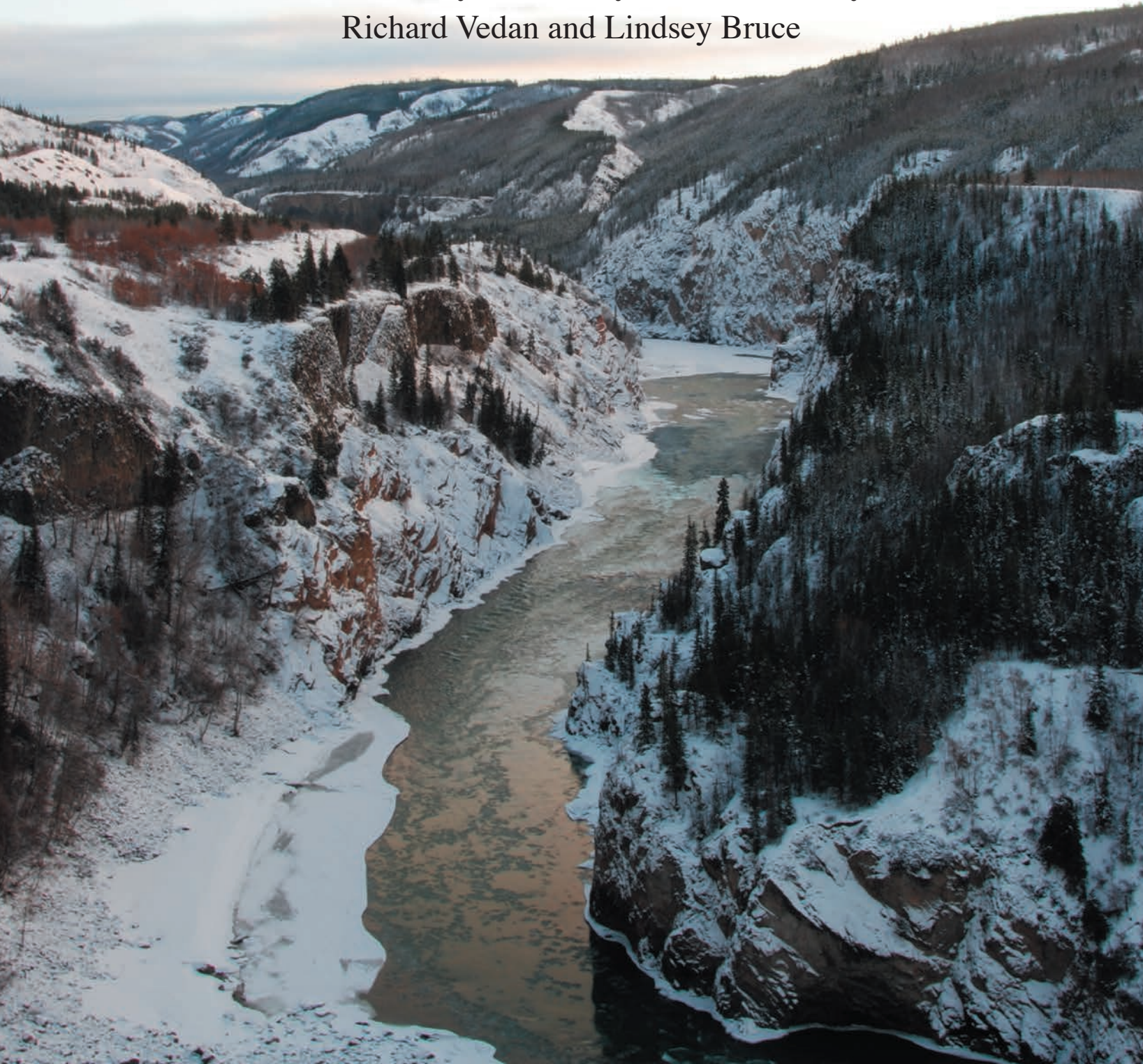


Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation



Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation

In Collaboration with
the Community Members of the Tahltan First Nation
and the University of British Columbia Research Team:
Shaun Stevenson, Judy Illes, B. Lynn Beattie, Emily Dwosh,
Richard Vedan and Lindsey Bruce

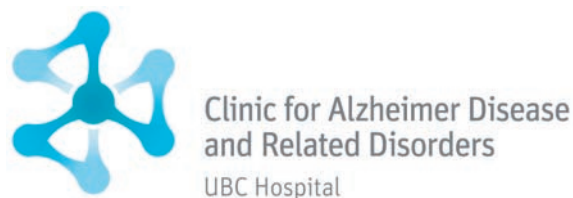


Acknowledgements

We express our immense gratitude to the Tahltan First Nation for welcoming us into their communities and sharing their experiences of early onset familial Alzheimer Disease. We especially acknowledge the project's Community Advisory Group and those community members who gave in-depth interviews and participated in focus groups with our research team. We thank you for sharing your stories and insights.

