

Converging approaches to understanding early onset familial Alzheimer disease: A First Nation study

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Abstract

Objectives: In 2007, a novel pathogenic genetic mutation associated with early onset familial Alzheimer disease was identified in a large First Nation family living in communities across British Columbia, Canada. Building on a community-based participatory study with members of the Nation, we sought to explore the impact and interplay of medicalization with the Nation's knowledge and approaches to wellness in relation to early onset familial Alzheimer disease.

Methods: We performed a secondary content analysis of focus group discussions and interviews with 48 members of the Nation between 2012 and 2013. The analysis focused specifically on geneticization, medicalization, and traditional knowledge of early onset familial Alzheimer disease, as these themes were prominent in the primary analysis.

Results: We found that while biomedical explanations of disease permeate the knowledge and understanding of early onset familial Alzheimer disease, traditional concepts about wellness are upheld simultaneously.

Conclusion: The analysis brings the theoretical framework of "two-eyed seeing" to the case of early onset familial Alzheimer disease for which the contributions of different ways of knowing are embraced, and in which traditional and western ways complement each other on the path of maintaining wellness in the face of progressive neurologic disease.

Keywords

Early onset familial Alzheimer disease, First Nation, geneticization, medicalization, crosscultural neuroethics, two-eyed seeing

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Introduction

Knowing it's coming to get you. (Participant 11, FG2)

In 2007, a novel pathogenic presenilin 1 (PS1) genetic mutation (L250F) associated with early onset familial Alzheimer disease (EOFAD)^{1,2} was identified in a large First Nation family living in dispersed communities across British Columbia, Canada. This rare form of Alzheimer disease is 100% penetrant with typical age of onset between 47 and 59 years of age. At present, 100 members of the family are known to be at risk. Building on a growing body of knowledge about EOFAD from this Nation,³⁻⁶ we explored how medicalization and geneticization have had an impact on the understanding of this illness and on the culture, traditions, acceptance, and interactions surrounding it. We further considered this question in the context of "two-eyed seeing," a theoretical framework that embraces the contributions of different worldviews or "ways of knowing."^{7,8}

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According to Mi'kmaq Elder Marshall, the idea of “two-eyed seeing” implies:

learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing, and to using both these eyes together, for the benefit of all.⁷

“Two-eyed seeing” has been used as a framework to understand differences between indigenous and nonindigenous health approaches, discussion around healthy communities, environmental education and planning^{7,8} and, more recently, is becoming part of new policy and other change efforts.

Medicalization

Medicalization is a sociocultural process that involves “defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to ‘treat’ it.”⁹ While medicalization literally means “to make medical,” it has come, as Conrad argues, to have wider and more subtle meanings. Medicalization is generally associated with negative connotations,^{9–12} in particular as it is commonly used referring to medical imperialism,^{13–16} to concerns about over medicalization,^{9,11,17} and to the way that the medical model can decontextualize social problems.^{15,18} However, medicalization is neither singularly good nor bad. Indeed, like other social processes, such as globalization or secularization, medicalization is a double-edged sword insofar as it has the potential to thwart human relationships and experiences as well as to maintain or facilitate them.^{11,19} Framing a condition as a “medical problem,” for example, can help individuals to take responsibility and engage in meaningful relationships and activities, but it can also undermine traditional knowledge.

Geneticization and medicalization of family

Recent scientific and technological developments are now propelling forward attempts to understand diseases at the level of individual genes and genomes, and partially displacing “previous emphases on germs, enzymes, and biochemical compounds.”¹⁴ This shift from more general explanations of disease to a focus on individuals’ genetic makeup is changing the way people increasingly see themselves and their behaviors—in the present and for the future.^{14,19–21} Lippman²¹ uses the word geneticization to describe the process “in which differences between individuals are reduced to their DNA codes.” A less morally charged definition, and the one we use in this article, sees geneticization as “an explicit link ... between a condition and a stretch of DNA.”²² Thus, geneticization takes place when one or more of the following conditions are met: (1) genetic terminology is used to define a problem; (2) specific genetic expertise is required

to deal with a problem; (3) genetic knowledge and technology lead to changing individual and social attitudes toward prevention and control of disease, health care, and reproduction; and (4) genetic imagery is linked to particular views on human identity, interpersonal relationships, and individual responsibility.^{20,21,23}

While there has been disagreement about whether geneticization is a philosophical²⁰ or an empirical concept,^{22,24} we use the term here to describe the interactions between genetics, medicine, society, and culture and to explain the different perspectives they bring.^{20,23,25} Indeed, both medicalization and geneticization are examples of more encompassing social processes that shape individuals’ experiences of reality, of their being, and of the world.^{18,20,21,25,26}

A focus on genetics involves family and kinship.^{20,26,27} Whether or not this has fostered geneticization per se, it has helped to medicalize relations^{19,28} and promote a “familiarization of genetics,”²⁷ both of which can have ethical and practical dilemmas for the individual, families, and medical practice.

