

Ian Anderson Continuing Education Program in End-of-Life Care

Module 10

INDIGENOUS PERSPECTIVES ON DEATH AND DYING



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Case Scenario

Mrs. Susan Nahdee is a 78-year-old traditional Ojibway woman. She has a history of non-insulin dependent diabetes and coronary artery disease. She speaks little English and is always accompanied by her daughter each time she visits you. She presented 2 days ago to your small community's hospital clinic quite short of breath. Through her daughter she admits to a four-day history of chest pain typical of her usual angina. Your physical exam reveals she was in congestive heart failure. You admitted her and investigations revealed that she likely had an acute myocardial infarction a couple of days ago.

While in hospital, she continues to worsen---it is difficult to diurese her and she remains quite dyspneic on lasix 250mg IV bid and metolazone 10 mg po bid. She develops more chest pain and becomes hemodynamically unstable.

It is becoming clear to you that Mrs. Nahdee will need to be transported to a larger hospital and, if she does not start to diurese soon, she will need to be placed on dialysis and possibly life support. Unfortunately, it is winter and the roads are snow covered and very icy.

You pull Mrs. Nahdee's daughter aside and start to tell her that her mother is having another heart attack and that you feel she needs to be moved to another hospital. She will likely need life support and you are not sure if she will survive....

Mrs. Nahdee's daughter listens to you. Not once does she look at you. When you ask her want she "wants to do", you are met with silence. Thinking that she either is in shock or maybe did not understand you restart the explanations somewhat impatiently since time is running out and a decision must be made SOON.....

Introduction: Life and Death

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.

The story of indigenous peoples in North America for the past three centuries has been all about survival and adaptation. Traditional cultures have survived, though they have also evolved, like any other culture. "Survival" is the appropriate term, since such concerted efforts were made by a powerful combination of state, church and economic forces to dispossess the people of their land and their beliefs.

The story of indigenous peoples in North America is also one of great diversity. It would be as wrong to suggest that there is a single "African" or "European" culture as it would be to declare that "Native American" cultures all believe the same things. Generalization is possible only in the broadest terms. In Ontario and Manitoba, there are two strong, surviving, quite distinct traditions.

The Haudenosaunee – the People of the Long House – are also known as the Six Nations Iroquois Confederacy. Their tradition is of villages and towns, of gardens and fields, and of a complex government under the Great Law of Peace. The Anishinabek – a term which can include the Ojibway, Odawa, Potowatomi, Saulteaux, Cree and Oji-Cree – bear traditions of smaller communities, more hunting and fishing, and more than three centuries of association with the fur trade.

Though traditional religious beliefs have survived, Christianity is the dominant religion in many communities. Missionary efforts, voluntary conversions, and intermarriage have all been factors in the shift to Christianity. Many communities include people of several faiths or creeds. In most communities, traditional beliefs have also survived. In some cases, they stand as organized ways of "religion" in their own right (though Longhouse people in Haudenosaunee communities prefer to call their path a "way of life" rather than a "religion"). In other cases, people maintain some aspects of their traditional beliefs while respecting Christian ways. Even in the most Catholic communities, traditional ways have survived and are enjoying a resurgence – especially after the Pope, in his visit to Penetanguishene in 1984, participated in a mass which included a sweetgrass ceremony and blessings in several indigenous languages.

This module is not about aboriginal peoples' Christianity: it is about their traditional beliefs about the paths and meanings of dying and death, and how "modern" medical practice can seek to understand, respect and accommodate them. The first step for the medical professional, though, is to recognize that "tradition", today, is not easily measured, and appears in shades of grey rather than black and white. Don't assume that a person is "traditional" just because the person is aboriginal; don't

assume that a Christian aboriginal person will bring attitudes toward death and dying that a European parishioner would share. A time of grief and bereavement is not time for the medical professional to receive a crash course in traditional beliefs and practices, and no time for the family to want to teach such a course.

This module describes traditions, as they are practiced today. You will be able to recognize aspects of them, ask about them tactfully, and accommodate them respectfully, if you know some of the basic beliefs and practices.

Your sensitivity, degree of empathy, and skill at questioning to retrieve the required answers will determine how well you will interact with the patient and family to provide end-of life-care. This module is intended to assist you in communicating with indigenous patients and families and in accommodating your institution to traditional indigenous dying ceremonies.

Objectives

- 1. Describe differences in culture, traditions and beliefs that may affect communication with Indigenous people at the end of life
- 2. Demonstrate knowledge about the traditions surrounding death and dying in Indigenous cultures
- 3. Describe how such traditions can be accommodated when caring for dying Indigenous patients

The Circle of Life:

An Anishnabe (Ojibway) Perspective on Life and Death

Birth In order to understand death, one must first embrace the circle of life. Birth, life, death and afterlife are four stages of the journey of the human spirit. The creation stories of the respective nations outline where we originated and how we came to our place on Mother Earth. The stories also speak of our "original instructions", laws, and codes of conduct, which govern our responsibilities to each other and to all aspects of the natural world.

We Came From The Stars: Origins

The Anishnabe Creation Story (see appendix 1) provides a meaningful view of the beginning of life on earth, the first human being, and original laws and responsibilities for all creation.

Creation stories provide a legacy of relationship with ancestors from the beginning of time to the present. Each of us is born with a spirit, a sacred name, a clan or nation, a set of beautiful gifts or talents and a destiny in which we will face many challenges. End of life ceremonies reflect a traditional person's name, clan, nation, and accomplishments, such as membership in a medicine society. Knowing where we come from helps us understand our purpose here on earth as well as our eventual destination when our spirits leave Mother Earth.

Life We are spirit having a human experience. We are made up of three parts: spirit mind, and body. As we are born, our spirit leaves the Creator and the spirit world, complete with its information containing innate gifts, talents and destiny. Spirit enters the baby's body and life begins. The child enters four stages of life: childhood, youth, adulthood, and elder years. During the lifetime, each person's challenge is to find the Creator, celebrate the Creator and be of service with one's gifts to one's people, to all of humankind, and to all life in Creation.

In this effort, we are challenged, experience failures, confront our weaknesses and embrace healing and spiritual training through the lodges, societies, and ceremonies of the nations. The nature of the spiritual training truly imprints the identity of the individual through adulthood and the elder years. Ceremonies, both individual and community-based, form a significant part of an individual's life.

Death At the point of dying, a traditional person will call for the ceremonies, medicines, and prayers that will guide his or her spirit from the physical world to the spirit world. A spiritual leader or medicine person close to the dying person will be called in to conduct end of life ceremonies. Family and perhaps clan members will be present. Specific ceremonies for a Chief or titled person of the nation are more complicated. Claiming and dressing the body, and the funeral rites, become similar to a state funeral, reflecting the person's service to the people.