The research project described here was completed in conjunction with the Tahltan First Nation, the National Core for Neuroethics at UBC, and the UBC Hospital Clinic for Alzheimer Disease and Related Disorders. The project was part of the National Core for Neuroethics' *Cross Cultural Understandings of Aging and Dementia Program*, directed by Drs. Judy Illes and B. Lynn Beattie. We acknowledge all of our researchers, genetic counsellors, trainees, community liaisons, collaborators and advisors who devoted time, insight, and effort to making this program possible.

This research was made possible through the generous support of CIHR (MOP-111240), the North Growth Foundation, and the Vancouver Foundation (UNR10-0748). This work was further enabled by support from CIHR (NCE 85117), the British Columbia Knowledge Development Fund, the Canadian Foundation for Innovation, the Canada Research Chairs Program, and the Vancouver Coastal Health Research Institute.



a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

Credits

Principal Investigators: Dr. Judy Illes, Dr. B. Lynn Beattie

Report Author/Research Coordinator: Shaun Stevenson

Co-Investigator: Dr. Richard Vedan

Research Team: Dr. Elana Brief, Lindsey Bruce, Laura Cabrera, Jen Mackie, Shaun Stevenson

Genetic Counsellors: Rachel Butler, Emily Dwosh

Community Collaborators/Community Advisory Group: Annita McPhee, Nancy Norby, Christine Ball, Richard Jackson, Deborah Brakeley, Charlene Jacobs, Rick McLean, Carmen McPhee, Marie Quock, Louise Framst

Liaisons to the Community: Gayleen Day, Shannon Frank, with special thanks to the Community Liaisons who helped with our Community Based Researchers.

Academic Advisors: Dr. Wendy Hulko, Dr. Phillip Lee, Dr. Dessa Sadovnick

Graphic Design/Editor: Christopher Doody

Photography: Elana Brief, Rachel Butler

Publication Information

Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation, University of British Columbia, National Core for Neuroethics, Shaun Stevenson (author), October 2014.



The beadwork images in this report are the work of Nancy Norby, Tahl-tan community health-care worker and Community Advisory Group member.



Tahltan Words for Dementia

Kadousah – Not knowing if you're coming or going

Edu M'Diid Sugo ta a – Not brain well



Contents

Project Summary	8
Motivation and Background	
Communities	
Participants	
Community Engagement and Knowledge Gathering	
Understanding Alzheimer Disease	12
What is Alzheimer Disease (AD)?	
What is Early Onset Familial Alzheimer Disease (EOFAD)?	
Genetic Testing	
Risk Factors and Prevention	
Experiences and Understandings within the Tahltan Nation	16
Dynamic Experiences with EOFAD	
Traditional and Western Understandings of EOFAD	
EOFAD and the Significance of Intergenerational	
Knowledge Transfer	
Caring in the Community	
Genetic Testing	
Resources Needed	
Conclusion	23
Additional Information	24



Project Summary

This report summarizes community perspectives of the Tahltan First Nation and their experiences with early onset familial Alzheimer disease (EOFAD). The report also provides information about EOFAD for dialogue within and across Tahltan communities.

Participants' perspectives and teachings form the basis of the research project and this resource guide, which bring together Tahltan First Nation views and values with Western medical knowledge about prediction, diagnosis, and care for people in the community who are affected by the disease.

The specific goals of this research project were to:

1. Determine how the Tahltan Nation understands Alzheimer disease within both traditional Indigenous and Western medical frameworks,
2. Identify how culturally relevant resources can improve understanding of the prediction, diagnosis and care of this disease, and
3. Contribute to the creation of resources that are culturally relevant and meaningful to Tahltan communities.

Motivation

Between 1998 and 2009, nine members of the Tahltan First Nation were referred to the University of British Columbia Hospital Clinic for Alzheimer Disease and Related Disorders (UBCH-CARD) for medical assessment in the context of a strong family history of early onset dementia.

Genetic testing was conducted on an affected family member in 2006, identifying a mutation in the presenilin-1 (PS1) gene and confirming a diagnosis of EOFAD. Although many other families around the world are known to carry PS1 mutations, the PS1 mutation identified in this family has never been seen before and can therefore be described as a new, or novel, PS1 mutation.

Review of the family history identified over 100 family members in direct lineage of affected individuals and at risk of inheriting this condition.

