The Mito Stories Project

An Australian mito organisation-led approach to learning from lived experiences in mitochondrial disease

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Thank you to everyone in the Australian mito community who have participated in the Mito Stories Project. Thank you to the Advisory Group members for volunteering their time and sharing their expertise.

This study has been approved by the Greater Western Human Research Ethics Committee.

Background

Mitochondrial diseases (mito) are a group of rare and complex conditions with diverse impacts across diagnosis, care, disability support and daily life.

While biomedical research in mito is well established, lived experience evidence remains limited and fragmented. Community members are often asked to share their experiences repeatedly across separate studies, services and consultations, creating emotional burden and reducing engagement.

The Mito Stories Project responds to this gap by building a centralised lived experience resource that supports ethical re-use of community stories and generates insights to inform more person-centred care, research and policy.

Where to next?

The next phase of the Mito Stories Project will focus on types of mito with therapies approved in the USA or Europe: TK2d, Barth syndrome and long chain fatty acid oxidation disorders.

Mito community perspectives provide important insights into disease burden, quality of life impacts, and the actual or potential value of emerging therapies. Capturing these lived experiences can help ensure that decision-making around access reflects outcomes that matter to affected individuals and families.

By using the same methods and tools, data collected will grow the Mito Stories Database, enabling future re-use.

Methods

Eligibility

Participants are:

- Australian mito community members aged ≥18 years
- Health professionals and service providers supporting people affected by mito

Recruitment

Participants are recruited through 2 complementary streams:

1. Existing community stories reviewed for potential ethical re-use
2. Invitations to participate through Mito Foundation channels, other organisations and health professional networks.

Data Collection and Analysis

Interviews are recorded, transcribed, anonymised and participant-reviewed. Data are analysed in NVivo-14 using deductive and inductive coding.

Insights so far

To date, 41 unique participants have contributed to the Mito Stories Project: 40 community members and 1 health professional. Community members represent a range of mitochondrial conditions and lived experience roles, including people living with mito, family members and carers.

These insights have informed multiple activities, including: Mito Foundation's policy submissions, an external research project developing a care plan for mito; Mito Foundation's disability related resources. The full report includes insights related to disability support and a publication on diagnosis experiences is underway.

Being heard, believed and understood is central to good care and support

Symptoms are often dismissed or misattributed.
"(I was told), 'We can't find anything physically wrong, therefore, go to a psychiatrist."
"...they just brush you off like it's nothing."

Limited mito knowledge can lead to dismissal and reduced trust.
"...everyone we talk to, they don't know anything about mito. They look at you like a deer in headlights."

Professionals who are approachable, willing to listen and learn about mito are valued.
"My doctor has read up about mito. She knows everything now...she's very, very good."

People with mito experience multiple barriers to accessing healthcare

Geography: Accessing specialised care is an ongoing struggle outside metro areas.
"It's a big day because we're leaving here at five o'clock in the morning, because they're 11 o'clock appointments...I'll be exhausted for [the next] couple of days."

Time: Extended waitlists for brief visits, difficulty reaching specialists.
"I think [respiratory physician] was about six months' wait or so. The genetics clinic was nearly two years. I think it was a year or so to see the neurologist at the hospital."

Cost: High out-of-pocket expenses for multi-disciplinary care, support and medications.
"I just say to my doctor, 'which [doctors] can I stop seeing?' because it's too expensive."

Care coordination and continuity of care are valued

Poor coordination and communication between health professionals, particularly specialists and GPs, is a recurring challenge.
"...I was struggling with...for example, my old specialist wouldn't talk to the neurologist and wouldn't talk to my GP. There was a lot of disconnect between everyone."

Continuity of care and approachability of health professionals allows relationships and trust to be built over time.
"I have an excellent GP. I went into her care about 14 years ago. ...because I've been able to see her consistently, she's seen changes in me and can understand me well when I communicate. I think I would be dead without her."

Frustration is the most common emotional response to healthcare experiences

Navigating healthcare often causes frustration and feeling dismissed.
"...my partner said, 'It's the first time I've really wanted to hit someone,' because it was just so frustrating...[the doctor] hadn't listened to what we were saying...But this time in the hospital, he actually saw what we'd been talking about."

Postive experiences usually come from knowledgeable clinicians or easier care pathways.
"...we were lucky enough that the doctor had done his sabbatical at a mitochondrial place, and he wondered if [my child] had mito, and it turned out they did."

Services have improved somewhat over recent years, including a growing awareness of mito and an increase in available support options.