Cultural understanding in the provision of supportive and palliative care: perspectives in relation to an indigenous population

Grace Johnston,1 Adele Vukic,2 Skylan Parker3

ABSTRACT

Objectives The provision of supportive and palliative care for an indigenous people in Nova Scotia, Canada, was examined to further our understanding and thereby improve cultural competency. Most of Nova Scotia’s indigenous people are Mi’kmaq. The Mi’kmaq Nation lives in Atlantic Canada as well as New England in the eastern USA.

Methods Themes were identified in the literature and through discussion with seven experts who have Mi’kmaq health and cultural research expertise. This paper has been reviewed and approved by two Mi’kmaq consultants who frequently speak on behalf of the Mi’kmaq people in relation to health and cultural understanding. Recommendations for non-indigenous care providers are presented.

Results The themes identified focused on jurisdictional issues and cultural understanding. They are interconnected and grounded in the historic Mi’kmaq context of colonialism. Jurisdictional issues experienced by the Mi’kmaq affect access, continuity and appropriateness of care. Cultural concepts were associated with worldview, spirituality, the role of family and community relationships and communication norms, and thereby with the alignment of values and language in the provision of care. Three Mi’kmaq concepts are noted: apiksiktatulti, nemu’ltus and salite.

Conclusion Through reflection on the situation of Nova Scotia’s Mi’kmaq, non-indigenous healthcare providers can assess how they might increase their cultural understanding in the provision of supportive and palliative care. Recommendations relate to the health system, relationships with individual persons and direction for research.
The themes that emerged are interconnected and grounded in the Mi’kmaq context of colonialism. The role of colonialism is included in table 2 but not developed further because it has been well documented by Twohig. The second theme is jurisdictional issues which relate to the three systems of support for the Mi’kmaq: federal, provincial and traditional indigenous. Third, cultural understanding is needed in relation to both values and language.

**Jurisdictional issues in providing palliative and supportive care for the Mi’kmaq**

The Canadian federal government has responsibility for the Aboriginal peoples. However, the delivery of health services in Canada is primarily a provincial responsibility. There are gaps and differences in services that are funded by each jurisdiction.

Supportive and palliative care have not been core services of Indian and Northern Affairs Canada (INAC), the department which has the responsibility of meeting the Government of Canada’s obligations for First Nations peoples through negotiations with them. Most Mi’kmaq communities have community health nurse(s) who are involved with families in providing care. Health Canada and INAC together developed a National Framework on Home Care for First Nations and Inuit communities using this definition: ‘a system of service delivery encompassing a range of insured, extended and uninsured health and social services for all age groups, addressing the wholistic, social and personal care needs of individuals who do not have, or have lost, some capacity for self-care.’ The INAC adult care programme can meet some supportive and palliative care needs. INAC may pay to provide care services including laundry, meals and housekeeping. To respect client

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal peoples</td>
<td>Indigenous people who have lived in Canada for thousands of years.</td>
</tr>
<tr>
<td>Mi’kmaq</td>
<td>First Nation people whose name roughly translates as ‘the family’. Oral tradition is important in the relational nature of the Mi’kmaq language.</td>
</tr>
<tr>
<td>Apiksitutultimik (pronounced abiskikaddimk)</td>
<td>A Mi’kmaq term used to describe when a person is thought to be dying, family and friends go to the bedside to partake in this act of mutually being present with each other which may include forgiveness or reconciliation. This has the intent of ensuring that the dying person will go to the spirit world without any burden while also preparing all involved for the inevitable.</td>
</tr>
<tr>
<td>Nemu’ltus</td>
<td>A commonly used Mi’kmaq saying which translates to ‘I’ll see you.’ It is mostly used as a form of goodbye, but is also used when someone is dying. The implication here is that death is not final. Life and death are events. Death is understood to be a verb since if it were a noun, it would be final. Life is also a verb as it is a process of living and of being alive.</td>
</tr>
<tr>
<td>Salite</td>
<td>Mi’kmaq feast after a person leaves this world. Feasts are common for First Nations peoples for closure after events. Usually the Elders are the first to begin the meal. This is a community event with everyone bringing goods for an auction. In the past, the Salite auctioned the belongings of the person who has gone to the spirit world. Today, community members bring goods to auction to help raise funds to pay for the wake and other expenses and debts the person may have had. Salite is an important aspect of care. It acknowledges the interconnectedness of the person who has moved on to the spirit world and the community.</td>
</tr>
<tr>
<td>Cultural competency</td>
<td>As a continuum, cultural competency encompasses sensitivity, awareness, knowledge, skills and competency. Cultural competency depends on provider efforts to understand unique aspects of indigenous cultures and is based on the premise that knowledge of cultural characteristics equips professionals to build trusting relationships and provide holistic care.</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Palliative care aims to improve the quality of life and care of patients and their families facing life-threatening illness through the prevention and relief of suffering by early intervention and treatment of pain and other physical, psychosocial and spiritual problems. In Canada, palliative care and palliative medicine are typically hospital-based and provincially organised. Palliative care developed in Canada during a time period when federal-provincial agreements provided public funding for hospital and physician care, and patchwork funding at best for community-based care. The role of the voluntary sector and the federal government is minimal in the delivery of palliative care in Canada.</td>
</tr>
<tr>
<td>Supportive care</td>
<td>Supportive care relates primarily to cancer services that help patients and families with their experience during the diagnostic, treatment, follow-up and palliative phases. It includes physical and symptom support as well as information, psychological and spiritual support.</td>
</tr>
<tr>
<td>Indian and Northern affairs</td>
<td>INAC is the Canadian federal government department with a mandate to fulfill constitutional responsibilities in First Nations affairs regarding the Indian Act which was established in 1867. Since 1949, matters of healthcare and First Nations have been directed to the federal department of Health Canada. INAC’s name was changed to AANDC in June 2011. AANDC is responsible for economic development and social well-being.</td>
</tr>
</tbody>
</table>