The identification of the genetic mutation in this family raised concerns regarding dissemination of information and provision of clinical services given constraints posed by geography and funding. At the same time, it introduced potential research and educational opportunities. Through a Family Day event organized at UBCH-CARD and a health fair held in

the Nation's territories in 2009, the Nation signaled its desire to pursue further exploration about the disease and embarked on a collaborative endeavour with the National Core for Neuroethics at UBC and UBCH-CARD.

Background

The project began with the hosting of a collaborative planning meeting in 2009 with community members and Elders. This meeting set the parameters for a project that would be inclusive, beneficial and relevant for everyone involved. It led to a signed research agreement in 2012 and the formation of a Community Advisory Group, both of which have guided research throughout the project.

Focus groups and a family interview were held at different locations significant to Tahltan people, both inside and outside of Tahltan territories. Participants varied in age from young adults to Elders.

The recruitment and interview questions

were undertaken in collaboration with a Community Based Researcher and the Community Advisory Group. Tahltan Community Liaisons helped to plan and organize research throughout the various territories.

The focus groups and interview were audio recorded and analyzed to determine the most significant themes and concerns related to Tahltan experiences with EOFAD. Community collaboration was a key element of the research project, and so any findings have been reviewed and approved by the Community Advisory Group as well as through collaborative sessions with Tahltan community members.

While this project cannot represent all Tahltan views on EOFAD, we believe that the breadth of the project allows for general conclusions to be drawn about what is important to Tahltan people relating to prediction, diagnosis, and care for those effected by the disease.



Nancy Norby, Gayleen Day,
and Christine Ball.



Drs. B. Lynn Beattie and Judy Illes.

Communities

Tahltan territory is located in northern British Columbia, Canada and encompasses about 93,500 km². Tahltan territory is comprised of three main communities: Telegraph Creek, Dease Lake, and Iskut. The Tahltan people have occupied their territories around the upper reaches of the Stikine River since time immemorial.¹

Recognizing that Tahltan people are located both in their traditional territories in northern British Columbia, as well as geographically dispersed throughout the province and beyond, we attempted to engage Tahltan people in as many communities as we could.

Research in the form of seven focus groups, one family interview, and two collaborative interpretive sessions was undertaken with Tahltan people across five locations, including Telegraph Creek, Dease Lake, Smithers, Prince George, and Vancouver.

Participants

77 people from the Tahltan First Nation participated in this research project. Participants included elders, young adults, public health workers, individuals suffering from EOFAD, and their family members. Of the 77 participants, 60 were women and 17 were men.

Participants were recruited with the help of a Community-based Researcher, Community Liaisons, members of our Community Advisory Group, and through word

of mouth. Either through collective focus groups, or family interviews, participants discussed their experiences with EOFAD, prompted by semi-structured interview guides that were developed in collaboration with the Community Advisory Group.

