicine” is understood as spiritual healing, ceremony, and Traditional Medicine to many Aboriginal people.
- Participants recommended in-house Elders to assist and guide individuals, family members and staff, and/or a contact list of Elders available to provide support for those receiving both hospital care and home care.
- Elders in the community experience and manage a great deal of requests for their participation, support, and involvement in both Aboriginal and non-Aboriginal events, boards of directors, leadership roles, community activities, etc. Any process established to increase the involvement of Elders in palliative care needs to take this into consideration and must be respectful of the demands placed on community Elders.

“It would have been good to have had an Elder there to help my Dad pass and to share what happens after he takes his last breath. I was scared in there, I wish I had an Elder or a Native organization to support me.” Female participant

Education

“Another idea I had was compiling resources both Aboriginal and non-Aboriginal to give out to people. I have lived here for four years, but I don’t know of anything out there. A booklet of resources would be incredibly helpful in terms of allowing me to find what is even out there.” Female participant

- A theme repeated throughout this project was the need for a palliative care toolkit for Aboriginal people. Recommendations included a toolkit or pamphlets outlining the local palliative care, grief and bereavement resources, and health care rights. Participants identified the need for information about funeral arrangements, wills, and lawyers, who to call and what needs to be done following death and information about which funeral homes would permit ceremony, including drumming, smudging and pipe ceremonies.
- An additional gap identified involved information about how a life threatening disease will progress. Participants identified they did not feel prepared or know what to expect as death was close. This information could be addressed through the development of an Aboriginal palliative care toolkit.
- Participants recommended training for Aboriginal people about the palliative care resources and services available. The Circles were held at local Hospices, one at Hospice Wellington and three at Hospice Waterloo. The majority of participants were not aware these resources existed in their communities.
- Recommendation for the development of a culturally safe and relevant training for both the Aboriginal community and those providing care to Aboriginal people. Training to include how to talk about the patient’s wishes in order to have these reflected in the person’s care plan. Developing training to facilitate awareness and respect for the patient’s wishes, and ensure dignity and self-determination are maintained. By ensuring the training is culturally safe and is focused on Aboriginal cultural end of life care, it can be provided to palliative care providers, cancer support organizations, doctors and nurses in training, hospital and community grand rounds, etc.

Hospital Care/Home Care/Hospice Care

Hospital Care

Participants identified barriers and gaps experienced within hospital care settings. These included:

- Significant challenges and barriers to doing ceremony including drumming, smudging, cedar baths and pipe ceremonies.
- Lack of appropriate space in hospital settings for the many family and community members wanting to be near when a loved one is dying. Participants identified difficulty accommodating family and community members in hospital rooms that are small and shared.

“Experiences in institutions have been horrible, denying children, no smudge, not helping family to be together.” Female participant

- It was recommended that a ceremonial room or space was needed in hospitals that could not accommodate ceremony in patient rooms.
- Participants recommended that hospitals have a list of in house or on call Elders to assist, support, and guide both family members and staff.
- Participants reported wanting the option of services that are integrated into health care spaces rather than segregated. They stated that integration of care must include holistic care options and culturally safe and respectful service delivery.

We need a list of Elders in the community, a list to help us have ceremony, if that is what is needed in addition to mainstream resources. We need Elders and those ceremonies.” Female participant

- Participants highlighted a lack of spirituality in hospital environments, identifying the importance of having spiritual support available for both the person facing end of life and their family. It was recognized that because there is great diversity in the beliefs of urban Indigenous people, it is important that spiritual support be available from both Christian perspectives and Indigenous spirituality perspectives.
- Participants reported being satisfied with pain and symptom management, although several participants expressed concern about challenges in doing ceremony – including smudging, cedar bath and drumming, which are also understood as medicine to some Aboriginal people.

“We need our family with us, young and old, at end of life, and we need our Traditional Medicines as well.”

Female participant

Home Care

- Participants highlighted a preference for home death over a hospital death. It was stated by many participants that they want home care and ideally home death to be a viable option. A predominant theme was the desire to be able to die at home, receiving care, support and comfort measures for as long as possible, ideally until death.
- Participants recommended increased resources and services to support Aboriginal people staying in their home and dying at home if that is their choice. The resources identified as needing to be strengthened include financial, cultural, spiritual, social, emotional and physical.
- Reasons most repeated for choosing a home death were freedom from restrictions on number of visitors, not having to follow complicated procedures to be able to do ceremony and not having to worry about bothering other patients with large number of visitors or ceremony.

“We were able to do ceremony after she passed. We cleaned her and did the preparations I have done in Mohawk territory. We dressed her and I stayed with her to make sure she wasn’t alone.” Female participant

- Participants recommended having Elders available to provide spiritual care and assist and guide both family members person who is ill and at end of life. Families new to the area may not know who to call or how to connect with an Elder in the area when their loved one is sick or dying.
- Participants recommended PSW’s, nurses, social workers and others coming into the home would receive cultural safety, cultural sensitivity and cultural awareness training.
- Participants recommended establishing a lending library for walkers, stability bars, shower chairs, etc. that are required during illness and when remaining at home.

Hospice Care

The feedback from participants about experiences in hospices was overall very positive. Those who had experienced hospice care spoke very highly of the care and support they and their loved one experienced. It was identified that drumming, smudging, pipe ceremony

and cedar bath were done easily and without complicated process and procedures needing to be followed.

The strengths identified in Hospice care included:

- Large rooms that easily accommodate large numbers of family and community members visiting
- Accommodating of ceremony including smudging, drumming, cedar baths, and pipe ceremonies, without having to follow complicated policies and procedures.
- Comfortable visiting rooms, kitchen facilities and the ability for people to sleep if the family wished to be present at all times
- A homey atmosphere that does not feel like an institution. It was identified that both the person who was palliative and the families felt comfortable and could be at ease in the Hospice setting.
- A few participants identified that the Hospice setting was preferable to being at home because while it felt like home, there were staff around who know how to care for their loved one. Family members noted they felt like they could just be a family member and not a caregiver in the hospice at the end of their loved ones life.
- A participant identified that a community hospice volunteer was helpful, respectful and not intrusive. The volunteer's support was really appreciated by the family.

“The Hospice accommodated all of us, all nine of us. It was a beautiful setting for him. A Circle was allowed at the Hospice.” Female participant

There were two suggestions given that applied specifically to hospice care;

- It was identified to have a place outside on the grounds of the hospice for a fire pit would allow for a sacred fire to burn; and
- Landscaping on the hospice grounds to include cedar trees.

Increased Support for Family, Caregivers and Community

- Participants recommended developing an Aboriginal health team to work with Aboriginal families and the health care providers. It was highlighted that Aboriginal families need support services that provide advocacy, assist with navigation of complicated and confusing systems and to provide assistance to the family while dealing with illness and following death.
- Participants pointed to the need to find ways to reduce burden on caregivers providing palliative care at home, particularly financial, social and emotional burdens. Aboriginal families experienced financial challenges and hardships when they provided care in their home for ill family members. Participants identified they worried about money when providing care at home; noting that they had difficulty making ends meet before providing care at home and this became more difficult when providing care for a dying loved one.
- Participants highlighted many challenges associated with the Compassionate Care Benefit, including the unpaid wait period, receiving only 55% of regular earnings and waiting many weeks before receiving the first I.E. cheque made things difficult for the family.
- One participant shared that their family decided to use the hospital towards the end of the illness because they could not afford to provide quality care at home.
- Participants identified the cost of walkers, safety bars, incontinence products and gauze pads were difficult to manage and created a financial burden.
- Participants recommended providing support and training for Aboriginal families focused on how to ask the right questions, better advocate for their loved one, and where financial assistance for medical and assistive supplies is available.
- Participants recommended developing Aboriginal culturally appropriate anticipatory grief and bereavement support for families and the community. Participants highlighted the importance of recognizing complicated and compound grief and loss and intergenerational trauma, and providing support that includes counselling for both the person who is dying and for their family.
- Recommendations were highlighted for Aboriginal grief counsellors. Within the Aboriginal community there is a great deal of loss, grief and bereavement. Participants highlighted the need for more emotional support for family and

“I needed more help with basic traveling needs, traveling to their medical appointments.” Female participant

“There needs to be outreach dollars to support those who are caregivers.” Female participant

“I wish I had been asked what I needed.” Female participant

community members dealing with compound and complicated grief and bereavement.