"Medicine", in this context, does not mean "medication" (though the person may have knowledge and ability in both herbal and spiritual healing). It refers to spiritual power – a combination of ability and authority – which is often linked to an ability to advise and to heal.

For people involved in tragic accidents, the unconscious, heart attack victims, and others who are not fully aware, the family members take over responsibility for the ceremonies that are the same, but at their discretion. At the point of death, it is said that our original mother, Mother Earth, who nourished our bodies, reclaims our physical forms. Our original father, the Creator, takes our spirits, to return them to their place of origin.

Afterlife The spirit can be seen and felt leaving the body. It travels westward across prairie grass, over a river and into the mountains. It ascends the mountains to the high clouds where a bright light guides it to a place where loved ones wait to embrace it. The spirit lives forever. It takes its place in the spirit world according to

the deeds completed on earth. The spirit completes its journey in the cycle of life to return to its place of origin.

The general view of the spirit world as understood by Iroquois and Ojibway people begins with acknowledging that there is a Creator. In Mohawk, the Creator is called Sonkwaiatison – "he made our bodies". In Ojibway, the Creator is called Kitche Manitou, which is usually translated as "the Great Spirit".

Anishinabe elders say that the Creator is neither male nor female, but a powerful, all-loving, all-knowing spirit who holds all power, all medicine, and all wisdom. The Creator is aided in his work by our Ancestors and Warriors, both men and women, who walked before us, and by spirit beings called Grandmothers and Grandfathers. There are four levels of the spirit world where the helpers of Creator work each day and night to teach us, heal us, guide us and help us plan our ceremonial life. They are directed by the Creator to do the following work.

The **first** level closest to the Mother Earth contains Creator's spirit helpers who bring us dreams. The dreams can teach us or warn us of future events. The **second** level holds spirit helpers who teach us and appear in ceremonies. Visions, by day and by night, often show us these helpers and the messages they carry. Spirit helpers in the **third** level act as consultants to assist us in planning healing ceremonies. They also warn of possible sources of trouble. The Spirit helpers of the **fourth** level are healers. In healing ceremonies, these spirits enter the lodge and the body and bring messages of how to go about the healing; they provide an understanding of the medicines that are needed.

The death of the body allows entrance into the world of spirit. Beliefs about this are similar in many traditional indigenous cultures. Special songs, prayers, speeches, medicines, and repentance rituals clear the earthly pathway so that the spirit can leave the body to travel to the sky world.

Anishinabe Ceremonies: Preparing to Die

The nature of ceremony and its practice varies from community to community. The type of Anishnabe ceremony presented here is a prototype, a guide to the kinds of things that the hospital, staff and physicians can expect when faced with a dying patient of traditional Anishinabe background. Many ceremonies are specific to the spiritual leader/healer who carries them. He or she has earned the gift and the right to perform particular ceremonies.

Pipe Ceremony

A medicine bundle containing a pipe and other sacred items is brought to the bedside of the dying person. Sacred tobacco and offerings of food and cloth are essential elements of this ceremony. In the pipe ceremony, the patient repents or makes right his relationship with the Creator. All those present pray to the Creator for safe passage of this spirit to the sky world. The Ancestors are invited to help guide the spirit of the dying person in its travels. Sacred medicines are burned (sage, sweet grass, cedar, sweet flag, diamond willow fungus) to purify the dying person, all family members and all others present. Family members will burn the food offerings and cloth outside the hospital in a fire pit or at home in a sacred fire. The family, clan members, and friends will keep vigil over the dying person to bring comfort, pray together and ease pain until the spirit leaves the body. Sacred songs are sung and family members each have an opportunity to each speak to the dying person.

The central item in many medicine bundles is the sacred pipe. Its bowl represents the woman; the stem represents the man. When they are brought together, life unfolds. Sacred tobacco is smoked in the pipe. Each time the pipe is raised, it is a celebration of life and all creation under the Creator. The Creator's guidance is asked for. Messages received through a pipe ceremony can be shared. For the Anishinabek, the most sacred tool of communication with the Creator is the pipe.

Preparing the Patient to Die

Primary The dying person needs to have privacy either alone with the spiritual leader or with the family present. In these teaching ceremonies, the patient hears about the love of the Creator, the nature of the spirit world, and the transition of spirit from the physical world to the sky world. Not only does the patient receive encouragement, strength, and support, but also the spiritual leader's role is to listen to the dying person's stories of life, dreams, visions, fears, regrets or guilt. The dying person's mind must be cleared of the negative force through prayer, smudging, pipe ceremonies and sacred songs. With a good mind, the patient can receive the teachings and prepare to proceed to the journey of the spirit.

Secondary Outside the hospital, family and clan members can perform supportive ceremonies at the sacred fire, prayers in the purification lodge, and also tend ancestor fires with the ancestor pipe and bundle. The sacred fire is a very special ceremonial tool central to the practice of ceremony. It is the source of communication with the Creator where all spirits, warriors and ancestors travel to the earth world and bring the will of the Creator to heal, teach, correct or protect human beings. The spirits also carry the prayers of the human beings made at the fire directly to the Creator. Visions, answers and guidance flow from the fire to the people. The fire was the first way that people had of keeping in direct communication with the Creator. Offerings of tobacco, cloth or food can be made at the fire on behalf of the dying person with a request for a safe journey to the spirit world.

The purification lodge, also commonly called the sweat lodge, is a beautiful, powerful spiritual experience. The lodges are called gifts from the Creator: they allow people the opportunity to purify, detoxify and heal in the presence of the Creator's power and love. Many kinds of healing are accomplished in the lodges: emotional, physical,

mental and spiritual healing. There are family prayer lodges, separate doctoring lodges for men and women, and lodges where men, women and children will gather to make special prayers for a particular purpose.

In the case of assisting a dying person, the lodge will likely be a family prayer sweat, where family members will go to pray, to let go of negative feelings, gather their strength, and make prayers and offerings for the dying person. For someone who has already passed on into the spirit world, the sweat lodge is called a journey sweat or a traveling sweat. The family can gather here to pray. Their prayers and offerings assist the spirit journey of their loved one.

The ancestor pipe bundle is a sacred bundle used to communicate with the Creator, Mother Earth and the spirits of the ancestors. The pipe has a black bowl and the stem is white, indicating this world and the spirit world, respectively. Each time the pipe comes out for use there must be food, tobacco and cloth offerings. Usually, an ancestor fire, similar to the sacred fire but with some technical changes, accompanies the use of the ancestor pipe. Thus, the need for a fire pit on or near the hospital grounds is strongly recommended.

