MULTICULTURAL GENETIC COUNSELING WITH ALASKA NATIVE AND CANADIAN FIRST NATIONS CLIENTS

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By
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ABSTRACT

Multicultural Genetic Counseling with Alaska Native and Canadian First Nations Clients

A thesis presented to the Genetic Counseling Program

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Over the past decade, the field of genetic counseling has become increasingly aware of the need for culturally informed genetic counseling for individuals from different cultures and ethnicities. However, there is very little information available regarding genetic counseling with North American Natives.

The purpose of this study was to gather information about genetics professionals’ experiences regarding their genetic counseling sessions with Alaskan and Canadian Native clients. We recruited study participants via the NSGC listserv. We then conducted audiotaped phone interviews with twelve genetic counselors/nurses that work in Alaska or Canada and have experience counseling Northern Native individuals. Following transcription of the qualitative interviews, we used ATLAS.ti software to identify common themes among interviews.

Respondents reported that their Native clients value their culture, families and rural communities. In terms of communication, they described their clients as reserved and quiet. Respondents also noted that, during sessions, it was hard to elicit factual and
emotional reactions from Native clients. They saw cultural differences and their clients’ perspective on genetics and medicine as underlying reasons for these communication challenges. Native clients were reported to be more accepting of (certain familiar) genetic diagnoses, but may have alternative explanations for diseases or be more worried about logistical (or other) issues, rather than genetic explanations. The remoteness of many Native villages and reserves is a challenge for clients and counselors: Native individuals are often intimidated by large cities and travel, while counselors/nurses struggle with the coordination of care and shipment of medical supplies. Study participants suggested strategies for improvement of services, such as taking time during sessions and establishing health care teams that provide care for remote communities. They also stressed the importance of learning from Native individuals about Native culture and perspective on medicine as a way to improve services for this clientele.
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I. INTRODUCTION

Over the past decade, the field of genetic counseling has become increasingly aware of the need for responsible and culturally informed genetic counseling for individuals from many different cultures and ethnicities. While North America is a continent of much diversity, the genetic counseling community itself is primarily Caucasian and highly westernized. In order to provide high-quality counseling services to clients from different cultures and ethnicities, genetic counselors/nurses need to become effective multicultural counselors: they need to increase their knowledge of relevant ethnocultural groups while, at the same time, becoming more aware of their own ethnocultural roots and beliefs (Weil, J. 2001).

Genetic counselors/nurses who work in Alaska and Canada with a Native clientele ideally should have general knowledge of the main Native groups in Alaska and Canada, their culture, their world-views and their belief systems. In addition, by understanding better the characteristics/challenges that are unique to sessions between non-Native genetic counselors/nurses and Alaskan/Canadian Natives, they can improve the quality of their counseling and better serve their Native clientele in Alaska and Canada.

Native clients in Alaska and Canada belong to a multitude of tribes/groups. However, the tribes/groups have the same historic roots in common:

The first Canadian and American Natives came from Northeastern Siberia to North America during the last Ice Age via an existing land bridge across the Bering Strait. Today, about 13.0% of Alaska’s population is of Native heritage, counting approximately 92,600 individuals. Alaska Native groups consist of over 225 federally recognized tribes
that belong to five major cultural/geographical groups. Two main Eskimo groups, the Inupiat and Yupik, live along Alaska’s coastlines. The Athabaskans live in the interior of the state. Aleut & Alutiiq Natives inhabit the Aleutian Islands. Alaska’s Southeastern Natives consist of the Tlingit, Haida & Tsimshian. The languages spoken by different groups stem from entirely different language families and dialects exist within certain groups. Approximately half of Alaska Natives live in urban areas while the remaining Natives live in remote and rural villages, maintaining a subsistence lifestyle (Allen, J. 2006; Hirschfelder, A. 1986). See Figure 1 for a map of Alaska Native groups.

Figure 1: Alaska Native groups (source: www.ankn@uaf.edu)

Today, approximately 3.8% of Canada’s population consists of Native tribes, counting approximately 1,172,800 individuals. When the Europeans arrived in Canada about 500 years ago, over 55 Nations populated the Canadian land. Currently, there are 615 recognized First Nation groups and 10 distinct First Nations language families in Canada. “First Nations” is an ethnic umbrella term for indigenous people of Canada that excludes Inuit people (formerly known as Eskimos) and Métis people (who have Indian and European ancestors). However, since Inuits and Métis people are also ancient
inhabitants of Canada, the term can include these populations as well. We will use the term “First Nations” throughout this study with the understanding that Inuit and Métis people are included in the term (see world wide web references). See Figure 2 for a map and pie-chart of Canadian Native groups.

Figure 2: Map and pie-chart of Canadian Native groups (sources: www.nfb.ca & Human Resources and Skills Development Canada)

Despite the fact that Native groups all across North America differ in tribal customs, rituals and language, it is widely believed that there exist shared cultural values that are common to the native groups inhabiting this continent. Generally, Indians have a holistic worldview which implies that life is lived in a circular fashion and in rhythm with nature (Struthers, R., & Peden-McAlpine, C. 2005, Hunter, L. M. et al. 2006, Heinrich, R. K. et al. 1990). As Heinrich et al. points out, holism usually includes unity of mind, body, spirit and nature. As a consequence, there is hardly any disconnection for Natives between daily activities, medicine and religion. According to Struthers et al., Indians connect with the real world through religion or spirituality and perceive the world through a different lens than Caucasians. Another major feature of the indigenous culture

The literature also compares the Native and the Western worldview. In contrast to the Western culture, Indigenous people of North America prefer natural explanations over scientific clarifications and live in the present, rather than the future (Garrett, M. T. & Myers, J. E. 1996). Furthermore, they value cooperation in contrast to competition and therefore also emphasize relationships over individuality. Native priorities also include humility and sharing of wealth. Contrary to this, Western values focus on gaining attention and saving for the future (Garrett, M. T. & Myers, J. E. 1996).

Because of such differences between the Native and Western worldview, challenges can arise in genetic counseling sessions involving non-Native counselors and Native (American) clients (Lockart, B. 1981; Weil, J. 2001). One major difficulty is the difference in communication styles. While counselors may expect their clients to be open and willing to share their thoughts, Native clients tend to share their thinking in accordance with their own inner timeline, which is tied to their trust in the counselor, rather than the session’s timeline (Smith, D. B. & Morrissette, P. J. 2001). This phenomenon is mainly due to the historic distrust that most Natives feel towards those from the dominant majority culture. Therefore, in order to stimulate open communication counselors may need to establish good inter-personal trust to overcome clients’ historic distrust (Lockart, B. 1981). Additional challenges may also arise in a session depending on the client’s level of acculturation and on the counselor’s cross-cultural viewpoint. As a result, the counselor should determine early in the session to what extent the client is immersed into the Western culture in order to tailor the session effectively (Heinrich, R.
K. et al. 1990). Counselors should also be aware of their own preconceptions with regard to the client’s cultural group and keep in mind that the client’s personal values and beliefs might differ from those of the client’s cultural group. Finally, counselors need to be self-aware about their own cultural backgrounds and beliefs since they will often play a role in their interactions with Native clients (Wang, V. O. 2001).

The work of Darou, Garrett and Heinrich recommends that counselors allow for ample time when counseling Native clients and that they sustain openness to different worldviews and other outlooks on health and disease. (Darou, W. G. 1987, Garrett, M. T. & Myers, J. E. 1996, Heinrich, R. K. et al. 1990). Even though the literature provides a general picture of the worldview of North American Natives and general counseling sessions with this clientele, there is very limited information available about genetic counseling with Alaska and Canadian Natives in particular.

The purpose of this study is to learn more about genetic counseling sessions involving Alaska Native or Canadian First Nations clients and non-Native genetic counselors and nurses. We were specifically interested in learning about the characteristics and challenges of such sessions and also wanted to identify the underlying causes of any multicultural counseling difficulties, if any - from the perspective of the genetic professionals. Finally, we hoped to develop a set of recommendations for improving genetics services for Alaska and Canadian Natives.
II. METHODS

Development of Interview Guide

We developed an interview guide for genetic counselors and nurses that consisted of 3 sets of questions: demographic questions, questions regarding specific genetic counseling sessions with Native clients and questions regarding counselors’ overall experience with the Native clientele. The questions inquired about characteristics of Native clients, session characteristics and challenges when counseling Northern Natives, underlying reasons for challenges that counselors experience, and suggestions for improving counseling services for the Native clientele. Altogether, the interview guide contained 34 questions, consisting of a mix of close-ended and open-ended questions. Some questions served as follow-up inquiries (see IRB protocol in the Appendix).

Recruitment of Subjects

After the Brandeis University IRB had approved the study, we posted a recruitment notice on the listserv of the National Society of Genetic Counselors. In order to be eligible for participation in the study, potential subjects had to be fluent in the English language and had to have clinical experience as genetic counselors or genetic nurses. Subjects also needed to have counseled at least a few Northern Native individuals or families. Ten genetic counselors and two genetic nurses responded to the recruitment notice. The principal investigator confirmed eligibility of the subjects via email and subsequently all twelve counselors/nurses participated in the study.
Interviews, Transcription, Analysis

The principal investigator conducted semi-structured qualitative phone interviews with each of the twelve study participants regarding their genetic counseling experience with Native clients. Interviews were audiotaped and lasted approximately 25 to 40 minutes, depending on the length of participants’ answers and number of follow-up questions asked. A third party transcribed the recorded phone interviews into Word documents. The principal investigator then analyzed the transcripts using the qualitative research software ATLAS.ti, marking text passages within the interviews to organize them under different codes (i.e. ideas). Each code had a specific definition and served to identify statements from all twelve counselors/nurses that answered the same research question (e.g. what counseling suggestions participants made with regard to quietness of clients). Organization of statements into codes allowed us to count how often counselors/nurses commented on a specific topic. After completion of the coding process, we identified the broader themes that contain a group of codes (e.g. counselors’ and nurses’ counseling suggestions). The themes matched the study aims: counselors’ experiences with Native individuals and counseling sessions, counselors’ difficulties/challenges as well as suggestions for improvement of genetic counseling services for the Native clientele.
III. RESULTS

A. DEMOGRAPHICS

We recruited and interviewed twelve genetic counselors/nurses* with varying degrees of genetic counseling experience; the participants’ experiences with Native clients varied as well. At the time of the interview, nine participants had counseled Native individuals for up to three years and three participants had counseled Native clients for more than ten years. All counselors were female and Caucasian. Table 1 summarizes the genetic counseling experiences of genetic counselors/nurses, the genetic services they provided to Native clients, and the professional functions and locations of their counseling positions.

*for the remainder of the text, the term “genetic counselors/nurses” may be summarized using the term “counselors”
Table 1: Classification of Participants

<table>
<thead>
<tr>
<th>Professional title</th>
<th>Genetic Counselor</th>
<th>Genetic Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>number of professionals</td>
<td>10</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total years of experience</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>3-5 years</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10-20 years</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>20-30 years</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years experience w. Natives</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>1-2 years</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>2-3 years</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>&gt; 10 years</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services provided</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>General, no cancer</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Pediatrics</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Specialty Clinics</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of professionals</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>in USA</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>in Canada</td>
<td>7</td>
<td>2</td>
</tr>
</tbody>
</table>

We asked study participants to estimate their Native patient volume.

