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


Disclosures: None

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