TITLE: Acceptability, Access and Equity: Issues associated with using Assisted Reproductive technology

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**ABSTRACT:**

Qualitative methodologies including *Indigenous Standpoint* and *Grounded theory*, designed to give primacy to the knowledge and lived experiences of Australian Aboriginal families living with Machado-Joseph Disease (MJD) in remote north Australia, are utilised to explore their understanding and perspectives of family planning and the use of assisted reproductive technology to manage genetic disease. The research explores the importance of worldview and health literacy on reproductive decision making.

Australian Aboriginal Families living with MJD report limited exposure to modern assisted reproductive technology. Women describe attitudes and understanding stratified by age. Older women recount traditional cultural concepts of family creation, including adherence to traditional marriage patterns along moiety lines. Middle-aged women also adhere to traditional relationship structures but describe awareness of mainstream Western/biomedical concepts learnt at school. Younger women have had lower school attendance and describe less strict adherence to traditional relationship structures and understanding of conception and pregnancy, reflecting both traditional and biomedical perspectives. All groups report limited working knowledge of invitro fertilisation and assisted reproductive technology.

**Discussion and Conclusion**

A biomedical Western worldview/framework dominates Australian approaches to the use of medically assisted reproduction to minimise disability. The fit with these families' worldviews requires careful consideration and the examination of standpoints from other cultural and sociological perspectives. This presentation will outline perspectives about family, marriage patterns, health literacy and the utility of the concept of disability for Aboriginal MJD families, which raise ethical, legal, strategic and public health issues related to the use or avoidance of technology and access to advice and support, which, although specific to this situation, will provide insights to guide the management of genetic disease in other culturally-diverse contexts.

The presentation will outline the issues associated with engaging with genetic health care in the form of medically assisted reproduction encountered by Aboriginal families living with Machado-Joseph disease in some of the most remote areas of Australia. These families should have equitable opportunities to access such technologies regardless of where they live. This can be achieved by implementing processes that incorporate improved engagement with Aboriginal communities, for example, by establishing place-based clinics, prioritising genetic knowledge within Aboriginal Health worker training and forming strategic collaborations with relevant stakeholders.

**REFERENCES**

Massey, L., Gilroy, J., Kowal, E., Doolan, D. and Clough, A., 2024. Aboriginal families living with MJD in remote Australia: questions of access and equity. *International Journal for Equity in Health*, *23*(1), p.187-195 doi.org/10.1186/s12939-024-02228-x

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