



Palliative Care

*Education Guide
for Health Professionals*

Fort McPherson

Gwich'in

Acknowledgements

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Providing Culturally Appropriate Palliative Care

Providing culturally respectful end of life care can be a difficult task. However, going into a situation with a better understanding of the individual's culture can help you become better prepared.

Purpose

This information guide is intended to assist health professionals in providing culturally respectful palliative care. This guide will provide an overview of the needs and expectations of the Gwich'in living in Fort McPherson. Although the majority of the community is Gwich'in, it is important to keep in mind that this is a general overview and may not be applicable to all individuals and their families.

Although it may not be possible to completely integrate the ideals of Western healthcare with Gwich'in traditions, this guide should help support a mutual understanding between the two. Providing individuals with palliative care that is both possible for health professionals and works for the patient is only achievable if we find a common ground. Taking the time to learn about the history, culture, traditions, values, and beliefs of the Gwich'in in Fort McPherson is the first step to providing culturally appropriate care.



Background Information

Who are the Gwich'in?

The Gwich'in are part of the Athapaskan language family, which is comprised of groups such as Slavey, Dogrib, Cree, and Chipewyan, whom are situated in most of the communities in the Northwest Territories. Gwich'in means "people." The Gwich'in used to be called "Loucheux" and "Kutchin."

In 1789, Alexander Mackenzie was the first explorer to encounter the Gwich'in. At the time of contact, there were nine different Gwich'in sub groups that belonged to the Gwich'in nation. These groups of people lived in the Northwest Territories, Yukon, and Alaska. Today, Gwich'in communities in the Northwest Territories include Fort McPherson, Akla-vik, Tsiigehtchic, and Inuvik. In terms of population, there are approximately 2,500 registered Gwich'in who are beneficiaries of the Gwich'in Tribal Council, which is a political organization that represents the Gwich'in of the Northwest Territories. The estimated total population for Gwich'in in the Northwest Territories, Yukon, and Alaska is about 5,000 people.

About Fort McPherson

Fort McPherson was established in 1839 by Hudson's Bay Trader, John Bell. The community was named after Chief Factor Murdock McPherson, another Hudson's Bay Trader.

Fort McPherson is known to the Gwich'in as Tetl'it Zheh, which means "the people" in the Gwich'in language.

The languages spoken in Fort McPherson are English and Gwich'in, with English being the dominate language. When residential schools were established in the North, the children were not allowed to speak Gwich'in, nor were they allowed to practice their cultural traditions. As per assimilation policies, the children were taught to adopt Euro-Canadian ideologies, and to behave as such. Gwich'in culture, as with all Aboriginal cultures in Canada, was disregarded and devalued. The impact of colonization has indeed impacted the Gwich'in in many ways, such as the loss of language and social issues. However, the Gwich'in are resilient and have managed to retain many valuable traditions, culture, and values.

History

Historically, the Gwich'in had their own traditional social structures where they lived in harmony with the land. Although they lived in a harsh environment, the Gwich'in maintained their survival as a hunting and gathering society. They essentially followed the caribou in the winters amongst the mountains, and moved along the rivers in the summer to harvest fish.

Present Day

Today the community continues to be predominately populated by Gwich'in. Although modern in many ways, the Gwich'in remain traditional when it comes to hunting, fishing and berry picking. Many families continue to thrive on wild meat such as caribou, moose, fish, and other small game, depending on the season. Caribou remains an integral staple for a majority of the people's diet, especially for the older population.

Traditions & Beliefs

Traditional Spiritual Beliefs

Because traditional spiritual beliefs were replaced by Christianity around 1890, they are not typically spoken of today.

Religion

The first missionary to arrive in Fort McPherson was a Roman Catholic priest named Father Grollier in 1860, although it was not until 1890, that a Catholic mission was established in the community. In 1868 Anglican Archdeacon Robert MacDonald moved to the community. MacDonald, who was of Cree descent, became instrumental in terms of the work he conducted amongst the Gwich'in. Consequently, it was the Anglican faith that the community followed. Presently, the majority of the community are of Anglican denomination.

“God is gonna take our soul and put it into new body. There's our strong belief that we get. Our soul is taken, our body is left down here, and we're into new bodies. And, I think till today our Gwich'in people believe that everybody is up there [Heaven].”

Gwich'in elder

The Gwich'in embraced Christianity once they learned about the Bible and God. Even out on the land, the Gwich'in were taught how to read the Bible, and were committed to learning as much as they could about the word of God. Today, religion remains very important and there are many who hold strong beliefs in the community. There are several local Gwich'in elders who have been ordained as Anglican Ministers in the community, and who facilitate the local Church services on a regular basis.