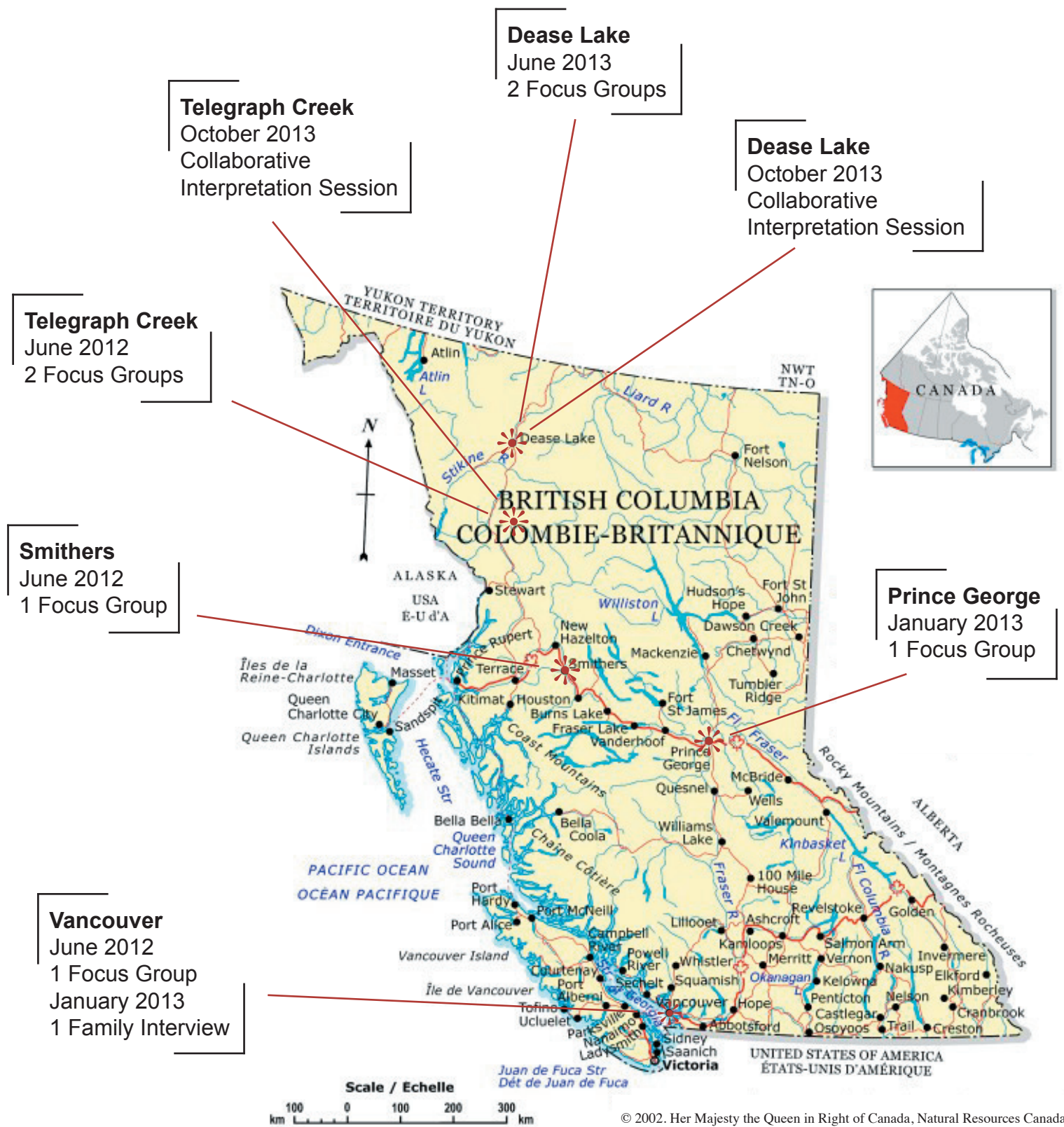
Community Engagement

The data collected and analyzed for this project stemmed from recorded and transcribed focus groups and family interviews that captured participants' experiences with EOFAD through semi-structured interview questions. These experiences were analyzed qualitatively using NVivo data analysis software that allowed the research team to determine, group, and measure emergent, significant, and recurring themes present in the focus group and interview discussions.

Qualitative data collection and analysis done in this manner is an attempt to understand the most important topics expressed by participants and, in the case of this study, aspects of the disease experienced by the community. This kind of qualitative analysis allows us to engage with participant experiences in both oral and written forms.

All identifying information was removed from the data collected, and all analyzed responses were also de-identified and made anonymous.

¹ For more information on the Tahltan Nation, including political structure, demographics and clan system, see the website of the Tahltan Central Council at <http://www.tahltan.org>.



Understanding Alzheimer Disease

What is Alzheimer Disease?

Alzheimer disease (AD) is the most common form of dementia. It is a progressive disease that occurs when abnormal proteins build up in certain areas of the brain. Individuals with AD start to experience memory loss and may eventually have personality changes and loss of control of bodily functions.

Late Onset AD: Most forms of AD occur in individuals over the age of 65.

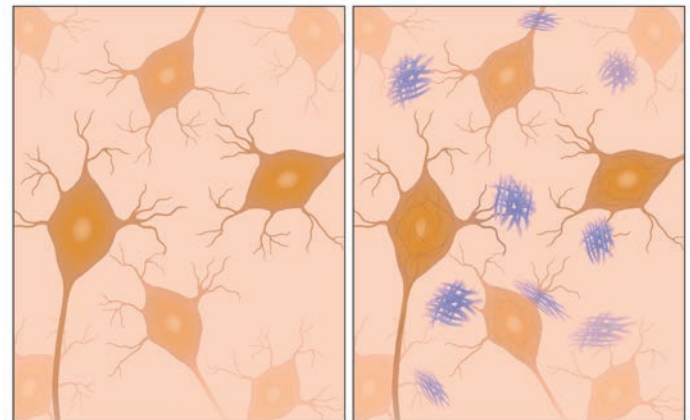
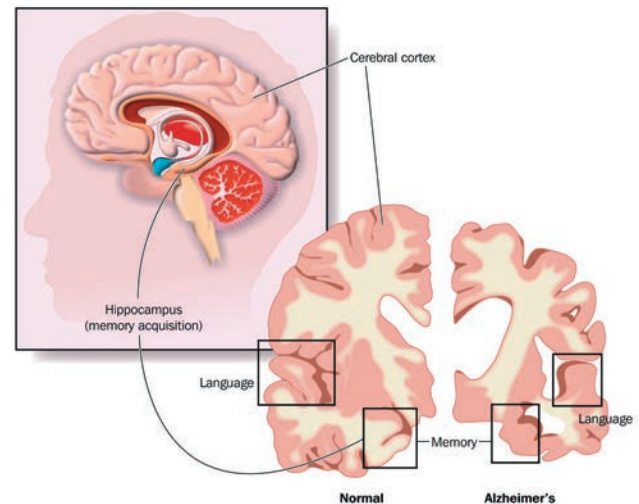
Early Onset AD: Approximately 7% of all AD occurs in individuals younger than the age of 65.