- Of the three counselors with less than 1 year of experience with Native clients, one reported that 10-20% of her current patients are Native. Another reported seeing a total of 5 Native patients and the third stated that she had seen 80 Native patients.

- One of the three counselors who had 1-2 years of experience with Native clients has seen a total of 4 Native clients; the other two counselors reported seeing 4-5 Native clients per month and 24-30 per year, respectively.
The three counselors with 2-3 years of experience with Native clients reported seeing a total number of Native patients ranging from 30-40 for one, 50-100 for a second, and 200 Native patients for the third.

Three counselors had over 10 years of experience with Native clients. Two counselors reported that 1-5% and 10-15% of their patients, respectively, are Native. The third counselor said that she sees approximately 15 Native clients per year.

B. THEMES

We analyzed the twelve transcripts and identified five themes (or categories), which can be seen as analogous representations of the study goals. The themes are:

- **Theme 1)** Counselors’ general impressions of Northern Natives and their counseling sessions with Native clients
- **Theme 2)** Challenges counselors have experienced during sessions with Native clients
- **Theme 3)** Underlying issues counselors have identified as contributing to session characteristics and challenges
- **Theme 4)** Suggestions for improving genetic counseling services for Northern Natives
- **Theme 5)** Overall thoughts and impressions about their counseling experiences with Northern Natives

We then subdivided each theme into several components (recognized as codes during analysis) in order to portray the multitude of aspects that speak to each theme.
In the following sections, we present each theme and its components. In each section we first give an overview in table form summarizing the components of each theme and the frequencies with which counselors’ statements fell into each component. The number of counselors who made each statement is listed in the last column. We then provide further specific examples (quotations) and explanations for the components in the text that follows each table.

**THEME 1) COUNSELORS’ GENERAL IMPRESSIONS OF NORTHERN NATIVES AND THEIR COUNSELING SESSIONS WITH NATIVE CLIENTS**

1.1) **COUNSELORS’ GENERAL IMPRESSIONS OF NORTHERN NATIVES**

Throughout the interviews, counselors talked about their overall impressions and knowledge of Northern Natives. Participants mentioned these various aspects since they seemed to be related to their counseling experiences, either directly or indirectly.

Counselors frequently commented on their clients’ calm manner and their quietness. A few comments were also made with regard to the clients’ lesser extent of expressed body language and facial expressions. Furthermore, study participants remarked on the perceived priorities and values of their clients as well as on their openness and willingness to interact. Some counselors mentioned psycho-social difficulties that Native groups and individuals are faced with. Table 2 lists the components of this theme, including frequency of counselors’ statements and number of counselors who commented on each aspect.
Table 2: General impressions of Northern Natives

<table>
<thead>
<tr>
<th>General impressions</th>
<th>Frequency of statements</th>
<th># counselors who commented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Native clients are calm and/or have a slow manner.</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Native clients are quiet and have a closed-off manner.</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>Native clients have an open and interactive manner.</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Native individuals value their culture(s), spirituality and family networks.</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Native clients show a lesser extent of body language and facial expressions/eye contact.</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Native individuals/communities struggle with drug and alcohol addiction and gang violence.</td>
<td>17</td>
<td>5</td>
</tr>
</tbody>
</table>

_Calm/slow manner_

Study participants remarked on the calmer or slower manner of Native clients when compared to clients from other cultural groups. Counselors often described their Native clientele as easygoing, relaxed, calm, and slower paced.

...they seem more calm. They seem not as rushed, not as hurried to answer questions or ask questions. (Counselor #9)

...they are never in a rush. Never, never, never. (Counselor #10)

They just have a slower way of life. Their pace is slower. (Counselor #5)

They are just very easygoing, and they just take it all in (Counselor #1)

_Quiet, closed-off manner_

Counselors said that they generally found Native clients to be quieter and less emotional in counseling sessions as compared to other clients. Likewise, counselors found that Native clients generally don’t talk as much and don’t ask as many questions.

...not as open about expressing emotions or that sort of thing, particularly if it’s an initial session. (Counselor #7)

...they are people of few words... (Counselor #1)
I don't seem to remember seeing anyone break down in tears or yell at me, where that's certainly happened with other groups. (Counselor #2)

**Open and interactive manner**

In contrast to some counselors’ statements describing Native clients as quiet and closed-off, others indicated that Native individuals are verbally open during sessions, interested, and desiring of information.

*I've found that there’s two different experiences. One is that they are no different from a Caucasian client, and they’re completely open and it’s no problem. And then the other extreme that I’ve seen closed, closed off.* (Counselor #7)

*I think I have found them to be pretty open, because I'm hoping, as usual you're trying to set up this feeling of, trying to help them feel comfortable, all the patients, so I think you get better and better at adapting to how the patient is, and I think I'm reading them okay, that they, I find that they talk to me fine...*(Counselor #4)

**Priorities and value of the family and culture**

Besides ethnicity, village culture, and elders, counselors mentioned that family networks, community, spirituality and rhythm of nature are of importance to Native clients.

*They value their ethnicity, their village culture.* (Counselor #5); *...sometimes they come with their grandparents, because the elders are very important in their society.* (Counselor #10)

*I'm really impressed by the support, the family networks and the social networks that exist.* (Counselor #9)

**Lesser extent of body language and facial expressions/eye contact**

Three counselors remarked on seeing fewer facial cues and/or less eye contact when working with Native clients.
…you’re not getting as many of the verbal or physical facial cues that you would get from a non-native client in terms of how they are interpreting the information or reacting to the questions that you are asking them. (Counselor #6)

Sometimes the clients don’t want to look me in the eyes, at least not for a long period of time…(Counselor #8)

Psycho-social difficulties

Counselor’s comments regarding psycho-social difficulties of Native communities referred to occurrences of drug- and alcohol addiction, physical abuse, gang-culture and high crime rate. Counselors also mentioned a high number of referrals for assessment of fetal alcohol syndrome in children. Furthermore, study participants remarked on societal issues that affect Native individuals. They specifically mentioned discrimination of Native individuals by either the Western society or by their own groups in cases where young people attend Western schools.

…a lot of my patients were kind of unfortunate – a lot of them do not have a lot of money, and have had really tough family situations with respect to multiple partner, many children, drug and alcohol issues. (Counselor #4)

I always think that’s just such an unfair thing for our aboriginals, at least here where I live in [name of town], because it’s a very difficult situation here in my community, and the young people that want to come into our town to go to school, it’s like they’re frowned upon by their own people, because they have left there, and they’re not accepted by our people here in the community. It’s very difficult. (Counselor #3)

1.2) COUNSELORS’ GENERAL IMPRESSIONS OF COUNSELING SESSIONS WITH NATIVE CLIENTS

When asked about session characteristics, counselors tended to compare sessions with Native clients to sessions with non-Native clients. Some study participants stated that they find sessions with Native individuals no different from sessions with other clients.
Other participants said that the multicultural sessions with Natives are unique and sometimes more difficult. *Table 3* summarizes the elements of these opposite statements.

**Table 3: Statements regarding presence and absence of session differences**

<table>
<thead>
<tr>
<th>Session features</th>
<th>Frequency of statements</th>
<th># counselors who commented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sessions with Native clients are no different from sessions with other clients.</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Sessions with Native clients are different compared to other sessions.</td>
<td>12</td>
<td>5</td>
</tr>
</tbody>
</table>

**Sessions are not different**

Six counselors stated that sessions with Native clients do not differ from sessions with non-native clients but they did not offer specific explanations for their overall impression that sessions seem more alike than different.

*...they’re just like any other group, and every interaction will be different. (Counselor #2)*

*I feel like every patient who walks in, you’re trying to read them specifically, and I can’t say that my native patients are oh so different to me in that way. (Counselor #4)*

*I’m not too sure that I could specify them any differently than other sessions. (Counselor #4)*

**Sessions are different**

On the other hand, five counselors remarked that certain aspects of sessions are different between Native and non-Native clients. Study participants described the differences in two ways: sessions with Native clients are either unique/distinct and/or they are more difficult/challenging. Counselors did not always offer detailed explanations for their perception that sessions are unique or distinct. However, those indicating that sessions are more difficult often cited conversational aspects (e.g. the slower pace and less interactive nature of conversations) as the main reasons for the differences.
...I think it definitely is distinct, and that’s not to say good or bad, but distinct in terms of the way that you then counsel and interact with that family. (Counselor #6)

I would describe them as being one-way conversations. It's very difficult to get information... (Counselor #12)

I think they're coming from a different cultural background, so the whole way that you deal with them is unique. (Counselor #2)

I think it's more challenging. So in all the ways that I've said. (Counselor #6)

**THEME 2) CHALLENGES COUNSELORS HAVE EXPERIENCED DURING SESSIONS WITH NATIVE CLIENTS**

When asked about challenges they experienced in sessions with Native clients, study participants talked most frequently about challenges with logistics and quality of care due to the remoteness of Native villages. Counselors also mentioned that they often have difficulties during sessions with their clients’ quietness and lesser extent of expressed emotion. Furthermore, counselors reported difficulties arising from issues related to appointment compliance. **Table 4** lists the main components of counselors’ challenges regarding their sessions with Native clients.

<table>
<thead>
<tr>
<th>Challenges with…</th>
<th>Frequency of statements</th>
<th># counselors who commented</th>
</tr>
</thead>
<tbody>
<tr>
<td>…Logistics and quality of care due to remoteness of Native communities.</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>…Clients’ quietness and lesser extent of expressed emotion.</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>…Clients’ poor appointment compliance.</td>
<td>7</td>
<td>2</td>
</tr>
</tbody>
</table>

**Challenges with logistics and quality of care due to remoteness of Native villages**

Counselors stated that the overall quality of medical care in remote Native communities does not reach the same level of quality as in larger cities and that specialty
health care is often not available for Native individuals. Therefore, Native individuals need to travel in order to obtain certain kinds of medical care as genetic counseling services. Participants further explained that their Native clients often face difficulties with regard to the approval of travel and payment of travel costs by third parties. This can prevent patients from coming to their appointments. In addition to cost barriers, counselors noted that Native clients are often intimidated by larger cities, creating an emotional hurdle that clients need to overcome in order to gain access to certain medical services. In addition, some counselors remarked on the logistical challenges that come with the shipment of medical or nutritional supplies to small villages via small aircraft. 

As a consequence, availability of such goods is a problem for many Native communities.

_We find that it’s much more difficult that in the villages they don’t have the amount of services and specialized services, and so it takes a little bit more effort to coordinate transportation or making sure that they’re getting hooked up with all the resources we can offer for them._ (Counselor #9)

_...the health care that they get when they are out on the reserve, when they are up in [name of area], is not the same that, as what someone would get in [name of town], so we frequently get thirty-week diagnoses of gastroschisis or something that if you had had an ultrasound in [name of town] should have been detected at sixteen, eighteen, twenty weeks, and then we have to deal with these patients at such a later point in the pregnancy, or it never comes to attention until the baby is born._ (Counselor #2)

_And sometimes the families don't quite understand the steps that they need to take, because there are so many more steps. You have to get the formula on a small plane to get to the village, and get that done regularly every month, that it's quite a lot of work, and you really need to get these families on board to understand that it is work, and yeah, so, so it's been a challenge in those regards._ (Counselor #5)

**Challenges with clients’ quietness and lesser extent of expressed emotion**

When asked about challenges that counselors encounter during sessions, participants reported several difficulties related to the conversation between counselor and Native
client. Many counselors said that they struggle with tailoring the counseling sessions appropriately since they do not get as much feedback from Native clients as compared to clients from other cultures. Counselors stated that it is generally harder to elicit both factual information as well as emotional reactions. Overall, there is less verbal communication from the clients than what counselors would expect. Some counselors commented on differences in communication patterns, which often results in less back-and-forth exchange between counselor and client.