- Participants identified they need someone from the Aboriginal community to sit with them while their loved one was ill and following their passing, suggesting an Elder or Indigenous social worker to talk to would have been helpful.
- Participants recommended increased respite for families providing home care. This was repeatedly suggested as being a significant gap in support. Participants identified the need for Aboriginal respite supports and services.
- Need was identified to have support groups for Aboriginal people providing care to a loved one and to have groups for Aboriginal people dealing with grief and loss of a loved one.
- Participants recommended greater support to children who are raised by grandparents, aunties and other family members. It was noted that children raised by grandparents and other relatives have experienced significant loss and need additional support when the their caregiver is at end of life.

Access to a Blend of Western Medical Care and Wholistic Traditional Medicine

- Participants highlighted a preference to access a combination of Indigenous and Western health care approaches, seeing these as complementary rather than either/or, and identifying that they valued aspects of both approaches. Participants recommended health services that provide a collaborative model of care involving traditional and mainstream health care options and providers.
- While not all Aboriginal people in Waterloo Wellington practice Traditional Healing, participants reported a desire to learn more about these cultural teachings and practices. One Elder shared that teaching traditional practices will provide local Aboriginal people with information to make health care choices and to learn more about culture, including Traditional Healing. This participant felt that this would help the community re-learn and become healthier.
- The same Elder suggested that when health care acknowledges and includes traditional practices for Aboriginal people, the quality of health care is improved for Aboriginal clients/patients as well as all people in Waterloo Wellington.

“My vision includes care Circles, mainstream organizations working with Native communities, wholistic help like smudging, ceremonies, and reiki, and having training for community members, families and caregivers.” Female participant

- Participants identified concern about difficulties in accessing or locating traditional healers. Participants recommended developing processes for accessing Elders, Traditional Healers, and Traditional Medicine to use in combination with mainstream medicine.
- Participants identified that palliative care issues for Aboriginal people must be understood within a wholistic context, including the life stages, cultural values, beliefs and life experiences. Participants identified the need for palliative care providers to understand the influence of mental health, poverty and racism, suicide, diabetes and other chronic diseases have on a person at end of life and their family. Participants recommended wholistic person-centred medical care services that respect Indigenous values and beliefs, including care of the mind (thinking), heart (feeling), body and spirit at end of life.

- Participants recommended the development of an end of life care model that ensures access to cultural ceremony and practices that are meaningful, while also providing the pain and symptom management available through Western medicine would be ideal.
- Participants recommended developing an Aboriginal health care team to support local Aboriginal people receiving end of life care services. Participants highlighted the need for an Aboriginal community health support team be developed to address Aboriginal health care, including palliative care. This team would provide education, advocacy, support, anticipatory grief and bereavement support, and build relationships between the Aboriginal community and the health care providers.
- Participants identified the importance of mainstream health care providers to become aware of the history of colonization, including residential schools and child welfare practices and policies and how these impact the level of trust some Aboriginal people have for Western mainstream services, including health care.

Building Relationships

Mainstream Health Care Providers and the Aboriginal Community

- Participants recommended developing relationships between the Indigenous community and the mainstream medical/health care community in order to build trust, respect, and reciprocity.
- Participants recommended holding joint training and information sessions for health care providers and the Aboriginal community. Participants highlighted a need to increase awareness on the part of mainstream care providers of: the challenges Aboriginal people face; awareness of Aboriginal cultural/traditional practices and beliefs; and, culturally relevant palliative care information. It was identified this would provide an opportunity to develop a stronger relationship between the health care providers and the Aboriginal community.
- Participants highlighted it would be helpful to bring Aboriginal community leaders, workers, families and mainstream health care providers together to create a framework for an Aboriginal end of life care service model.
- It was recommended to provide training opportunities that would involve health care providers and the Aboriginal community to offer reciprocal training and relationship development.
- Participants recommended establishing opportunities for Western medical care providers and Elders and Aboriginal community leaders to meet together and share a meal, talk and get to know each other.

“I think both mainstream and traditional care is important. I wouldn’t be here without both. Sometimes I can’t tell mainstream doctors when I am accessing traditional care. Sometimes the cooperation between the two is not there.”
Female participant

Aboriginal Leadership in Palliative Care Services

- Participants identified that Aboriginal people hold concepts of health and wellness that are often different from mainstream health care providers and recommend that any project development, programs and strategies developed for Aboriginal people are developed of, for, and by Aboriginal people. This does not preclude the involvement of mainstream service providers, rather it means that the Aboriginal community is responsible for identifying who, when and how mainstream care providers are involved in program development and delivery of services to Aboriginal people.
- Participants recommend Aboriginal people are involved in all steps of planning, research, policy and program design, noting that it is important to have Aboriginal people involved in the decision making processes. Participants highlight that projects supporting Aboriginal people need to be built on Aboriginal cultural knowledge.
- Participants identified value in mainstream organizations and services recognizing the wisdom and experience of Indigenous healers and working together to health provide quality health care to the Indigenous community.
- Participants recommended Aboriginal representation at Regional levels involved in health care provision, and in local Community Health Centres and agencies that provide health care to Aboriginal people.
- Participants recommended Aboriginal health related initiatives, including palliative care service, have Aboriginal leadership and involve Aboriginal organizations and individuals, to ensure culturally safe and relevant program development.

Aboriginal-Specific Palliative Care Guidelines and Protocols

- An Elder recommended that palliative care services for Aboriginal people need to be developed based on wholistic care principles and cultural considerations.
- An Aboriginal participant involved in the health care profession identified the need to create training, culturally specific resources, policy and best practice for palliative care to the Aboriginal people.
- Several participants suggested there is a need to train palliative care providers to talk to Aboriginal patients about their wishes. This might involve working with Elders, accessing Traditional Medicine and ceremony, and talking about how to bring together the things that are identified as important and specific to Aboriginal people for end of life care.
- Participants highlighted the need to create simpler, accessible, and realistic policies and practices involving smudging, drumming, ceremony, and Traditional Medicine within hospitals. These must be clear, easily available and easily implemented. Several stories were shared involving barriers and challenges in arranging to do ceremony in hospital settings. Participants noted that this made the difficult situation of experiencing the end of life of a loved one even more difficult.
- Participants identified the importance of developing the relationship between health care provider and person/family receiving palliative care, and the need to ensure that the care is focused on the person not just their illness.
- It was repeatedly identified by participants that Aboriginal people experience a wide range of death and dying, including traumatic death, suicide, chronic life-limiting illnesses, diabetes, cancer, etc. Palliative care services to this population may need to be offered over a longer period of time than some current practices and may additionally require longer bereavement support to address complicated, compound and traumatic grief and loss.
- Several participants noted it was important to their loved one to stay at home as long as possible, and ideally die at home. These participants identified that it was important to create procedures that could respond quickly when there needs to be a change in the service, nature of the support and location of care.
- Participants identified that palliative care services need to be wholistic and person-centred and to be created in harmony with the values and beliefs that recognize the role of community and the whole person, body, mind, heart and spirit.

Aboriginal Health Navigation Team

- Participants identified the need for a program in the health care system to provide advocacy, education, support and respond to the unique health care needs currently faced by the urban Aboriginal community. The participants used a number of different descriptions and titles for this program including: Aboriginal Health Navigation and Aboriginal Health Coordination.
- Participants recommended establishing a team or program to work with mainstream health care providers, Elders and Traditional Medicine Healers, with hospital staff to arrange ceremony, to advocate for culturally informed care, provide grief and bereavement support that understands intergenerational trauma, compound and complicated grief and bereavement.
- Participants highlighted the need for end of life care that provides the greatest possible range of options to Aboriginal families with the least possible barriers and challenges. Participants identified that advocacy in the form of Aboriginal Health Navigation could help with this and would benefit the local Aboriginal community.
- Participants recommended an Aboriginal Health Navigation program that would provide support to patients and their family to navigate the health care system, including accompaniment to medical appointments, helping Aboriginal people understand medical conditions, knowing options and assistance with connections to Elders, Healers and ceremony. It was also noted that health navigation could help health and palliative care providers to learn about Aboriginal culture, understand what culturally safe care involves, and how to communicate and interact more effectively with Aboriginal clients.
- Participants recommended an Aboriginal health navigation program that would be connected to the Aboriginal organizations and be of, by and for the Aboriginal community.

“I feel that if we had a patient navigator, they would know where to get the medicines, how to find an Elder. It would make the process easier. Someone who could be with the family to the end.”
Female participant

Building Community Capacity

Aboriginal Community

Building on the strengths, commitment and current capacity in the Aboriginal community.

