Behavioural Problems in Preschool Children with Cystic Fibrosis

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Background

Cystic Fibrosis is the most common severe autosomal recessive disease of childhood

Incidence: 1 in 2500
Carrier frequency: 1 in 25

Clinical manifestations include:
- progressive, irreversible suppurative lung disease
- pancreatic exocrine insufficiency
Median life expectancy is mid-30s

(Massie, MJA 2005; 183 (10): 501-502)
**Background**

Newborn screening:
- Early diagnosis
- Better disease management and health outcomes \(^1\)

... but at what cost to the child and family mental health and functioning?

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\(^1\) Merelle et al, Cochrane review 2007
Previous Research

Mealtime behaviour problems
• More problem child behaviours $^{1,2}$
• More parental strategies used $^{1,3,4}$
• Parenting interventions improve caloric intake $^5$

Parent mental health and family stress
• Early diagnosis associated with parental depression $^6$
• Poorer family functioning $^7$

Child behaviour, treatment adherence, sleep problems – little evidence in preschool children

Clinical Impressions

Child behaviour, sleep, mealtime and compliance problems are common in preschool children with CF

Adversely impacts on child and family health
Background

In healthy preschool children:

• Sleep, eating and behaviour problems are common
• Parenting strategies improve child behaviours
Background

Same may be true for preschool children with CF, but…

Need to know

• prevalence of behaviours
• which parenting styles are associated
• whether parents would like parenting information
Aims

• Describe the prevalence of child behaviour problems and primary care giver sleep and mental health problems

• Describe associations between problems and parenting styles

• Obtain information about the desire for, and structure of, a potential parenting program
Hypotheses

• That there is a high prevalence of child problem behaviours

• That modifiable parenting styles are associated with problem behaviours

• That primary care givers would welcome parenting information
Methods

Design: cross sectional survey

Participants: parents of all children aged 6 months to 5 yrs with CF, recruited from RCH, MMC and SCH

Measures: validated and study designed measures
Measures

Child sleep
• Parent report “no”, “small”, “moderate” or “large” sleep problem

Parent sleep quality
• Single item, parent report of “very good” to “very bad”
Measures

Externalizing and internalizing behaviours
• Child Behavior Checklist (CBCL) – 99-item measure

Parent mental health
• Depression Anxiety Stress Scale (DASS) – 21-item

Behavioral Pediatric Feeding Assessment Scale (BPFAS)
• 25 items
Measures

Parenting

• 6 item (harsh parenting), 9 item (over-involved/protective) and 5 item (inconsistent) measures

Adherence to treatment

• 3 items, study designed, 7 point scale from “no problem” to “severe problem”
Analysis

Comparison of child outcomes with healthy children

- Australian population data ¹
- Victorian community data ²
- Normative data ³,⁴

1. Longitudinal Study of Australian Children
3. Behavioral Pediatric Feeding Assessment Scale, Crist et al, 2001
4. Achenbach CBCL normative data
Analysis

Outcomes
• Means and SD normally distributed data
• Medians and interquartile ranges (IQR) skewed data
• Proportions for categorical data

Relationship between child outcomes and parenting styles
• Unadjusted and adjusted regression analyses controlling for child age, gender and maternal education
Results – Sample Characteristics

148 eligible – 5 excluded, 4 did not consent
139 enrolled
Participation rate 84.2%

Child characteristics
  • Male – 54%
  • Zero hospital admission previous year – 61%

Primary caregiver characteristics
  • Mother – 92%
  • Mean age 34.6 years
  • Completed tertiary studies – 53%
Sleep problems were common

<table>
<thead>
<tr>
<th></th>
<th>CF</th>
<th>LSAC data</th>
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</thead>
<tbody>
<tr>
<td><strong>Small problem %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 6 mo – &lt; 2 yrs</td>
<td>26.3</td>
<td>25.9</td>
</tr>
<tr>
<td>≥ 2 – &lt; 4 yrs</td>
<td>27.5</td>
<td>28.4</td>
</tr>
<tr>
<td>&gt; 4 yrs</td>
<td>41.7</td>
<td>20.1</td>
</tr>
<tr>
<td><strong>Moderate/large problem %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 6 mo – &lt; 2 yrs</td>
<td>29.0</td>
<td>17.5</td>
</tr>
<tr>
<td>≥ 2 – &lt; 4 yrs</td>
<td>17.5</td>
<td>12.2</td>
</tr>
<tr>
<td>&gt; 4 yrs</td>
<td>19.4</td>
<td>13.5</td>
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</tbody>
</table>
Results – Child Eating

