Naotkamegwanning First Nation

Wii’Zogi’Dati’Win Needs Assessment

“In the Hospital, you got to get out at a certain time, certain number of people, but when you’re at home, people can go in and out, people can sit there and sit with you for hours on end. That is one of the reasons people like being in their household…”

Centre for Education and Research on Aging & Health
Lakehead UNIVERSITY
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

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Introduction

The need for comfort care services for First Nations people is increasing due to an aging population and the high burden of chronic and life-limiting disease. Many First Nations people want the opportunity to journey in their home communities where they have lived all of their lives; however First Nations communities have limited access to culturally relevant and formalized comfort care programs.

The research, funded by the Canadian Institutes of Health Research, is conducted with four First Nations community partners: Fort William First Nation, Naotkamegwanning First Nation, Peguis First Nation and Six Nations of the Grand River Territory.

A Project Advisory Committee was developed in each community to ensure local control and lead the implementation of the project. The committee also ensures that the research project addresses the needs of the community and is respectful of the culture. The Project Advisory Committees approved all of the instruments and interview guides that were used in the community assessment to ensure they were locally appropriate.

The research project follows the principles of OCAP (Ownership, Control, Access and Possession) which are sanctioned by the First Nations Information Governance Committee and the First Nations Regional Longitudinal Health Survey, to ensure self-determination in all research concerning First Nations.

The goal of this project is for each community is to develop a community based comfort care program and team within to support members who are sick. This will offer community members more culturally relevant choices for journeying, provide better care for the Elders in the community, and help with training health care staff, community members and family caregivers.

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Purpose

This report presents the results from a community needs assessment conducted in Naotkamegwanning from May 2011 – September 2012 . An Aboriginal Community Facilitator interviewed and surveyed community members about understandings and experiences in providing comfort care; perceived barriers and supports; education and program needs; along with external health care providers input.

Participants

Elders, identified by the Project Advisory Committees, were invited to share their Indigenous understanding of end-of- life care through unstructured narrative interviews. In these interviews, participants would share stories and teachings of end-of-life care.

Community members were asked about their knowledge of comfort care and their previous experiences caring for a very sick loved one. They were also asked about their perception of whether members in their community prefer to journey at home or elsewhere, and what additional community programs, services and education would be required to support very sick people and their families in their community. Existing attitudes and values surrounding very sick community members and life-limiting illnesses were explored.

Health care professionals who serve the community, but are not locally based, were interviewed about services they currently provided in the First Nation community, their potential contribution to developing a comfort care program, and perceived barriers and opportunities to provide enhanced comfort care.

Acknowledgements

This project has involved the hard work and determination of many people. First, we would like to thank the Elders, community members, health care providers and members of leadership who invited us into Naotkamegwanning First Nation and participated in the data collection, as well as the external health care providers who supported the process and participated in interviews and focus groups. These individuals provided us with valuable insight, sharing their personal experiences, feelings and beliefs regarding end-of-life care. The level of understanding and knowledge gained in this project was only possible through the sharing of information from the grassroots of the community.

We would like thank the members of the Advisory Committee: Maxine Ranville, Daniel White, Lulu Kabestra, Darlene Copenace, A.J. White, and Raven Crow. The organizational support and guidance received from their programs facilitated the success of the project. The expertise and experience of these individuals provided the project with a foundation to build upon and assisted with building rapport within the community. We would also like to acknowledge Tom Grinnell, who was hired as the Aboriginal Community Facilitator on the project and was responsible for the data collection.

Finally, we would like to acknowledge and thank the Canadian Institutes of Health Research for their financial contribution and support of the research.

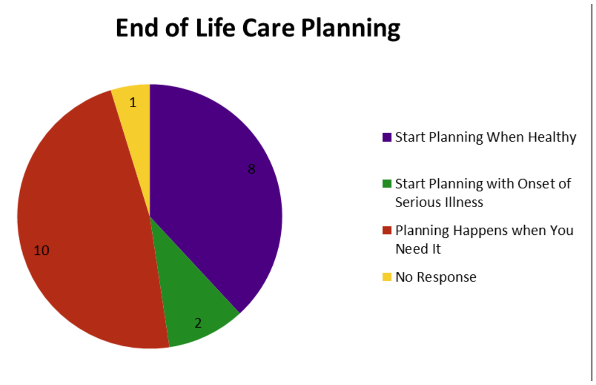
Section 1:

Understanding and Experiences in Providing Care

71% of the participants that completed the survey had heard of the term ‘palliative care’ and over 80% of respondents believed that palliative care services were intended for people who were at the end of their lives, regardless of their illness. 62% had either personally cared for, or knew of a family member who had provided care for someone who was not doing very well. The majority of this care was provided in the home.