As a patient's illness progresses, you may notice an increase in religious discussions. The presence of a Minister, prayers, and hymns may be common when treating a patient at home or in the hospital.

Some patients feel at peace before they die because they know they are going to be with Jesus soon. If you are comfortable doing so, you may engage in discussing religion with them. If not, try not to let it show. It is important to be accepting and understanding as this will help put patients and families at ease.

Some patients may also talk about their loved ones or community members that have passed on before them. For example they might share how they saw the deceased in their dream or they may talk as if the contact clearly happened. This means that the end is near.

Beliefs Surrounding Palliative Care

“They won’t tell you that they are scared, they tell you in a different way, stay with me, I don’t want to be alone.”

Fort McPherson Community Member

The term “palliative care” is relatively new to Northern communities, and Fort McPherson is no exception to this. When discussing it with the patient and/or their family, the terms “passing away” “passing on” are better understood.

Past Ways of Dealing with and Treating Palliative Care and Death

Long ago when someone got sick either out on the land or in the community, there was a strong element of respect and reverence involved. The people would become very quiet throughout the area where the patient resided on the land, and in the area where the patient lived in town.

“As kids we were told we have to be quiet. And then they told...those days kids can’t go see sick peoples. So, they told us to be quiet. We can’t make noise. And, I think we were just kept in, so that when we go outside, we’re yelling and screaming. They won’t allow that. Everything had to be quiet. Yeah, quiet.”
Gwich'in elder.

When someone became ill, the community would become involved in whatever capacity they could. The women would assist the family members in terms of taking care of the patient. The men would ensure that the family had enough food, wood, ice (for making water) and so forth. People would demonstrate a high level of sharing, caring, and respect towards the affected family. The Gwich'in ensured that they shared whatever they could in terms of traditional food, traditional medicine, and the provision of hands on care, to the patient and family.

“When people died, the community, they all took turns [helping], and if this person is dying, they take turns looking after that person. Like day and night. There’s always people being with that family and the patient. And, they try to give the best food they could. They still do that today. Things like light soups, and what a person could take down. And, traditional medicine is one of the things that still goes on today.” Gwich'in elder

Death has always been viewed as a sacred time. Prior to the establishment of the community, burials were conducted at the grieving family’s camp, in which several families typically resided. Burial sites can be found all over the Gwich'in settlement area, up and down the Peel River, including areas in the Yukon Territory.

As soon as someone passed away, the community would provide support to the grieving family. Community members would prepare traditional food and bring it to the family’s home, where people would gather to provide support and comfort. At the same time, there would be food served to all visitors in the home.

The Gwich'in strived towards ensuring that a burial took place as soon as possible, as they believed that the deceased person’s body needed to be put to rest, otherwise their Spirit would not rest. Throughout this period, including an unknown period afterwards, the community would remain quiet, and no other events would take place, even following the funeral, out of respect for the family.

Before the missionaries arrived, drum dancing was one of the traditions that followed a feast whenever a person passed away.

“They used to put on drum dance. I think we asked him [my father] why, he said “Well, for the person to continue on their journey. The missionary came, they took the drums away from the people, it never, ever got back to us”...The Minister told them that it was not good. Drum dancing was not good. So, he took it away, and it never came back.” Gwich'in elder

Traditional Medicine

Prior to the availability of western medicines, the Gwich'in heavily relied on traditional medicines which they used from the land. The medicine was used for many ailments including infections, cuts and pain to name a few. They would make medicines from spruce boughs, and various plants and animals. Fundamental to the success of traditional medicines, was the fact that the people, including the patient, had to believe in the power of the medicine people and the traditional medicine.

“That was the real miracle, that medicine, because a lot of people used it, and it cured a lot of people...You know...like I say... whenever we had headaches, they made sure they made some kind of medicine, we drank that. And, today they call rat root... you know that they use those for headaches, for stomach ache... all these things, they had things to use you know. We take those medications, and in a day or so, we're back on our feet again. I give them credit for that you know. Because today, if we all took the time to learn about this traditional medicine, we'd spend less time on medication.” Community Member

Once the funeral and feast is completed, community support seems to dissipate. Families may find this time extremely difficult, as they feel like they no longer have their support system. Affected families may be open to offers of emotional support from the health care professionals. Or, they may just want to be alone to process their feelings.

Current Ways of Dealing with Palliative Care and Death

Today family and community involvement, and the inclusion of the health profession are central. It is common to have many visitors, extended family, and relatives visit the patient and his/her family to offer prayers, food, hymns, and emotional support. People appear to be open to talking about death, although speaking about it in the presence of the patient could be disrespectful or offensive to some.

People consider a “good” death to be a death without pain and a death that is as natural as possible. To the Gwich'in, death is as much a part of life as is birth.