- Participants recommended training Aboriginal workers about end of life care supports and resources and to build capacity within the Aboriginal community to facilitate appropriate referrals and connection to medical and non-medical palliative care support.
- Participants recommended bringing youth and elders together to share the teachings about living a good life, the Seven Grandfathers, the Medicine Wheel and other cultural teachings. It was identified this would encourage youth to learn the teachings, strengthen culture within the Aboriginal community, strengthen the connection of the youth to the Aboriginal culture, and provide a cultural foundation that can strengthen the community's ability to respond to the end of life and palliative care needs.
- One Elder highlighted if the youth know their culture this will build Aboriginal families and the community's capacity to care for community members. Participants made the point that it would be ideal for youth to have exposure to the traditional teachings before entering mainstream Western education programs.
- Participants recommended development of a resource toolkit with information and resources to guide Aboriginal families facing end of life experiences. The goal would be to ensure families have access to information about services and supports and are informed about their options so that they can access the care that most suits the needs of the dying person and their family. A common theme discussed was the need to build capacity within families to care for their family member at end of life by developing and distributing practical information.
- It was recommended to develop a strategy to increase the number of Aboriginal care providers and to encourage Aboriginal youth to enter health care professions. Recommendations included the development of opportunities for mentorship and education.
- Participants highlighted the need to increase the Aboriginal community's capacity in palliative and bereavement care. One strategy highlighted was to include Aboriginal participants in hospice care training, and involving Aboriginal people in the development of training to ensure Aboriginal understanding and approaches to death, grief, and loss.

“When I think of end of life, it is a transition from one state of being to another state of being. I think about the spirit beginning to soar. I think we are in a position to help our loves ones transition. We can support each other tremendously.” Female participant

Western/mainstream Community

- Develop Training for health care providers including social workers, doctors, nurses, PSW's home care support workers, etc., to ensure wholistic culturally safe and appropriate service delivery to the Aboriginal community and individuals. It was recommended that training be developed by the Aboriginal community and be informed by Aboriginal culture, a wholistic worldview and take into account body, mind, heart and spirit.
- Participants highlighted the need to ensure Indigenous cultural medicines and ceremonies are respected and supported by mainstream care providers and that Aboriginal people are supported to die in a good way while maintaining cultural and traditional values if this is important to them.
- It was identified that there are vast differences in the values, beliefs, and cultural practices of urban Aboriginal people. Cultural competency training can support mainstream palliative care providers to work from a person-centred framework and to increase understanding of Indigenous culture to help health care providers meet the unique needs of the Indigenous people they work with. It was recommended that the training and resources required to meet this goal be directed, designed and developed by the Aboriginal community.
- Participants recommended the need to create ongoing opportunities for palliative care health providers to meet with Aboriginal agencies and Aboriginal service providers to develop an understanding of the wholistic model of care, to share information and to develop relationships.
- The need to increase mainstream health care providers' understanding of family and kinship relationships within the Aboriginal community and the role this plays in end of life care was recommended by participants..
- The nurses, doctor, and social worker who spoke to the project coordinator indicated a clear desire to have greater cultural awareness, noting a belief that this would facilitate their ability to provide helpful care. The mainstream care providers reported that they felt they currently lacked sufficient knowledge about Aboriginal cultures. These care providers indicated they wanted more knowledge and information about Aboriginal cultures and spirituality, Aboriginal views about death and dying, and the significance of rituals and ceremonies such as smudging, drumming, sweet grass, etc. It was noted that they recognized that every family is unique and they cannot assume that every Aboriginal family has the same beliefs.
- Participants recommended providing presentations focused on Aboriginal end of life care to palliative care providers, bereavement centres, cancer support organizations, doctors/nurses in training, at hospital and at community grand rounds, etc. It was suggested that this would assist in increasing awareness and cultural safety in delivery of service to Aboriginal people by mainstream health care providers.
- Participants recommended training to non-Aboriginal people about Aboriginal culture be done in the Aboriginal way, in Circles using traditional protocol, and process. It

was suggested that this would further help Western care providers to know about “Aboriginal ways of knowing being, and doing”.

- Several participants identified that Elders are considered the keepers of knowledge and may be able to provide a valuable link and resource for health care practitioners to learn and increase their understanding of Aboriginal traditional knowledge, values, beliefs, ceremonies and culture.

“I would love to see palliative care Indigenized. Wouldn't it be nice to have Circle after a person passed? To respect and honour that person and to put Indigenous into Hospice. To be able to have ceremony and people to do ceremony. To reteach the people about how to take care of people when they pass. To make that journey into the next realm and to incorporate the Seven Grandfather teachings.” Female participant

Acknowledging and Addressing the Impact of Colonization

- Participants recommended training for Western healthcare providers to educate and about the impact of colonization, residential schools and historical trauma on Indigenous people. They highlighted Aboriginal health and wellness must be understood within the context of the intergenerational impact of social, political, economic and cultural marginalization and assimilation policies, and this has resulted in a lack of trust in the medical system.
- Participants identified the need for provision of culturally safe programs to be available in the Aboriginal community that offer support for anticipatory grief, bereavement, compound and complicated grief, and that incorporates recognition of the connection between grief, loss and bereavement and the history of colonization and intergenerational trauma experienced by Indigenous people in Canada.

“I look forward to a time when hospitals are truly and sincerely open to our ways and ceremonies and hospital staff are open and supportive of Aboriginal ceremonies.”
Female participant

WWLHIN Aboriginal Initiatives

- Participants expressed cautious hope that the WWLHIN will continue to work with the local Aboriginal community to develop a collaborative working relationship that will further develop understanding of the Aboriginal community's palliative care needs. Participants identified desire for WWLHIN to work with the Aboriginal community to ensure that Aboriginal palliative care needs will be addressed, recognizing that initiatives must fully involve Aboriginal leaders, and incorporate traditions and cultural practices.
- Participants recommended WWLHIN continue providing funding and ongoing commitment to develop palliative care services for the local Aboriginal community. It was highlighted that any future funding opportunities to develop Indigenous palliative care must involve the Aboriginal community to identify, design and deliver new initiatives. There is a strong belief by the participants that programming for Aboriginal people must be developed of, by, and for the community. It was stated that this does not mean the Aboriginal community will not want to work with mainstream organizations and service, rather they feel strongly that they need to have control and decision making about who, what and how they involve mainstream community partners and resources in the development of initiatives for Aboriginal people.
- Participants recommended an Aboriginal health navigation program or a Community Health and Wellness program that would be tailored to meet the specific wholistic care needs of the Aboriginal community and to better serve the health care needs across the life span from birth to death. It was identified that an Aboriginal health care program could offer a blend of Aboriginal and Western approaches to health care in culturally safe and appropriate ways.
- Participants recommended WWLHIN promote meaningful Aboriginal community participation in any strategies for collaboration between the Aboriginal community and service care providers. It was highlighted that this would help develop cultural awareness and knowledge and promote culturally safe health care practices. It was recommended to use Talking Circles and apply traditional circle protocols as a means of helping Western and mainstream service providers understand 'Aboriginal ways of knowing being, and doing'.
- An Elder identified that because of the current inequalities in health status and health outcomes between Aboriginal and non-Aboriginal people and the fact that the urban Aboriginal population is growing fast, WWLHIN must place more attention on the challenges faced by urban Aboriginal people within the health care sector.
- Participants recommended WWLHIN provide funding to the local Aboriginal community, to design, plan, and implement cultural training and education to ensure health care providers are able to provide care that acknowledges and respects the cultural traditions, beliefs and spirituality of Indigenous people.

- Many participants expressed both hope and significant doubt that Aboriginal end of life care would continue to receive support from WWLHIN. While the members of the Aboriginal community who participated in this project expressed expectations that the conversation started during this project will continue, they are very cautious about holding out hope that this will happen.

“Palliative care is care offered at end of life. End of life is part of the journey, just a part of life. We need help with that part of the journey to ensure comfort and care to support the transition into the Spirit world.”
Female participant

Implementing the Recommendations

Hospice of Waterloo Region, Hospice Wellington, the Kitchener Downtown Community Health Centre and the Guelph Community Health Centre

- In partnership with the Aboriginal community develop both an online and hardcopy resource toolkit for Aboriginal Palliative Care that would provide information for both the Aboriginal community and mainstream palliative care providers.
- Provide palliative care training and support to Aboriginal agencies, workers and community volunteers.
- Host ongoing meetings such as lunch and learns with Aboriginal Elders and Healers and mainstream palliative care service providers with the goal of developing relationships and deepening understanding of the Aboriginal community.
- Establish a process for developing collaborative and respectful relationships between mainstream palliative care providers and Aboriginal Elders, Healers and the Aboriginal community.
- In partnership with the Aboriginal community, develop culturally appropriate information and services focused on end of life care for Aboriginal individuals and families that will enable health care providers and their Aboriginal patients to have fulsome and meaningful dialogue about palliative care and to make care plans that take into account and respect cultural values and beliefs

Hospitals located in Waterloo Wellington

- In partnership with the Aboriginal community, develop policy and procedure to remove existing barriers to conducting ceremony including smudging, drumming, cedar bath, and pipe ceremony.
- Establish sacred space that can accommodate providing ceremony.
- With the Aboriginal community, develop policy and procedures to create spaces able to accommodate the visiting needs of large families and community visitors.
- In partnership with Aboriginal agencies and community, develop the role of Elders and Healers in the care of Aboriginal people receiving hospital care. Develop policy and collaborative practice to support Elders and Healers to provide care to Aboriginal people in hospital including provision of parking and financial support to cover costs incurred in providing care.
- In partnership with the Aboriginal community, develop and deliver ongoing staff training for cultural safety, cultural competency and culturally appropriate service delivery to Aboriginal people.
- In collaboration with the Aboriginal community, create policy and procedure to ensure the Aboriginal community receives culturally safe service and support, including having Indigenous representation on hospital, hospice and other health care service board of directors.

