



**COMPASS
RESEARCH CENTRE**

FACULTY OF ARTS
THE UNIVERSITY OF AUCKLAND

Whare Wānanga o Tāmaki Makaurau

17 August 2021 – Auckland

**Tauhi lelei:
Caring is everything
– not just anything.
If so, then what?**

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National
SCIENCE
Challenges

AGEING WELL

Kia eke kairangi ki te
taikaumātuatanga

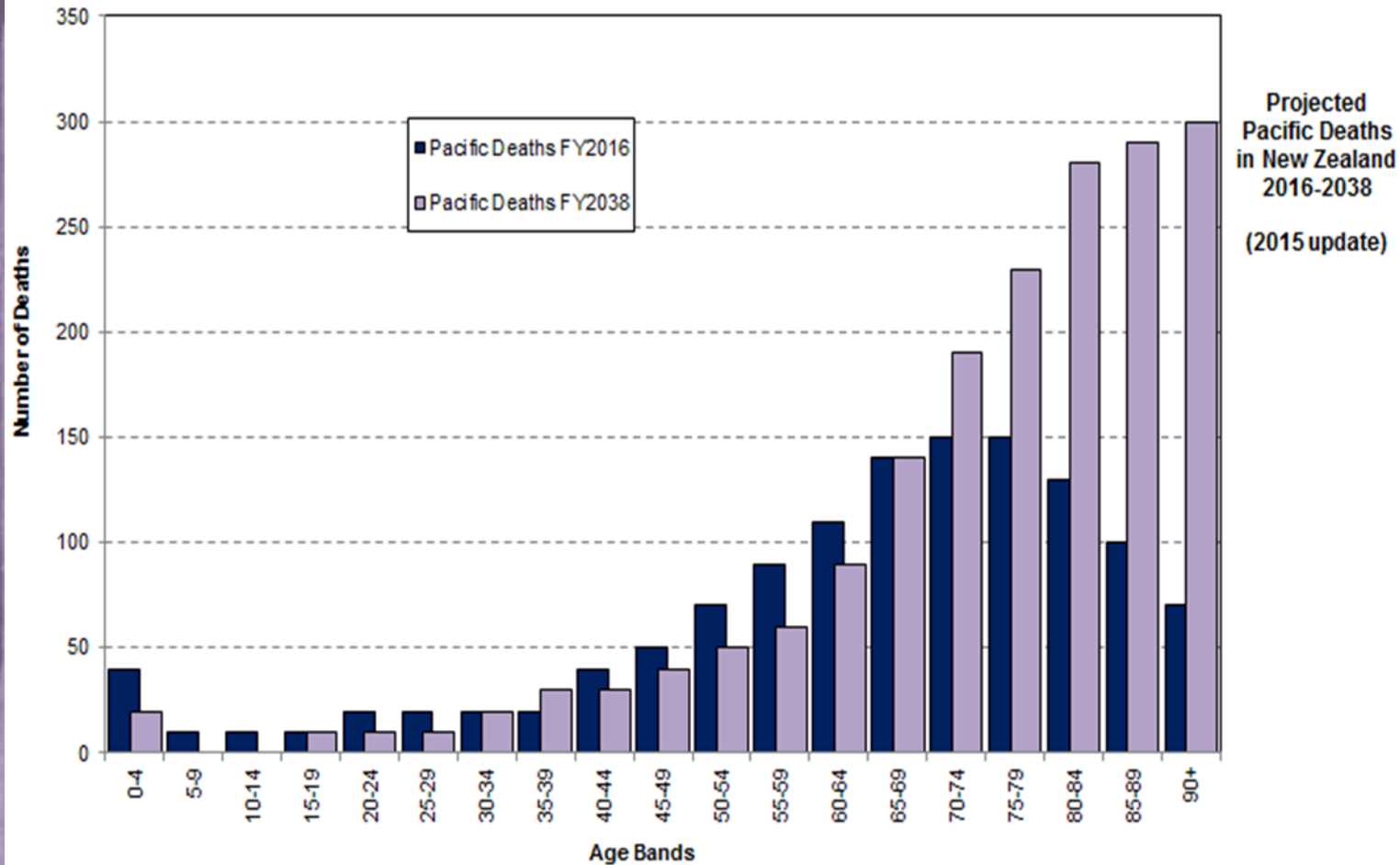
Overview

- Background
- Question and Objectives
- Design & Methods
- Preliminary findings
- Implications
- Next steps
- Disclosure statement
- Acknowledgements

Background

- >430,000 carers – health & disability sector
- Family carers estimated to provide 75–90% home-based care
- High levels of unmet needs and poor access to social and health services
- Need to understand how best to maximise potential of significant workforce in Pacific aiga (family) carers
- Mahi Aroha – Carers’ Strategy Action Plan 2019–2023 (Ministry of Social Development)

Projected ageing of deaths



The projected ageing of deaths over 2016–2038 is significant. Projected to be more deaths at older ages, fewer deaths at younger ages.

