Genetic Counselling in HDGC – the bi-cultural context

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Hereditary Diffuse Gastric Cancer (HDGC)
E-Cadherin/CDH1

Testing is indicated in the following situations:

- person with DGC before the age of 40 years
- person with both DGC and lobular breast cancer, with one cancer diagnosed before the age of 50 years
- person with GC at any age, who has one or more first/second degree relative/s with gastric cancer at any age, where there is at least one confirmed DGC
- person with DGC who has one or more first/second degree relative/s with lobular breast cancer, with one case diagnosed before the age of 50 years
- person with lobular breast cancer who has one or more first/second degree relative/s with DGC, one case diagnosed before the age of 50 years.

Testing could be considered in the following situations:

- personal history of bilateral lobular breast cancer, with both cancers diagnosed before the age of 50 years
- person with lobular breast cancer and a family history of lobular breast cancer, with two cases diagnosed before the age of 50 years
- person with DGC and cleft lip/palate
- person with precursor lesions for gastric signet ring cell carcinoma.
Non-Engagement with GHSNZ by Ethnic Group

- Māori
- Samoan
No Effect on Non-Engagement by Geographical Area

Clinical locations covered By Auckland
Eurocentric model

- Genetic Counselling model grew from person centered approach
- Reflects the cultural norms and values of *western society* autonomy and informed consent - Universalisation
- Purpose of medicine is to treat disease – but Colonialisation
- Ignores other cultural and health beliefs
Cultural Issues with the Eurocentric approach for health care and Genetic Counselling

- Cultural differences are a barrier to health care engagement and compliance

- Health institutions should recognise culture as a positive resource – increase engagement

- Need to recognise that all beliefs about health including values and practices are culturally shaped

- Era of healthcare transformation – patient centeredness (cannot assume we know what is important to an individual)
Genetic Counselling

“Genetic counselling is a communication process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions.”
Eurocentric model moving forward....

• Cultural competency is included in Genetic Counselling Masters and CPE.

• National Genetic Counsellor Society – webinar, online courses

• But what is cultural competency? – recognition and respect of multiculturalism but does not necessarily truly encapsulate other views e.g. “I am not racist, I treat everyone the same...”

• Moral and professional responsibility to have health equity.
Treaty of Waitangi in relation to health care
“Our right to good health stems from the enjoyment of our land, our forests, our seas, lakes, rivers and Whanau”

Partnership – relationship between whānau and health professional

Protection – respect of Māori cultural and health beliefs

Participation – access to health services
Māori Health Model
“Whare tapa whā”

4 key elements:
• Wairua (spiritual)
• Hinengaro (psychological)
• Tinana (physical)
• Whānau (extended family)

Karakia (blessing or prayer) has an essential part in protecting and maintaining these elements.

Genetic Counselling for Māori Whānau

• Eurocentric approach is culturally unacceptable - cannot simply convert it to work
• Adhere to collective notion of the self
• Health decisions made by group
• Family involvement at times of illness is a traditional and culturally necessary
• Māori – feel that DNA testing may interfere with Whakapapa
• **Family Focused** predictive testing for improved access and engagement
• **Family Focused** predictive testing is a change in response to cultural preferences
The pursuit of an ethical approach

• Research partnership negotiated
• Elders were part of the research committee
• Legal Agreement drawn up - Whakapapa and DNA remained the property of the whānau
• Including 4 concepts – empowerment, active involvement, cultural and spiritual safety, intellectual property rights (Treaty)
• Effort - use Kaitiatanga elements – what can we and must we do to ensure your wellbeing.
• Co Design – transformative health care
Changes and challenges of Family Focused Testing

• Tikanga Māori - correct way of doing something.
• Concept of counselling vs Whanau’s embodied experience of HDGC
• Family most likely to make the decisions for the wider group
  – Informed consent
  – autonomy
• Decision-making achieved by consensus within the family - take
• Primary relationship is not between GC and an individual
• Dealing with large family group
• Overriding importance of developing trust and rapport
• Location - Medical settings = Eurocentric.
• Marae based= Hui. Addresses Māori Health model
• Management of blood and DNA
How do we act - Concept of Ata and application to practice

Ata – growing respectful relationships

• Encorporates Planning and Positioning – how we use our service to engage

• Used as a tool to build cultural relationships and promote respectful engagement:
  – Relationships – people together for purpose. Reciprocity
  – Conduct – consider Whānau view and respectfulness
  – Planning – Effort and Energy
  – Transformation – what is the Koha (contribution)
  – Reflection – consider loss, needs, traditions as this informs interactions. Critical analysis.
How – Kaitiakitanga Elements

- **Te Tiaki** – to care
- **Te Arataki** – to guide
- **Te tautoko** - to support
- **Te pupuri** - to hold
- **Te tuku** - to transmit
- **Te tohutohu** - to instruct
Why it can work - Family Focused Predictive testing CDH1 Whanau

• Whānau major source of information and support – driven family.
• Strong elder leaders in Whānau – Guide and Instruct and engage
• Communication with extended family – Support and Hold
• Whakapapa/family tree –trust and Reciprocity
• Importance of maintaining contact - They know me, my background and my experience
• Hui and maintained communication with Elders – positioning and planning
• Having a plan – to guide the large group and give time for individuals
• 16 CDH1 positive NZ Families and at least 60 positive individuals (not all Māori)
Problems?

• **Autonomy** - group discussions collective information sharing plus individual time

• **Informed consent** – does not require that individuals decisions not be influenced by cultural, social or familial context
MCNZ Statement on Cultural Competency, Partnership and Health Equity (22nd Sept 2015)

“Much progress has been made in health care overall, but we still find strong evidence of health inequities for Māori. We all have a professional and moral responsibility to work to eliminate such inequities. Council strongly encourages all health organisations to carefully examine their partnership with Māori through genuine representative participation”

NZ MoH: Equity of Health Care for Maori: A Framework (June 2014)
Acknowledgements

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• Pauline, Maybelle, Erin and Whānau
References