- In partnership with the Aboriginal community, establish process and practice for developing collaborative and reciprocal relationships between mainstream palliative care providers and Aboriginal Elders and Healers

CCAC, Community Health Care Service Providers and the Local Health Integration Network

- In collaboration with the Aboriginal community, deliver training for home care and community palliative care service providers for ongoing cultural safety and culturally appropriate service delivery to Aboriginal people.
- With the Aboriginal community, establish a process for developing collaborative and reciprocal relationships between mainstream palliative care providers and Aboriginal Elders and Healers. This might include hosting lunch and learns, staff and volunteer training, information evenings, etc.
- In partnership with the Aboriginal community, develop policy and procedure to ensure the Aboriginal community receives culturally safe service and support.
- In collaboration with the Aboriginal community, develop culturally appropriate information and services focused on end of life care for Aboriginal individuals and families that will enable health care providers and their Aboriginal patients to have fulsome and meaningful dialogue about palliative care and to make care plans that take into account cultural values and beliefs.

Waterloo-Wellington Aboriginal Community

- Develop and support groups focused on providing grief and bereavement support.
- Offer circles and cultural gatherings bringing Elders and youth together to share cultural teachings and build cultural connection, understanding, and healing.
- In collaboration with mainstream health care services, actively encourage and develop mentoring opportunities to introduce Aboriginal youth to the health care professions, including palliative care career opportunities.
- Build relationship with mainstream palliative care and health care providers. Host Circles and lunch and learns for mainstream palliative care service providers with the goal of developing relationships and deepening understanding.
- Establish a process for developing collaborative, reciprocal and respectful relationships between mainstream palliative care providers and Aboriginal Elders and Healers
- Develop a process for identifying Elders and Healers who would be available to provide palliative care and support to Aboriginal people in hospital, hospice, home and community.

Cultural Safety/Cultural Competency

One of the goals of this research project was to develop recommendations for a model for the integration of effective culturally appropriate care services within the palliative care system. The National Aboriginal Health Organization (2009) identifies it is important to be aware of the distinctions between cultural awareness, cultural competence and cultural safety. An exploration of these terms provides a context for understanding what defines effective culturally appropriate services.

O'Connor, Small and Cooney (2007) suggest race, ethnicity, culture, and experience greatly affect how individuals understand, interpret and react to the world around them. The Aboriginal Nurses Association of Canada (2009) highlights, "Culture is more than beliefs, practices and values. Culture has commonly been defined as the worldview, lifestyle, learned and shared beliefs and values, knowledge, symbols, and rules that guide behavior and create meaning within a group of people", (p. 1). The College of Nurses of Ontario (2009) suggests, "Culture refers to the learned values, beliefs, norms, and way of life that influence an individual's thinking, decisions and actions, (p. 3). It can be understood that programs and services will reflect the cultures of their developers. While individuals from the dominant culture may try to be unbiased and culturally neutral, it is likely that,

"[P]rogram and service developers' own cultural perspectives will be reflected in the decisions and assumptions they make as they design the program. Therefore, it is important to question whether the "culture" of a program is a good fit for participants of various cultural backgrounds, and how that fit might influence the effectiveness of the program with those participants," (O'Connor, Small, &Cooney, 2007, p. 2).

It is important to recognize that there is not just one approach to cultural safety and competence; rather there is a need to include a range of elements within the context of a culturally safe and responsive process (Canadian hospice Palliative Care Association, 2007). Sutherland, Maar and Freel (2013) refer to the definition of cultural safety created by Irihapeti Ramsden, a Maori nurse in Aotearoa (New Zealand) in 1990. This understanding of cultural safety requires moving beyond cultural sensitivity and cultural competence, with the practitioner needing to have knowledge about the culture of "the other". Ramsden's understanding of cultural safety involves an analysis of power imbalances in society, and embraces the political values of self-determination and decolonization.

Prince and Kelley (2010) suggest that in order to "create cultural safety when working with Aboriginal people, there must be: respect for individuals' and communities' values, beliefs, and traditions; recognition of the diversity among Indigenous people; and, understanding of the health and social challenges of the community", (p. 49).

“Cultural safety involves self-reflection and an understanding that cultural values and norms of the client may be different due to unique sociopolitical histories. Self-reflection leads to empathy, the capability to share another being's emotions and feelings, which in turn improves the therapeutic encounter with clients and their communities, leading to better health outcomes,” (Sutherland, Maar & Freel, 2013, p. 51).

The 1996 Royal Commission Report on Aboriginal Peoples (RCAP) (1996) suggests that along with recognizing the negative impacts of colonization, Canadians also need to recognize that Indigenous cultures in Canada are vibrant and distinctive, not only historically, but also today. While Aboriginal people have been wounded and harmed as a result of the colonial experience, and are in danger of losing aspects of their culture including language, they continue to maintain a fundamentally different world view from Euro-Western settlers.

A theme that was repeated many times throughout the individual and Circle meetings was a clear preference by participants towards the term cultural safety over cultural competence. The National Aboriginal Health Organization (2009) suggests that cultural safety within Aboriginal health care means that the health care provider can “communicate competently with the patient in that patient’s social, political, linguistic, economic, and spiritual realm.” An absence of cultural safety would involve any “action that diminishes demeans or disempowers the cultural identity and well-being of an individual,” (NAHO, 2009).

The Aboriginal Nurses Association of Canada (2009) refers to cultural safety as moving the practitioner beyond cultural awareness and the acknowledgement of difference. The College of Nurses of Ontario (2009) suggest that in order to deliver culturally sensitive care, health care providers must recognize how the perceptions of the clients are both similar as well as different from their own. One of the Advisory group Elders, Gale Cyr, is known for her promotion of the idea of coming to know “the similarities in our differences and the differences in our similarities”.

Mainstream service providers who practice self-reflection and look honestly at their own culture, values and beliefs, can become more able to develop understanding of how their culture, values and beliefs may impact others, and will have greater understanding of how each person is influenced by their own values and beliefs. Developing a culturally safe practice requires self-examination rather than looking at romanticized and idealized aspects

of another culture. Self-reflection can facilitate a process that will support health care providers to decolonize their practices and responses to Aboriginal people, (Edwards & Taylor, 2008). Decolonization can be described as, “a process of acknowledging the history of colonialism; working to undo the effects of colonialism; striving to unlearn habits, attitudes, and behaviours that continue to perpetuate colonialism; and challenging and transforming institutional manifestations of colonialism”, (Haigh, 2012, p. 47). Edwards and Taylor (2008) describe decolonising as an opportunity to develop a new way of seeing and relating between Aboriginal and non-Aboriginal people.

Anishnawbe Health Toronto identifies **cultural safety** as incorporating:

- Cultural awareness: acknowledgement of difference;
- Cultural sensitivity: recognition of the importance of respecting difference;
- Cultural competence: which focuses on the skills, knowledge, and attitudes of practitioners;
- Self-reflection and understanding cultural values and norms may be different due to unique socio-political histories;
- Self-reflection leads to empathy, the capacity to share another being’s emotions and feelings improves therapeutic encounters with clients and their communities leading to better health outcomes
- Empathy can lead to advocacy and social justice work on behalf of clients and their communities

<http://www.aht.ca/aboriginal-culture-safety/cultural-safety>

Leanne Simpson in *Alliances, Re/Envisioning Indigenous-non-Indigenous Relationships* (Davis, 2010) suggests that building relationships is a helpful strategy for change, noting that not all relationships develop easily, and often encounter cross-cultural misunderstandings, poor communication, stereotypes, and racism. Stienstra and Chochinov (2012) make the point that our individual attitudes are often the result of longstanding cultural and societal beliefs that we are taught in relation to specific groups of people. These authors suggest such attitudes are present in all people in society and shape how we relate to others. Our assumptions or attitudes about groups of people may influence what we believe about various groups of people and how we provide care and service. When service providers provide cross cultural care without becoming informed, aware and developing respect and an understanding of both themselves and those who have a different cultural background, the differences in beliefs and worldviews can lead to frustration, disregard and oppression.