AANDC, Aboriginal Affairs and Northern Development Canada; INAC, Indian and Northern Affairs Canada.

**Table 1** Descriptions of terms related to providing Mi’kmaq supportive and palliative care

preferences, family members may provide these services. Personal care can include pain management, spiritual support and comfort measures, familial support and care planning related to disease as well as the settling of personal affairs. Personal care workers funded by INAC have some training in personal care.

The lack of extensive educational and employment opportunities for Aboriginal care givers reinforces marginalisation and results in female Aboriginal caregivers being disadvantaged socially and politically. Other issues include coping with the stress of physical illness, the role of the family in treatment and decision-making, financial burdens, transportation to health services and provision of support for emotional and spiritual health. A lack of quality housing is also recognised as a fundamental challenge in providing adequate home-based care.

The Mi’kmaq population is primarily rural and small. Therefore, choices are limited. Beyond INAC and Health Canada services, some communities have a relationship with a provincially funded palliative care programme to assist in managing pain and other symptoms. Each of the nine district health authorities across Nova Scotia operates a palliative care programme. While the Nova Scotia Department of Health and Wellness recognises the importance of cultural competency in the care of indigenous peoples at end of life, complexity is inherent in gaining a deep understanding of language.

### Cultural understanding in the provision of supportive and palliative care

#### Values

The lack of alignment between the values implicit in Western medicine and indigenous peoples is problematic. Cultural understanding can act as a bridge for understanding indigenous values such as the interconnectedness of the physical, social and spiritual dimensions of self and the impact this has on health decisions. Rather than being universal and unchanging, values differ, often subtly, by family and individual as well as from community to community.

#### Language

Acknowledging culture as a part of an individual’s healing process is vital to understanding health choices and preferences. The integration of spirit as a part of healing occurs through the inseparable interrelationships among self, family and community. Different world views, language and cultural contexts reflect the divide that needs to be bridged to attain cultural competency in the care of indigenous peoples at end of life.

### Table 2

**Themes emerging from a review of literature and discussion with informants on culturally competent supportive and palliative care for the Mi’kmaq**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Historic context of colonisation</td>
<td>It is critically important to recognise the role of colonialism in shaping policy and its impact on what services are available to Canada’s First Nation peoples. Unlike other parts of the country, there has been no land surrender in Nova Scotia. Continuity of care may be lost as individuals require care outside their community and move between provincial and federal services.</td>
</tr>
<tr>
<td>Jurisdictional issues</td>
<td>Continuity of care may be lost as individuals require care outside their community and move between provincial and federal services. Values: lack of alignment between values implicit in Western medicine and those of the Mi’kmaq culture can be problematic. Using a holistic health approach can act as a bridge for understanding indigenous values such as the interconnectedness of the physical, social and spiritual dimensions of self and the impact this has on health decisions. Rather than being universal and unchanging, values differ, often subtly, by family and individual as well as from community to community. Language: acknowledging culture as a part of an individual’s healing process is vital to understanding health choices and preferences. The integration of spirit as a part of healing occurs through the inseparable interrelationships among self, family and community. Different world views, language and cultural contexts reflect the divide that needs to be bridged to attain cultural competency in the care of indigenous peoples at end of life. Complexity is inherent in gaining a deep understanding of language.</td>
</tr>
<tr>
<td>Cultural understanding</td>
<td>Language: acknowledging culture as a part of an individual’s healing process is vital to understanding health choices and preferences. The integration of spirit as a part of healing occurs through the inseparable interrelationships among self, family and community. Different world views, language and cultural contexts reflect the divide that needs to be bridged to attain cultural competency in the care of indigenous peoples at end of life. Complexity is inherent in gaining a deep understanding of language.</td>
</tr>
</tbody>
</table>