Both early onset and late onset AD have the same disease progression and are caused by similar changes in the brain.

How Does Alzheimer Disease Affect the Brain?

Abnormal proteins (nutrients needed by the body for growth and maintenance) build up in the brain cells and form structures called plaques and tangles. These structures interfere with the normal functioning of the brain cells and cause shrinkage of the brain.

Plaques and tangles cannot be seen on brain scans such as Computed Tomography (CT) or Magnetic Resonance Imaging (MRI). They can only be seen if there is an autopsy of the brain.



Healthy

Alzheimer's

Is Alzheimer Disease Inherited?

Sporadic AD: Most AD presents in a random or “sporadic” manner. In sporadic AD, both genetic and environmental factors contribute to the disease. First-degree relatives (children, brothers, and sisters) of individuals with sporadic AD have a higher chance of developing AD than the general population, but it is most likely that they will not develop AD in their lifetime.

Familial AD: 5-25% of individuals with AD have a strong family history of AD, with several other affected family members in multiple generations. This is referred to as familial AD. Familial AD is caused by an altered gene that can be directly passed on from one generation to the next. First-degree relatives (children, brothers, and sisters) of individuals with familial AD have a 50% chance of inheriting this altered gene and developing AD.

Both sporadic and familial AD can be early onset (onset before 65) or late onset (onset after 65).

What is Early Onset Familial Alzheimer Disease (EOFAD)?

Early onset familial Alzheimer Disease (EOFAD) refers to familial AD (see previous section) that begins before the age of 65. EOFAD is caused by an altered gene that can be directly passed down from one generation to the next.

Three genes have been discovered that cause EOFAD: presenilin-1 (PS1), presenilin-2 (PS2), and the amyloid precursor protein (APP).

In the Tahltan family affected with EOFAD, the symptoms of AD generally onset in the late 50s to early 60s, but specific ages of onset for any additional affected family members cannot be predicted with absolute certainty.

A unique alteration in the PS1 gene has been identified within a Tahltan family affected by EOFAD.

This genetic alteration is inherited in an “autosomal dominant” manner. This means that children of affected individuals have a 50% chance of inheriting the EOFAD gene and eventually developing AD. It also means that the alteration can be passed on by both men and women to both sons and daughters.

The disease has 100% penetrance. This means that if you inherit the altered gene, you will definitely develop EOFAD.

Genetic Testing for AD

Genetic testing for AD is not available in most cases:

Sporadic AD: No testing is currently offered.

Late-Onset Familial AD: No testing is available because the genes that cause this type of AD have not yet been discovered.

Early-Onset Familial AD: Genetic testing for alterations in the PS1, PS2, and APP genes is currently offered on a research basis to affected individuals with a family history that meets specific criteria. There are also private laboratories that charge a fee for testing these three genes.

A unique alteration in the PS1 gene has already been identified within a Tahltan family affected by EOFAD. Members of this family have the option of pursuing genetic testing to find out if they carry this alteration. This testing can be arranged by the UBC Hospital Clinic for AD and Related Disorders (UBCH-CARD).

Risk Factors and Prevention

For More Information on Genetic Testing

The UBC Hospital Clinic for AD and Related Disorders offers the services of a genetic counsellor who specializes in assessing family histories of dementia. If you would like your family history assessed or are interested in the option of genetic testing, you can ask your family doctor for a referral to the Clinic. If you do not have any memory concerns, please ensure that you specify that you would like to be referred only for genetic counselling and not a full neurological assessment.

UBCH-CARD Administrative Office:
t. (604) 822-7031
f. (604) 822-7191

What are Risk Factors for Sporadic Alzheimer Disease?

There are no certain or known causes of **sporadic Alzheimer Disease (AD)**. Researchers have identified risk factors that appear to play a role in the development of sporadic AD, but no definitive causes have been found for this complex disorder.

In cases of **familial AD**, if one possesses the genetic alteration for the disease, there is no way to prevent the disease. Some research suggests that avoiding the following risk factors and adhering to the following risk reduction practices has the potential to delay the age of onset, however more research is required.