Edwards and Taylor (2008) suggest that cultural awareness alone does not help non-Aboriginal people understand the resilience, adaptability and capacity of the Aboriginal cultures in Canada today. These researchers identify that for non-Aboriginal health care providers to develop a decolonizing and culturally safe practice they need to examine their understanding of history and any preconceptions they hold about Aboriginal people, and to recognize that health policies and services in Canada are founded on and privilege Western cultures and world views. Edwards and Taylor (2008) make the point that creating culturally safe practices “requires non-Indigenous people to change their responses rather than repeating them. By decolonizing, there is an opportunity for transforming practice to a more socially just position,” (p. 33).

A participant noted that it is not realistic or practical for healthcare and palliative care providers to learn all of the traditions of all Aboriginal people in Canada, suggesting instead that health care providers need to learn how to ask Aboriginal people what is important to them in their care, what their wishes are, and to take the time to learn about the values and beliefs of the individual as they relate to their illness and death..

McGrath (2000) identifies when patients are receiving palliative care, they and their family, are faced with many difficult decisions which can be made more difficult when health care providers are not of the same cultural background as the patient. Research done by Kelly and Minty (2007) demonstrates that communication and decision making take on greater challenges when the patient and the health care provider are from different cultural backgrounds. Hampton et al (2009) highlight that culturally respectful interventions increase Aboriginal participation in health care services. McGrath (2000) suggests that when health care providers have an understanding of what care means based on their own cultural teachings and develop the knowledge and skill to be able to deliver service that is culturally relevant to the patient, care becomes more meaningful and effective for the person receiving care. Cultural safety reflects the recognition that the individual and community are the experts of their own experience and health care providers engage and communicate with the individual in a manner that takes into consideration the person’s social, political, linguistic, economic, and spiritual realm (Prince and Kelley, 2010). Cultural values and beliefs must be respected and care practices need to be uniquely adapted to recognize the cultural world view of the individual if the patient is to have confidence in the care provided to them (Hampton et al, 2001). DeVerteuil and Wilson (2010) are clear that it is important to be careful to not assume that all Aboriginal people will want health care services that provide a combination of both contemporary care and traditional healing. Providing

culturally safe care requires the health care provider avoid making any assumptions about the patient's care needs.

Unless cultural values, beliefs and traditions are taken into consideration, health care services and supports to Indigenous people may be experienced as inadequate, even when all the technical medical care is provided in a competent manner. McManus (2012) suggests that a patient and their family's level of stress and trauma while experiencing end of life care can be decreased if the care provider has an awareness of the patient's cultural beliefs and incorporates these into the care plan. The Canadian Hospice Palliative Care Association (2007) notes that it is important for palliative care providers to be able to respectfully gather the information and understanding that is necessary for them to provide culturally safe care. Health care providers need to have enough understanding of the history of colonization and resulting intergenerational trauma to understand how these factors may affect their Indigenous patients, and be willing to work actively to gain their trust.

Health care providers and those delivering end of life care to Aboriginal people are in a position to develop their role as ally to Aboriginal people in Waterloo Wellington. Being an ally can be a vital component of developing a practice and services that are culturally safety for Aboriginal people.

Conclusion

This project involved 87 participants in total including four Talking Circles with 53 Aboriginal participants and 30 individual conversations with 20 members of the Aboriginal community and 14 non-Indigenous palliative care providers including nurses, a doctor, a social worker, a volunteer, and hospice staff in Waterloo and Wellington. Participants highlighted the value of being engaged in this project and the opportunity to gather together to talk about palliative and end of life care for the Aboriginal community.

This needs assessment looked specifically at palliative care needs and recommendations for the urban, off-reserve Indigenous population residing in Waterloo Wellington, highlighting barriers, challenges and the vision the Aboriginal community has for palliative care for its members. The stories, experiences, and insights shared and collected in this project are intended to guide development of best practices, services and a model for providing end of life care in the local Aboriginal communities.

- All participants identified the importance of building end of life and health care services for Aboriginal people living in Waterloo Wellington through wholistic Indigenous knowledge and practice.
- Participants identified the challenges faced by urban Aboriginal people due to the lack of services and supports that integrate culture or have culturally relevant aspects including wholistic care, Elders and spiritual ceremonies.
- It is recommended that WWLHIN establish an Aboriginal Advisory group for the local LHIN to ensure Aboriginal representation in health care decisions that impact Aboriginal people in Waterloo Wellington. Collaboration is occurring among the local Aboriginal agencies and services to formulate a plan to work together to strengthen health care for local Aboriginal people. A decision was made at the monthly Ogiima meeting, a gathering of local Aboriginal service providers, to support White Owl Native Ancestry Association as the local Aboriginal agency to work with WWLHIN to explore future funding opportunities. In order to implement the recommendations of this needs assessment, it will be essential to secure funding to continue the work that has begun with this process.
- Individual Aboriginal beliefs and values need to be understood and explored within a respectful, trusting, compassionate and open relationship between the palliative care providers and those receiving care. There is tremendous resiliency and strength among the local Aboriginal people, and an investment and commitment to building Aboriginal community and culture in Waterloo Wellington

- Combining Aboriginal wisdom and wholistic healing with mainstream resources and knowledge has the potential to create strong and effective services and supports that will ultimately benefit all residents of Waterloo Wellington.
- Ongoing funding and commitment from WWLHIN is critical to ensure the findings from this needs assessment are implemented by the local Aboriginal community. The community requires Aboriginal end of life and health care providers to deliver service built on mental, emotional, physical and spiritual resources.

Appendix 1: Project Participants

Akiesha Absolon Winchester	Kellie Grace
Alicia Blore	Kelly Laurila
Andrea Misquadis	Kim Cronier
Angela Jenkins	Laurie Minor
Amanda Mandanoub	Lila Bruyere
Barb Belleau	Lilas Meadus
Beverly Stanger	Lois MacDonald
Carol Levis	Maegan Boyter-Mandanoub
Carol Musgrove	Marion Goulais
Christine Hauck	Mary Ann Cheesequay
Corrine Vautour	Mary Ann Nawagesic
Cynthia Hoy	Melissa Robinson
Cynthia Martin Pinnau	Michelle Lee
Cynthia Missabie	Myeengun Henry
David Stewart	Nina De Shane-Gill
Dorinda Kruger Allen	Pauline Moon
Dr. Gus Hill	Patricia Nawagesic
Dr. Kim Kenney	Peter Howlett
Ela Smith	Rebekka Peacock
Elaine Garner	Robyn Buswa-Eadie
Fran Garvey	Rose Mary Meadus
Gale Cyr	Samantha Porte
Geri Duguid	Sandi Wey
Heather Majaury	Sandy Montero
Hope Engel	Sharla Johnston
Irene Peacock	Sidney Dokis
Jan Sherman	Tamie Coleman
Jean Becker	Vernon Nawagesic
Jennifer Parkinson	Vicky Lucas
JoAnne Absolon	Wendy Stewart
Katrina Graham	

Ogiima Meeting – Donna Dubie (Healing The Seven Generations), Rosie Weiler (Healing The Seven Generations), Laurie Turcotte (K-W Urban Native Wigwam Project), Ela Smith (White Owl Native Ancsetry Assossociation), Particia Nawagesic and Vernon Nawagesic (Wholistic Child and Youth)

Non-Aboriginal Contacts - Hospice of Waterloo Region, Hospice Wellington Lisaard House, HPC Consultation Services Waterloo Wellington – Pain and Symptom Management Consultants, Kitchener Downtown Community Health Centre, Guelph Community Health Centre, Grand River Hospital – Spiritual Care and Social Work, Waterloo Wellington Community Care Access Centre