The Mi’kmaq community approaches life in the context of a worldview which may include traditional medicine and an interconnectedness of physical, mental, spiritual and environmental well-being. Ruth Whitehead described the family in pre-European contact times as ‘the centre of the universe’ and emphasised the role of alliances created by birth, marriage or adoption as being priorities in life. The collective mindset that frames kinship is still a cultural imperative for the Mi’kmaq and characterises the role of family and community in a Mi’kmaq worldview. Consequently, family and community play a predominant role in ethical decision-making and confidentiality. The preferred process for leaving the physical world
is in the company of loved ones and choices are made with the family either involved or kept in mind.

Community preparation and participation in the journey to the spirit world is important. Wakes and funerals are commonly accepted as social gatherings where people converse openly, laugh, share stories and celebrate life which supports the tradition of strong family and community connectedness. Healing or prayer circles as well as ceremonial sweats are openly, laugh, share stories and celebrate life which supports commonly accepted as social gatherings where people converse.

Respect for handling sacred objects or personal belongings and knowing who can handle certain objects is important. A woman who is on her moon time (menses) should not touch sacred objects because women are believed to be very powerful during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.

Historically, coping with illness, bereavement and pain is considered acceptable when met with even-temperedness and suppression of grief rather than public displays of despair and inconsolable grief. Whitehead spoke of the value of patience during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.

Historically, coping with illness, bereavement and pain is considered acceptable when met with even-temperedness and suppression of grief rather than public displays of despair and inconsolable grief. Whitehead spoke of the value of patience during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.

Historically, coping with illness, bereavement and pain is considered acceptable when met with even-temperedness and suppression of grief rather than public displays of despair and inconsolable grief. Whitehead spoke of the value of patience during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.

Historically, coping with illness, bereavement and pain is considered acceptable when met with even-temperedness and suppression of grief rather than public displays of despair and inconsolable grief. Whitehead spoke of the value of patience during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.

Historically, coping with illness, bereavement and pain is considered acceptable when met with even-temperedness and suppression of grief rather than public displays of despair and inconsolable grief. Whitehead spoke of the value of patience during this time. Culturally competent advocacy on the part of healthcare providers is fundamental to providing care that is grounded in the understanding of this journey to the spirit world.

Healthcare providers can play a critical role in providing an environment that positively affects the individual and those in attendance at end of life by learning the values and beliefs of the individuals and families who are willing to accept their care.
Historically, care giving was defined within the context of reciprocity, and was often experienced throughout the lifespan. Today, there are differences in the availability of supports that exist on and off reserve which has led to changes in care, particularly around the role of the community in providing assistance and the role of family in providing respite care.

A sense of family, community and traditional views of spirituality frame the view of health among Mi’kmaq. There is a rooted belief in the strength of prayer and faith in its ability to cure as much as any intervention. More value may be placed on quality of life rather than on pursuit of a cure when life balance and wellness are a part of the holism that is ethically equated with mental, physical, emotional and spiritual health.

Aboriginal worldviews see health as more than a lack of disease. Health is linked to the economy, the land, community and culture. Emphasis on biomedical treatment through technological interventions may be associated with a colonial approach to health, while at the same time diverse perspectives regarding aggressive treatment and technology abound. A study reported that 66% of a sample of 100 Mi’kmaq patients with whom they are working, and to strive for an understanding of English, some Mi’kmaq may not speak Mi’kmaq individuals with whom they are working, and to strive for an alignment of values in the provision of care.

Language
The words that are used and a lack of common understanding of terms can lead to miscommunication and misinterpretation of needs and services. For example, terms such as home care, supportive care and palliative care are sometimes used interchangeably by federal and provincial service providers even though they may imply different ideas.