> It’s like pulling teeth to get them to ask questions. Well, it is. It’s difficult. (Counselor #3)

> ...their emotional reactions are pretty difficult to read. The reaction appears to be that there’s no reaction. (Counselor #4)

> But they will, the way, it's like we don't have the same kind of dialogue. We don't intervene all the time. I speak a lot, they will listen very much, then they will speak a lot. So it's like if they take their time for almost everything. (Counselor #10)

> It's very difficult to get information, to get the normal information and details from them. Even very concrete, objective things that are easy for us in our culture, like family history information, is more difficult to elicit in those patients. (Counselor #12)

**Challenges with appointment compliance**

Two counselors mentioned that there is a higher rate of occasions where Native clients do not come to appointments or follow-up appointments. They also said that their Native patients are not always on time for counseling sessions. These counselors suspected that complicating factors in peoples’ lives might play a role in preventing patients from coming to the sessions. The participants also thought that Native individuals may have a different sense of time or timeliness in general.
I guess organization has maybe stood out more with respect to them being organized enough to come to their appointments, and I don’t know if it’s organized or that there’s so much going on sometimes in their life to come to their appointment... (Counselor #4)

...and to follow through with all the things that genetic counselors often request of their patients, like getting people’s permission to get records and things like that. Coming back for follow-up appointments. I’d say there seems to have been a higher frequency of that not happening. (Counselor #4)

Less frequently occurring difficulties

In addition to the challenging aspects already mentioned, some counselors commented on a few less frequently occurring difficulties when counseling Native clients. Four participants reported that they had problems interpreting their clients’ reactions to information since the clients avoided eye contact or did not show facial expressions. Other comments referred to challenges with sessions because of time constraints and a lack of a comfortable counseling environment. Counselors also mentioned that they had difficulties gaining their patient’s trust.

Because coming here, being rushed to [name of town] to the university hospital and being in crisis isn't really the right setting to create that trust. Of course it's the best we can do with what we have, but I would love to see a day where we can do more. (Counselor #8)

THEME 3) UNDERLYING ISSUES COUNSELORS HAVE IDENTIFIED AS CONTRIBUTING TO SESSION CHARACTERISTICS AND CHALLENGES

Throughout the interviews, counselors offered reasons, explanations and assumptions for challenges encountered during sessions or other phenomena that counselors came across with Native clients.

The highest frequency of comments addressed the issue of communication challenges, especially the challenges with clients’ quietness and lesser extent of
expressed emotion (as outlined in the previous section), and the generally different nature of sessions when counseling Native clients (as explained in the first section). Counselors identified four potential reasons for these challenges/differences: reasons inherent to the Native culture; Natives’ perspective on genetics and medicine; rural lifestyle of Native communities; and triggering factors brought on by the counselors or circumstances related to the appointment. Some study participants who commented on the communication challenges were unable to offer an explanation for these challenges. They stated that they felt unsure about where these difficulties stem from. Table 5 lists each of the aspects explaining the communication challenges and other challenges.

Table 5: Underlying reasons for challenges

<table>
<thead>
<tr>
<th>Reasons for challenges lie in…</th>
<th>*</th>
<th>**</th>
<th>***</th>
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</thead>
<tbody>
<tr>
<td>…Cultural differences/the Native culture.</td>
<td>7</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>…Natives’ perspective on genetics and medicine.</td>
<td>7</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>…The rural lifestyle of Native communities.</td>
<td>3</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>…Triggering factors brought on by the counselors or circumstances related to the appointment.</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Counselors can not explain where communication challenges stem from.</td>
<td>8</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

* Frequency of statements with regard to communication challenges  
** Frequency of statements with regard to all challenges and phenomena  
*** Number of counselors who commented with regard to all challenges and phenomena

As mentioned above, counselors identified underlying issues and reasons for communication challenges and session differences. Some of these underlying issues also explained other challenges (e.g. mistrust) or phenomena (e.g. Native clients’ accepting nature of diagnoses). Figure 3 summarizes the connection between underlying explanations given by counselors (rectangles) and observed characteristics or experienced difficulties (ovals).
**Reasons inherent to the Native culture**

Some interviews showed that counselors think that cultural reasons might be the underlying factor for communication challenges.

*I couldn’t help her in that way, because she was not able to express her sadness to me. Couldn’t or wouldn’t, for cultural reasons, I guess. So that sticks out in my mind as being challenging from a counselor’s point of view. (Counselor #12)*

In addition, we found that counselors suspect cultural reasons to form the basis for three other aspects: Participants noted that Native clients seem more accepting of genetic diagnoses compared to other clients and believed cultural factors to play a role.
There might also be this thing where it may not be part of their culture to go get everything investigated to the Nth degree. Like if someone's born with a problem, they might be more accepting of it, and they don't really need to know exactly why this happened, how it happened, it's just that that's how this person is. I could see that being potentially a bit more, their culture depends probably on how westernized they are. (Counselor #4)

Likewise, counselors saw cultural differences as an explanation for the lesser extent of eye contact and the fact that time/timeliness does not have the same importance for Native individuals as for Westerners.

Native perspective on genetics and medicine

As mentioned above, cultural reasons can explain communication differences and clients’ greater acceptance of medical diagnoses. Likewise, the perspective of Native individuals on genetics also seems to underlie these characteristics.

I'm thinking, "Am I not coming across approachable?" All of those evaluations you do on your own sessions. And I haven't been able to pinpoint anything. Sometimes I think it's just a discomfort with being one on one, looking at a topic that is foreign to them. (Counselor #3)

Overall, many counselors simply stated that they believe their clients to have a different point of view with regard to genetics. Participants also pointed out that day-to-day care of affected family members or psycho-social issues are of greater importance in their clients’ lives than genetic mechanisms. In addition, counselors found that Native clients often have their own alternative explanations for genetic conditions.

I think a lot of individuals who particularly live in small towns, way up North, there are so many things that they have on their plates, and worrying about a family history of X condition typically isn't the first thing they're going to worry about that day. (Counselor #8)
In addition, counselors commented on genetic conditions that are more common among certain Native communities and suspected that the patients’ easy acceptance of these conditions stems from the clients’ familiarity with them.

...in some of the smaller villages there may be multiple individuals from different families who are somewhat related families, actually, who have a similar genetic condition, so it's not as big of a, it's more normalized in those communities, because they have seen other people with the same condition...(Counselor #6)

Participants also hinted that Natives’ different outlook on genetics or genetic conditions may be the reason for their mistrust toward westernized medical viewpoints.

And so I was trying to present this information to the families without freaking them out too much, because it is a milder condition. (...) So it was probably really eye-opening for me to try to work with the native populations, because so many of them were just, they didn't know why we were so bothered by this, the fact that it was so mild. And also some of the elders in the villages and the native groups, they were also bothered by the fact that they felt like the natives were being exploited. So it's been a little rocky path to tread here...(Counselor #5)

**Rural lifestyle of Native communities**

Some counselors saw a connection between rural lifestyle of their Native clients and the communication differences between counselor and client in the session.

Generally, I find if they're from a really isolated community, it's a lot harder to communicate. I don't know why that is. I don't know if it's because they have such a lack of services in those types of areas...(Counselor #7)

In addition, counselors mentioned that the remoteness of villages and reserves causes reduced quality of medical care individuals are receiving. It also appears as if Native clients from rural areas are less informed about medical services, such as genetic counseling. Counselors stated that these factors seem to result in fewer referrals for genetic counseling or greater difficulties explaining the benefits of genetic services.
[Talking about contracting] Which really should be done with every family, but many of the times non-native families have been fairly well prepped as to why they are coming to genetics, and so they're anticipating that level of detail already. So I guess that's the difference that there would be. (Counselor #6)

**Triggering factors (counselor or circumstances) and uncertainty of counselors regarding underlying reasons for difficulties during counseling sessions**

Two counselors stated that both the circumstances surrounding a counseling session (such as the involuntary nature of genetic consults) as well as counselors' actions during a session might trigger some of the communication challenges as well as other session challenges.

*I would say hard to elicit emotion and feeling. Sometimes the clients don't want to look me in the eyes, at least not for a long period of time, or want to avoid the topic, or maybe I get the sense that they're just there because someone told them they should be. I mean, a lot of the time that actually is what happens, because of those in-hospital consults it's not exactly a choice.* (Counselor #8)

INTerviewer: Do you think it's easier to kill a session compared to other clients from other cultures? Do you think that happens easier than with other clients?

Interviewee: I think it does, to be honest. I would say in general it's easier to, I might do something that I don't even view as being rude or inappropriate or, and I might actually close that person off right away, and not even recognize why I've done it. Some of that might be their own past, some of it might be that culturally I did something that was maybe offensive and I don't know it. So I would say in general it's maybe easier to do that, and I try to be a little bit more careful in how I say things or word things. But like I say, I might be doing things to the - say that I don't realize or recognize that they're wrong. (Counselor #8)

Many counselors stated that they are not sure what factors could explain the communication challenges that counselors experience in sessions with Native clients.

*And I always find when I'm not getting feedback from a patient that you're not really sure is it because they have no interest, or because they don't understand anything that I'm telling them, or they just don't care. So I guess that would be my number one -- they're less responsive. That makes it more difficult.* (Counselor #2)
I really had no idea what it meant. I interpreted it as perhaps a lack of engagement in the genetic counseling process, lack of, well, I just really didn't know what it meant…(Counselor #12)

THEME 4) SUGGESTIONS FOR IMPROVING GENETIC COUNSELING SERVICES FOR NORTHERN NATIVES

We identified three areas that may be helpful for improving genetic counseling sessions and services for Native clients: (4.1) Practical strategies for improving sessions; (4.2) Suggestions for the future; (4.3) Informative medical and psycho-social aspects.

4.1) PRACTICAL STRATEGIES FOR IMPROVING SESSIONS

Counselors’ statements made clear that most counselors who interact with Native clients come up with counseling strategies in response to their clients’ quiet and reserved manner as well as to cultural differences between counselor and client. Counselors often tailor their counseling approaches to take into account their clients’ different perspective on genetics and the slower pace of sessions. Two counselors stated that they do not use any special counseling techniques when counseling Native clients. Table 6 summarizes these strategies.