Some spiritual leaders may do a pipe ceremony with the dying person, or they may do an ancestor pipe ceremony to ask the ancestors to assist the spirit on its impending journey to meet the Creator. Each spiritual leader will have his or her preferred way of doing things, based on their particular gifts, teachings and spiritual training. The spiritual leader will make known to the family the procedures that he or she intends to follow and will indicate the family's responsibilities to prepare offerings.

The ancestor fire is also, like the sacred fire, a direct line of communication with the Creator, Mother Earth and the ancestors. The offerings to the fire are similar to those accompanying the ancestor pipe.

Both the ancestor pipe and the ancestor fire are very important ceremonies demanding a high level of spiritual knowledge and capability, so as not to upset the balance in the spirit world.

Tertiary Funeral rites are determined by the family, clan and nation according to the duties/position that the deceased occupied in life.

Funeral ceremonies are specific in nature as to the claiming of the body, cleaning the body, dressing the body and conducting each section of the rituals at home and in the ceremonial lodge.

A spiritual leader will usually be present at the claiming of the body, to speak to the spirit and the body. The family may or may not choose the services of a funeral home. In any case, the body will be cleaned and dressed either by the funeral home or by the family and clan members.

Funeral rites will be conducted in the ceremonial lodge by the elders and spiritual leaders associated with the tradition.

As the body is led to the cemetery, the old tradition of placing it in a horse-drawn carriage is returning. The spiritual leaders, chiefs and eagle staff carriers walk behind the carriage to the cemetery. In many communities, as the funeral procession in vehicles makes its way to the cemetery, all other non-associated vehicles on the road stop and pull over to show respect for the grieving families.

It is also common for the close family members to hold a 24-hour ancestor fire for their loved one on his or her birthday. This ceremony honours the memory of the loved one and helps family members, especially children, to understand that they are the most recent in a long line of ancestors leading back to the beginning of time when the Creator placed the first man and first woman on earth. A Death Feast always accompanies this Ancestor fire.

Preparing the Family for the Death of a Loved One

Primary The spiritual leader will bring a medicine bundle into a meeting with the family. He will listen to the fears, worry, dreams, or visions of family embers. He will help the family begin the process of grieving by letting go of their loved one. In this process, the spiritual leader will provide an understanding of death, afterlife, the spirit world and the Creator. He will encourage, strengthen, support, and provide a positive "good mind" to the suffering of the family. Hospital based ceremonials help the grieving family move from anger, fear, guilt, remorse or internal division to expressions of love, acceptance of fate and peace. Pipe ceremonies, medicine songs, smudging and offerings help strengthen the spirit of family members and help the family to be mutually supportive at this difficult time. Both men and women are spiritual leaders, medicine keepers, lodge conductors and so on. Sometimes men and women will work together with family members and the dying person to bring balance to their ceremonies.

Secondary There are ceremonial activities in which the family can participate outside the hospital. They include the ancestor fire, the purification lodge, the sacred fire, doctoring ceremonies and the Ghost Dance.

Healing ceremonies include the pipe ceremony, special medicines and sacred songs; these work together to heal the spirits and hearts of the family members. Sacred messages of comfort and courage come from the pipe. In those ceremonies, the Creator's spirit messengers enter the lodge and bring messages, dreams and visions. They lift grief from the heart, confusion from the mind and they heal the physical effects of grief. The ceremonies can be held in the home, in lodges, or in

the hospital depending on the agreement of the spiritual leader for the location where he or she is most willing to work.

The healing ceremonies are very important to help family, friends and clan members in letting go of the spirit of the deceased. If the grieving cycle is not complete the grieving person may walk through life emotionally wounded or mentally challenged as life progresses.

The Ghost Dance is an annual ceremony that is usually held in the fall when the leaves have fallen from the trees. It is conducted at the full moon for four nights from sunset to sunrise. It is a community celebration of the ancestors. Four nights of dancing and fasting occur. Special offerings of cloth, tobacco and traditional foods are given to the ancestors to thank them for their prayers for the people in this world and to show them that they are remembered, and that the people still do their best to honour them and live a sacred way of life as they did.

Many people attend this ceremony to re-establish the connection with their ancestors and to renew their responsibilities to honour their ancestors through ceremonial practice. By doing so, dancers earn the assistance of those ancestors which is especially needed in times of sickness, accidents or death.

The Ghost Dance is a communal gathering. Teachings are given by the Elders and the spiritual leaders with each evening. They admonish the dancers to always remember their ancestral lineage, and to understand that we are the sum total of all that our ancestors represented. Prophecies, markings on land, petroforms, rock carvings, rock paintings, star formations are all spoken of with the deepest respect because the ancestors have left them so the people can be proud of their identity, and understand these for the future.

Many dancers have visions of the ancestors and their loved ones at this ceremony. The departed loved ones come to the lodge to receive their gifts, food offerings and love of the people. This lodge is a powerful tool in assisting those who are still grieving. Many spirits visit the lodge to provide answers to hearts still filled with pain or loneliness.

This ceremony is practiced in parts of northern Ontario and not yet in the south. It is common in southern Manitoba and Wisconsin.

Tertiary Funeral rites are directed by the family, clan, and nation. They take a variety of forms and are usually four days long. There is a wake in the home where sacred songs are sung; a feast is offered and family members keep vigil over the body all night and all day. Funeral ceremonies are held in the sacred lodge and are conducted by the Elders, spiritual leaders and speakers.

The Sky World:

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Haudenosaunee (Iroquois) Perspectives on Life and Death

Birth, life, death and afterlife are integral aspects of Haudenosaunee cosmology. In order to understand death and to accept the journey to the Sky World, it is crucial to understand the origin of life, its laws, codes of conduct, challenges and consequences.

The Haudenosaunee Creation Story (see Appendix 2) provides deeper insights into the beginning of life, the first human beings, and all aspects of creation. It defines the relationships between all life on Mother Earth to the spirits in heavens and the beings in the Sky World.

Richard Hill, a Beaver Clan Tuscarora, and Peter Jemison, a Heron Clan Seneca, prepared a paper on "mortuary practices", mainly to explain Haudenosaunee beliefs to museums in the context of the repatriation of human remains. They explain:

There is a great universal contest between the upper world of benevolence, and the lower world of disarray. Humans have to negotiate between these spheres of influence both in life and death. Upon death, there are spirit forces at work that try to disrupt the long spiritual journey of the soul back to the Sky World. As a result, the Haudenosaunee believe that the dead have power and it is considered very dangerous to neglect the spiritual needs of the dead. The souls of the dead have a path of destiny that they must follow. The Haudenosaunee refer to this as their journey after life.

A special annual ceremony is held called Ohgiwe, or the All Night Dance or Dance of the Dead, whereby we please and feed the lingering spirits of the dead. Respect for the dead must be shown at all times. It is important to know that the Haudenosaunee believe that when this ritual is performed, the spirits of all dead Native Americans, from across the entire Turtle Island, are believed to join in with them. The Haudenosaunee extend their cultural affiliation and spiritual obligation to each other. With the dead, we do not believe there are any tribal, language or cultural barriers that separate them from us...

