



Measuring the health & well-being of mothers caring for a child with Rett Syndrome

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BACKGROUND

- Mothers with a RTT child are challenged by the many things related to their child's condition, personal and socio-ecological factors.
- Mothers caring for a disabled child are known to have worse physical & mental health than mothers without a disabled child.
- The health & well-being of mothers has not been specifically examined in Rett syndrome.



HYPOTHESES

Physical & mental health increase as:

- the level of functional ability in the child increases.
- the severity of the child's disability & behavioral phenotype decrease.
- resources and social support increase.
- family functioning increases and the more well adjusted the mother's marriage.
- the perception of services being delivered in a family-centered way increase.



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METHODS

- Follow-up questionnaire mailed to 187 families in 2002
- Measures completed:
 - SF-12 -WeeFIM -RSBQ -MPOC
 - Support Functions Scale
 - Family Resource Scale
 - Family Support Scale
 - Abbreviated Dyadic Adjustment Scale
 - McMaster Family Assessment Device
 - Depression Anxiety Stress Scale



METHODS

- Analysis
 - Linear regression
 - Univariate
 - Multivariate



RESULTS

- 135 mothers completed the SF-12
- Mother's age range: 21-60 years
- Child's age range: 3-27 years
- 39.1% only completed some high school
- 26.3% are full-time homemakers
- 24.1% are not working because their daughter has RTT



RESULTS Cont...

- 47.7% are financially stressed
- 43.7% are either highly or very highly disadvantaged (SEIFA)
- 59.3% live in major Australian cities
- 23.0% are single/not in a relationship
- 62.3% have 1-2 children in addition to their RTT child



RESULTS Cont...

- Physical Component Summary
 - Average score = 48.6 (SD 10.1)
 - Range 23.1-64.5
- Mental Component Summary
 - Average score = 42.4 (SD 10.2)
 - Range 20.7-60.6



RESULTS Cont...

- Univariate analysis: Physical Health
 - Low disadvantage
 - Working Full- or Part-time
 - Low financial stress
 - No breathing problems in last 2 years
 - No sleeping problems in last 2 years
 - Private health insurance
 - No structured therapy at home
 - High social support



RESULTS Cont...

- Multivariate analysis: Physical Health
 - Working Full- or Part-time
 - No structured therapy at home
 - Low need for help and assistance
 - Helpfulness of social support
 - Less severe RTT symptoms



RESULTS Cont...

- Univariate analysis: Mental Health
 - Working Full- or Part-Time
 - Low financial stress
 - No fracture in last 2 years
 - RSBQ scales: General mood, Face movements, Fear & Anxiety
 - Low need for help and assistance
 - Adequate time resources
 - High marital adjustment
 - High family functioning



RESULTS Cont...

- Univariate continued...
 - Low DASS scale scores
- Multivariate analysis: Mental Health
 - Working Full- or Part-Time
 - No fracture in last 2 years
 - Children with low scores on RSBQ: Face movements sub-scale
 - High marital adjustment
 - Low stress score



CONCLUSIONS

Important factors that are modifiable:

- Social support
 - Ability to socialise, whether through work or some other means.
 - Utilising support available from family & friends.
- Healthy functioning family
 - Communication between family members
 - Feeling accepted & getting along with each other



CONCLUSIONS Cont...

Important factors that are modifiable:

- Well adjusted marriage
 - Agreement on things believed to be important
 - Being happy in your marriage
- Child-related factors
 - Management & prevention of breathing and sleeping problems and fractures
 - Acceptance of the more socially ‘unacceptable’ characteristics (ie. facial & mouth grimaces)



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