Potentially more deaths with multi-morbidity, frailty and dementia. This is expected to challenge communities and models of delivery.

Question

What are the experiences of younger Pacific aiga carers and the challenges they face while caring at home for family living with a disability, chronic condition, or at end of life?

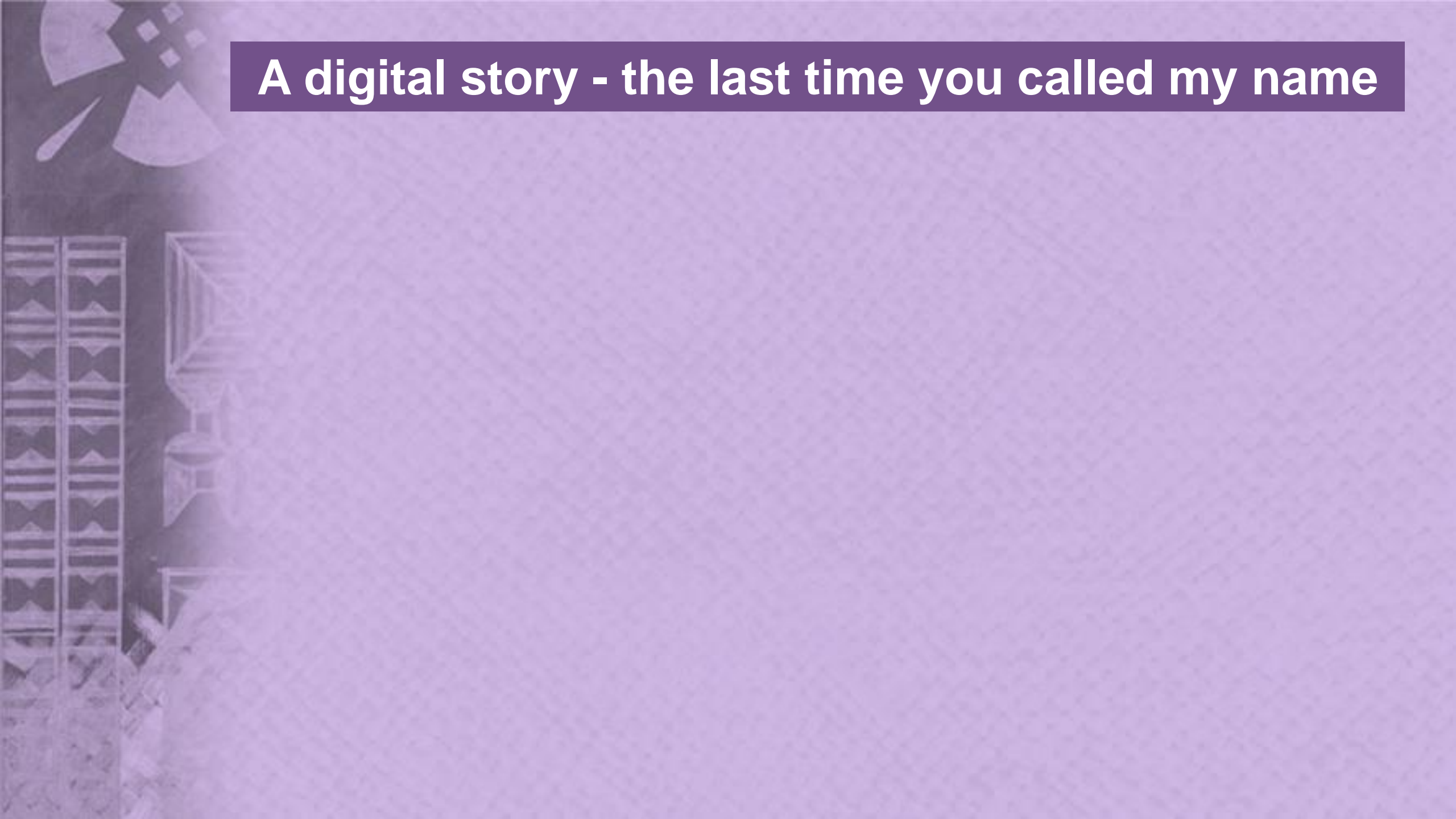
Objectives

- Determine caring experience
- Identify barriers and enablers
- Identify unmet physical and social needs
- Explore satisfaction with and appropriateness of publicly-funded services
- Determine extent to which expressed priorities for care were met
- Consider ways in which families and their communities can be better supported
- Identify implications for providers and policy decision-makers
- Disseminate findings