End-of-Life Care Planning

- Only 20% of people surveyed felt that talking about death and dying was acceptable, while 40% did not know.
- 40% felt talking about death and dying was not acceptable due to cultural and traditional teachings and the idea that talking about death and dying will bring it about.



Community members expressed that they do not make end-of-life care preparations or discuss their end-of-life care wishes. The perception of some community members was that First Nations people do not talk about end-of-life wishes or make preparations. It was expressed that it is preferred not to have to think or worry about it until the time comes. Since death and dying is not talked about in a straightforward manner, family members may try to prepare their loved ones for their passing in their own way.

Community members pointed out how not having discussions about end-of-life care wishes can cause confusion and stress for family. Community members talked about how difficult decisions such as determining appropriate burial arrangements and ceremonies, can be for family members without pre-planning.

Participants shared some of the challenges they had experienced while providing care for an ill family member, such as the fact that caregiving can be very tiring and viewed by some to be a burden. If the person is experiencing pain, this can create a more challenging situation when it comes to care provision without having the necessary knowledge related to proper caregiving techniques, such as turning and lifting.

Participants expressed that family members can feel powerless if they are not allowed or supported to bring their family member home if that is their wish. Furthermore, they experience feelings of guilt if they choose to support the advice of the medical personnel instead of the wishes of their loved one.

Preferred Place for Receiving End-of-life Care

86% of people surveyed and the majority of focus group/interview participants felt that if services were available and adequate, more community members would choose to receive comfort care in-home.

> *“But I guess she kind of, prepared us. I guess you can probably say without telling us that she was passing away, but she kind of prepared us because she told us, she called us all of the time, all the time, all the time. So the day when she passed away none of us shed a tear. Because we’d already… Without knowing, us knowing that she knew”.*

Section 2:

Barriers and Supports

BARRIERS:

Naotkamegwanning community members identified many barriers to being able to die at home:

- Doctors not allowing patients to come home,
- Lack of available services in community,
- Lack of trained staff,
- Lack of knowledge related to pain management and that the administration of pain medication,
- Lack of essential services for homes such as heat and working appliances,
- Lack of medical equipment (raised toilet seats, for example),
- Lack of transportation,
- Lack of accessible infrastructure,
- Lack of funds/funding, and
- Not having family members who are able to assist with caregiving responsibilities, or a lack of family support.

> *"Another barrier, I think is fear, because if there's, if someone's in the hospital and they're coming home, the family members may be fearful just because they're not educated and they haven't ever dealt with something like this before".*

Respondents reported that barriers to being able to commit to providing care included: work and family-related responsibilities; a lack of other supports; personal, physical, and emotional health issues, the size of families has gotten smaller over the years, and; living too far away from the person.

However, when asked if participants could devote the amount of time they perceived necessary to take to care of a loved one at home given their current schedules, 70% of respondents indicated that they could.

Participants also shared that family conflict or a lack of agreement can also be a challenge when trying to support a loved to receive care at home.

SUPPORTS:

Naotkamegwanning community members identified many advantages of remaining in the community:

- Familiarity and comfort,
- Able to be near to family and friends,
- Less stressful on family,
- Economic advantage since travelling and associated costs would be avoided,
- Transportation would not be an issue, and
- Community members would have access to culturally appropriate services and care.

Family support was recognized as a key facilitator of a community member being able to remain or return home when they are very ill. A family that is present and looks after one another, keeps each other informed and plays a role in caregiving was viewed as being essential.

> *"I think family involvement is a big thing, I think family involvement means, anything … you know, if someone in lots of lots of pain at two in the morning, well odds are there's not gonna be a staff member available, I mean unless one because there is someone on call. But family it kind of all falls on family, in a community like this".*

Community members expressed that the community comes together to offer support in times of illness and was described as a naturally emerging process of caring for one another that has been present among the people throughout history.

