Attitudes of Australian women and/or couples affected by mitochondrial disease towards mitochondrial donation

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BACKGROUND

• Maternally inherited mitochondrial diseases are characterised by a broad spectrum of symptoms and severity
• Current prenatal testing technologies cannot always accurately determine the risk of a child developing mitochondrial disease
• Mitochondrial donation (MD), utilising donor egg cytoplasm through IVF can greatly reduce the risk that a couple will pass on a maternally inherited mitochondrial condition
• At present, MD is not available in Australia
• MD is undergoing clinical trials in the UK

OBJECTIVE

• To explore the views of maternally inherited mitochondrial mutation carriers and their partners regarding current reproductive options and MD

METHODS

• Ethics approval was granted by the Royal North Shore Hospital HREC (LNR16/HAWKE/465)
• Sampling and recruitment: purposive sampling of affected women attending the Neurogenetics clinic at Royal North Shore Hospital. Recruitment is on-going
• Participants: 30 contacted, 5 participated
• Data collection: qualitative, semi-structured telephone interviews lasting 30-45 minutes
• Data analysis:
  • De-identified transcripts are being coded with concordance assessed by three independent coders.
  • Themes are being identified by thematic analysis using an inductive approach

Demographics

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>5</th>
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<tbody>
<tr>
<td>Average age, years (range)</td>
<td>52.6 (38-68)</td>
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<tr>
<td>Females/Males</td>
<td>5/0</td>
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<tr>
<td>Mitochondrial conditions profiled</td>
<td>3243 A&gt;G</td>
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Preliminary Themes

1. Perceived value
   • All participants thought MD would be very valuable
   "I would have chosen to have it, whether I had to fork the money out myself, I would’ve chosen to have mitochondrial replacement therapy for myself" - P01

2. Utility
   • Most found current reproductive options to be limited
   "For me, because except for the mutated mitochondria, my eggs are totally fine – I have many of them, and I would like my own child, and I am able to have my own children, those options have never ever come into my thinking to reproduce for myself" – P01

3. Access
   • Several barriers to accessing MD were identified
   "Time away from families, how long it’s going to take to have it done – each thing you’ve got to go through before the main big D-day arrives. Those sorts of things, in addition to others – funding, religion, everything else.” P01

4. Awareness
   • Need for awareness and the potential for stigma identified
   "I mean I probably know as much about this as most people and probably more than most. However, when I’m out talking to people, I have to really be careful and explain it in very simple terms for them to understand" P03

CONCLUSION

• Data collection and analysis is ongoing
• MD is perceived to be of real value to Australians
• This study is an initial exploratory study – further research is needed to inform the revision of current laws.

LIMITATIONS

The sample size is small and there was a low response rate.

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REFERENCE


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