Cross-cultural perspectives on wellness and illness

There is a fundamental philosophical difference between indigenous and biomedical perspectives on wellness and illness, including the essential dimension of spirituality and its much more comprehensive focus on restoring balance to individuals and communities.^{29,30} Wellness over illness is the emphasis of the health continuum, along which the physical, emotional, mental, and spiritual aspects of a person which are connected to family, community, and the land.³⁰ Traditional healing practices are designed to promote mental, physical, and spiritual well-being based on beliefs that go back to the time before the spread of Western biomedicine.²⁹ They are guided by the acknowledgement of the profound interdependence of the environment, people, and the spirit.^{29–31}

Indigenous concepts of health and wellness thus shape explanations of disease and illness.³² The implicit explanatory model underlying the discovery of the gene mutation found within members of this First Nation community is a biomedical model focused on biological processes. In particular, it characterizes EOFAD as a pathological and familial condition of cognitive impairment, somatic in etiology and, currently, without possibility of cure. However, this model is not necessarily consistent with concepts of health used by cultural groups who have developed other explanatory models for health and illness.^{4,30} Thus, even though medicalization has the potential to create new understandings about social processes involved in the construction of medical knowledge in general, different readiness or rejection of medicalized definitions may differ for different populations.³¹ The different approaches that a group takes in relation to wellness are also shaped by medicalization, as the process involves not only adopting a medical framework to

understand a problem but also using medical intervention to address it.⁹

In light of the different ways in which medicalization shapes and is shaped by social processes, the central research question underlying the present work is: What impact, if any, has medicalization had on this Nation's knowledge and approaches to wellness in relation to EOFAD? To answer this scientifically, culturally, and socially poignant question, we examined how members of this Nation understand EOFAD within a framework that is shaped by both biomedical knowledge and traditional teachings.

Methods

We conducted a secondary content analysis of discourse data acquired in the context of a community-based participatory research project conducted under a research agreement with the Nation and ethics approval from the authors' institutional research ethics board. All results were vetted with community advisors and exchanged with the community. (In January 2015, the Research Agreement with the Tahltan First Nation was readdressed and confidentiality lifted. The issues presented in this article reflect the research agreement prior to the change. Our important work with the Nation continues with this new openness today.)

Data collection and analyses

The secondary analysis used data collected in seven inter-generational focus groups and one family interview during 2012 and 2013. The participants from the family interview were interested in participating in the study but requested an interview rather than participation in a focus group for confidentiality. A total of 48 persons from the Nation who either had an EOFAD-affected family member or had knowledge through their community participated. The average number of people per focus group interview was seven. The family interview consisted of two participants; 38 of the 48 community participants were women.

The focus groups and family interview were guided by semi-structured questions developed in collaboration with the community advisory group. The original study had the overall objective to elucidate the impact of EOFAD on individuals, care partners, and the community and perceptions about genetic testing for the disease. The dataset from the first-order study provided a rich foundation on traditional and biomedical knowledge and practices³ that made this second order, in-depth exploration of the impact of medicalization an important next step.

For the analysis, we combined the data from the focus groups interviews and family interview. We used inductive content analysis with each individual segment of raw data (phrase, sentence, or paragraph) as our unit of analysis, resulting in 413 data points to code. One author (L.Y.C.) reviewed and systematically coded the interview transcripts

using a constant comparative analytic approach to identify major emergent themes and, together with another member of the team (J.I.), revised these to establish a consensus list of codes.³³ The codes were grouped into categories and sub-categories that were developed from a triangulation of the emergent themes, the main research question, and key literature. Illustrative quotes highlight major points. Noncontent words and expressions are removed for readability.