Section 3:

Community Identified Needs

Community members believe that culture is very important to Naotkamegwanning and feel that Elders view the sharing of cultural knowledge with youth as being a very important way to ensure the younger generation has cultural understanding.

> *"what I have now, is I just feel so comfortable when I go through, you know, when you go through life sometimes, ups and downs, knowing that, that the beliefs in our culture, spirituality, spirits watching over you is so embracive. So I think that's so important to, to help a person to understand what they don't understand, that help them to be connected."*

PROGRAMS AND SERVICES:

- After hours care (nursing/respite/physician – home visits),
- Counselling services (including grief counselling),
- More health care providers (homemakers, RNs, RPNs, physicians), occupational therapy/massage/ exercise,
- Transportation services (to attend appointments/ medical supply delivery),
- Volunteer service (respite/support),
- Cultural component incorporated into all care and services (e.g. sweat lodge),
- Financial management assistance, and
- Band Assistance.

EDUCATIONAL NEEDS:

Education for Family Members:

- Family members need knowledge and training in numerous aspects so that they are able to assist with care such as toileting, changing, turning/ lifting, food preparation, and pain management.

> *"Although our community doesn't talk about death and dying, I think we should start so it won't be such a shock – death and dying is a natural part of life. Caring for our family members in the community will be something to bring us together and make it easier when they do pass on."*

Education for Community Members:

- Palliative care training in the community (incl. wound care, what to expect at end-of-life, roles & responsibilities, proper forms and uses),
- First aid/CPR training,
- services available in the community, and
- Workshops, information resources and traditional teaching methods (sharing circles) should be used to deliver such education.

> *"I think we need to address those kind of barriers, and see where everybody stands, sometimes individually even, and, I think just educating our community as a whole too in assuming we got issues like that, the easier it is, and the more successful, that person will be that they can stay at home, because issues that are difficult to talk about only get more difficult when someone's ill".*

Education for Health Care Providers:

- Training of local people to provide care in the community,
- Quality training in general for all health care providers; including registered nurses, nurse practitioners, paramedics and support workers,
- Need for health care providers to share information with each other in order to clarify roles and responsibilities, and
- Communicating with family and counselling skills.

Section 4:

External Health Care Provider Input

ACCESSING CARE:

The main way for Naotkamegwanning community members to access care, either in the community or at health care facilities outside the community, is through a referral process. Furthermore, there is collaboration between health care teams/providers to ensure access to care.

For the most part, referrals are handled through health care providers, between professionals or through the medical facility one is receiving care at.

BARRIERS TO PROVIDING CARE:

External health care providers stated that the cultural traditions surrounding discussing death and dying are a hurdle in providing quality care on-reserve. A tradition that does not allow for frank discussions limits their ability to create a proper care plan.

Participants pointed out that a lack of local resources, such as medical equipment, support for family and not having a building such as a hospice were potential barriers to providing quality care in the community .

Existing funding formulas and budget guidelines as barriers to providing quality care, the biggest barrier is that palliative care is not an essential service covered.

> *"...information in terms of you know what specifically does Whitefish want … I don't think that we can take any sort of cookie cutter approach and say well this worked on this First Nation community here or this worked there so we're gonna make it work, you know for another community that we may not necessarily know all that we should before we pursue an endeavour such as that …"*

OPPORTUNITIES:

Participants highlighted many opportunities to further develop or enhance palliative care programming, which include:

- Creating care options,
- Collaboration with community partners,
- Community designed and driven programming,
- Education and training, and
- Human resources.

> *"I can say that I did have a palliative client on Whitefish, approximately two years ago. She did remain at home for some time, but then chose to actually pass away in the hospital, and you know I'm not sure if that was partly because there…was a lack of support there. , it did seem like that was a potential concern within her consideration."*

POTENTIAL PROGRAM CONTRIBUTIONS:

External health care providers highlighted two main areas they can contribute to program development—Education and Human Resources.

Education Contributions:

- Education/training offered within the community, especially care training in the home for individuals/families/community members, and
- Making available health promotion teams and palliative care trained staff to offer education and training in the community.

Human Resources:

- Make staff available for consultations and information sharing and collaboration.