Table 6: Session strategies

<table>
<thead>
<tr>
<th>Strategies in response to…</th>
<th>Frequency of statements</th>
<th># counselors who commented</th>
</tr>
</thead>
<tbody>
<tr>
<td>…Clients’ quietness and reserved manner.</td>
<td>26</td>
<td>8</td>
</tr>
<tr>
<td>…Cultural differences between Caucasians and Natives.</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>…Clients’ perspective on genetics.</td>
<td>18</td>
<td>6</td>
</tr>
<tr>
<td>…Slower pace of sessions with Native clients.</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Counselors did not use any special counseling techniques in sessions with Native clients.</td>
<td>2</td>
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Strategies in response to quiet and reserved manner of Native clients

The interviews showed that many counselors accentuate certain counseling techniques when counseling Native clients from whom it is harder to elicit thoughts and feelings. Generally, counselors stated they check in more frequently with the client and ask more questions, sometimes in a very direct way. Counselors also reported they contract longer in the beginning of a session. Some counselors emphasized that it is crucial to wait for a client’s response (even if this results in a pause in the conversation), and not to interrupt the client when she/he is talking. One counselor said that she tells an example (of two partners who are both carriers of a recessive condition) in the form of a story at the beginning of the session.

...don't be long-winded. Ask your questions in a straightforward way and just pause, and wait until they respond to your question. (Counselor #11)

I would say to be patient. And don't try to interrupt them when they start to speak. And don't give up because you have the feeling that you don't have feedback immediately. Don't give up because you have the feeling that they are not interested because they don't assume any questions. Take your time. Do like them. They look at you, and listen with you. Do the same thing. (Counselor #10)

Strategies in response to cultural differences

Many counselors emphasized the importance of self-awareness in these multicultural counseling sessions and stated that it is essential for counselors to be open, flexible, non-judgmental, accepting, fair and equal. Participants also said that it is important to learn about the Native culture from clients in order to gain a better understanding of cultural differences. In addition, some participants thought that it is helpful to accept the fact that many of the sessions with Native individuals feel differently.

Just to be open and flexible and non-judgmental. (Counselor #1)
...I know my limitations, and I don't know some of the groups very well, but I love to learn from them, and I try to convey that back to them that I am learning from them as much as they can learn from me. (Counselor #5)

**Strategies in response to clients’ different perspective on genetics**

Counselors stated that they approach clients’ differing perspective on genetics and/or their unfamiliarity with genetics by making genetic related concepts clearer and easier to understand. Many counselors said that they spend more time contracting, give smaller pieces of information, use more analogies, and provide resources at an appropriate literacy level. Some counselors believed that a more directive counseling approach is helpful with Native clients. A few counselors commented on the fact that many of the metabolic conditions prevalent among different Native groups clash with the Native lifestyle and dietary habits. Those counselors suggested that it is imperative to help clients understand the hereditary nature of these conditions and the reason for dietary changes.

...I tend to use analogies a little more than I would, or at least take them to different levels and keep going with them probably more than I do with some [other clients]... (Counselor #5)

...it may be confusing to be too ambiguous about the different options, and to say that ultimately this is your decision, but, I don't know [...] how to express it correctly, but it just feels like you need to be a little bit more directive, but still leaving open options, but helping them more through the thought process than the non-native clients that we deal with or help. (Counselor #6)

I think the basic thing is shock, and also trying to relate to what does that really mean for them. And so with that my role I felt like was getting more in touch with trying to help them sort out how they can get the condition to kind of work in with their family. [...] Also when I'm trying to explain the genetics of it, I initially get a lot of those glassy-eyed, "I have no idea what you're talking about," so I feel like it's my responsibility to try to help them understand it, because there is a chance that they could have more children with that, and helping them through with knowing the recurrence chances, other people in the family that might be carriers. (Counselor #5)
Strategies to slower pace of sessions

Many counselors believed that it is important to be patient when working with Native clients. They also said that it is essential not to rush and to talk at a slower speed.

*Just that we're on a different time frame and time schedule and it's noticeable to me in that I need to consciously make an effort to slow down and match their affect and way of speaking and speaking slower.* (Counselor #9)

*I learned to be more Zen. [...] I mean, to wait, to take time, and to try to don't be in a rush all the time, and mainly it's about that.* (Counselor #10)

Absence of specific counseling strategies

The counselors who said that they do not apply any particular strategies explained that they use the same counseling techniques with their Native clients as with any client.

*...I don't think I did anything differently because she was a native patient. It was the same thing I would have done in any situation if I didn't know what my patient was understanding...* (Counselor #11)

*...I think it's just part of counseling. Where if I find that I'm talking to someone and I've got a blank stare, I think, "Oh, okay, this isn't going to do," so I change my tack. So I think it's much the same. I think it's just what we do. I don't think it's any more so than anyone else.* (Counselor #1)

4.2) SUGGESTIONS FOR THE FUTURE

During the interview process, we asked study participants how they would improve genetic counseling services for Native individuals if circumstances were “ideal,” if there were no limitations of funding or resources. One of the two most mentioned ideas was for counselors to gain knowledge directly from Native colleagues or individuals. The other idea was to improve genetic and medical services in villages or reserves.
Learning from Native individuals

Many counselors explained that they would like to gain more specific knowledge about Native beliefs and cultures as well as sensitive topics as they pertain to the genetic and medical field. They also wished to gain insights into their clients’ way of communicating. They believed that an improved understanding in these areas would help them to better connect with their Native clients, enabling them to be more effective and supportive of Native clients.

Participants stated that cultural awareness classes, which are commonly offered by hospitals in Northern Canada and U.S., are rather ineffective since they only offer historical and factual information regarding Native groups. They reported that deeper insights into cultural aspects and beliefs are usually not shared.

Therefore, counselors suggested that it would be most helpful if they could gain this knowledge from Native individuals directly. They thought that Native health care professionals, liaison workers, consultants, individuals who received genetic counseling and elders would be excellent resources. Participants believed that either one-on-one interactions with such individuals or classes, workshops and published materials would be of great help to mediate a better understanding of cultural and communicative aspects important to genetic counseling sessions.

I think it would be fascinating if there was a native individual who was trained in some kind of health care profession that would make a video or write a book or talk to other health care professionals to help us get the inside perspective. But I would say that’s the big thing is just more education in some way about the cultures and the beliefs and ways that would help us interact with them more efficiently and provide them better patient care. (Counselor #2)
Because I think unfortunately the issues that we're dealing with, in terms of really sensitive issues, aren't necessarily the kinds of things that would be covered by that. [cultural awareness class] And is there some way that we could have more access to some of the sensitive topics, like, what is the custom, or what are people's views on termination. (Counselor #7)

Improvement of genetic and medical services in villages/reserves

Many counselors suggested strategies on how to improve medical and counseling services in rural regions for Native communities.

Some counselors thought that the formation of health care teams, consisting of primary care providers, nurses, and counselors would be beneficial. This way, coordination of supplies and health care services for families could be organized among team members, with one professional (usually a nurse) being the local contact person for that family. Some counselors pointed out that, oftentimes, certain conditions are not only of relevance for one family, but a whole village, making an informed local health care provider even more important.

In addition, counselors thought it would be better if counselors/nurses could travel to Native communities for counseling appointments and outreach clinics instead of asking patients to travel to the hospitals. Such an approach would help to establish health care in rural areas and to build trust between health care providers and Native communities.

It's just that it's been so hard to get them here. They live way up North, and they need to be flown in, and if it were me, if I could make changes, and hire a bunch of genetic counselors, get a whole bunch of funding for more people. In my ideal world, we would go out to the communities, and we would build trust, and we would give people this information, because they do care, and they do deserve it. (Counselor #8)

...we are now trying to work with the local doctors and with the family to provide village counseling, if you want to call it that. That this is a public health issue beyond just this family, because there are many families within the village who are somewhat inter-related...(Counselor #6)
4.3) INFORMATIVE MEDICAL AND PSYCHO-SOCIAL ASPECTS

Throughout the interviews, counselors offered factual pieces of information of importance for their genetic counseling sessions with Native clients. We categorized these insights as medical and psycho-social knowledge. One needs to be aware, however, that some insights might only apply to certain Native groups. The sections below provide a listing of the insights shared:

Medical pieces of information

- CPT-1 deficiency (carnitine palmitoyl transferase deficiency) is more common among certain Native groups in comparison with the general population. Research identified one common mutation, which seems to be a variant, probably causing milder symptoms of CPT-1. However, childhood death has been suspected to be related to the variant/condition.

- There is a high level of consanguinity in some villages, causing a higher prevalence of certain recessive conditions.

- Generally, termination is not prohibited in the Native culture.

- To keep in mind for family histories:
  - Some Native groups are matriarchal and children may carry their mother’s last name.
  - Some Native groups are organized in extended families where adoption of children is common. Therefore, “relatives” are not always blood relatives.
**Psycho-social pieces of information**

- Some Native groups celebrate the life of a baby that has passed away shortly after birth (from a lethal condition) in a ceremony involving the burning of sweet grass. Certain hospitals have adapted to this custom and now offer rooms that are suited for such ceremonies and permit the burning of tobacco/sage/sweet grass.

- Sometimes, families carry out funeral rites within 24-48 hours after a loved one passed away. This can have implications for medical studies and bereavement counseling.

- Families of certain groups will pick a name and organize a funeral in their community for a prematurely born baby as long as the sex of the baby was known beforehand. Therefore, knowledge of the gestational age of the mother is important in such situations.

- Native clients may not make important decisions during a counseling session. Instead, individuals may discuss these matters at home with family and elders and inform the counselor of their decision at a later time.

- Native clients may process events and situations through storytelling. Storytelling may also be an important component of achieving understanding.

- Native clients may not trust other people (counselors) on the first visit; instead, trust develops over the period of several interactions.
THEME 5) OVERALL THOUGHTS AND IMPRESSIONS ABOUT THEIR COUNSELING EXPERIENCES WITH NORTHERN NATIVES

As outlined previously, many counselors tailor their counseling approaches to their Native clientele. Even though most counselors develop specific counseling strategies, a great number of study participants expressed doubts about their effectiveness as counselors in sessions with Native clients. At the same time, many counselors stated that they enjoy working with Native clients and admire their culture. Table 7 summarizes these reflections.

Table 7: Reflections

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<thead>
<tr>
<th>Reflections</th>
<th>Frequency of statements</th>
<th># counselors who commented</th>
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<tbody>
<tr>
<td>Counselors expressed doubts about their counseling effectiveness when working with Native clients.</td>
<td>26</td>
<td>10</td>
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<tr>
<td>Counselors expressed their admiration for the Native culture.</td>
<td>21</td>
<td>8</td>
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Counselors’ doubts

Many counselors expressed doubts regarding their counseling effectiveness with Native clients. Participants questioned their success when eliciting verbal and emotional responses from clients and when trying to make them feel comfortable in the counseling environment. Counselors also wondered how they could achieve a greater awareness of their clients’ culture, spirituality and beliefs.

...I think I fall back into doing the same thing I would do with anyone, which is asking if they have any questions, or is there anything I could clarify, but if I still don't get anything from them, I'm at a loss as to what to do. (Counselor #2)

And I felt useless. I felt completely useless. I felt like I didn't help that family at all. I got nowhere. I didn't even know if they understood the stuff that I was talking about in terms of the medical implications. It was awkward for me personally, and I felt like I didn't help them. (Counselor #7)
...I feel very ignorant about the different tribes and the differences in their backgrounds and their spirituality and their beliefs, and I know very little of that, and I feel like I should get to know more about that. (Counselor #8)

Counselors’ personal thoughts and impressions about Native culture

Many counselors shared some personal thoughts and impressions regarding their experiences with Native clients. A majority of participants said that they admire the Native culture and are impressed by the family and social networks inherent to that culture. Other counselors stated that they enjoy working with Native clients and admire the calm and peaceful manner of their clients.