According to Haudenosaunee beliefs, when a person dies, their breath of life is taken by the Faceless One, the destroyer who brings death. However, the spirit of the individual takes a number of days to get used to the death of the body and prepare to take its journey skyward. Ceremony and culturally based practices have developed to assist the spirit on that path, which is said to be the Milky Way. The association of stars with souls or spirit shows an affinity with the cultural world view of the Haudenosaunee. When a human dies, the Grandmother Moon obtains some of their hair. One hair detaches itself and comes directly to her. This is the sign that someone has died in the lower world and has begun the journey to the Sky World. She then weaves this hair into the mantle. Grandmother Moon explained: "Moreover, mark this well, that when He shall cause the death of human beings on the earth below, it shall then and not before be possible for me to finish the mantle on which I'm working; and the number of hairs in this mantle will then bear witness to the number of persons who have visited the earth below while it lasted" (Taken from Jeremiah Curtain and J.N.B. Hewitt, Seneca Fiction, Legends and Myths, Smithsonian Institution, Washington, 1918).

This means that birth and death are connected, as the Grandmother Moon also has domain over the fertility of women and when children are born into this world.

The Haudenosaunee came to understand that humans have a "soul" that has its own destiny after death. The soul is different from the life spirit that makes the body alive. Huron Miller (an Onondaga subchief and elder) does not like to use the word "soul" because of its connotations in the English language. It should be seen as the inner life force that was given to the body by the Creator. It is his breath that brought life to the first humans, and as long as we breathe air, that life force continues to exist. When we die, the life force leaves our body. When life leaves the body, the life force/soul generally does, but it may linger for ten days, necessitating a feast to send it on its way back to the Sky World.

The life force/soul is like a light or vapor, or can be seen as a body without substance. These force/souls retain their personal identity and may inhabit other forms of life. The soul may also leave the body while a person is alive, and go to any place to acquire knowledge. Such knowledge is then revealed to the person in the form of dreams.

The Creation story sets up the desire to have the spirits of the humans return to the House of Souls in the Sky World. There are three aspects to this process:

- a. The deceased in the Sky World were placed in a tree.
- b. The first person to die on the Turtle Island was dismembered, her body was buried, from which life-giving plants grew; her head was first placed in the upper bunk of the longhouse, then high in a tree, and eventually up in the sky, where it became the moon.
- c. The first humans, the ongwehonwe, copied the practices of the Sky World and placed the dead in a tree.

There is a House of Souls in the Sky World where all the souls of humans come from, and return to. Each soul has its own path, leading from that Soul House, to the body, to the Great Sky Road (Milky Way), which is the good sky path. Another sky path is for the evil souls and leads to a place halfway between the earth and the Sky World. Ga-do-waas lives in the upper sky, and has four eyes to watch the four corners of the turtle island. He once lived on earth, but began to destroy all of the game, so he was transplanted to the gate through which all souls must pass if they want to complete their journey to the Soul House. He had a powerful hunting belt that had the power to attract game, upon which he paced stars and cast into the skies. The star belt provides light for the Sky Paths. Light from the belt also casts to the longhouse of the dying to guide the departing soul away from the body. These light rays are visible only to the soul.

The South Wind accompanies the soul until it reaches the gate where Ga-do-waas lives. As their soul passes this portal, Ga-do-waas reaches into the sky and adds another star to his great star belt that will guide the soul on its journey. When the soul crosses the entire sky, he removes the star from his belt and returns it to its place in the sky.

The souls that are at peace travel back to the Sky World by way of the Milky Way. There they enjoy a pleasant eternal abode with the other souls. Along that journey, flowers, lights, pleasant smells, refreshing water springs and sweet strawberries can be found. Souls of those who died restless are forced to repeat painful tasks that are symbolic of the misdeeds perpetuated in life. The souls of the dead are thought to have power to affect the living great respect must be show to the dead and the souls of the deceased need to be cared for.

Haudenosaunee Ceremonies

Preparing to Die

To the Haudenosaunee, death is a natural transition from the physical, earthly world to the sky world. It is the responsibility of the patient to make known his wishes to family, friends and medical teams before death, so that the appropriate ceremonies can be prepared. The ceremonies are as much for the grieving person as for the person who is preparing to die. Ceremonies provide comfort, ease pain and bring families together. It's advisable that ceremonies not be left to the last minute as a last option, but be an integral part of life.

Speaker of Sacred Words

In this context, a "Chief" is one of the traditional chiefs of the Iroquois Confederacy, not an elected leader of a band council under Canada's Indian Act. Traditional chiefs – *rotiianeson* (the term means "men who are of the good", a reference to their good mindedness, and their essential niceness) bear the burden of being mentors to all the people, as well as maintainers of ceremonies.

In the best case, the dying person will have passed through some ceremonies at home before going to the hospital. Special speeches are said by the Chief or speaker at the bedside which effectively release the dying person's spirit from duties

on Earth and gives sanction to the spirit to move on to the sky world. The chief who will give the speech will be from the opposite moiety of the dying person.

In traditional Haudenosaunee society, each person has a clan derived from their mother except in special circumstances. In the ceremonies, the longhouse is divided into two parts, which anthropologists have called "moieties". Much of Haudenosaunee tradition, including law and government, reflects the essential "duality" of the world. There is male and female, light and dark, old and young, good and bad. When a person dies, the world is also divided in two, between the people whose minds are grieving or clouded, and the "clear-minded ones", their friends, who carry the obligation to first respect and make room for the grief, and then to raise up the minds again. Thus, a "clear-minded person" from the opposite moiety is the one who is responsible for reminding the family that life goes on, that one can let the spirit of the deceased person go on its journey.

The speeches indicate that all the dying person's cares and wishes will be looked after. In this way, the dying person can have a clear mind unburdened with worry and can go to the hospital to die peacefully. The home ceremony involves the burning of tobacco, the speeches, a repenting ritual, the releasing of spirit and comforting the family. The ten-day feast, which follows after the funeral rites, ensures that the last wishes are fulfilled. In past centuries, grieving could continue for years and could lead to a thirst for revenge. The laws and ceremonies that uphold the peace of the Confederacy place a maximum limit on formal grieving: after ten days, a feast is held to help the spirit on its journey.

A private room set aside specifically for this ceremony at the hospital is also a possible alternative especially for traditional people who are suffering from cardiac arrest, accident trauma, coma or other emergency threats to life. In these emergency cases, one of two options are available. A ceremony can be done at home using one of the person's shirts or blouses. Then a visit can be made to the hospital by the Chief or another family member to comfort the grieving ones He will take with him a small portion of the food that was used in the ceremony. The ceremony that is done in the home community also has the power to be effective and need not necessarily be done in the hospital.

