

# Experiences of mothers whose school-aged children were born extremely prematurely

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# Introduction, Background, Methods

- Qualitative descriptive
- Recruitment through advertisement
- 9 participants
- Semi-structured interviews
- Thematic analysis

What support services and follow up to caregivers utilise and do they perceive any gaps in service delivery?

What are some of the long-term challenges caregivers identify in raising their child?

How do caregivers describe their quality of life raising a four to six year-old extremely prematurely born child?

# Results

## Traumatic Beginnings

- Unimaginable mothering debut
- Family planning
- PTSD
- Maintaining appearances



*“There are still movies  
I can’t watch, I’m pretty sure it’s  
from that experience.  
It changes you...and that feeling,  
I still get that feeling actually that  
if I started to cry  
I’d never stop”*

# Results

## The horror-miracle contradiction

- Anti-climatic homecoming
- Invisibility of prematurity
- Shared likeness
- Downward comparison

*“We’re really lucky.  
People say they feel sorry for  
us with the boys.  
I feel incredibly fortunate really, very  
lucky that we have got two boys, it  
could have been really different, we  
could have had one  
or none.”*



# Results

## Labour-intensive parenting and managing the MDT

- Orchestration of appointments
- Integration to mainstream services
- Loss of special status

*“It was really hard  
to transition from people who  
knew us so well and were really  
special,  
to people who had just no idea of  
what we’d been though and  
hadn’t been on that journey with  
us.”*



# Results

## Stigma and storying the meaning of PTB

- Hallmarks of prematurity
- Heroic tales of survival

*I get really warm fuzzies  
when people say,  
'Ohh aren't they tall. They don't look prem'.  
[One daughter's] got a beautiful round  
head.  
[The other twin] is sort of more squareish  
and sort of big, elongated a bit.*



# Conclusions

- Parenting a prem is incredibly satisfying – but isolating and exhausting
- Mothers are grateful for their current situation despite having gone through some of the worst experiences of their lives
- Perceived lack of appreciation on part of generalist clinicians
- Limited maternal follow up systems beyond a year post NICU admission

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