I think it's a wonderful culture. I think the respect that they have for the environment and for life and some of their celebrations and different customs that way are amazing. (Counselor #1)

I'm really impressed by the support, the family networks and the social networks that exist. (Counselor #9)

[talking about difficulties related to life on reserve] And the fact that they can still make this [genetic counseling] an important part of their care when everything else in their life sucks big time, the majority of people, of families, it impresses me tremendously that they would make that effort when so many other things, their whole life is chaotic, and to make the effort to follow through just impresses me to pieces. (Counselor #3)
IV. DISCUSSION

In the following discussion, we will contrast counselors’ perspective on the Native communication style with the perspective of a Native individual, who shared her thoughts on this issue. Then we will highlight some differences between counselors with high and lower levels of experience counseling Native clients. We will conclude the discussion with some suggestions for improving counseling services for the Northern Native community.

In terms of communication style, most counselors said that their Native clients express their emotions to a lesser extent than clients from other cultures and counselors found their clients’ body language hard to read. Counselors also said that their clients have a relaxed/calm demeanor. None of the counselors we interviewed are of Native origin or are otherwise fully immersed into the Native culture. Some said that they have contact with Native colleagues at work, but no study participants stated that they have private relationships with Native individuals. Their statements with regard to Native communication style(s) therefore reflect a Western viewpoint.

When we talked to a Native individual (N. Charlie-Runfola, 2009, pers. comm., 16 April) who was willing to share her viewpoint on the subject of Native communication style, she emphasized that Natives are just as emotional as other individuals, but that they are more reserved about expressing their emotions. Native individuals use very fine body language to express their feelings and emotions. In fact, we learned that “Native individuals don’t need many words to express themselves; they rely on body language and quiet signals”. For example, the simple act of “looking down” is a Native way to express a feeling of discomfort or disagreement. From a Western perspective, this is a
very inconspicuous signal, but easy to pick up on for Native individuals as it is an obvious piece of body language in their culture. We also learned that the relaxed or calm demeanor of Native individuals in counseling sessions may not necessarily be a true reflection of their inner state of mind. The reason for their calm manner lies in their respect for other people and their goal to have good relationships with those around them. Native individuals do not wish to burden others with tension that they are experiencing and may keep their worries to themselves. As we learned, Natives think that it would bring bad luck to bother others with their feelings.

It is obvious that the expression and interpretation of communication and body language is different between the Native and Western culture. This can make cross-cultural communication difficult, as most of our study participants experienced. In addition, English is a second language to many Natives. We also learned from our Native resource, that counselors should use simple grammar and keep in mind that words do not always translate well between languages. Counselors should check-in frequently with their Native clients and ask directly: “Did you understand?” We also found out that Natives perceive the Western communication style as fast paced and intimidating. Therefore, counselors should speak more slowly and take their time.

One genetic counselor (whom we did not interview) with experience counseling Northern Native individuals recommended videos and articles by Melanie Cueva as resources for other counselors who work with Native clients. The videos give insight into the use of storytelling for educational purposes. This counselor also suggested two books by two other authors that she found helpful for improving her understanding of the Native culture and Native beliefs. We listed these resources in the appendix.
Even though all study participants commented on communication differences between the Western and Native culture, not all counselors perceived sessions with Native clients as different or more conversationally challenging compared to any other clients. Counselors with over ten years of experience counseling Native clients and two counselors who are fairly new to the profession but who have seen a large number of Native clients share a different perspective compared to those with less experience counseling Natives. The highly experienced counselors said that they find their sessions with Northern Natives no different from sessions with other clients and use the same counseling approaches. They also said that they generally tailor sessions specifically to the needs of each client, regardless of the client’s cultural background. Interestingly, these counselors did not emphasize any communication challenges with their Native clients but simply explained away any communicative issues with their own “growing pains” as genetic counselors. The more experienced counselors also spent more time talking about some of the psycho-social issues that Native individuals face and seemed to have a higher level of understanding of the Native culture. They also expressed a lot of admiration for the Native culture and their statements account for the high frequency of positive comments regarding Native culture and characteristics of Native clients.

*I think it's a wonderful culture. I think the respect that they have for the environment and for life and some of their celebrations and different customs that way are amazing. I guess another example I was thinking of, it wasn't a patient I was directly involved with, but a family who had had a prenatal diagnosis of a lethal condition, so they had planned the baby's birth, and they had a native celebration with the burning of sweet grass and when the baby was born, so that they made the most of his life, and celebrated his short life. And it was just beautiful. It was, it incorporated so many of the different, their cultural beliefs, and all the important people around, and it was really nice. I think it's a wonderful culture to learn about. (Counselor #1)*
It makes sense that more experience in working with individuals from a different culture leads to a better understanding of the culture as a whole and the way in which individuals from that culture communicate and interact. Thus, this might explain why highly experienced study participants hardly mentioned session differences or communication difficulties and talked about psycho-social issues instead. In contrast, less experienced counselors are not only new to interacting with clients from different cultural backgrounds, but in addition, have less experience with different personalities overall. This might explain why less experienced counselors in this study talked more about session differences and struggled more with the Native ways of communication.

However, a high level of counseling experience with Natives did not necessarily eliminate a counselor’s doubts about their own counseling effectiveness. Even counselors with many years of experience expressed doubts about whether or not they are able to reach their clients and meet their needs. Put differently, even though some counselors did not perceive communication and cultural differences as a difficulty, they still wondered if they were effective as counselors. Only two counselors did not express any doubts. One has seen a large number of Native clients throughout her career and the other works exclusively with Native clients. All other study participants described difficulties in connecting with their clients conversationally or culturally (when clients are extremely quiet or when counselors feel like they might be culturally insensitive). It is possible that counselors misinterpret silence as counselor ineffectiveness. It could also be that doubts arise from unrealistic expectations. Maybe counselors would feel more efficient if they accepted slower pace and less fluency in conversations, instead of interpreting these differences as indicators of their own ineffectiveness. Therefore, it may be important for
counselors who work with Native clients to allow for a different kind of dialogue and become more comfortable with silences and pauses in conversations when it seems appropriate. However, not all Native individuals communicate in the same way and client-specific counseling and tailoring of sessions should be the first goal when approaching any client.

Finally, we would like to summarize some suggestions for improvement of services for the Native clientele. Many counselors that we interviewed thought that learning about Native culture(s) and beliefs from Native individuals directly, such as health care professionals, elders and clients, would be most beneficial. They also suggested establishing working relationships/teams with nurses and physicians that provide services in Native communities. This way, counselors could draw on their colleagues’ experiences with Native clients, and, at the same time, provide accessible genetics services to remote villages. Many counselors suggested that it would be helpful if counselors traveled to Native villages/reserves, instead of their clients traveling to the cities. This way, it would be possible to create a new platform for genetic education and counseling sessions. Counselors and other health care providers could provide educational group sessions to the whole community, followed by individual counseling sessions. Maybe flexible walk-in sessions would also be possible if genetics clinics took place in Native communities directly. This way, the counselors could establish trust while introducing themselves to the whole community. In addition, clients would be able to discuss their thoughts with family members and make difficult decisions together with their families. When we talked about this suggestion with the Native individual who gave us her insight earlier, she thought that bringing genetic services to Native villages would be an excellent
approach as it would take away the stress of travel. She explained that many Native individuals who live in remote areas do not like to leave their homes and feel intimidated by Western cities. Therefore, holding genetics clinics at the villages would make Native clients more comfortable.

Learning about another person’s culture – in this case a Native culture(s) – is difficult and will entail personal initiative outside of the clinical setting. The clinical setting often constitutes a stressful environment to clients that does not lend itself to relaxed accumulation of cultural knowledge. Furthermore, in a clinic, the counselor and the client do not meet as equals. Better approaches could include: counselors attending Native cultural events, such as the “Eskimo Olympics” or simply spending some time in Native communities. This way, they could observe how Native individuals interact with each other. They would also have the opportunity to interact with Natives themselves and make contacts in a comfortable environment. Such contacts with individuals might even develop into relationships that allow for conversations about Native perspectives on genetic counseling specific topics. Maybe a combined approach of learning about Native culture(s) outside of the clinical setting as well as in clinic will be most efficient in increasing cultural understanding and improving genetic counseling services for Northern Natives.
V. LIMITATIONS

There are several limitations to this study. First and foremost, we could not recruit and interview any Native individuals who had received genetic counseling. Ideally, we would have liked to interview both counselors and Native clients. This would have allowed us to compare counselors’ and clients’ impressions of each other as well as their thoughts on these multicultural genetic counseling sessions. Furthermore, Native individuals would have been able to answer many of the questions that this study is unable to elaborate on. For example, we would have learned if clients feel that counselors meet their needs. This could have validated or dismissed the doubts that counselors have regarding their effectiveness in sessions with Native clients.

In addition, we could only recruit a small number of study participants and none of the counselors were immersed into the Native culture. Ideally, we would have liked to interview many immersed counselors since they might have been able to better explain culturally related differences (such as the differences in communication patterns between Caucasians and Natives).

Another limitation consists of the subjective data analysis by the principal investigator, a drawback of many qualitative research studies. The principal investigator identified some codes and themes common to all interviews, but may have been subjective in the selection of these topics. Ideally, a number of researchers would have coded the interviews and identified themes. This would have ensured a more objective selection of subject matters and the most common themes could then have served as study data.
VI. CONCLUSIONS

The interviews with genetic counselors and genetics nurses showed that these health care professionals have a great interest in learning more about the Native culture(s) and strategies for improving genetic counseling services for this clientele. All counselors emphasized that there is a need for input from Native individuals and knowledgeable medical professionals with regard to these multicultural genetic counseling sessions. Specifically, counselors expressed their wish to gain insight into Native viewpoints on genetic counseling related issues. In addition, counselors would like to understand what Native clients think of genetic counseling sessions and whether or not clients feel satisfied with the genetic counseling services the counselors are providing.
VII. REFERENCES


http://www.ucalgary.ca/applied_history/tutor/firstnations/civilisations.html,
http://en.wikipedia.org/wiki/First_Nations
VIII. APPENDIX

A. **Resources**

- Movies available to view at the ARCTIC HEALTH website:
  
  http://www.arctichealth.org/anthcvideos.php

- Movies available at no cost from “Native CIRCLE” at:
  
  http://www.nativeamericanprograms.org/index-circle.html


- Hammerschlag, Carl, M.D. Theft of the Spirit: A Journey to Spiritual Healing.
B. Literature Review

Multicultural Genetic Counseling with Alaska Native and Canadian First Nations Clients

Literature Review

“Although Native Americans are a small minority of the U.S. population, they are burdened with a disproportionate share of social and economic problems. They are often caught between two cultures; their own historical tribal culture has been oppressed, often violently, by a dominant culture that has consistently devalued and ignored the achievements of the tribal culture, glorifying instead the ideal of cultural assimilation (the so-called melting pot). And yet, because of the confiscation of their lands, Native Americans must in some way depend on the dominant culture for the provision of basic life necessities while often feeling in conflict with the values and models of success of that culture.” [10]

I. Overview: Alaskan and Canadian First Nations Natives

The first Canadian and American Natives came from Northeastern Siberia to North America during the last Ice Age via an existing land bridge across the Bering Strait. Today, about 2.6% of Alaska’s population is of Native heritage. Alaska Native groups consist of over 225 federally recognized tribes that belong to five major cultural/geographical groups. Two main Eskimo groups, the Inupiat and Yupik, live along Alaska’s coastlines. The Inupiat belong to a group of culturally similar indigenous peoples called Inuit who live in the arctic regions of Alaska, Canada, Greenland and Russia [20]. The Athabaskans live in the interior of the state. Aleut & Alutiiq Natives inhabit the Aleutian Islands. Alaska’s Southeastern Natives consist of the Tlingit, Haida & Tsimshian. The languages spoken by different groups stem from entirely different language families and dialects exist within certain groups. Approximately half of Alaska Natives live in urban areas while the remaining Natives live in remote and rural villages, maintaining a subsistence lifestyle [04,20].