If the family chooses the second option, a ceremony can be done for the dying person in the hospital in a private room, attended by family and clan members and the Speaker for the speeches. In each of these three different cases, the purpose of the ceremony is to acknowledge that one's spirit lives forever and will return to the Creator. The body will return to Mother Earth, our original mother and life sustainer. The Speaker will address the spirit of the dying person before it leaves the body, to tell the body and the spirit that they are going home. The person is released from earthly duties at this time. The spirit is addressed at the hospital bed after death. The spirit will also be addressed as the undertaker takes the body; usually the speaker is the same in both locations.

It's important that the body be brought to the place where he/she lived because the mind will still be with the family, and the people at home. The body is cleaned, washed and traditional clothing is put on. The wake, at the family home, is conducted by a speaker who addresses the family and guides them in beginning new relationships with one another now that the dying person has passed on. The funeral is conducted at the longhouse, where the speaker speaks to all the assembled people. At each step of the way from the hospital bed to the home, to the wake, and funeral rites, the speaker helps guide the loved one and the family on a spiritual journey and new relationships.

Allocating a room for these last ceremonies for a dying person will bring comfort, relaxation and privacy, especially to grieving families. It is important to make a spiritual connection to the person suffering in the hospital. It is also important that the room can be used for healing as well – it should not be only a "death room".

Spirits – especially unhappy, angry or confused spirits – often linger in places where they were disconnected from the body. A place of death is therefore sometimes seen as a place of bad luck, of continuing misfortune or illness. Some people are also concerned that the last users of the place might not have done the ceremonies properly, or that the person's death may have cast a negative pall on the room itself. It is bad enough that the hospital is sometimes seen as a place one goes to die – it would be worse if the room the hospital set aside out of respect for traditional beliefs were seen to be associated with negative power. The best practice is to understand and plan for this beforehand: discuss with spiritual leaders what the room should contain, how the hospital staff can help, and what can be done to purify or restore the room after a death, and to protect the room between uses.

The chiefs or their representatives could play an active role in a training program with hospital staff, doctors and nurses in health care facilities near Haudenosaunee territories. i.e. Toronto, Hamilton, London, Kingston, Cornwall, Parry Sound, Brantford, Ottawa and Niagara Falls. An understanding of procedures and ceremonies on both sides would help avoid any misunderstandings during the difficult times. Their guidance is crucial to setting the appropriate community-hospital relationship.

Funeral Rites

Richard Hill and Peter Jemison explain Haudenosaunee funerals as follows:

At a traditional funeral among the Haudenosaunee, the speaker will tell the assembly that the deceased is still among us but is about to begin a long journey on what is called the "spirit world path of the deceased". This is why many items that were placed in the older graves as the belief was that we will need all the things along that journey that we use in this life. Tools, utensils, medicines and weapons would be critical to the success of that other journey...

Often the speaker will say: We have now returned the remains to the earth, which the Creator made to create the Original People. So the remains shall be returned to the earth, our mother.

Neglect for feeding the spirits of the dead can cause illness to the living. A special Death Feast is offered for the departed relatives...

The clans are important in many ways, especially during the funeral of a relative. When death occurs, the immediate family and the clan go into mourning. The clans from the opposite moiety are supposed to step forward to conduct the wake and funeral. Ten days after the funeral a feast is held to distribute the personal property of the deceased and to send them on the final journey. During the month of March most longhouses have a special dance dedicated to all of the dead to assure that they are properly taken care of in death.

The mother of a young man was heard to say these words at his funeral:

"My son, listen once more to the words of your mother. You were brought into life with her pains. You were nourished with my life. I have attempted to be faithful in raising you. When you were young, I loved you as my own life. Your presence has been a source of great joy to me. Upon you I depended for support in my declining days. I had expected to gain the end of the path of life before you. But you have outstripped me, and gone before me. Our great and wise Creator has ordered this. By his will, I am left to taste more of the miseries of this world. Your friends and relatives have gathered about your body, to look upon you for the last time. They mourn, as with one mind, your departure from among us. We, too, have but a few days more, and our journey shall be ended. We part now, and you are conveyed from our sight. But we shall soon meet again, and shall look again upon each other. Then we shall part no more. Our Maker has called you to his home. There we will follow".

There are certain activities that now happen during the wake of a family member in a traditional funeral. It is common that the wake is held in the family home. A speaker will address the family and guests as well as the body of the deceased. A midnight "lunch" is held to help appointed friends from the opposite clans stay awake. They are asked to remain with the body at all times until the actual burial. It is thought that the spirits of the dead are still around and could return to take someone with them, so special precautions must be shown during the period of the wake. The bowl game, dice game or a guessing game might be held during the wake as well to help the attendees stay awake, but also to help recall the struggles in life. The moccasin or glove game is a guessing game, where two teams play against each other to guess which moccasin or glove has a stone or marble in it. Each team takes turns trying to guess, by using a long cane as a pointer, as the opposite team sings special songs. For each successful guess, a short stick is given to keep a score. When all fifty sticks are obtained by one side the game is completed.

There is an address given at the Longhouse funeral, called Aweyendo Gawennotago in Seneca. It is similar to the Condolence offered for a deceased chief, and helps the family deal with their grief at the loss of a loved one.

Ten days after the death of an individual, a special feast is held to release the soul from the earthly bonds. Food is offered to the extended family, those that helped with the wake and funeral, as well as the spirit of the departed. Tobacco is often burned to say goodbye and encourage the spirit to make its way on the next part of the journey. The spirits of the dead are thought to travel to the Sky World by way of the Milky Way. The stars are like the footprints of the thousands of ancestors who have passed on.

Every March, the Longhouse holds a communal ritual to honor all of the dead relatives of the community. A special dance called Ohgiwe is held. A women's society conducts this ritual.

Seneca oral history speaks of the wanderings of an unsatisfied soul who needs human intervention to make things right. In doing so, humans learn a critical lesson of life and make the world more enjoyable for future generations. The ceremonies are ways in which the living people fulfill their responsibilities to the ancestors who have passed on.

Accommodation in the Hospital Setting

Visitors

Canadian hospitals are used to coping with the nuclear family, not the extended family. There are good administrative and medical reasons for this. Rooms tend to be small, and are often shared. The last thing a hospital needs is large numbers of visitors exposing residents and patients to additional diseases. During the past two decades, though, the large numbers of immigrants from places where the extended family is the rule have forced hospitals to adjust to family demands. The adjustment has not been easy, either for the families of for the hospitals. A rule that allows only immediate family members to visit is likely to offend members of the clan and extended family, some of whom have an obligation to assist, or to stand vigil. Even in situations where a person is not dying, you should expect many visitors.