Design & Methods

- Qualitative study – 12 months
- Auckland setting
- Participants
 - 30 aiga carers, age 16–32
 - 80% Female
 - 22 stakeholders in 3 Focus Groups
- Data analysis, NVivo
- Dissemination
- Ethical Approval

A digital story - the last time you called my name



Role

- Occasional vs Full-time

“This role is more like full-time work, and if family member is bed-bound it is more like a 24/7 carer.” (YC)

- Honourable and sense of duty

“So ever since I was born, literally raised by my grandma, and over time as I watched my grandma grow old while she was watching me growing up as well, things started to hit the fan in terms of her health I guess it’s just my turn ... giving back that sort of care for her that she gave me since I was a little girl.” (YC)

“We have been role modelled since childhood of how to care for our own people.” (FG)

Tasks

- Wide-ranging, perceived as they do “everything”
“I get his pills ready for him to take. He also has diabetes so I have to get his insulin ready.” (YC)
“My son ... he does my dad’s dialysis, so he’s actually my dad’s dialysis nurse ...” (FG)
- Important tasks
- Relentless

Challenges

- Communication issues – language
- Schooling, other commitments

“You sacrifice a lot. Like you don’t realise how much you miss out on or how many things you have to just say no to. Just to be able to help my grandparents out.” (YC)

“When my dad first had his stroke in 2017 I was studying in Unitec I had to drop out of studies. I felt pretty gutted, but that’s my dad. Can’t do much since I’m the youngest.” (YC)

- Practical – transport, lack of training, setup of the home

Needs

- Mixed emotions – sadness, anger, frustration

“Oh, it’s hard, it’s really hard in terms of my mental health and my wellbeing.” (YC)

- Cultural

“....yes they’ll want to do the best that they can for their elderly family member, but are so limited because of the lack of skills or training or holistic support that the carer is receiving.” (FG)

- Practical – equipment for use in the home, information and training, financial, transport.

COVID-19 related issues

- Cancellation of services and medical appointments

“It was hard to get into my online classes because he was also in the living room and if he needed anything I’d have to put myself on mute and go and see if he needed a hand and then ask my friends to let me know of any work that I missed.” (YC)

- Social isolation

“I was worried to go to school because I’m looking after grandma, I think it would be a high chance of putting her at risk.” (YC)

- Difficulties with end of life priorities e.g. funerals

What assisted carers

- Physical activities

“Mentally I just like to go to the gym or just burn it off in an active way, in a healthy way as well.” (YC)

- Time out

“Getting out of the house is a big part for me because he’s there 24/7, so for me being away from home gives me the mental break that I need.” (YC)

- Belief in caregiving role

“It’s quite rewarding just being able to do small things for my grandparents, you see a big smile on their face at the end of the day ... and you feel grateful that you’re able to just do something for them.” (YC)

Preliminary findings

- Range of significant lived experiences
- Extensive caregiving tasks, major challenges
- Practical needs not met
- Accessing formal support mixed
- Financial and training assistance needed
- Caring for aiga at home very important
- Time out effective coping strategy
- Informal supports (culture, church, community, extended family, friends) played key role for family carers

Implications

- Aiga carers must be involved in developing programmes and services to support them
- Strategic plans, policy and services must be tailored to the specific needs of the aiga carer and family they care for at home

If so, then what?

- Complete final data analysis
- Disseminate results and recommendations
- Link back to Ministry of Social Development Mahi Aroha – Carers’ Strategy Action Plan 2019–2023 focus on Pacific younger and older carers
- Work with key stakeholders to turn results into action for impact, from the community up
 - Tui moe Amanaki Pilot Project

Acknowledgements

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- Pacific Homecare
- Vision Maturanga
- Aiga Carers
- Stakeholders

Disclosure

I have no commercial relationships to disclose.



Music video – I'll care for you



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