Appendix 2: In the Words of the Participants

Quotes and Ideas Shared in Circles and Individually

- “I was raised by my grandparents. When my grandmother was sick no one ever reached out to me from the health community. It seemed like all the emphasis was on palliative rather than wholistically looking at the situation.” (female participant)
- “The hospice accommodated all of us, all nine of us. It was a beautiful setting for him. A Circle was allowed at the hospice.” (female participant)
- “I wish I was asked what I needed” (female participant, caregiver)
- “He wanted to have some palliative care and then he decided not to because he was concerned that they would say ‘oh just another Native’”. (male participant)
- “I remember I went to visit him. He was at his home. He was comfortable with his family being there. He was very calm, he had comfort that his people were there” (female participant)
- “The spiritual part is not being taken care of.” (male participant)
- “There needs to be outreach dollars to support those who are caregivers.” (female participant)
- “We don’t really talk about end of life – it is like we are inviting it.” (male participant)
- “It would have been good to have had an Elder there to help my Dad pass and to share what happens after he takes his last breath. I was scared in there. I wish I had an Elder or a Native organization to support me.” (female participant)
- “There needs to be more support for the families when their person is sick and to help with the loss.” (female participant)
- “I needed more help with basic traveling needs, traveling to their medical appointments” (female participant)
- “Nurses come out and do what they have to, it was almost like a production line.” (female participant)
- “I would hope that I could ask for an Aboriginal guide at end of life, when I am sick.” (female participant)
- “I was scared. A Native Elder may have been able to explain things to me.” (female participant)
- “We need it to be wholisitic” (female participant)
- “Death is a part of living, we live until we die. We need to embrace and accept that.” (female participant)
- “We need to heal before we cross over.” (female participant)
- “I would love health institutions that were Indigenous friendly – like having a medicine wheel symbol. Then we would know we could go there and get Indigenous type help”. (female participant)
- “I accessed March of Dimes, CCAC, Indian Northern Affairs, Saugeen First Nations. I have a chair and a railing at home. I got diapers for Mom. I went through a lot of organizations. Don’t let anyone say it can’t be done, never give up” (female participant)

- “When Mom died we smudged Mom there, we cedar bathed mom and we sang for her.”
- “We had an experience with a nurse in the hospital; she was very negative and unsupportive. She said things to us like ‘she can’t hear you’”. (female participant)
- “Health professionals need to be more compassionate and understanding and to be there for the family too.” (female participant)
- “Provide educational material for the family on the different stages of the end of life process.” (female participant)
- “Being able to accommodate family and having your family around is very helpful for the person who is dying and family is very important”. (female participant)
- “There were issues of the number of people in the room, room is limited. There should be no limit, family is important to be with the dying person.” (female participant)
- “You have to ask what they need and want, be open to what people want. This means talking ahead of time. It is about sitting down with the family and asking what do you truly want.” (female participant)
- “The energy is the same as at birth, when one leaves the ancestors are there in the same way.” (female participant)
- “Experiences in institutions have been horrible – denying children, no smudge, not helping family to be together.” (female participant)
- “Our community, Aboriginal people, don’t know how to advocate for our dying. Our community has been so hurt in so many ways.” (female participant)
- “We can feel isolated and might not have trust for doctors.” (female participant)
- “We had to go to Toronto to get medicine to make cedar tea. We had challenges connecting with Elders in KW.” (female participant)
- “The hospital did not have space for us to visit and do ceremonies. The staff broke the rules to accommodate a smudge.” (female participant)
- “What we needed was a health care navigator to help us through the journey of palliative care. Someone to help us through the process, someone to be there from beginning to end. And we need a place in the hospital to do our ceremony.” (female participant)
- “We need our family with us, young and old, and we need our Traditional Medicine as well.” (female participant)
- “The person may at times feel fear, a longing or need to do something or having something done. They need a spiritual person to help.” (female participant)
- “We needed to prepare him traditionally for the journey.” (female participant)
- “We had a Native nurse, with her support and help we were able to do the ceremonies we needed to do.” (female participant)
- “There needs to be a full acceptance of Indigenous practices” (female participant)
- “All of the facilities should be educated on the diversities of our peoples, and the traditional ceremonies of our people.” (female participant)
- “We were told only one of us could sit with her, we had to take turns.” (female participant)
- “Just before she died she accepted her heritage, on the paper she identified as Metis.” (female participant)

- “There needs to be more guidance for medical staff, more teaching and education about our culture.” (female participant)
- “It doesn’t end, I had a dream and I know I am unconditionally loved. Creator is telling me do not be afraid to die.” (female participant)
- “If we keep the Circle strong we have the power to bring the traditional teachings into the dying process.” (male participant)
- “It is important for us to see this project through. It can be done – what we are doing here is a great start. We have to carry this on.” (male participant)
- “Who will look out for the person on the park bench who is dying with no family?” (male participant)
- “We need a pool of resources of people who can help wrap around the family to help with the dying process. Train Aboriginal people to help with the dying process.” (female participant)
- “We need our Traditional Medicines to help us” (female participant)
- “One thing that would help is to create a pool of resources to help us do this work.” (female participant)
- “The community came together and donated a bus ticket, food, blankets, etc. We really need this. The mother was grateful.” (female participant)
- “The medical people should be more sensitive to people’s beliefs.” (female participant)
- “I feel that if we had a patient navigator, they would know where to get the Medicines, how to find an Elder, it would make the process easier. Someone who could be with the family to the end.” (female participant)
- “Having only one or two people in the room is like a slap in the face. We had to wheel her outside near the end to see her grandkids.” (female participant)
- “We were able to do ceremony after she passed, we cleaned her and did the preparations I have done in Mohawk territory. We dressed her and I stayed with her to make sure she wasn’t alone.” (female participant)
- “My vision I guess is for a time when there’s a full acceptance of traditional Indigenous practices when they are wanted, if the family is asking, It should not be an oddity. Most time people make accommodations. It should not have to be fought for. All these facilities ought to have training about our people and the diversity of our people and the beautiful ceremonies from our diversity cultures. We need to have a place here, this is our country, and we have a lot of little ones.” (female participant)
- “She didn’t want to be alone, but only one person could stay, not all.” (female participant)
- “Having the drum and singing around the casket, it is so beautiful to me. I am realizing that there is a beautiful side to this.” (female participant)
- “Where is the protocol in institutions? Bring in traditional people to advise the administrations” (male participant)
- “Nothing is put on any form for First Nations. They are the ones that are lost.” (male participant)

- “If we don’t follow through, people will still not be able to get the passing that they deserve. I think this is a good start as long as it continues, as long as it can become a catalyst of movement.” (male participant)
- “All of our diversity needs to be honoured, my mother was full native but didn’t practice her tradition and that needs to be honoured too.” (female participant)
- “A patient navigator would be awesome.” (female participant)
- “We need to honour our diversity. We need a patient navigator. We need a pool of resources, to help families go through the tough time.” (female participant)
- “There is a lack of knowledge and community awareness of hospice in our community.” (female participant)
- “If it wasn’t for my sisters friend walking us through the stages, and the doctors and nurses used jargon I couldn’t understand. It is a foreign language. It helps if someone could be there that could explain things.” (female participant)
- “Everyone was there, and after three days had passed everyone was gone. The person who has lost someone is left alone. Luckily I had the lodge to go to and to go through the grieving process.” (female participant)
- “The ceremonies are important. The power of tobacco and prayers and the power of the heart.” (female participant)
- “I really like the sounds of hospice. It sounds softer so that maybe family may have an easier time.” (female participant)
- “We need a list of Elders in the community, a list to help us have ceremony, it that is what is needed in addition to mainstream resources. We need those Elders and those ceremonies” (female participant)
- “An important issue is that not all people have traditional background. We need to ask what is acceptable for the diverse Native backgrounds. Are there common things we can all agree on? We need to think about those things.” (female participant)
- “When I think of end of life, it is a transition from one state of being to another state of being. I think about the spirit beginning to soar. I think we are in a position to help our loves ones transition. We can support each other tremendously.” (female participant)
- “Wouldn’t it be fabulous if we could get an Aboriginal hospice?” (female participant)
- “It is our teachings, coming from the spirit world and returning to the spirit world.” (female participant)
- “I would like to see palliative care indigenized. Wouldn’t it be nice to have Circle after a person passed? To respect and honour that person, and to put Indigenous into hospice. To be able to have ceremony and people to do ceremony. To reteach the people about how to take care of people when they pass. To make that journey into the next realm and to incorporate the Seven Grandfather teachings.” (female participant)
- “We need to educate people in institutions about indigenous protocol so that our people do not have to feel alienated, to feel like you are being weird. That is really important.” (female participant)