As a matter of practice, if possible, a dying indigenous patient should have a private room, close to an entrance, so that the many visitors will not disturb other patients, and so that the family will have privacy as well as access. The same family members will likely be present at death and therefore at the dying ceremonies.

Room Allocation and Smoke

A room should be designated within the hospital for ceremonial purposes, much like the chapel is set aside for religious purposes. The room should be big enough to comfortably accommodate between 10 and 25 people and a hospital bed. The room requires an air filtration or cleaning appliance to deal with the smoke from the medicines which must be burned as cleansing incense (i.e., sage, sweet grass, etc.) or as offerings and to accompany speeches (tobacco). Preferably, the room will have no smoke detector or it will be on an electrical system where the smoke alarm can be turned off manually for the duration of the ceremony. Around 10 chairs or a couple of comfortable sofas, a small lamp, a hot plate and small cast-iron frying pan, and a table are all that are required for the room. Generally, visitors and elders will bring their own pipes, tobacco, sage or sweetgrass, and the containers necessary for burning them – but a thoughtful hospital might have some supplies and equipment on hand in the room. It is not uncommon, for example, for distraught people to forget to bring their own sacred tobacco (a distant relative of commercial tobacco); while they generally share with those who haven't forgotten, a supply in the room might be welcome.

The room should provide a sense of dignity and freedom: windows would help; windows that open would be even more helpful; windows that look out over part of the natural world, or gardens, would be far better than a grey cityscape.

Room Location and Offerings

The room will ideally be in a section of the hospital where the songs, drums, rattles, speeches and pipe ceremonies will not disturb other patients. The family's spiritual leader or medicine man/woman will lead the family in gathering the appropriate offerings of

- 1. Medicines tobacco, sage, sweet grass, cedar, sweet flag, abalone shell
- 2. Food offerings to Ancestors
- 3. Candles log burning, multiple wicks in place of a sacred fire outside

There will also be quiet times in the ceremonies: at times like these, the noise of fans and air cleaners, announcements over hospital speaker systems, and other typical hospital sounds will be intrusive. Soundproofing works both ways: it keeps the ceremonies from disturbing the rest of the hospital, and the rest of the hospital from disturbing the ceremonies.

If there is a park near the hospital or a place on hospital grounds where a sacred fire can be lit, the offerings can be burned in the fire. Special permission can be obtained from the fire department for a ceremonial fire pit in the city. This area can also serve as a focal point for family gatherings to pray. An urban hospital is often a very alien environment for a person who has lived a life close to nature: it can feel cold and distant. A natural setting, as a retreat for the family and a place for the fire, can seem like an oasis of the natural world.

Administration

Nurses and other staff – including cleaning staff – as well as attending physicians should be apprised of this module. It is important for both physicians and nurses to be educated in the realm of patient needs, and to receive support from the institution to do so.

Ceremonies should not be interrupted. Where a patient is dying, the family will generally feel that it is more important to attend to the person's spiritual needs, which are permanent, rather than the dying person's physical needs, which are transient. An interrupted ceremony is sometimes said to have been flawed, and sometimes ineffective. It leaves an unfulfilled feeling, but it is usually not possible to do it again (imagine a flawed funeral, to understand the parallel). A sign on the door indicating that a ceremony is in progress and should not be disturbed can be enough, if combined with a staff understanding of the nature and importance of the ceremony to the family and the patient.

While the person conducting the ceremony ought to be able to give an estimate of the length of the ceremony, the basic rule is that it takes as long as it takes. That can be from several minutes to an hour or more. While the basic ingredients and principles of the ceremony will be the same each time, the length of the ceremony will vary according to how many people are taking part, how much detail the person conducting the ceremony goes into, and how that person perceives the needs of the people involved. There is a parallel in "western" medicine: the length of an operation varies according to the needs and condition of the patient and the approach and practice of the surgeon.

Communicating

Human beings facing the prospect of the death of a loved one can often be numb and unresponsive, and this is not helpful to a doctor trying to understand what the family expects or wants. Aboriginal people face the same dilemmas as anyone else in an age when life can be prolonged artificially without any prospect of recovery (or even recovery of consciousness). The physician's approach to the family on these questions will not be much different for aboriginal patients as for anyone else. They are hard questions, with no right answers.

In some communities, people consider direct eye contact, especially with strangers, to be rude and aggressive. Do not be offended or upset if people don't look you in the eye. They may be looking somewhere else, but they are hearing and remembering what you are saying. In cultures that avoid confrontation, it is often true that important information is communicated indirectly – and that includes situations where the person may be looking away from you, and referring obliquely to ideas or problems, in order not to confront or offend you.

Students in training are not usually welcomed by a person or family members in this stressful situation. Personal space and modesty prevent indigenous patients from being open to "viewing" by those other than the attending doctor or nurses.

Don't expect an immediate response to your questions, even when they are clear, "yes or no" questions. Aboriginal cultures teach people to take time with answers, as a matter of respect. If the question were easy, you wouldn't be asking: respect demands that people give the question careful thought. Wait for a complete answer: there will often be pauses between parts of an answer, longer pauses than you are used to. Avoid overly technical terms, but don't "talk down" to people: they may not share your technical vocabulary (though you may find yourself embarrassed by some who do), but neither are they unintelligent. Avoid raising your voice. Plain English, and a simple explanation of the situation, together with a plain question, will often be enough. Generally, the hard decisions will be made by people talking things over together, rather than by one person. Give the family time to discuss things, internally. While it will often be the case that the family will choose a single person to speak for them to the hospital staff, it is advisable that the attending physician should speak to the waiting family as a whole when communicating vital information.

Indigenous people value compassion, kindness and gentleness. If you show these when you meet with them, you will be respected. Maintaining a professional distance will not engender the same respect: take the time to be human, visiting with people for a while, making conversation, before getting down to business. These ideas are true for most humans; they are especially true for tribal peoples.

Attending Ceremonies

Hospital staff and attending physicians will often be welcome in the ceremonies, if the request is made respectfully, quietly and carefully. As with many other aspects of death and dying, the approach should be made slightly indirectly. You could ask the chief or elder: "I have come to like (this person) very much. It would help my own spirit if I could attend some of the ceremonies to ease his passing and his family. I wonder if the family would mind. Could you ask for me?"

