

A Cross-Cultural Perspective on Neuroethics: Barriers, Misconceptions, and Nuances

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Context

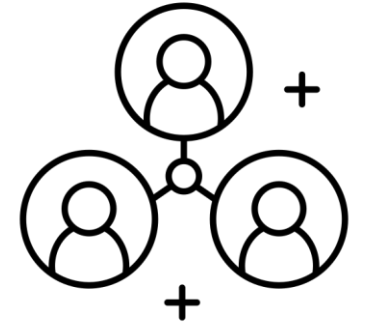
- **Gaps in cultural understanding** limit effective, impactful application of clinical neuroethics
- Situations in which patients are diagnosed with neurological conditions, receive medical treatment, and participate in research trials
 - Cultural, spiritual, social, historical, political, and economic frameworks
- **Comparative exploration** of real-life neuroethics cases from **Japan** and **Canada**



The Brain's Role in Defining Our Sense of "Self"

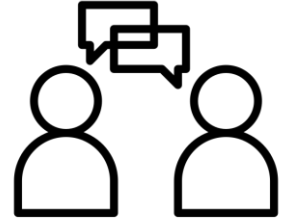
- **2009:** Japanese legislature passes bill to revise Organ Transplant Law, specifically regulations for brain death
- **2012:** Kumamoto University Graduate School of Medical Science researchers conduct study on **public perception of brain death and donation**
- Japan has low proportion of organ donors
- **Brain exceptionalism:** brain's unique status compared to other bodily organs
- Separation of brain and body → **detaching one's sense of identity after death**
- Keeping family's wishes in mind

Individual vs. Familial Autonomy



- Family members **substituting as decision-makers** during times when patient's state is impaired
- **No legal violation** for family's decision to overturn deceased individual's decision regarding brain death
 - Conflict with western perspective of patient's wishes standing after death
- **1998 to 2009:** study with First Nations kindred community at University of British Columbia Hospital Clinic for Alzheimer Disease and Related Disorders (UBCH-CARD)
 - Strong familial history of early-onset Alzheimer's Disease
 - Novel gene mutation placed 100+ relatives at risk
 - Forced to obtain long-term care outside of traditional territory
- Cross-cultural lens **promoting equal dynamics of negotiation** for both individual patient and family members

Informed Consent and the Relationship with the Researcher/Physician



- Conduct **routine check-ins** to understand patient's understanding of self-participation
- **Medical mistrust** as an obstacle based on **historical encounters**
- Informed consent as a **two-way relationship**
- **Research *with*** indigenous community members **vs. research *on* or *about*** members
- Building rapport through **shared language** to **combat “outsider-insider” dynamic**
- Investing in continuity of **long-term medical care**

Confidentiality of Health Information and Social Implications



- Determining precise biological relationships to build pedigree frameworks for assessing genetic risk
 - Navigating unfamiliar familial structures
 - Need for **knowledge of social dynamics to reduce personal biases**
- Relationships in close-knit rural communities have greater overlap between healthcare providers, colleagues, family members, etc.
 - Pressure of **social stigma** and **cultural attitudes** surrounding risk disclosure
- Cultural misunderstandings about **communication methods**

*“The **complicated nature of maintaining confidentiality** in this particular kindred is poignantly illustrated by the concerns of one family member who **wished to disclose her carrier status** to her children who are at 50% risk to inherit [early-onset familial Alzheimer’s Disease] EOFAD. She hesitated to do so based on her fear that her children **could not be relied on to maintain her privacy within the community**, given their tendency to alcoholism and binge-drinking episodes” (Butler et al. 2010)*



Spiritual and Cultural Misconceptions

- Japanese views based on **Shinto, Buddhist, and Confucian practices**
- Unnatural brain death **departs from “Mogari” custom**
- Memory loss and dementia **contrast traditional** “going through the full circle of life” with the “shémá [white] way”
- Alternative **ways of understanding disease causes**
- Concerns about **straying from traditional ways of living**



Financial and Geographic Barriers

- Time-intensive, expensive, and weather-dependent travel to UBCH-CARD research site
 - Loss of pay and childcare needs
- Genetic testing as an **additional budget expense** beyond immediate medical needs
- **Stress** of visiting unfamiliar location
- **Accessible information divide** between urban and rural communities
- Less willing to participate if no **prior precedent** within community members



Conclusions

- Social stigma, spiritual traditions, autonomy, financial costs, geographic limitations, and confidentiality as considerations for expanding our application of clinical neuroethics
- Comparative lens for understanding shared needs and gaps across cultural communities

Thank you!

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References

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Disclosures: None

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