Findings

The findings are grouped into two main categories: (1) knowledge and understanding of EOFAD and (2) approaches to wellness around EOFAD. Each category has two main subcategories: biomedical or traditional. Overall, we found that a biomedical framework dominates the knowledge and understandings of EOFAD. However, in terms of approaches to wellness around EOFAD, traditional views are given equal consideration.

Knowledge and understanding

Biomedical knowledge and understanding. Participants' knowledge of EOFAD was shaped to a great extent by a biomedical framework (49% of total coded data points). Evidence of this is participants' common usage of biomedical labels and concepts:

Now we actually say Alzheimer's. (Participant 15, FG5)

In a few instances participants discussed disease progression and different medical stages. There was also a desire for additional information related to EOFAD, in order to cope with and take better care of those with the disease:

[...] we need more information just to make it easier to deal, and easier to be more supportive, and help those cope with it. (Participant 11, FG2)

Another main theme related to the impact of the disease on family and kinship and the different experiences of participants with the disease through their families or members of their community:

It's in all of our family [...] like all my older siblings have passed on—they all died mostly of Alzheimer's ... So it's in the family—I know it's in the family. (Participant 2, FG2)

The impact on family and kinship was most commonly framed as negative, for example, it creates denial among family members. There were few instances in which participants describe it as an opportunity to rethink family ties:

[...] the real positive part of this family gene is because [...] we come from a big enough family ... that can be all kind of cared for within the family. (Participant 19, FG1)

Another prevalent theme was related to a focus on individuals' genetic makeup:

I only know of a couple people who have been—done the testing and have been out there with, “yes I do have the gene. I don't have symptoms yet but I do have the gene.” (Participant 11, FG2)

[...] its in our genes. (Participant 30, FG2)

Some participants recognized the ambivalent feelings that came as a consequence of this genetic understanding, from uncertainty about whether or not they would like to know that they have the gene to reproductive decisions:

At first I was like I want ... to know. And then secondly I was [...] no I don't want to know. [...] knowing if I have this—this gene, how does that change anything for me? (Participant 19, FG1)

[...] with my daughter, ... she's decided [...] “I don't know and I'm not going to pass this gene on.” [...] that's a huge decision to be made not knowing whether or not you carry the gene. (Participant 5, FG2)

We also found that as part of an increased biomedical understanding of the disease in the community, stigma is perceived as having diminished:

[...] the more information that's out there the less stigma for some families there'll be. (Participant 20, FG4)

I could feel that it's passing the stigmatism that it carries [...]. (Participant 9, FG5)

Overall, the findings suggest that participants frame the disease in terms of the biomedical model, that they emphasize its genetic component, and that biomedical knowledge around the disease has decreased stigma in the community around the disease.

Traditional knowledge and understanding. Knowledge and understanding of EOFAD was not only framed by a biomedical model, but there were also instances in which these were framed by a more traditional perspective (33% of total coded data points). Participants commented that in the past, people talked about individuals presenting symptoms as

[...] they kind of said there that people has been crazy. (Participant 14, FG1)

It's a hex. It was a hex. (Participant 8, FG3)

They were witched. (Participant 12, FG3)

A common theme here related to a lack of understanding around the disease in earlier generations:

[...] at that time nobody understood the disease. (Participant 2, FG2)

They didn't understand it was such a thing as, you know, the name Alzheimer's [...]. That's probably more [what] our generation found out. (Participant 4, FI)

While the knowledge and understanding about EOFAD in current generations has been mostly shaped by interactions with family or community members who have the disease:

[S]ome of us have had neighbours or know people that had it—not necessarily close family members, but we've all—it's all touched us in one way or another. (Participant 10, FG3)

We also found that earlier generations did not talk about EOFAD:

They just seemed like the elders keep things to theirself [...] They don't explain it to us. (Participant 13, FG7)

[M]y grandmothers and my mother never said anything about that family if anything was wrong with them. But they did come down with it. (Participant 14, FG1)

These quotes are examples of the role that elders and older family members had in shaping younger generations' knowledge and understanding about EOFAD, which can be one of the ways in which the biomedical framework has crept in and permeated the knowledge and understanding of today's generations.