Once you are in the ceremony, you become part of a circle. While your modesty and your unfamiliarity, and the fact that you are not fully part of the family, will prevent you from pressing right up front, or too close to the person, you should not shrink to the back of the room, either. If in doubt, quietly ask someone where you should

stand (or sit). Watch what the person next to you does, and do that. Realize that you should do what people of your gender do – for example, sometimes men will smoke a pipe, while women (who have the power to bring forth life, and can sometimes affect a pipe's balance) often will only touch the stem. It is usually good practice to watch what other men are doing (if you are male) or other women (if you are female), and do what they do. You can also whisper questions to the person next to you. Generally, people will tell you what to do. Once you are in the circle of the ceremony, you are expected to stay for its entirety. Of course, turn off your pager and cell phone, and don't take notes (!).

The ceremonies are times of dignity, healing and departure. For you and the staff to take part in them, appropriately, is to send a message of respect that will pass to the entire community. Quickly. Your respect and empathy will be helpful to you in future dealings with the community, and will help the hospital appear to be more than just "the place one goes to die". On the other hand, an insincere or disrespectful participation in the ceremonies will be known in the community just as quickly and could increase the distance between institution and community. Tact, respect, modesty and good judgment are the rule: they are talents rather than learned attributes – just as a good bedside manner is a gift.

If a ceremony is private, you will be told that. Often, where people belong to medicine societies or other spiritual groups, a ceremony might be held that would exclude not only hospital staff but also non-members of the society, including some family members.

When a Person Dies in the Hospital

In some communities, the practice when a person dies in a room is for the family and friends to leave the room, to pray in the hallway or elsewhere, in order not to crowd the person's spirit, and to give it time to leave on its journey. At such times, the hospital staff should be careful not to rush in and remove the body before it is ready--or, perhaps more appropriately, before the family is ready. The key values, respect and dignity, are common to all cultures and are taught to all hospital staff: when to proceed with addressing hospital issues like determining the time of death or dealing with the body are matters of judgment that can be discussed with the spiritual leader or elder who has been helping the family.

Autopsies and Handling Bodies

Hospitals are often used to dealing with and respecting the religious beliefs of people whose faiths require that human bodies remain intact (like Orthodox Jews). As a rule, aboriginal people prefer that the bodies of their dead relatives be taken home as soon as possible, and be interfered with as little as possible. The rule is not absolutely universal--but you will find some people strongly resist the idea of an autopsy, especially one where some parts of the person are separated from the rest of the body. In cases where the law requires an autopsy, the hospital staff, the

coroner and the family's spiritual advisors can discuss ways to accommodate both the law and the family's beliefs.

Often a patient's family will request that body parts removed during surgery should be returned, so they can be placed back in the land in a special ceremony.

You may find a dead person wearing a medicine pouch around their neck, or clutching wampum beads in their hands. Wampum beads are short, tubular (about 1 cm. by 4 mm.) beads made of white and purple shells. In Haudenosaunee tradition, they are sacred as they recall the first ceremony of condolence, and the origins of the Great Peace. They are evidence of pledges, repentance, or a person's status as a chief, faithkeeper or clan mother. The best advice: leave these things alone, and ask the family representative, as indirectly as possible, what the family wants done with them. More often than not, they will tell you to leave them where they are. And you should pass that message on to other staff who will deal with the body.

Administration After Death

Hospitals are used to dealing with bereft and grieving people. There are some aspects of dealing with aboriginal people after a death that the staff may not know about, and as a result they may give offense or cause pain unnecessarily. In both Haudenosaunee and Anishinabe culture, there is a practice of not mentioning the name of a deceased person. One reason for this is the need to "let the person go": mentioning the name is like calling the spirit back. Another is the other side of letting go: it brings a person freshly back to mind, bringing the grief forth again. While it takes a little time to learn to avoid saying the dead person's name, the staff and physicians can learn to do so without much effort. Terms like "the man who has just passed away" are appropriate. So is mentioning the person according to his relationship to the person you are addressing. You should avoid saying "the body"--this is still part of a person, though we will not mention his name.

Telephone Lists of Indigenous Healers/ Spiritual Leaders

Each hospital should have a list of indigenous spiritual leaders or medicine men/women who live in the city or close to the city to assist families at this time. Small hospitals in towns close to reserves will have access to this information more readily through the reserve health department. City hospitals can contact Anishnabe Health Toronto, a freestanding Indian Health Center, or De Dwa Da Dehs Nye Aboriginal Health Center in Hamilton and their Brantford location for telephone lists. The social work department of each hospital should keep records of spiritual leaders, and medicine men/women who can travel to assist families, or who may be available locally.

Financial Assistance

Studies have shown that over half of the province's indigenous population now lives in towns and cities away from reserves. Of this group, 48% live below the poverty line. If the family cannot pay for the travel, meals, or accommodation for the traditional healer to come to the hospital, each hospital should have a designated donor fund where families can draw financial assistance for this time limited purpose. Some provincial governments may also have programs to help with these needs.

Hospital Pamphlets Publicizing the Service

Certainly the challenge is for the hospital and staff to create a welcoming environment serving a wide spectrum of attitudes, diversity in beliefs and spiritual orientation and consistency in meeting dying patients needs. Often indigenous people will not identify themselves as such. So much oppression, fear, and anger have been experienced by many indigenous persons that a family may never even expect for a moment that the hospital would honor their end-of-life wishes for their loved one. Most traditional indigenous families believe hospitals are foreign environments controlled by Euro-Canadians with primarily Christian attitudes. They quietly accept the social mores and conventions of the institution that is caring for their loved one. Very rarely will a family ever put forward specific requests for end-oflife ceremonies.

Staff Training

The roles of staff should be clearly delineated to accommodate requests from families seeking end of life ceremonials. Whose responsibility is it to ask the family? Whose decision prevails in each case, the doctor, the head nurse, the nurse practitioner, the nurse in charge? Specific culture-related staff training sessions should be designated during the course of annual training plans whereby indigenous speakers residing close to the hospitals can be invited to explain local customs for death and dying ceremonies. They will add to the information presented in this discussion. These sessions should be lively and interactive with much discussion on issues that the staff and physicians will identify as very real concerns and observations. Likely there will be some problem solving and planning in this session. Spiritual leaders/healers from indigenous territories have offered to participate in training to bring in their own experience and ceremonial knowledge of their local areas. Expect complaints about past problems: turn these into part of a positive process by accepting that mistakes were made, and asking what can be done to avoid them in future.

Spiritual Care Committee

Some hospitals near large indigenous communities are now forming these committees (Hotel-Dieu in Cornwall, Ontario, near Akwesasne) to address the spiritual needs of a wide range of multicultural groups and faiths. The committees meet three to four times a year for planning and training. The participants include

hospital staff, doctors, nurses and clergy of different faiths. It is recommended that committees of this nature be established in every hospital for the purpose of creating staff awareness and education and promoting a working relationship of mutual respect. In most indigenous languages, hospitals are referred to as "the place where one goes to die", a negative image, yet very real and one that needs to change in this millennium. The image invokes feelings of distrust, non-compliance, fear, sometimes anger and usually resistance. All of these emotions work strongly against healing. Together, we can change attitudes, strengthen relationships and share the very best of practice.