Approximately 2.2% of Canada’s population consists of Native tribes. When the Europeans arrived in Canada, over 55 Nations populated the Canadian land. Currently, there are 615 recognized First Nations groups and 10 distinct First Nations language families in Canada. “First Nations” is an ethnic umbrella term for indigenous people of Canada that excludes Inuit people (formerly known as Eskimos) and Metis people (who have Indian and European ancestors) [21]. However, since Inuits and Metis people are also ancient inhabitants of Canada, the term can include these populations as well. I will use the term “First Nations” with the understanding that Inuit and Metis people are included in the term [21].
II. The “dominant” culture and the Native culture

1. General themes regarding the Native culture

Native groups all across North America differ in tribal customs, rituals and language. Yet researchers believe that there exist shared cultural values that are common to most Native groups inhabiting this continent [06].

Generally, Indians have a holistic worldview which implies that life is lived in a circular fashion and in rhythm with nature [01,09,10]. As Heinrich et al. points out, holism usually includes unity of mind, body, spirit and nature. As a consequence, there is hardly any disconnection for Natives between daily activities, medicine and religion [10]. According to Struthers et al., Indians connect with the real world through religion or spirituality and perceive the world through a different lens than Caucasians [01]. According to this, it seems natural that Natives interpret the etiology of any difficulties they face differently than other cultural groups. Therefore, they seek different approaches to effect changes or find solutions to problems [06]. For example, Darou lists some values common to many Indian groups that may have implications for counseling sessions. According to Darou, “six values appear to be common to most Native groups: co-operation, lack of interference, respect for elders, the tendency to organize by space, not time, and dealing with the land as an animate, not inanimate, object. These are not necessarily values common among trained counselors” [03]. Another author also lists some values mutual to Indians of North America. These moral principles include respect, generosity, wisdom, spirituality, stewardship of the earth, humility, honor, identity, oneness, balance, harmony and connectedness [01].

Another major feature of the indigenous culture consists of the oral tradition and the use of narratives as a means to convey knowledge and wisdom [01,10]. Hunter et al. emphasizes the importance of oral tradition in the Native culture in a report on aboriginal healing. The report explains that verbal narrative is a part of the circle of life in the Native culture as well as a way to share experiences regarding health services [09]. From an Indian point of view, illness represents a disturbance in the harmony of life or a break in the hoop of life [10]. Holism and the use of oral tradition are essential in the healing process. Hunter et al. concludes his research as follows: “Healing holistically starts at any point in life and includes following a cultural path (losing and regaining culture), regaining balance (physically, spiritually, emotionally and mentally), and sharing in the circle of life (respectful interactions with others). This process does not have an endpoint, but rather it continues throughout the life span and becomes part of living” [09].

2. Circle of Life and the Rule of Opposites

Many Native groups believe that all life exists in a web of interdependence. They also think that humans live in cycles, likewise to the earth that rotates cyclically. Similarly, humans have a circle of self which includes mind, body, spirit and circle of family [06]. While the Western culture often perceives phenomena in terms of opposites, the Indian culture perceives these events as part of a circle. Accordingly, Natives see opposites as part of themselves (like the two opposing hands of the same body). Consequently, they view the choice between opposites as a source of their difficulties. This perspective is
called the rule of opposites and helps Natives to examine and understand their behavior and intentions [06]. The rule of opposites also implies that one can find truth in between two poles, rather than one extreme end of two poles. Therefore, the rule indicates that everything serves an important function in life. In addition, it demands that all humans question their assumptions, uncover underlying truths and live in balance [06].

The circle of life and the rule of opposites are important to understand when working with Natives in a counseling setting. They give the counselor some insight into the circular fashion in which Indians experience life and the way in which everything (good and bad) serves a useful function in their lives [06].

3. The Vision Quest

Traditionally, Native groups use a rite called the vision quest to help adolescent boys in their search for their role within the Native community and in life. The vision quest also serves adult men to bring about religious renewal [10]. Usually, a custom called sweat lodge experience precedes the vision quest.

Customarily, Native communities build the sweat lodge from birch bark, hides and saplings. This cubicle usually contains a pit filled with hot stones and a bed of sage and cedar. A medicine man and the adolescent pour herbal water over the stones in order to create an intense steam that symbolizes the ascending prayers of the boy’s tribe. The sweat lodge experience serves to prepare the adolescents’ minds and bodies for the vision quest. The quest is a four day long search during which each of the boys concentrates on identifying a path he is to follow for the rest of his life [10]. The adolescents spend the four days of the quest in a remote location, fasting and focusing on a vision pertaining to their purpose in life [10].

Native traditions like this can be helpful for the process of counseling and healing. Just like psychotherapy, the vision quest is a transforming ritual, encompassing three steps: severance, threshold and reincorporation. The three phases of the vision quest are equivalent to stages that individuals go through in psychotherapy: isolation from everyday life, transition and incorporation of changes into the everyday life [10]. The sweat lodge ritual and vision quest can therefore serve as metaphors that counselors can use in counseling sessions. Some alcohol treatment programs actually use the sweat lodge practice [10].

4. Differences between the Western and Native culture

It is evident that there exist major differences in world-view between the Native American and Anglo-American culture [06]. In contrast to the Western culture, Indigenous people of North America focus on a unity with nature, rather than a mastery over nature. They prefer natural explanations over scientific clarifications and live in the present, rather than the future. Furthermore, they value cooperation in contrast to competition and therefore also emphasize relationships over individuality. Native priorities also include humility and sharing of wealth. Contrary to this, Western values focus on gaining attention and saving for the future [06]. Heinrich et al. provides a quote by Richardson (1981) that describes the attitude of the ‘Western’ culture in a rather blunt and direct manner: (…) “the dominant culture is obsessive-compulsive, arrogant, has a
fetish for an all-or-nothing approach to life, and discounts its own inadequacies, which it partly suppresses and partly projects as an inadequacy of other people” [10].

5. Historic Distrust

After the Europeans arrived in North America in the 16th and 17th century, conflicts developed between the Indians and the Europeans. The Europeans had a materialistic view of the land and its environmental resources. The arrogant, exploitive attitude of the Westerners led to war when they claimed the Indians’ land. In a treacherous massacre at Wounded Knee, South Dakota in 1890, U.S. cavalrymen killed hundreds of Indian men, women and children. This massacre marked the end of the war and the beginning of the subjugation of the Indian culture by the Westerners.

Therefore, Native individuals may harbor a profound mistrust toward Western culture and individuals. This mistrust has its roots in the Native experience of colonization and marginalization by Western society. Therefore, it is not surprising that North American Natives often meet Caucasians with suspicion and sometimes even with hostility [02,05,10]. In addition, Western society continued to reinforce Natives’ distrust throughout history by continuing to give Aboriginals a feeling of inferiority [08].

This theme may also hold true in counseling settings and can pose a challenge for Caucasian counselors who works with Native clients [05]. In such a counseling relationship the counselor has to try to establish personal trust with the Native client while acknowledging the historic distrust the Indian may feel toward the dominant majority culture, of which the counselor is a representative of [08]. In order for effective counseling to take place, it is imperative for the counselor to recognize the duality of the issue of trust (inter-personal trust and historic distrust) and its magnitude [08].

It is likely that some of the difficulties that arise in counseling sessions have their roots in historic distrust. The Native clients may appear silent and withdrawn as a result of a suspicious “wait-and-see attitude.” Native clients may simply wait to determine whether or not the White (counselor) will listen or stop to pay attention as has happened countless times throughout history [08]. Natives may also expect certain manners from Caucasian counselors that are not welcome. These manners include giving advice, expecting change, judging, being inconsistent and moving too fast [08].

In order to be effective, Western counselors need to be aware of historic distrust and its consequences. In addition, time is critical to a counseling session. Lockart describes the issue of time in the following way: (...) “whereas Indian people have had to learn about the Anglo in order to survive in America, the Anglo has not reciprocated. If and when the Indian client wants the counselor to know anything of a personal nature, he will present the information, when he thinks the counselor is ready” [08].

6. Acculturation

Today, many North American Natives live in two cultures: their own tribal culture as well as the majority (Western) culture. Natives have to interact within the majority culture. Caucasians, in contrast, do not necessarily need to interact with the Native culture. As a consequence, this one-sided relationship can cause feelings of anxiety in Native individuals. These feelings of discomfort and anxiety are further heightened by
the past and current history of cultural abuse and discrimination of the Native community by the majority culture [07]. As a result, many Natives are caught in a predicament. On the one hand they try to avoid the loss of contact with their indigenous way of life. On the other hand, they struggle to become accepted in professional settings within the White society while fighting social rejection by their tribe if they become “too acculturated” [07]. The dilemma of maintaining both a Native and Western cultural identity can be distressing for some Aboriginals. Others may be competent navigating in both cultures [07]. One study reports that Cree adolescents who attempt to belong to both traditional and White societies show signs of identity conflict [03]. Another study emphasizes that Indigenous language and cultural constructs are subject to loss in the process of assimilation [01].

However, Bruce points out that (…) “first nations have not abandoned their culture in the same way that they have surrendered their land. (…) Fortunately, the churches could not undo tens of thousands of years of “Aboriginality” (…) [02].

Currently, there exists a continuum of acculturation among Native Americans. Some lead a traditional lifestyle or are at home in both the Western and Native culture. Others lead an entirely Western way of life and have few roots in the Native culture. Consequently, the interest of Native individuals in traditional culture may vary [10].

III Multicultural Genetic Counseling

Weil defined culture as a socially transmitted body of values, beliefs and behaviors. Furthermore, he defined ethnicity as the membership in a group that describes itself through culture, language, religion, race and geographic origin [14]. According to Weil, culture and ethnicity cause feelings of group identity and lead individuals of a certain group to perceive their culture as “truth”. In contrast, individuals view other cultures as external influences and as an assembly of cultural characteristics, not as an integrated whole [14].

Besides cultural roots, ethnocentrism is a part of every society. Ethnocentrism is based on the belief that one’s own culture is advanced/superior compared to other cultures and holds the ‘right’ societal norms and rules [18]. As Fisher points out, ethnocentrism is a barrier to effective genetic counseling. Therefore, counselors should be aware of their own set of beliefs and values. This is important since ‘American’ or ‘Western’ values can not only be foreign, but even repulsive to individuals from other cultures [18]. Genetic counselors should try to come to an acceptance of other people’s behaviors and beliefs that are inherent to their culture. This concept is commonly called “cultural relativism” [18].