Approaches to wellness

Biomedical treatment and interventions. Participants mentioned a number of biomedical interventions, including genetic testing, access to a medical care facility, and pharmacological interventions (26% of total coded data points). The most commonly mentioned intervention was genetic testing. Participants expressed both positive and negative attitudes toward genetic testing. Some participants noted potential benefits of genetic testing including opportunities for future planning and preparation:

[...] I think early detection comes in perfect, because then you could at least say, “Okay, when I get to this point please send me out.” (Participant 23, FG4)

However, some participants also expressed fears about genetic testing based on how this could negatively impact their quality of life:

And then I think that the big scare is getting tested and finding out you do have it, and then your quality of life after that. Knowing it's coming to get you, so to speak, at some point. (Participant 11, FG2)

In some other instances, the option of genetic testing for EOFAD was surrounded by ambivalence:

I myself think it's a good thing, but it's also very [...] scary [...] If you have the gene and stuff. But it's also good because if you have children, at least they could find out, ... or know later in life that maybe they should go for genetic testing. (Participant 3, FG6)

Medical facilities such as clinics, hospitals, or long-term care facilities were generally mentioned as a last approach when care at home by the family was no longer an option, either because of the person has lost control of functional autonomy making it difficult for the family to continue care at home, the stress on the care-taker, and in some cases even violence. Some participants reported negative views about these facilities as been places where they keep people "drugged up" (Participant 26, FG1). Others questioned not only the frequency of drugs but also their efficacy:

[...] I started noticing it ... soon as he started taking them ... He was just getting ... crazier ... made it worse. (Participant 16, FG7)

While participants expressed some negative feelings about both pharmaceutical interventions and medical facilities as illustrated here, these were not a dominant feature of our dataset.

Traditional practices. Medicalization shaped participants' knowledge and understanding of EOFAD to a great extent, but this was not the case in terms of approaches to wellness. We found that the participants hold a traditional approach to family and community care-giving as key to wellness (25%). Some even emphasized this as a key value of First Nation people:

You take care of them. They're a part of the community. You don't oust them ... We don't know what it is, but it is who they are. (Participant 3, FG6)

There's more physical contact, there's more nurturing. It's not give them a pill and shut them down. [...] we take care of our elders, we don't just pop them full of pills and stick them in a corner. (Participant 7, FG7)

I think that is definitely a value of us as First Nations people is we take care of our sick ... you treat them like you would treat anybody else, regardless of whether or not they remembered you or not. (Participant 20, FG4)

Even while taking care of people is a community value, participants acknowledged that caregiver wellness relies on support and that at some point is just not an option to continue care of the individual at home:

[...] there's a point too when they require round the clock care, ... that's a point where ... it does get dangerous. One person can't do it. (Participant 21, FG4)

Connection to the land and food is also regarded as important aspects of wellness. In particular, the land is seen for its role in health as well as how it allows people to connect with their community:

Everything's slowly being taken from them, but those are the things that they hold on the most is the land ... (Participant 5, FG2)

Healing is on the land. (Participant 3, FG6)

[...] this is their home. (Participant 23, FG4)

Caribou leaves, balsam bark, and lily pads were mentioned as examples of traditional medicine; however, it was recognized that there was uncertainty about what elders used to prepare with these.

Discussion

Medicalization, as a way of knowing with a focus on biomedical causes and interventions, shapes many key areas of people's lives, including the understanding of underlying biological processes and approaches to wellness. In relation to the First Nation community we work with, we found that while a biomedical way of knowing dominantly shapes knowledge and understandings of EOFAD, there is equal consideration for medical and traditional approaches to wellness around EOFAD.

Medicalization: a creeping phenomenon

There is an assumption that Western cultural perspectives, definitions, and understanding of health and well-being are different from indigenous worldviews.³¹ Our results suggest that biomedical terms and explanations are increasingly used among our participants to explain and understand EOFAD. From this perspective, it can be said that the community's worldview around this illness has been medicalized. This finding is consistent with those of other scholars who have explored the impact of a Western diagnostic label on the interpretation of behavioral and personality changes, and the shift from traditional perspectives to biomedical ones.^{31,34-38}

Previous research has also shown that interactions with clinicians, genetic counselors, and other service providers reinforce a biomedical framework around illness processes.³⁹ Given the interactions that members from this family group have had since 1998 with the clinical environment and genetic technologies, it is likely that these interactions have also contributed to the medicalization of EOFAD within this community.

In addition, colonial practices, such as residential schooling removed several generations of children from their families and communities. This created not only a generational knowledge gap but in some cases loss of connection to the land, culture, language, and traditional ways

of life.⁴⁰ In this context, medicalization found fertile ground to promote an explanatory model of the disease that counter-balanced the lack of knowledge around EOFAD and promoted the sharing and spreading of biomedical information.