Detailed Case Scenario

Mrs. Susan Nahdee is a 78-year-old traditional Ojibway woman living in a small community 30 km from a regional hospital. She has a history of non-insulin dependent diabetes and coronary artery disease. She speaks little English and is always accompanied by her daughter each time she visits you. She presented 2 days ago to your small community's hospital clinic quite short of breath. Through her daughter she admits to a four-day history of chest pain typical of her usual angina. Your physical exam reveals she was in congestive heart failure. You admitted her and investigations revealed that she likely had an acute myocardial infarction a couple of days ago.

Her past history is significant for ischemic heart disease, having had 2 myocardial infarcts in the last 10 years. Her last MI was 3 years ago. She was found to have an 80% stenosis of her LAD and underwent angioplasty. At this time an echocardiogram was done and revealed an EF of 30%. Since her last MI she has had class II angina.

Mrs. Nahdee is a widow with 5 children. She speaks Ojibway as her first language. She has lived all her life in the same community with her children. Mrs. Nahdee is a survivor of residential schools. She follows traditional Ojibway teachings and sees a traditional healer in addition to you. Her medications at the time of admission are metoprolol 150 mg bid; lasix 80 mg tid and Nitropatch 0.8 mg on qAM off QHS. She is also on some traditional medications but you are not sure what she is exactly taking. Her daughter tells you that the reason for her not coming to see you sooner is that she went to see the Healer first and hoped he would be able to make her feel better...

You have been her family physician for 6 months. In this time, you feel that she is reticent in discussing her health with you. You only discovered that she was seeing a Healer after much probing. You were not happy about this since you were concerned about potential serious adverse effects and drug interactions with the regimen you prescribed. You tried to discourage her from taking these traditional medicines and from seeing the Healer however you were unsuccessful.

While in hospital, she continues to worsen---it is difficult to diurese her and she remains quite dyspneic on lasix 250mg IV bid and metolazone 10 mg po bid. She develops more chest pain and becomes hemodynamically unstable.

It is becoming clear to you that Mrs. Nahdee will need to be transported to a larger hospital and, if she does not start to diurese soon, she will need to be placed on dialysis and possibly life support. Unfortunately, it is winter and the roads are snow covered and very icy.

You pull Mrs. Nahdee's daughter aside and start to tell her that her mother is having another heart attack and that you feel she needs to be moved to another hospital. She will likely need life support and you are not sure if she will survive....

Mrs. Nahdee's daughter listens to you. Not once does she look at you. When you ask her want she "wants to do", you are met with silence. Thinking that she either is in shock or maybe did not understand you restart the explanations somewhat impatiently since time is running out and a decision must be made SOON.....

Physical Exam

Unable to lie flat, she is sitting in bed. Her respiratory rate is 36 breaths/minute on 50% O2, HR 125 irregular and BP 90/45. She is in obvious respiratory distress and can speak in 3 word sentences only. She is somewhat confused. She has inspiratory crackles throughout.

Teaching Instructions for Facilitators

- 1. Begin with a recap of outstanding issues from the last session
- 2. Distribute the case scenario. Allow the participants a couple of minutes to read the information or have one of the participants read the scenario
- 3. Ask the participants to identify issues. Write these on a flip chart.
- 4. The participants need to identify a number of topics for discussion including:
 - How do her traditional beliefs affect her care?
 - How does her culture affect communication and decision-making?
 - What factors are important to consider beyond a person's culture?
 - How do your own beliefs, culture, values, and previous experiences as a clinician affect the care options you discuss with your patients?
 - How does the style in which you communicate affect your approach to decision-making? What assumptions do you tend to make when approaching decision-making with patients and families?
 - How have your previous experiences caring for someone from a different cultural background – e.g. an indigenous background – affected how you approach communicating and decision-making around end-of-life issues with Mrs. Nahdee?

- How do your own beliefs about death and dying affect your decision-making and the care you provide for people at the end of life?
- What is the role of traditional Healers in end-of-life care? How does the involvement of a Healer affect the care you provide? What do you think of the role of alternative medicine in care at the end of life?
- How do your beliefs about traditional healers influence the care you provide?

TIP: Ask participants about their experiences in caring for Indigenous people in the past? Did their Indigenous patients follow traditional practices? What role did traditional beliefs play in their patient's lives? How did they respect these beliefs?

- 5. Ask participants how Mrs. Nahdee's daughter's cultural background may be affecting her discussions with the physician
 - What are your beliefs regarding family centered care vs. patient centered? How do these beliefs impact on the care you provide?
 - How would you approach decision-making with Mrs. Nahdee and her daughter?
 - What role would her experience in residential schools play in her relationships with non-aboriginal people?
 - How does the language barrier affect her ability to communicate and understand information in order to provide informed consent? How does it affect the way you convey information?
 - How has your hospital accommodated needs for translation?

TIP: Ask participants to reflect on how their own personal values and beliefs affect their decision-making? What role has cultural differences played in their previous encounters with patients and families?

Case Continued

Mrs. Nahdee's daughter tells you she has to meet with the Chief and her brothers and sister in order to reach a decision. While she leaves to discuss things with them you wait, growing more and more impatient....

Finally, you are told the family is ready to meet with you. You enter the waiting room to find 40 people present. The Chief tells you that Mrs. Nahdee would not want to be transported to the large hospital; she would rather be cared for in her community, surrounded by her family. You agree with this decision and inform them you will do your best to keep her comfortable. The family asks if they can have the Healer see her and if they can perform their traditional ceremonies to ease her dying. You agree

and leave the room. When you inform her nurse, she says:" What did you tell them? Do you know what you just agreed to????"

Directions for Facilitators

- 1. What role does the family play in decision-making in traditional indigenous culture?
- 2. What are your beliefs regarding family centered care vs. patient centered? How do these beliefs impact on the care you provide? On your ability to facilitate decision-making with your patients?
- 3. Ask participants to discuss the traditional indigenous ceremonies around death and dying.
- 4. Ask participants how they would respond to the nurse's concerns.

TIP: It may be useful to role-play the discussion they would have with Mrs. Nahdee's nurse.

5. Ask participants how they accommodated indigenous traditions around death and dying in the past

TIP: Ask them if they have encountered situations in which traditional Indigenous beliefs and practices have lead to conflict. How did they resolve these issues?

- 6. How has your hospital or community accommodated indigenous patient's spiritual needs in the past?
- 7. What hospital support services are missing that would help you do a better job in meeting the needs of indigenous patients?
- 8. Ask participants to develop a strategy to accommodate indigenous traditions around death and dying in their communities.

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