Known sporadic AD risk factors:

- Age is the most significant risk factor
- Family history and genetics

Potential contributing sporadic AD risk factors:

- **Cardiovascular disease:**
 - High blood pressure that may damage blood vessels in the brain.
- **High cholesterol and obesity**
- **Type II diabetes**
- **Brain injuries**
 - Sports or accident related.
- **Substance abuse**
 - Alcohol, tobacco, marijuana, and hard drugs like heroin or methamphetamine.
- **Education**
 - Lower education levels.²

² Source: Alzheimer's Disease Research, American Health Assistance Foundation, 2012; Alzheimer Society of BC.

Can Alzheimer Disease be Prevented or Cured?

There is no absolute prevention or cure for AD. Research so far has not proven or shown that any single or combination of interventions plays a role in preventing AD or other dementias. However, risk reduction may play a role in prevention. The Alzheimer's Society of BC recommends:

- Eating a well-balanced and healthy diet.
- Avoiding smoking and excessive alcohol.
- Maintaining your weight.

- Keeping your cholesterol and blood pressure levels in check.
- Exercising regularly.
- Getting regular sleep.
- Maintaining a social network.
- Stimulating your brain by doing cross-word puzzles, taking dance lessons, learning a new language, or participating in other activities.
- Protecting your brain by wearing a helmet when you bike ride.

Is AD More Common in First Nations Peoples?

There is currently very little known about either sporadic or familial AD in First Nations populations. More research is needed.



Experiences and Understandings Within the Tahltan Nation

This project collected diverse experiences of Tahltan people and their families, in and around Tahltan territory, related to early onset familial Alzheimer Disease (EOFAD).

The following are the six major themes discussed by participants in this project, reflecting the most important practices and understandings in the Nation:

1. Dynamic experiences with EOFAD
2. Traditional and Western understandings of EOFAD
3. Intergenerational knowledge transfer
4. Care in the community
5. Response to genetic research and testing
6. Resources needed

1. Dynamic Experiences with EOFAD

While linked genetically to one specific family tree, EOFAD has had an impact on the entire Tahltan community to varying degrees. There are social, economic and cultural impacts for those with the disease, their families and caregivers, and the broader community.

EXPERIENCES OF THOSE SUFFERING FROM EOFAD

“It seems to me that each case is its own case, and everybody exhibits different symptoms and so on.”

- There is a range of emotional symptoms and responses to the disease, which range from anger and confusion, to acceptance and humour.
- There is some denial of those suffering from the disease, particularly in men.
- Wandering, mild to significant memory loss, communication with deceased relatives, and remembering stories from childhood are notable behavioral and cognitive symptoms.

EXPERIENCES OF CAREGIVERS

“The caring has already been there for generations.”

“At a certain point you just have to learn to let go of being angry. And just – and enjoy them for what they are then.”

- “We take care of our own” is the guiding principle of many caregivers.
- There is often an emotional strain on caregivers.

- Caregivers need more family and community supports. Short-term relief goes a long way.
- Caregiving can be isolating.
- Female caregivers seem to maintain more social connections for the person for whom they are caring, while men have a tendency to isolate themselves and their affected family member or spouse.

EXPERIENCES OF FAMILIES AND FAMILY MEMBERS

“I just thank God for this great family, because I don’t know where I would be without them, you know, and without the support systems.”

- Family experiences are varied, from collective acceptance and support, to denial and lack of support within a family.
- Denial may stem from fear and worry that younger family members will inherit the disease.
- Strong familial support is consistently necessary for coping with the disease.



Rocky Jackson, Claire Quock,
and Elana Brief.

EXPERIENCES OF THE COMMUNITY

“None of us are – at community level are untouched by this... it affects every family.”

- The community has learned to watch out for those with EOFAD.
 - Understanding and support for those affected is increasing.
 - Positive community support plays a huge role in families’ and individuals’ ability to cope with the disease.
 - Smaller communities feel greater community support and understanding than larger communities.
 - More public outreach is needed.
 - Stigma and other negative factors affecting mental health exist within the communities and are discussed heavily within the workplace, such as the mines.
-

“I’ll say in this reserve, in this community, we are far off better than any other community I believe. Because we accept people for who they are and what they are. Because [...] we have people living here with sicknesses, and nobody’s pushing them down and looking like [they’re] not human anymore.”

2. Traditional and Western Understandings of EOFAD

“Nobody could say what had happened... It was a hex.”
“They were witched”
“They think they put medicine on them.” ... “I used to hear that, and people talk like that.”
“She would say they’re ‘ishkoti’, they’re crazy.”

“I always just remember it being called Alzheimer’s.”

The focus group and interview participants mentioned that some Elders describe the disease in a way that is rooted in spirituality and tradition, while many individuals from the younger generations base their understanding of the disease in the Western biomedical framework.