The concept of grieving is complex, as there are historical beliefs indicating that it was okay to cry specifically during the day, but not at night. The beliefs are different amongst the people. There were beliefs in place which indicated that one should not grieve too long or cry too long, because the tears held the deceased person from going on their journey to Heaven. However, nowadays grieving is encouraged and supported.

“And what better place to go than to go to the land. You go to the land, and you release your emotions there. Because that’s where you grew up, that’s where you grew up with your family, and that’s where you feel comfortable, dealing with your emotions.” Community Member

There are many traditional aspects that continue to be carried out whenever a death occurs in the community. Local men will voluntarily dig the grave, while others will go hunting for the community feast. Women will cook traditional foods for the bereaved family, coupled with western foods. Others will tend to the family home to pray, to offer support and to provide any assistance that they can. The family home will become open to the public and anyone is welcome to visit and have something to eat or drink. Attending the family home is a signal of respect.

The community also takes an initiative to donate money to the grieving family, to assist with funeral costs, including travel for family members who live outside the community.

A community feast is held after the funeral service which allows the community to pay a final tribute to the deceased. This also signifies community support for the family. All kinds of foods will be served from traditional dishes such as caribou soup, boiled meat, to western dishes including a variety of salads, hams, turkeys, and many desserts. Once the serving and eating is completed, an elder will say a closing prayer and then speeches begin. Leaders, including the Chief and elders, will deliver speeches. Usually speeches focus on the life of the deceased person. Family members or relatives will also speak to the community, expressing gratitude for support and prayers.

Home Care vs. Hospital Care

“I am going to stay at my house, this is my house.”

Community Member

Caring for the individual at home is preferred as it is what is natural and traditional. Many individuals and their families have never left the community. Providing care at home also allows easier access to the patient for visitors.

Traditional foods are very important; having the patient at home makes it easier for the family to provide it to them. The family is in control of how the patient is treated and cared for. The assistance of a health provider is appreciated, but it is secondary to family care.

Because of a lack of resources and because of the individual's needs, home care is not always possible. If an individual needs to be treated at the hospital it is important to still involve the family. They should be allowed to visit often and should still be involved in the care of their family member.

Family Involvement

Gwich'in from Fort McPherson have demonstrated outstanding resilience in sustaining their traditional customs and values. From generation to generation, they continue to remain solid in times of stress and hardship. They deeply care for each other, and will come together during difficult times, to provide comfort and support to each other. As such, family is very important to everyone, and to describe the community is akin to describing a unified family.

Sources of Comfort

- Family
- Elders
- Community Leaders
- Homecare
- Prayer
- Gwich'in Hymns
- Doctors and Nurses
- Ministers
- Friends
- Traditional food
- Story telling
- Religious music
- Keeping warm
- Keeping a light on
- Touch/physical contact
- Quiet
- Visitors

Although the patient is the only person requiring treatment, the family should always be allowed to be part of the process. Family care must be respected, as taking care of the patient can be healing for the family.

In most circumstances a large number of family members, including extended family and friends, will want to be involved. Even after the patient passes away, it is never recommended to tell the family to leave. Unless the patient tells you otherwise, always allow the family to be involved in all aspects of care. Although a large amount of visitors may be disrupting to the family who lives in the home, it is up to them whether or not the visitors can stay. If you feel like the family is overwhelmed with the visitors, it is okay to talk to them about it.

Throughout the care of the individual, encourage the family to be in control. Provide them with necessary information to allow them to help the individual.

Typically family members will want to spend every moment with the individual. They may not take any time for themselves because they feel guilty. They may not willingly leave the individual alone, so it is important to let them know that you are available, or you may be able to arrange for someone else to be available while they take a break.

When the individual is being taken care of at home, it may be helpful to determine the family member most likely to give consent on the their behalf. This can be difficult as family care will evolve as time passes. Many people may be involved at first, but it may taper off over time. The primary caregivers will stand out over the course of care.

Family Concerns

The family may be concerned about the following:

- Why the individual sleeps so much. If the medication is making them tired, the family may be upset because they feel they are missing time with them.
- Some family members may not like that the individual is taking medication. In addition, if the individual refuses medication the family may be concerned about the pain they are experiencing. Try to put them at ease by describing what the medication is, what the side effects are, and how it is helping.
- After discussing any treatment or care options, please ask if your explanation has been understood as many Gwich'in will not question a health provider.

Things to Consider

- The individual may be resisting death because they feel they have an obligation towards their family. If you believe this is happening, talk to the family. Let them know that it is okay to give the individual permission to pass on.
- If you think a family member is becoming run down, offer them respite.

Pre-Planning

Although the following topics are difficult, discussing them with the individual and their family is necessary. Approach the subject when you feel the time is right.