Problem behaviours at mealtimes occurred frequently

<table>
<thead>
<tr>
<th>Frequency of behaviours</th>
<th>CF</th>
<th>BPFAS data</th>
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</thead>
<tbody>
<tr>
<td>Mean score (SD)</td>
<td>52.4 (15.5)</td>
<td>46.6 (10.3)</td>
</tr>
<tr>
<td>Clinically significant %</td>
<td>26</td>
<td>-</td>
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</table>

<table>
<thead>
<tr>
<th>Problem score</th>
<th>CF</th>
<th>BPFAS data</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;1 problem behaviour %</td>
<td>71.6</td>
<td>51</td>
</tr>
<tr>
<td>&gt;4 problem behaviour %</td>
<td>40.2</td>
<td>21</td>
</tr>
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</table>
# Results – Child Behaviour

No increased prevalence of externalizing or internalizing behaviours

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<thead>
<tr>
<th></th>
<th>CF</th>
<th>CBCL data</th>
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<tbody>
<tr>
<td><strong>Externalizing problems %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; Borderline</td>
<td>11.6</td>
<td>15.8</td>
</tr>
<tr>
<td>&gt; Clinical</td>
<td>5.8</td>
<td>8</td>
</tr>
<tr>
<td><strong>Internalizing problems %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; Borderline</td>
<td>16.3</td>
<td>15.8</td>
</tr>
<tr>
<td>&gt; Clinical</td>
<td>10.5</td>
<td>8</td>
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Results – Adherence

Parents report problems with:

- Physiotherapy adherence 50.4%
- Enzyme and electrolyte adherence 6%
## Results – Primary Caregiver

<table>
<thead>
<tr>
<th>Mental health</th>
<th>CF</th>
<th>Population Data</th>
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<tbody>
<tr>
<td><strong>Depression %</strong></td>
<td>33.3</td>
<td>8.5</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>6 (0-10)</td>
<td>2 (0-8)</td>
</tr>
<tr>
<td><strong>Anxiety %</strong></td>
<td>16.4</td>
<td>5.8</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>2 (0-6)</td>
<td>2 (0-6)</td>
</tr>
<tr>
<td><strong>Stress %</strong></td>
<td>34.2</td>
<td>10.7</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>12 (0-16)</td>
<td>8 (2-14)</td>
</tr>
<tr>
<td><strong>Sleep quality</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bad or very bad</td>
<td>37.6%</td>
<td>(30.6 - 32%)</td>
</tr>
</tbody>
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1. TWT data  
2. LSAC data
Logistic regression

Only harsh parenting was associated with internalizing problem behaviours
(Associated OR 3.99, 95% CI 1.15 – 13.85, p = 0.03)

Harsh parenting and externalizing problems
(OR 2.17, 95% CI 0.56 – 8.41)

Overprotective parenting and internalizing problems
(OR 2.25, 95% CI 0.69 – 7.38)

Overprotective parenting and sleep problems
(OR 2.01, 95% CI 0.75 – 5.41)
Parenting Program

Caregivers of children with CF reported that:

- 74% welcome a parenting program
- 78% want information before problems arise
- 84% would like a health professional to run the session
- 40% indicated they would attend 3 or more sessions
Conclusions

Children with CF have:

• More mealtime and sleep problems

• Primary caregivers suffered depression, anxiety, stress and poor sleep quality
Conclusions

Harsh parenting is associated with internalizing problem behaviours
Conclusions

Most parents seek information:

• About common child behaviour problems
• Before the onset of problems
• From a health professional
Limitations

No control group

22 (15.8%) non-responders
• No statistical difference with respect to age, gender and SES

Primary caregiver report – may bias outcomes
Where to Next?

Results will inform planned pilot of parenting program to address common child behaviour problems identified in this survey.

Add to the evidence in order to help support families of children with Cystic Fibrosis.
Acknowledgements

Louise Caterford
Dr Harriet Hiscock
Dr John Massie
Research Staff at CCCH

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Conflicts of Interest Declaration

This research was funded by the Centre for Community Child Health, RCH and the Department of Respiratory Medicine, RCH.

All researchers have declared that they have no financial interests in this research or its outcomes, or any relevant affiliations.
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