The fact that EOFAD is 100% penetrant likely creates a different degree of geneticization and medicalization in comparison to multifactorial conditions or genetic diseases with reduced penetrance. Moreover, the fact that EOFAD is a dominantly inherited disease explains the geneticization and medicalization of family. These processes have been reinforced in the community due to the prevalence of affected individuals, a collective familiarity with disease symptoms and progression, and shared concerns regarding the recurrence risks for family members. Both of these processes, medicalization and geneticization, provide us with an opportunity to examine the relationships between a biomedical framework and modern indigenous communities in relation to their knowledge and understanding of EOFAD.

Genetic ideology: shaping interpretations and understandings for the community

Participants not only used genetic terminology to talk about EOFAD, but they also used genetic imagery to discuss issues related to their identity, interpersonal relationships, and individual responsibility.

Consistent with previous findings, concerns were raised among our participants about the negative impact that the knowledge of having a particular gene can have on quality of life, a person's identity, and reproductive decision making.^{23,24,41} As Poudrier⁴² has argued "there is a concern about the clinical problems of fatalism associated with learning of genetic susceptibility," in particular as members in afflicted families redefine their reality by "experiencing a new vulnerability that draws them into the biomedical domain."⁴¹

However, our data also shed light on positive dimensions of *medicalization and geneticization* within this First Nation community. In the case of medicalization, the biomedical framework permeating the knowledge and understanding around EOFAD in our data can be regarded as satisfying people's needs and interest.³⁸ In particular, the findings suggest that a biomedical explanatory model of the disease has not only diminished the stigma associated with EOFAD, but it has also fostered a more open discussion around the disease and ways to cope with it, empowering the family and the community.

We also provide some insight into the way that geneticization can provide individuals with a sense of self-determination, as knowledge about genetic predisposition to disease can both help people take preventive measures and prepare for the future.

Tradition: the trump to medicalization and geneticization in approaches to wellness

Traditional values, practices, and beliefs play an important role in the approaches to wellness endorsed by different populations.^{29,39} Although many of the participants have moved to more urban settings, and Canadian indigenous history is tainted by a history of colonialism that outlawed and marginalized indigenous culture, knowledge and practice of indigenous ways of knowing have persisted.^{43,44}

Our findings show that participants still reflected on the traditions and practices that have been at the core of their history. Evidence of this is the importance given to family and community care, as well as to the land as a source for healing. This is consistent with evidence that culture—beliefs around the role of family—helps indigenous groups to cope and care for those with dementia.^{35,37} Thus, regardless of the impact that medicalization has had on knowledge and understanding, it has not had a similar transformative impact on approaches to wellness. This represents a strong assertion of the place of indigenous approaches to wellness in an increasingly medicalized domain.^{35,44} Nonetheless, we cannot underestimate the fact that there are other areas in which traditional approaches have eroded. The primary analysis and feedback from the Nation suggest that many fractures in intergenerational knowledge may be attributed to the displacement of children and youth to residential schools.

Overall, through the guiding principles of "two-eyed seeing," the complementarity between ways of knowing can be pursued, weaving back and forth between different cultures' actions, values, and knowledges.^{7,8} In the context of wellness and EOFAD, "two-eyed seeing" embraces the strengths of indigenous and Western ways of knowing, reminding us of the importance of giving just consideration to diverse worldviews in health care. In the case at hand, the strengths of indigenous approaches to wellness interweave with the strengths of Western knowledge about EOFAD and call on us to use both eyes to see the full circle of health and disease of affected individuals and their communities.

Limitations

Secondary analyses can be limited given the lack of control over how data were generated;⁴⁵ however, the good fit in terms of the primary dataset and the overall emerging findings with the new research question here removes this concern as a significant factor in this work.^{46,47} The purposive sample of participants does not represent the views of the broader First Nation population. This means that while the results are transferable, they are not necessarily generalizable. Finally, even though we used the same semi-structured protocol for the focus group interviews and the family interview, the fact that we analyzed together the data from both sources together can be seen as a limitation of this study.

Conclusion

Our data shed light on the dynamic ways in which traditional and Western worldviews are interwoven in understanding a degenerative neurological disease and preserving wellness in the face of it. The results highlight their fundamental complementarity in any strategy undertaken to promote not only First Nation health but the neurologic well-being of the aging population overall.

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