- Have you created a will? Most people will just expect that their personal items will go to who needs them most.
- DNR wishes. Explaining the various options available from the very beginning is desirable.
- Distribute the End of Life Care package forms when appropriate.

Communication

When speaking with the individual or their family use simple language that is easily understood. Do not leave anything open to interpretation; you may be using a metaphor, but it might be taken literally. Ensure the family understands by providing examples and physically showing them what you are talking about.

English will not always be understood. Ask family members to interpret if needed. If using an interpreter, ensure clear language is used so there can be no misunderstanding. Be aware that the interpreter may relay the information as they see fit. If the news is upsetting they may not want to say it.

When discussing the well-being of the individual, tell them everything they may need to know. Direct questions are uncommon, most people will circle a subject rather than referring to it directly.

When having a conversation be careful not to mistake silence for misunderstanding. Thoughts and opinions are not freely expressed. Watch body language for a reaction. People will do a lot more thinking than talking.

Effective Behavior

Respect is very important. Establishing a respectful relationship between health providers and family is crucial. This allows them to feel comfortable asking questions, as people may be hesitant questioning, or asking questions to an authority figure.

Be prepared that they may not be friendly in return. They may appear distant or unresponsive and will not show much emotion towards you. Do not be deterred; people appreciate a respectful disposition, although they may not show it.

In this culture, touch is very important. If you feel the individual is comfortable with you, it is good to hold their hand or touch their hair. If you find yourself alone with them, try to maintain physical contact. This is comforting to the individual, and it will put the family at ease.

Things to Consider:

- When patients are near the end, they may revert to their native tongue. Family members should be able to assist you in communicating with them if this happens.

Relationship with Healthcare Provider

“They will just more or less take anything the doctor gives them, like any advice any medication, they are just like so compliant, cause that’s a cultural thing right, and family members sometimes wont either, they just assume that this person (doctor/nurse) knows what needs to be done.”

Community Member

Individuals and their family might expect more from you than you can give. It is important to establish what you can reasonably provide. Individuals and their family may expect:

- Around the clock care. They may not understand why you are not always available to them. It is important to let them know when you are available.
- Many prefer that the health provider be the one to tell the individual that they are going to pass away, but the family should be present when they are informed.
- Pain control. Individual's and their families will look to the health provider to keep the individual comfortable.

Meetings

During all meetings, especially the initial meeting with the individual and family, it is important to keep open lines of communication “I’m here to help; here is what I can do. What can I do for you?”

When the doctor, social worker, or long term health care provider is present in any patient/family meetings, explain to them why they are there. Try to put the individual and family at ease.

Meetings and discussions should include whomever the individual and family deems appropriate. Ask them to discuss their concerns with you. If they decline, try to think of concerns they may have and address them.

Trust and Respect

Trust can be difficult to obtain. Although many individuals and their families will see you as an authority figure, this will not always garner trust and respect. To be ‘accepted’ by the family, you will have to go beyond the role of a traditional health provider. Although this is not mandatory, the following are suggestions to gain trust from the community:

- Community activities
- Feasts
- Have tea with patients/ families
- Socialize

Do not expect this to happen over night. It takes time to forge relationships and friendships. If you are working with a palliative care patient over a longer term, it will be important for you to be accepted by the family. If you are only working with the family for a short period, it will not be possible to form a solid friendship.

Things to Consider:

- Individuals may not ask for medication to help with pain relief. They also may be attempting to hide pain. It may be beneficial to talk to the family about this as well so they can monitor the individual when the nurse is not around.
- The individual may want to return to the land, or go to a special place to pass away. If they come to you with this request try to find the resources to make it happen.

Additional Information

Translations

Although the majority of the Gwich'in people in Fort McPherson speak English, the following are phrases you may come across:

English	Gwich'in
Good Day	drin gwiinzih
Good	gwiinzih
How are you?	Ne'engit da'goncho
Thank you	Mussi cho
Cold (It is Cold)	gwiniik'oh
Warm (It is warm)	gwiniidhaa
Minister	Giikhii
Sickness	Nurii devazhee
Sickness (spreading)	ts'ik
What is your name?	ts'ik nahdaatth'ak
Hospital	elts'ik zheh

HealthLine

Phone: 1-888-255-1010

Fort McPherson Social Services

Phone: 867-952-2250 or 867-952-2802

Fax: 867-952-2133

Fort McPherson Wellness Workers

Phone: 867-952-2250

Tl'oondih Healing Society

Phone: 867-952-2025

Fax: 867-952-2733

Language Centre

Phone: 867-952-2377

Fax: 867-952-2433

National Directory of Hospice Palliative Care Services

<http://www.oulton.com/chpca>