- My vision is huge, an actual Indigenous facility, or a wing for Indigenous people, or a health centre. This is my vision, I am dreaming big.” (female participant)
- “There needs to be counselling for children during and after. This is really important. I was raised by my grandmother. After she got sick I was very angry for a long time. Both grandparents died so close together. It is hard to function without the people who raised you. There needs to be more help with grieving and everything.” (female participant)
- “I think both mainstream and traditional care is important. I wouldn’t be here without both. Sometimes I can’t tell mainstream doctors when I am accessing traditional care. Sometimes the cooperation between the two is not there.” (female participant)
- “I think sometimes the health care practitioners put too much focus on the medical model, put too much focus on treating palliative care as an illness, instead of viewing it in a more wholistic way that all human beings must go through in order to complete their life. I think there is a lack of knowledge and education regarding the wholistic way.” (female participant)
- “Another idea I had was compiling resources both Aboriginal and non-Aboriginal to give out to people. I have been here for four years, but I don’t know of anything out there. A booklet of resources would be incredibly helpful in terms of allowing me to find what is even out there.” (female participant)
- “Wholisitcally, it is important to keep all family members in balance when a member is dying.” (female participant)
- “I have dealt with end of life and palliative care. I would say that there has to be more of a support system for families because everything is centred on the patient, like comfort and pain management. As for families, it is really hard for family during and trying to cope afterwards.” (female participant)
- “I wonder if people are afraid to go to those places for care. If there are ways to bridge that somehow and to get people to not be so afraid to interact with those institutions.”
- “My vision includes care circles, mainstream organizations working with Native communities, wholisitc help like smudging, ceremonies, and reiki, and having training for community member, families and caregivers.” (female participant)
- “The Circle is important to our people. I think that’s what our people want and have been asking for. If anything comes out of this, if we could even provide that, it is good. It is just the circle of life. To do things using our ways and have a happy outlook.” (male participant)
- “My friend recently wanted a form of palliative care but there was none available and he didn’t know how to get it. Then again he didn’t really want to go because he didn’t want to receive the racism against Aboriginal people.” (male participant)
- I know what health care provides at end of life and I know what they don’t do. The medical part is being taken care of but the spiritual part is not being taken care of. I hope for Aboriginal people that someone could come and give the Traditional Medicines instead of just mainstream medicines.” (female participant)

- “Death is a transition to the Spirit world. It is an important transition and not to be avoided. The transition needs to be honoured.” (female participant)
- “Doctors and nurses must be able to be learners as well as medical experts. They must be able to be humble and ask people what is important to them at end of life.” (female participant)
- “Hospice needs to be visible in the Aboriginal community. Maybe have information at Pow Wows, Aboriginal Day and community events.” (female participant)
- “Care needs to be directed by the individual, and those providing care need to respect the individual’s wisdom and decisions and not impose a care plan. They need to ask the person what they need and then work with the person to make this happen” (male participant)
- “Death needs to be a smooth transition from one world to the other” male participant
- “White agencies need to learn our cultural knowledge and how to indigenize health care and end of life care.” (female participant)
- “Our people are coming into treatment at stage four cancer because they may have come into an emergency department at stage one, then they get sent home and don’t come back until stage four.” (female participant)
- “Aboriginal people don’t know to fight and advocate for health care, we are not forceful like that. We need someone to advocate for our people, workers or volunteers who know how to advocate.” (female participant)
- “Visibly there is nothing in the hospital that we can connect to” (female participant)
- “It is a good time to be starting this conversation about Aboriginal Palliative care” (Elder)
- “Palliative care is care offered at end of life. End of life is part of the journey, just a part of life. We need help with that part of the journey to ensure comfort and care to support the transition into the Spirit world.” (female participant)
- “When I was providing care I would have liked a book in simple terms that talked about caring for someone who has a terminal illness. (female participant)
- “I want someone to come and sit with me when I am a caregiver and when I am terminally ill.” (female participant)
- “I look forward to a time when hospitals that are truly and sincerely open to our ways and ceremonies and hospital staff who are open and supportive of Aboriginal ceremonies and we are allowed to do our ceremonies without having to go through a difficult/complicated/demotivating process.” (female participant)
- “I want doctors and care providers to be respectful of the whole person – mental, spiritual, emotional and physical.” (female participant)
- “We deserve to be treated with dignity, we are all human, white, black, red or yellow and we should all be treated the same.” (female participant)
- “We cannot let the conversation we are starting today stop – not let it die – we need this for our community.” (female participant)
- “Whatever is created for end of life for Aboriginal people needs to be for all Aboriginal people, not just status.” (female participant)

Appendix 3: Survey



298 Lawrence Avenue, Kitchener, ON N2M 1Y4

Phone: 519-743-4114 Fax: 519-743-7021 www.hospicewaterloo.ca

Charitable Number 14041 5795 RR 0001

Thank you, Miigwech, for taking time to provide the following information.

1. Do you identify as:

- | | |
|---|--|
| <input type="checkbox"/> Status First Nations | <input type="checkbox"/> Non-Status First Nations |
| <input type="checkbox"/> Metis | <input type="checkbox"/> Inuit |
| <input type="checkbox"/> Mixed heritage | <input type="checkbox"/> Not First Nations, Metis or Inuit |

2. Please indicate the name of your home community/First Nation?

3. What city do you live in?

4. Gender

- Female
 Male

5. Please indicate the age group you are in:

- | | | |
|------------------------------------|-------------------------------------|--|
| <input type="checkbox"/> 15-19 yrs | <input type="checkbox"/> 36-50 yrs | <input type="checkbox"/> 71& over |
| <input type="checkbox"/> 20-35 yrs | <input type="checkbox"/> 51- 70 yrs | <input type="checkbox"/> prefer not to say |

7. When you access health care services, do you self-identify as an Aboriginal Person?

- Yes, always
 Sometimes
 No, Never

8. Please share your reasons for deciding if you will or will not identify as an Aboriginal person with health care providers.

For this survey, the word palliative care is used to describe a variety of supports and services offered to relieve suffering and improve the quality of life for people living with or dying from a life threatening illness. These services are also offered to family members and caregivers of the individuals.

10. Who do you think palliative care services are for?

- Everyone at the end of their life, no matter age or illness
- Only those dying of a life threatening illness like cancer, AIDS, etc
- Other _____
- I don't know

11. If you needed information about services and supports for someone who is dying, who would you go to for information?

- | | |
|---|--|
| <input type="checkbox"/> Family Doctor | <input type="checkbox"/> Community Health Centre |
| <input type="checkbox"/> Health Nurse | <input type="checkbox"/> Hospital |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Priest/Minister/Pastor | <input type="checkbox"/> Friend/Family Member |
| <input type="checkbox"/> Traditional Healer/Elder | <input type="checkbox"/> Other _____ |

12. Have you ever discussed your end-of-life care and/or wishes with a family/friend/community member?

- Yes No

13. Have you been involved in providing end-of-life care to a family/community member at end of life?

- Yes No

15. Were the people, services and supports provided in a way that was respectful of your values and beliefs?

- Yes No Somewhat

Please Explain

16. What do you feel were the strengths in the care and support that was provided?

17. What areas in the palliative care you experienced do you feel could have been strengthened or improved?

19. What do you feel are important things to be part of palliative/end of life care for Aboriginal people in Waterloo Wellington?

20. What are your thoughts about the role of Traditional Aboriginal Medicine at end of life care for Aboriginal people living in Waterloo Wellington?

21. Which statement comes closer to the way you feel:

- Ideally people die in their own home
- Ideally people die in their own community
- Ideally people die in hospital
- Ideally people die in a hospice care facility
- Other _____

22. In your opinion, what additional services, supports, or programs are needed to improve the experience and care of people who are living with a life threatening illness in your community?

23. Please share any thoughts, stories, and experiences you would like us to know about palliative, end of life, hospice care. (Please feel free to write on the back of the page)

Thank you for taking the time to complete the questions and share your thoughts. Your participation is very much appreciated! Chi Miigwech