While traditional explanations offer valuable historical and cultural understandings of EOFAD, the community appears to largely focus on the Western-biomedical model today. Participants recognize historical concepts and terms as culturally relevant and historically significant, but now primarily consider AD a disorder of the brain within a Western biomedical framework. This said, there remains a desire to foster and reinvigorate traditional and cultural perspectives of caring and prevention from a uniquely Tahlitan perspective.

TRADITIONAL UNDERSTANDINGS	WESTERN UNDERSTANDINGS
There are accounts that people once referred to dementia-like symptoms as ‘mysterious’ and ‘a sickness’, describing it as ‘a hex’ or ‘witchcraft’, or that someone ‘put bad medicine’ on a person.	Many participants discuss the disease in terms of its biomedical characteristics.
There is partial information regarding a traditional story for how the disease came to the community, but we did not hear a complete telling of this story and so were unable to determine (or fully understand) its significance.	There is a strong desire to know more about the biomedical model of the disease.

3. EOFAD and the Significance of Intergenerational Knowledge Transfer

“I think with the Alzheimer’s... a lot of our traditions are leaving with that. Our Elders, not even necessarily our Elders, but with the Alzheimer’s we lose our traditions.”

There was significant discussion of a gap in knowledge transfer between older and younger generations.

- Older generations and Elders are described as being reluctant to talk about EOFAD.
- The legacy of colonialism and traditions of silence are a factor in discussing death and sickness with youth.
- Imported disease, Christian missionaries and residential schools have contributed to the breakdown of traditional knowledge.
 - Missionaries taught that traditional beliefs were wrong.
 - Those with knowledge of traditional medicines have died off from disease and old age. The knowledge is not being continued into the next generations.

“There was a gap after residential school and all that stuff where nobody talked about anything with their kids.”

Despite the challenging loss of knowledge, community members identified the importance of bridging the knowledge gap for their youth, and signaled a commitment to talk with their children about AD in their community. An initiative to have a children’s resource created about the disease began in one of the focus groups and there is a strong desire to bring forward more traditional stories within the communities.



Fish Camp, Telegraph Creek,
July 2009.

4. Care in the Community

“Us as a Nation, as a First Nation’s people... it seems really foreign to hear that somebody’s being treated like that because of their Alzheimer’s... I think it’s because of my values. Another family member who has Alzheimer’s, it’s progressing, but she’s being taken care of by her husband, and by the community that we live in here.”

The Tahltan Nation has fostered a strong culture and expectation of care within and by the community.

CULTURE OF CARE

- Care within the community is the guiding principle behind the community’s role in the life course.
- People are expected to take care of one another. This expectation appeared as a strong value of the Nation across communities.
- There is pride in attentive caregiving and in ensuring that individuals are cared for as long as possible within their communities and by community members.

PLACE OF CARE

Caregiving and the significance of place are important for community members.

- Participants described how individuals generally prefer to be on their traditional territories.
- Land and place provide a spiritual connection to those with AD, and remaining in a familiar place allows them to maintain social connections and engage in traditional activities, such as hunting and fishing.
- Caregivers generally prefer to be in the community, as it facilitates a sense of belonging, safety and accessible help.
- Significance of place varies between generations, with participants from older generations feeling a particularly strong connection to the traditional territories compared to the feelings expressed by younger participants.

Some participants have less connection with traditional Tahltan territories and are satisfied with being cared for in places like Prince George, where they have fostered their own sense of community.

“It’s hard when people have to send their family members away, and it doesn’t matter if it’s to Whitehorse, or Terrace, or Smithers, or Vancouver – just away out of the territory. It’s hard on the family members, it’s hard on the people providing care, and it’s hard on the actual person who’s sick.”

The overarching emphasis on place and care in the community speaks to the need for more support systems on Tahltan territories and more public health outreach to bring all community members into the culture of care.

5. Genetic Testing

“If people were aware 10 years before... talking about the expense of having to send someone out... you would have more time to prepare for that... you might be able to afford to put them in their own personal unit.”

The response to the genetic research that led to the discovery of the risk for EOFAD in this community has generally been positive. People appreciate the medical certainty, resulting public education, and community-wide discussion that the identification of the gene has fostered.

The individual response to the application and availability of predictive genetic testing, however, is mixed.

Although some family members might consider diagnostic genetic testing once AD symptoms emerge, uptake of predictive genetic testing (which would identify gene carriers prior to symptom onset) has been limited. This is similar to what has been observed in other families with EOFAD.



Church at Old Telegraph Creek.

There remains a lack of clarity and awareness as to the availability and process of genetic testing. This may influence concerns regarding the positive and negative implications of predictive and diagnostic testing and is a knowledge gap that must be bridged.

“Once they’re diagnosed, if they are, well then life’s not over. They could prolong their life if they eat healthy, do exercise, and limit the alcohol and drugs.”