Language barriers also affect the understanding of care plans. Even if interpretation services are available, they may not be accessed because persons are not identified as having this need since the Mi’kmaq generally have some level of understanding of English, some Mi’kmaq may not speak Mi’kmaq or because interpreters may not be readily available. Furthermore, interpretation services may not adequately handle the nuances of Mi’kmaq terms and the wording used by non-Mi’kmaq healthcare providers.

It is important to note that traditional Mi’kmaq do not use the term ‘end of life’ since they view the present life as a continuum into a next life. Mi’kmaq terms, which are not well understood by non-Mi’kmaq care providers, are very relevant. Three of these (apiksiktatulti, nemul’tus and salite) are introduced in table 1. Mi’kmaq traditions associated with the journey to the spirit world are culture-specific and individually determined.

Beyond access to publicly-funded health services and historic Mi’kmaq ways of caring for each other, there can be an additional dimension. Jesuit priests introduced the Mi’kmaq to Roman Catholicism which remains important to varying degrees among the Mi’kmaq in terms of both values and language; for example, heaven may be the term used for the spirit world by some Mi’kmaq.

DISCUSSION
By separating and reflecting on the issues of jurisdiction and cultural understanding, progress can be made toward greater cultural competency. Inclusion of indigenous ways of knowing about health is critically important for ensuring cultural competency. Non-Aboriginal healthcare providers often discuss and provide supportive and palliative care from a Eurocentric approach either due to lack of knowledge or lack of system support to provide culturally competent supportive and palliative care. Cultural competency transcends cultural understanding. It includes ensuring that the healthcare system is inclusive of different worldviews in the planning, implementation and evaluation of healthcare services.

The authors recommend that indigenous leaders undertake a more indepth study of supportive and palliative care needs in their communities by using an integrative framework to guide this research. This paper demonstrates the need for understanding across conceptualisations and is in accord with the report of the Canadian Hospice Palliative Care Association, which advises building on strengths and working together to improve Aboriginal hospice palliative care.

The authors recommend that consideration be given to having palliative care researchers work with the Mi’kmaq using research processes that respect the community. The purpose would be to explore how current perspectives on palliative and supportive care might be enhanced or reconstructed through a greater understanding of the Mi’kmaq ways.

CONCLUSION
The identification of both juridical issues and cultural understanding in the historic context of the Mi’kmaq is important for enhancing the cultural competency of non-Mi’kmaq care providers. Best practice indigenous supportive and palliative care may be contrary to conventional Western healthcare assumptions and practice. Through reflection on the situation of Nova Scotia’s Mi’kmaq, non-indigenous healthcare providers can assess how they might critique and increase their cultural competency. This paper will hopefully raise awareness of the need to more broadly understand and incorporate an indigenous cultural context when providing supportive and palliative care.

Acknowledgements The authors thank and acknowledge the following for sharing their insight, understanding and guidance in the preparation of this manuscript: Theresa Meuse, Mi’kmaq educator, advisor and author; Sister Veronica Matthews, retired Aboriginal nurse and Mi’kmaq Elder; Charlotte (Loppie) Reading, Human and Social Development, University of Victoria, and formerly School of Health and Human Performance, Dalhousie University; Peter L Tヴohig, Canada Research Chair in Atlantic Canada Studies, Saint Mary’s University; Angela Robinson, Social/Cultural Studies, Anthropology, Sir Wilfred Grenfell College, Memorial University; and Ruth Whitehead, Curator Emerita, Nova Scotia Museum.

Contributors GJ was responsible for overall conceptualisation of the paper and guidance especially in relation to palliative and end of life care for vulnerable populations as well as critical reflection, interpretation and editing. AV advised on Mi’kmaq information sources, conceptualisation and design, and assisted with the critical review, understanding of the Mi’kmaq culture, liaison with Mi’kmaq consultants and editing of the manuscript. SP carried out the initial literature review and meetings with strategic informants, prepared the first draft of this paper and contributed to revisions. All authors contributed to the literature review and have read and approved this final manuscript. GJ and AV jointly are the guarantors for the content of this paper based on their respective areas of expertise and through ongoing consultation with two Mi’kmaq consultants.

Funding This report was carried out with support from a Canadian Institutes for Health Research Interdisciplinary Capacity Enhancement for vulnerable populations grant number FRN-80087.
Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES