

# Popping The bubble wrap



Coping mechanism's and strategies of whānau caring for a child with a life threatening medical condition: A summary of preliminary findings.

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# CONTEXT



Personal journey  
2 operations 7 & 10

- Chemo
- Radiation
- Intense rehab – 3 yrs
- Re learn – walk/talk
- Lost short term memory

**13 yrs now**

# PhD QUESTION



**How do other whānau cope?**

**2 primary objectives**

Whānau/RMH

17 whānau/10 stakeholder interviews

**Whānau perspective**

# FINDINGS

Perceived protective  
mechanisms

Generational  
differences

**Whānau**

**Child  
views**

*Normalising*

*Women*

*Supports*

*Grand parents*

**Men**

**Stakeholder coping**

# GENERATIONAL DIFFERENCES



## YN

**Use of social media**

**Talk openly**

**Embraced lots of visitors**

**Naivety**

## OG

**Private matter – family**

**Too many visitors**

**Weighed up risks more**

**Researched extensively**

**Inc cultural mechanisms**

**Bought items in**

**Church/prayer/Minister**

# PERCEIVED PROTECTIVE MECHANISMS



Protecting child – isolation from other kids  
Withholding information – stress, anxiety, mistrust  
Withholding positive information



# SUPPORT MECHANISMS



Family, friends, doctors, support services  
**Other parents** going through similar journey  
**Smokers area** – hospital/RMH  
**Receptionists** – wards/support services  
**Cleaners**

# NORMALISING



VIP

Admissions/tests

Cleaning

Schooling – recs - better liaison with schools

Parents re-identifying their role – PICU/HDU

Whanau – eating together, **sitting** together,  
cooking/meal prep



# WOMEN



Reliance on family & community

## **Intuition**

Very focused/tasks set

Emotionally driven

Group type activities

Wrote more

Hyper-vigilant

Hit the wall a year later

# MEN



Needing to be strong

Physically present even if they didn't do much – women and stakeholders

Work important aspect for men – keeping home fires burning, found comfort in their work, sense of powerlessness

Pacific men identified feeling offended when it was suggested that they have a break from the child or the hospital saying they didn't see their child as a burden to them

# GRAND PARENTS



Hard on grand parents  
No legal rights in Western  
world Court process –  
decisions parents  
All the rights in Maori world

Constant negotiation to see  
child outside visiting hours  
Often not part of the  
discussions re treatment  
To undertake their own  
rituals or what is their  
'normal'

# Whānau