As Wang describes in her paper “Multicultural Genetic Counseling: Then, Now and in the 21st Century,” multicultural genetic counseling has evolved from a cross-cultural approach [12]. Traditionally, the term ‘cross-cultural’ refers to people who are members of visible racial-cultural groups. Scholars of cross-cultural teachings have emphasized the importance of identifying visible racial cultural group-specific values, beliefs and behaviors as well as group-specific information about country and heritage. Awareness of these cultural characteristics helps minimize cultural barriers in the multicultural genetic counseling process [12]. However, Wang states that the cross-cultural focus has neglected to see clients as individuals whose values might differ from those of the
cultural group they ‘belong’ to. In addition, the author points out that the research community has underestimated how important it is for counselors to be aware of their own worldview. Wang explains that this awareness is crucial in order for counselors to overcome this ‘other-focused’ frame of reference and to approach a realistic understanding of themselves and others [12].

Multiculturalism, on the other hand, emphasizes the need for counselors to develop self-acceptance and to clarify their own set of beliefs, values, and cultural identities. This clarification is important since the counselors’ awareness of their cultural bases will affect their counseling skills [10,12,15,19]. It is important - in order for effective multicultural competence to take place - to realize that culture is not visible and that both genetic counselors and their clients are racial-cultural beings [12].

In conclusion, counselor and client are aware of each other’s ethnic background. Therefore, the counseling session is a bidirectional process in which transference and counter-transference play a role [13,14]. For that reason, counselors should try to dismiss stereotypes, especially when working in a multicultural clinical setting [11].

“Ultimately, (…) multicultural genetic counseling is a lifestyle that lends itself to an openness of understanding who people are rather than what some imagine they should be” [12].

IV Counseling Challenges

Research has identified some general challenges that commonly occur when Western health care providers counsel clients from non-Western cultures. Fisher explains that genetic concepts are particularly difficult to convey to individuals whose medical viewpoints conflict with Western medical approaches. For example, genetic counseling may not even be part of the patient’s beliefs. Also, clients may dismiss prenatal care as unnecessary since pregnancy is a private and natural process [18]. In addition, Fisher makes clear that difficulties often arise due to communication differences between counselor and client. These differences mainly concern verbal and non-verbal communication patterns. For example, non-Western clients may maintain less eye-contact, pause more frequently before answering questions and may not express their emotions as openly [18].

Researchers, who have studied counseling sessions involving Western counselors and Native Americans in particular, came to similar conclusions as Fisher. Garrett & Myers state that Native Americans often have different explanations for the causes of their problems. This can make the counseling process more challenging [06]. Heinrich et al. explains that the Natives’ distrust toward Western individuals can create a substantive barrier for effective counseling. In addition, Natives frequently perceive counselors’ queries as intrusive. As a result, the clients react with silence and passive non-compliance which create struggles for the counselors [10].

Darou specifically describes challenges that arise in counseling sessions involving Caucasian counselors and Canadian Native clients. The author explains that most counseling challenges arise from the different (cultural) approaches and expectations that counselors and Natives bring to the table [03]. For example, Native clients may expect the counselor to behave like a doctor or priest. However, this is most likely not the case.
Furthermore, Native individuals may only show little eye contact and give short answers, which are acts of respect in the Native culture. Unfortunately, counselors most often misinterpret this way of communication as resistance [03].

V Counseling Suggestions and Strategies

Researches have made helpful suggestions with regard to multicultural counseling in general and counseling North American Natives in particular.

First and foremost, it is important for counselors to understand their own ethnocultural background and belief system. At the same time, counselors should try to achieve a stereotype-free, accepting attitude toward individuals from other cultures. Ideally, counselors should also be open for different outlooks on health and disease [10,12,15,17].

Furthermore, counselors who work with Northern Natives should evaluate their clients’ level of acculturation with Western society. Hence, it is important that counselors familiarize themselves with their clients’ cultural background. However, counselors should always pay close attention to their clients’ personal values and beliefs as these may differ from the knowledge counselors acquired regarding the Native culture [03,05,10]. Learning about Native groups and cultures as well as listening to individual stories can also be very helpful in avoiding stereotypes [05,06].

Lockart, a member of the Modoc tribe and alcoholism counselor in Boston, MA, sees a connection between Natives’ distrust toward Western (medical) professionals and counseling challenges. She suggests that counselors should not appear all-knowing, give too much advice or question excessively. Counselors should not expect self-disclosure from Native clients as it is not consistent with their culture [08]. Instead, she advises counselors to rely on their patients’ non-verbal cues. Counselors should also remember that Native clients might watch the counselor closely for any inconsistencies which might reinforce feelings of distrust [08,10].

Heinrich et al. recommends practical changes in the counseling approach such as changing the typical ‘50 minute hour’, attempting sessions outside of the office and permitting drop-ins [10]. He also suggests that counselors expose themselves to Native cultures by visiting reservations and attending rites.


C. Brandeis University IRB Protocol

Multicultural Genetic Counseling with Alaska Native and Canadian First Nations Clients

IRB Protocol

STUDY PURPOSE

Multicultural Genetic Counseling and Northern Natives
Over the past decade, the field of genetic counseling has become increasingly aware of the need for responsible and informed genetic counseling for individuals from many different cultures and ethnicities. While North America is a continent of much diversity, the genetic counseling community is primarily Caucasian. In order to become an effective multicultural counselor, genetic counselors need to increase their knowledge of relevant ethnocultural groups while, at the same time, becoming more aware of their own ethnocultural roots and beliefs (Weil, J. 2001).

Genetic counselors/nurses who work in Alaska and Canada with a Native clientele therefore need to have general knowledge of the main Native groups in Alaska and Canada, their culture, their world-views and their belief systems. By learning about the characteristics/challenges that are unique to sessions between non-Native genetic counselors/nurses and Alaskan/Canadian Natives, the quality of counseling can be improved and the Native clientele in Alaska and Canada can be better served.

The following paragraph will provide an overview of the major Native groups in Alaska and Canada and clarify the use of some terminology as it pertains to this study.

Introduction to Northern Natives
The first Canadian and American Natives came from Northeastern Siberia to North America during the last Ice Age via an existing land bridge across the Bering Strait. Today, about 2.6% of Alaska’s population is of Native heritage. Alaska Native groups consist of over 225 federally recognized tribes that belong to five major cultural/geographical groups. Two main Eskimo groups, the Inupiat and Yupik live along Alaska’s coastlines. The Athabaskans live in the interior of the state. Aleut & Alutiiq Natives inhabit the Aleutian Islands. Alaska’s Southeastern Natives consist of the Tlingit, Haida & Tsimshian. The languages spoken by different groups stem from entirely different language families and dialects exist within certain groups. Approximately half of Alaska Natives live in urban areas while the remaining Natives live in remote and rural villages, maintaining a subsistence lifestyle (Allen, J. 2006; Hirschfelder, A. 1986).

Today, approximately 2.2% of Canada’s population consists of Native tribes. When the Europeans arrived in Canada, over 55 Nations populated the Canadian land. Currently, there are 615 recognized First Nations groups and 10 distinct First Nations language families in Canada. “First Nations” is an ethnic umbrella term for indigenous people of Canada that excludes Inuit people (formerly known as Eskimos) and Metis people (who
have Indian and European ancestors). However, since Inuits and Metis people are also ancient inhabitants of Canada, the term can include these populations as well. I will use the term “First Nations” throughout this study with the understanding that Inuit and Metis people are included in the term (see world wide web references).

**Study aim**

The purpose of this study is to explore genetic counseling sessions involving specifically Alaska Native or Canadian First Nations clients and genetic counselors/nurses.

By interviewing genetic counselors and genetic nurses who have counseled Alaska Native or Canadian First Nations clients, I hope to learn about:

- Specific characteristics (and challenges, if any) genetic counselors/nurses have experienced during these multicultural counseling sessions
- Underlying issues contributing to these characteristics (and challenges, if any)
- Suggestions for improving genetic counseling services for Alaskan and Canadian Native clients

This study will provide knowledge about genetic counseling sessions with Northern Natives of Alaska and Canada. The source of this knowledge is the experience of study participants. The study will lay out the suggestions given by the study participants of how to improve these multicultural genetic counseling interactions. Therefore, this study will help improve knowledge and provide guidelines for practice of genetic counselors/nurses who work with Alaska and Canadian Natives, especially those professionals who are new to the field or Alaska/Canada.

**STUDY SPONSOR**

Brandeis University Genetic Counseling Program.

**PRINCIPAL INVESTIGATOR'S QUALIFICATIONS TO DO THE RESEARCH**

The Principal Investigator is a student in the Brandeis University Genetic Counseling Master’s Program and is conducting this research project as a requirement for the Master’s Thesis.

**RESULTS OF PREVIOUS RELATED RESEARCH**

As reported repeatedly in the literature, genetic counseling involving non-Native counselors and Native (American) clients can be challenging (Lockart, B. 1981; Weil, J. 2001). These challenges are due to a variety of factors, one of which is the difference in values and beliefs (world-view) between the Western and Native cultures. For example, the Native’s holistic world-view and their tendency to organize by space, not time, may be foreign to the non-Native counselor (Darou, W.G. 1987). Another potential difficulty is the difference in communication styles. While counselors may expect their clients to be open and willing to share their thoughts, Native clients tend to share their thinking in accordance with their own inner timeline, which is tied to their trust in the counselor, rather than the session’s timeline (Smith, D.B. & P.J. Morrissette 2001). This phenomenon is mainly due to the historic distrust that most Natives feel towards those from the dominant majority culture. Therefore, in order to stimulate open communication
counselors may need to emphasize establishing inter-personal trust to overcome clients’ distrust (Lockart, B. 1981). Additional challenges may also arise in a session depending on the client’s level of acculturation and on the counselor’s cross-cultural viewpoint. As a result, the counselor needs to determine to what extent the client is immersed into the Western culture in order to tailor the session effectively (Heinrich, R.K. et al. 1990). The counselor also needs to be aware of her/his assumptions with regard to the client’s cultural group and explore whether the client’s world-view is different from what the counselor expects it to be based on the ethnic/cultural background of the client. In addition, counselors need to be self-aware about their own cultural backgrounds and beliefs since they will play a role in multicultural interactions with clients (Wang, V.O. 2001).

Despite the fact that Native groups all across North America differ in tribal customs, rituals and language, it is widely believed that there exist shared cultural values that are common to the native groups inhabiting this continent. The literature has described these common values and beliefs as they pertain to (genetic) counseling and includes a number of general counseling suggestions. For example, a holistic world view, story-telling as way of conveying information and experiencing medicine and spirituality as connected entities are inherent to Native cultures. Therefore, research has suggested to allow for ample time when counseling Native clients and to sustain openness to different outlooks on health and disease. (Darou, W.G. 1987; Garrett, M. T., & J. E. Myers. 1996; Heinrich, R. K. et al. 1990). However, there is limited information about genetic counseling with specific Native cultures in the literature.