BENEFITS OF GENETIC TESTING	CONCERNS OF GENETIC TESTING
<ul style="list-style-type: none">• Preparation, including family care plans, financial plans, and emotional changes.• Reduced stigma through the establishment of networks of care and support early on in the process of the disease.	<ul style="list-style-type: none">• Stress and worry following a positive test.• Deciding not to have children with a person who tests positive.• Stigma from others.• Material obstacles to getting tested, such as time off work and travel logistics and expenses.

6. Resources Needed

Our findings suggest that there are two major resources needed for the Tahltan communities coping with EOFAD:

- (1) More public health education.
- (2) Long-term community and residential care support within the Nation's territories.

1. Many families who are directly affected by the disease feel they have a high degree of knowledge about it, but participants illustrated a desire to learn more about AD, and to open dialogue within and across communities to a greater degree:

- Education topics should include:
 - Prevention strategies, understanding initial symptoms, and care responses for advanced stages of the disease.
 - The process and availability of predictive genetic testing.
- Education should focus on:
 - Adults in the community, as well as younger generations. (A book for Tahltan children called *The Mind Thief* has also been published as part of this project to meet this goal.)
 - The community and extended families.

Advancing knowledge of the disease was understood as a means of aiding caregivers, families and those suffering from the disease in their process of coping and care, reducing stigma across communities, and educating those with less direct experience with EOFAD.

2. Participants also expressed the need for improved long-term care resources within the Tahltan Nation to allow affected individuals to remain at home and on the territory for as long as possible, in keeping with the importance of sense of place for affected individuals and their caregivers. Key aspects include:

- An on-reserve long-term care facility and respite care.
- More training for non-professional caregivers.

Like many First Nations located in remote and rural areas, access to the required resources and funding for adequate healthcare proves challenging. Given the prevalence of EOFAD in the Tahltan community, these challenges are especially pressing. We hope that the results of this research project may be utilized in advancing efforts to obtain the necessary resources for the Tahltan First Nation.

Conclusion

Throughout the duration of this project we maintained a focus on the community values of the Tahltan Nation. Our research within Tahltan communities suggests that the Tahltan First Nation experiences and understands early onset familial Alzheimer Disease (EOFAD) in unique and culturally specific ways.

We determined that cultural factors, such as the importance of care on traditional territories, the maintenance of connection to place and community, and the revitalization of intergenerational knowledge transfer all play a significant role in Tahltan experiences, wellness, and understandings of diagnosis, care and prevention surrounding the disease.

Further, we determined that Western biomedical understandings of EOFAD also have a significant role in how the disease is discussed and understood within the Tahltan Nation. The Western medical

framework is the dominant mode of communicating experiences and understanding of the disease, and there is a strong desire to increase understandings of the disease across Tahltan communities.

Therefore, our research with the Tahltan First Nation illustrates the significant intersections between traditional Indigenous and Western medical understandings of a disease such as EOFAD.

In a broader context, our results confirm that culturally diverse communities experience and perceive brain diseases associated with aging in unique and significant ways. The results also suggest that effective research on the brain must meaningfully consider and engage with the ethics and values of the affected individuals, and that the careful consideration of culture leads to better, higher impact brain research and health care.



Additional Information

Online Resources

Alzheimer Society of British Columbia

<http://www.alzheimerbc.org/>

Alzheimer Society of Canada

<http://www.alzheimer.ca/en>

Centre for Research on Personhood in Dementia

<http://www.crpdp.ubc.ca>

Indigenous Resources – Alzheimer’s Australia

<http://www.fightdementia.org.au/understanding-dementia/indigenous-resources-1.aspx>

International Indigenous Dementia Network

<http://www.ihrdp.ca/iidrn/>

National Core for Neuroethics

<http://www.neuroethicscanada.ca>

Video Resource

“The Alzheimer’s Project”

HBO Film

<http://www.hbo.com/alzheimers/>

Print Resource

Rising Tide: The Impact of Dementia on Canadian Society Alzheimer Society of Canada

http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf

Medical Assistance

UBC Hospital Clinic for Alzheimer Disease and Related Disorders

Djavad Mowafaghian Centre for Brain Health

2nd Floor

2215 Wesbrook Mall

Vancouver BC V6T 1Z3

(604) 822-7031

<http://www.centreforbrainhealth.ca/clinics/clinic-information/CARD>

First Nations Health Authority

<http://www.fnha.ca>

Tahltan Health and Social Services Society

<http://www.tahltan.ca/programs-services/tahltan-health-social-services-authority>



On behalf of the National Core for Neuroethics,
University of British Columbia, the Clinic for
Alzheimer Disease and Related Disorders, UBC
Hospital and the Tahltan Central Council, Meduh,
Thank you.