Bibliography

- Aboriginal Affairs (nd). Ministry Of Aboriginal Affairs Quick Facts. Retrieved from:
<http://www.aboriginalaffairs.gov.on.ca/english/services/datasheets/Aboriginal.pdf>
- Aboriginal Affairs and Northern (n.d.). Fact Sheet: Urban Aboriginal Population in Canada Development <http://www.aadnc-aandc.gc.ca/eng/1100100014298/1100100014302>
- Aboriginal Nurses Association of Canada (2009). Cultural Competence and Cultural Safety in Nursing Education. A Framework for First Nations, Inuit, and Metis Nursing. Retrieved from, www.anac.on.ca.
- Absolon, K. (2010). Indigenous Wholistic Theory: A Knowledge Set for Practice. *First Peoples Child & Family Review*, Vol. 5, No. 2, pp. 74-87.
- Anishnawbe Health Toronto (n.d.). Aboriginal Cultural Safety Initiative. Retrieved from:
<http://www.aht.ca/aboriginal-culture-safety>
- Attorney General (n.d.). Retrieved from:
http://www.attorneygeneral.jus.gov.on.ca/inquiries/ipperwash/policy_part/research/pdf/Spotton_Profile-of-Aboriginal-Peoples-in-Ontario.pdf
- Baskin, C. (2011). Strong Helpers' Teachings. The Value of Indigenous Knowledges In Helping Professions. Canadian Scholars Press Inc, Toronto, Canada.
- Browne, A.J., McDonald, H., & Elliott, D. (2009). Urban First Nations Health Research Discussion Paper. A Report for the First Nations Centre of the National Aboriginal Health Organization. Ottawa, ON: National Aboriginal Health Organization.
- Canadian Hospice Palliative Care Association (2007). Moving Forward by Building on Strengths: A Discussion Document on Aboriginal Hospice Palliative Care in Canada.
- Caron, N. (2006). Caring for Aboriginal patients: the culturally competent physician. *Royal College Outlook*, Vol. 3, no. 2, p 19-24.
- Castleden, H., Crooks, V., Sloan Morgan, V., Schuurman, N., Hanlon, N., & Inter Tribal Health Authority (2009). Dialogues on Aboriginal-focused hospice palliative care in rural and remote British Columbia, Canada. Final Report.
- Centre for Social Justice (n.d.). Aboriginal Issues. Retrieved from:
<http://www.socialjustice.org/index.php?page=aboriginal-issues>
- College of Nurses of Ontario (2009). Practice Guide: Culturally Sensitive Care.

- Correctional Service Canada (n.d.). Aboriginal Corrections. Retrieved from: <http://www.csc-scc.gc.ca/aboriginal/index-eng.shtml>).
- Davis, L. (Ed), (2010). *Alliances, Re/Envisioning Indigenous-non-Indigenous Relationships*. University of Toronto Press Inc., Toronto, Canada.
- DeVerteuil, G., Wilson, K., (2010). Reconciling indigenous need with the urban welfare state? Evidence of culturally-appropriate services and spaces for Aboriginals in Winnipeg, Canada. *Geoforum*, Vol.41. pp. 498-507.
- Edwards, T., Taylor, K. (2008). Decolonising Cultural Awareness. *Australian Nursing Journal*, Vol14, No. 10, p. 31-33.
- Haigh, Rebecca S. (2012). "Working and Thinking Across Difference: A White Social Worker and an Indigenous World". *Open Access Dissertations and Theses*. Paper 7406.
- Haines, A., Heath, I., & Smith, R. (2000). Joining together to combat poverty: Everybody welcome and needed. *British Medical Journal*, 320: 1, p. 18-19.
- Hampton, M., Baydala, A., Bourassa, C., McKenna, B., Saul, G., McKay-McNabb, K., Goodwill, K., Clark, V., Christiansen, J. (2001). Seven Years of Completing the Circle: End-of-Life Care with Aboriginal Families. *CJNR*, Vol.43, No. 3, pp. 119-125.
- Hampton, M., Baydala, A., Drost, C., McKay-McNabb, K. (2009). Bridging Conventional Western health care practices with traditional Aboriginal approaches to end of life care: A dialogue between Aboriginal families and health care professionals. *Canadian Journal of Nursing Informatics*, Vol 4, No. 1, p. 22-66
- Health Council of Canada (2012). Empathy, dignity, and respect: Creating cultural safety for Aboriginal people in urban health care. Innovative Practices Health Council of Canada.
- Health Council of Canada (2013). Canada's most vulnerable. Improving health care for First Nations, Inuit, and Metis seniors.
- Hick, S. (2007). *Social Welfare in Canada: Understanding Income Security, Second Edition*.
- Hunter, L., Logan, J., Goulet, J., Barton, S. (2006). Aboriginal Healing: Regaining Balance and Culture. *Journal of Transcultural Nursing*, Vol. 17 No. 1, p13-22.
- Hwang, S.W. (2001). Homelessness and health. *Canadian Medical Association Journal*. Vol. 164, p. 229-33)

- Jacklin, K. & Kinoshameg, P. (2008). Developing a Participatory Aboriginal Health Research Project: "Only if it's Going to Mean Something", *Journal of Empirical Research on Human Research Ethics*, 3(2): p. 53-68.
- Lewis, J., DiGiacomo, M., Currow, D. (2011). Dying in the Margins: Understanding Palliative Care and Socioeconomic Deprivation in the Developed World. *Journal of Pain and Symptom Management*, Vol.42, p. 105-118.
- MacKinnon, S. (n.d.) First Nations poverty and the Canadian Economy: Aligning policy with what works. Retrieved from: <https://www.policyalternatives.ca/publications/commentary/first-nations-poverty-and-canadian-economy>
- McGrath, C. (2000). Issues influencing the provision of palliative care services to remote Aboriginal communities in the Northern territory. *Australian Journal of Rural Health*, Vol. 8, p. 47-51.
- McManus, R. (2012). Culture, death and dying with dignity. *Health Sociology Review*, Vol. 20(4), p. 370-372.
- The Métis Nation of Ontario (n.d) Retrieved from: <http://www.metisnation.org/about-the-mno/the-metis-nation-of-ontario>.
- O'Brien, V. (2012). Person Centred Palliative Care: A First Nations Perspective. (2012) Open Access Dissertations and Theses. Paper 7501
- O'Connor, C., Small, S. A., Cooney, S. M. (2007). Culturally Appropriate Programming: What Do We Know About Evidence-Based Programs For Culturally And Ethnically Diverse Youth And Their Families? *University Of Wisconsin-Madison and University Of Wisconsin*, Issue #1, p. 1- 5.
- Prince, H., Kelley, M. (2010) An Integrative Framework for Conducting Palliative Care Research with First Nations Communities. *Journal of Palliative Care*, Vol. 26, No. 1, p. 47-53.
- Royal Commission on Aboriginal Peoples, (1996). Report of the Royal Commission on Aboriginal Peoples, Vol. 1, Looking Forward, Looking Back. Government of Canada.
- Stienstra, D., & Chochinov, H. M., (2012) Palliative care for vulnerable populations. *Palliative and Supportive Care*, Vol. 10, p. 37-42.
- Statistics Canada (2008). Aboriginal peoples in Canada in 2006: Inuit, Métis and First Nations 2006 Census. Ottawa, ON: Ministry of Industry, Catalogue no. 97-558-XIE

- Statistics Canada (2006). Aboriginal Languages. Retrieved from:
<http://www12.statcan.gc.ca/census-recensement/2006/dp-pd/tbt/Rp-eng.cfm?LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GID=0&GK=0&GRP=1&PID=89149&PRID=0&PTYPE=88971,97154&S=0&SHOWALL=0&SUB=733&Temporal=2006&THEME=73&VID=0&VNAMEE=&VNAMEF=>
- Strand, J., & Peacock, T., (2003). Nurturing Resilience and School Success in American Indian and Alaska Native Students. *The International Child And Youth Care Network*. Issue 59
• December 2003.
- Sutherland, M., Maar, M., Freel, S., (2013) Dignitas International Feasibility Study Draft Report, *Improving Access To Quality And Culturally Safe Health Care For Aboriginal Communities In Canada*
- The Record (2012). Retrieved from: www.therecord.com/.../2606867-new-program July 5, 2012.
- T.D. Economics (May 15, 2013). A Demographic Overview of Aboriginal Peoples In Canada. Retrieved From:
http://www.Td.Com/Document/Pdf/Economics/Special/Sg0513_Aboriginal_nhs.pdf
- Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2010). Chapter 9, Research Involving the First Nations, Inuit and Metis Peoples of Canada
- Townson, M. (2005). Poverty issues for Canadian women. Ottawa, ON: Status of Women Canada, Government of Canada, 2005, [hwww.swc-cfc.gc.ca/ cgi-bin/printview.pl?file=/resources/consultations/ges09-2005/poverty_e.html](http://www.swc-cfc.gc.ca/cgi-bin/printview.pl?file=/resources/consultations/ges09-2005/poverty_e.html)
- Wilson, D., Birch, S., Sheps, S., Thomas, R., Justice, C., MacLeod, R. (2008). Researching a Best-Practice End-of-Life Care Model for Canada. *Canadian Journal on Aging*, Vol. 27 No.4, pp. 319-330.
- Wilson, D., Macdonald, D., (2010).The Income Gap Between Aboriginal Peoples and the Rest Of Canada. Canadian Centre for Policy Alternative Growing Gap.Ca. Retrieved From:<http://www.policyalternatives.ca/Sites/Default/Files/Uploads/Publications/Reports/Docs/Aboriginal%20income%20gap.Pdf>
- World Health Organization, (2008). Closing the gap in a generation: Health equity through action on the social determinants of health, Geneva: WHO.