This study will focus specifically on the characteristics and challenges encountered in genetic counseling sessions involving genetic counselors/nurses and clients from the Alaska and Canadian Native cultures. In addition to describing the counseling challenges from the viewpoint of the genetic professionals, the study will also attempt to identify the causes of any multicultural counseling difficulties from the viewpoint of the genetic counselors/nurses. By studying genetic counseling interactions with Natives from Alaska and Canada, I hope to develop a set of recommendations for improving genetics services for Alaska and Canadian Natives.

SUBJECT CHARACTERISTICS
Study participants will be genetic counselors and genetic nurses who have worked or are currently working in Alaska or Canada and have experience in genetic counseling with Alaska Natives or Canadian First Nations clients. Genetic nurses are licensed professional nurses with special education and training in genetics.
SUBJECT INCLUSION/EXCLUSION CRITERIA
In order to participate, a subject must:

- Speak English
- Have worked/be working clinically as a genetic counselor in any field of genetic counseling or have worked/be working as a genetic nurse, providing genetic information to clients
- Have counseled Alaska Native clients and/or Canadian First Nations clients

JUSTIFICATION FOR USE OF ANY SPECIAL/VULNERABLE SUBJECT POPULATIONS
No special/vulnerable subject populations will be recruited for participation in this study.

STUDY DESIGN
I will conduct qualitative phone interviews with 10-12 genetic counselors and genetic nurses regarding their genetic counseling experiences with Alaska Natives and/or Canadian First Nations. Prior to the interviews, the interviewees will receive a written paragraph outlining some key questions from the interview guide (Appendix II) in order to give them an idea of the main topics that we will explore.

STUDY PROCEDURES
Recruitment
I plan to recruit genetic counselors and genetic nurses via word-of-mouth as well as through a recruitment notice that will be posted on the NSGC (National Society of Genetic Counselors) listserv (Appendix I). My contact information will be included in the post. Potential participants will be able to contact me via phone or email.

Prior to enrolling a participant in the study, I will first determine his/her eligibility using a brief screening tool (Appendix IV). If a potential participant responds to my recruitment via phone, I will administer the screening tool via phone. If I am contacted via email, I will administer the screening tool via email.

Screening tool to determine eligibility criteria of potential study participants:

1. Do you speak English?
2. Are you working/have you ever worked clinically as a genetic counselor or genetic nurse?
3. Have you ever counseled individuals of Alaskan Native/Canadian First Nations heritage?

If a potential participant is able to answer all questions with “yes,” she/he is eligible to participate in this study.

Data Collection
I will interview each study participant by phone, and the interviews will be audiotaped. The interview questions will consist of open-ended and close-ended inquiries. The first set of questions will gather demographics and find out the level of experience each
The counselor has had working with Alaska Natives and First Nations. The next set of questions will stimulate responses from the genetic counselors/nurses with regard to particular sessions and the encountered characteristics/difficulties they encountered, their causes and possible counseling alternatives. The main focus of this set of questions will be to explore specific psychosocial interactions between genetic counselor and client. I will include any type of genetic counseling interactions (prenatal, pediatric, adult, cancer). At the end of the interview, I will ask more open-ended questions about the overall experience a counselor or nurse has had with the Native clientele (Appendix II).

**Data Analysis**
A transcriptionist will transcribe the audio taped interviews. I will analyze the transcripts using ATLAS software. I will then identify themes in the data, including specific as well as general characteristics (and difficulties) of genetic counseling sessions with Northern Natives. Another theme will consist of genetic counseling suggestions for these multicultural counseling sessions.

**INFORMED CONSENT**
Prior to the phone interviews, I will mail a consent form to each study participant (Appendix III). I will then review the informed consent form (ICF) by phone with the study participant. The study participant will then fax the signed ICF back to me, and will mail the original in a preaddressed, postage paid envelope. Upon receiving the signed ICF, I will sign as the Principal Investigator. No study interviews will take place until I have received the signed ICF.

**ADVERSE EVENTS**
I do not anticipate any adverse events related to study participation.

**COMPENSATION**
There will be no compensation for study participants.

**PRIVACY/CONFIDENTIALITY**
I will not store any information regarding individuals who are not eligible to participate in the study as determined by the screening tool. Accordingly, I will destroy handwritten notes I may have taken regarding an individual’s information during a phone call. Likewise, I will delete email responses to screening questions from individuals who are not eligible to participate. I will not store email addresses from such individuals in my email address book and I will delete the emails I have sent to these addresses from my email account. I will store information regarding eligible study participants as follows: I will store consent forms and audiotapes in a locked filing cabinet. I will store the participant’s demographic and identifying information in a password protected Excel sheet. In a separate password protected Excel sheet, I will link each study participant’s name to a coded ID number. Throughout the interviews, I will address each study participant using the ID number, instead of the participant’s name. I will use the coded ID numbers to label the interview audiotapes as well as transcripts of the interviews. Upon completion of the study, I will delete both password protected Excel sheets that contain the participants’ demographic and identifying information and the link between...
participants’ names and coded ID numbers. I will delete the Excel sheets from both the file folder they were stored in and from the computer’s recycling bin.

**COSTS**
There will be no cost to study participants.

**REFERENCES**


http://www.ucalgary.ca/applied_history/tutor/firstnations/civilisations.html
http://en.wikipedia.org/wiki/First_Nations
Appendix I
Recruitment Notice

○ Have you ever counseled Alaska Native or Canadian First Nations clients?

I am a graduate student in the Genetic Counseling program at Brandeis University in Waltham, Massachusetts. I am conducting a study on genetic counselor’s and genetic nurse’s experience with counseling Alaska Native or Canadian First Nations clients. I am interested in learning about the session characteristics and challenges that genetic counselors and genetic nurses have experienced when counseling members of these populations.

Participation is open to all genetic counselors and genetic nurses who have ever worked clinically with Alaskan/Canadian Native clients, and who are willing to be interviewed on the phone about their experiences.

Each interview will take about 30 minutes and I plan to conduct all interviews between January 1st and February 1st of 2009.

If you are interested in participating, please contact me by email (kelly@brandeis.edu) or phone (781-879-2566). If you know of anyone who might be interested in participating, please forward this notice to him/her.

Thank you for your interest and I look forward to hearing from you.

Sincerely,

Anke Kelly, MS
Genetic Counseling Graduate Student
Appendix II
Interview Guide

Opening Script:
Thank you for your willingness to participate.

For protection of your privacy, I will address you by using a coded ID, instead of your name.

I would like to begin by asking some demographic questions. After that, I would like to ask about specific counseling sessions with Native clients. Please feel free to elaborate and to bring up anything that is important to you. Towards the end of the interview I would also like to hear about your overall experience with the Native clientele.

1. Demographic questions:
   - How old are you?
   - What is your gender?
   - What is your ethnic background?
   - How many years have you worked in the genetic counseling/nursing profession since your graduation?
   - What fields of genetic counseling/nursing have you worked in so far (prenatal, pediatrics, cancer, adult, other)?
   - Which type(s) of genetic counseling/nursing do you currently practice (prenatal/pediatric/cancer/general)?
   - Do you currently work with Native clients? If yes, for how long have you been working with Native clients? If no, when did you work with Native clients and for how long?
   - What kinds of services have you provided to Native clients (prenatal/pediatric/cancer/general genetic counseling/services)?
   - How long have you been in your current position/the position in which you provided counseling/services to Native clientele? How many clients do you/did you see each month? What percentage of the clients are/were Native?
   - Approximately how many Native individuals/couples/families have you seen during your career so far? How many, on average, do you/did you see every month?
   - Other than through your work, have you had/do you have contact with the Native persons? For example, do you have friends or neighbors who are Native?

2. Questions regarding genetic counseling sessions:
   - What adjectives would you use to describe typical counseling sessions with Native clients? If you had to describe Native clients using three adjectives, what would they be?
   - What do you feel is unique about Native clients?
   - Do counseling sessions with Native clients differ from sessions with clients from your own culture?
- How do they differ? Can you give me some examples?
- Do you think these differences are unique to these clients being from a Native culture?

- Can you think of a particularly culturally challenging session with a Native client or family that stands out?
- What exactly made this session difficult for you?
- Was the difficulty due to the nature of the case or the fact that the client was from a Native culture?
- Where do you think this challenge stemmed from?
- Is there anything you could think of in terms of counseling strategy that could have helped minimize the challenges you described?
- Would you have done anything differently in this session?
- Is this type of session or level of challenge typical or atypical for you when working with Native clients?

- Can you think of a session with a Native client or family that was not especially different or unique from any other session with any other client?
- What distinguished this session from the more challenging one?
- Would you have done anything differently in this session?
- Is this type of session typical or atypical when working with Native clients?

3. Questions regarding the overall experience of the genetic counselor with the Native clientele:
   - Overall, do you experience challenges or difficulties when counseling Native clients? If so, about what percent of the time? What are challenges or difficulties that you encounter regularly with Native clients? Is time for each session one of them?
   - If so, what do you think causes these challenges?
   - What aspects of Native culture are most difficult for you to understand?
   - What are the most important things you have learned from your work with Native clients?
   - Do you have any words of wisdom for genetic counselors/nurses who will be working with Native clients for the first time?
   - Are there unique or different aspects to the counseling sessions in Alaska/Canada as compared to other places? If so, what is unique or different?
   - Are there any articles or movies you can recommend for students or counselors/nurses interested in learning more about Northern Natives?
Appendix III
Informed Consent Form

Participation Agreement:

I understand that this is a research study designed to explore genetic counselor’s and genetic nurse’s genetic counseling experiences with Alaska Native and Canadian First Nations clients. The purpose of this study is to learn about genetic counseling characteristics and/or challenges people have faced when counseling Native clients, possible underlying cause(s) of these challenges if any, as well as suggestions for effective counseling strategies for those counseling Northern Native individuals in the future.

I understand that the interview will last approximately 30 minutes, and will be audio taped. I understand that the researcher will remove and destroy my identifying information (name, city/state/country of residence, phone number or email) after completion of the interview and analysis process. The researcher will never refer to me by my real name, or any other identifying information, in any written or oral reports based on my interview. I understand that the researcher will assign a false name/ID if she will quote or refer to me in any written or oral reports of the study.

I understand that my participation in this study is voluntary and that I may discontinue my participation at any time and for any reason without consequence.

I understand that I may contact the Principle Investigator (PI), Anke Kelly, at 781-879-2566 or email kelly@brandeis.edu, if I have any questions or concerns during or following my interview and/or the study.

Should I have questions regarding my rights as a research subject, I understand that I may contact the Brandeis Committee for Protection of Human Subjects: Lorrie Clark, Compliance Administrator, mclark@brandeis.edu.

I agree that my phone interview will be audio taped. Yes ☐ No ☐

I agree to participate in this study under the terms outlined above. Yes ☐ No ☐

Please sign below:
Participant signature ________________    PI signature ________________
Participant name ________________    PI name ________________
Date ________________    Date ________________
Screening tool to determine eligibility of potential study participants:

1. Do you speak English?
2. Are you working/have you ever worked clinically as a genetic counselor or genetic nurse?
3. Have you ever counseled individuals of Alaskan Native/Canadian First Nations heritage?

If a potential participant is able to answer all questions with “yes,” she/he is eligible to participate in this study. I will then ask for her/his contact information:

➢ What is your contact information?