

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?

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 depression⁶
- Poorer family functioning ⁷

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

1. Crist et al, J Dev Behav Pediatr 2004; 2. Powers et al, Pediatrics 2002;
3. Sanders et al, J Pediatr Psychol 1997; 4. Stark et al, J Pediatr 2000;
5. Power, J Pediatr Psychol 2006; 6. Balfour-Lynn, Arch Dis Child 2008;
7. Mitchell et al, J Dev Behav Pediatr 2004



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
2. Hiscock et al, BMJ 2008
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%



Results – Child Sleep

Sleep problems were common

	CF	LSAC data
Small problem %		
≥ 6 mo – < 2 yrs	26.3	25.9
≥ 2 – < 4 yrs	27.5	28.4
> 4 yrs	41.7	20.1
Moderate/large problem %		
≥ 6 mo – < 2 yrs	29.0	17.5
≥ 2 – < 4 yrs	17.5	12.2
> 4 yrs	19.4	13.5



Results – Child Eating

Problem behaviours at mealtimes occurred frequently

	CF	BPFAS data
Frequency of behaviours		
Mean score (SD)	52.4 (15.5)	46.6 (10.3)
Clinically significant %	26	-
Problem score		
>1 problem behaviour %	71.6	51
>4 problem behaviour %	40.2	21



Results – Child Behaviour

No increased prevalence of externalizing or internalizing behaviours

	CF	CBCL data
Externalizing problems %		
> Borderline	11.6	15.8
> Clinical	5.8	8
Internalizing problems %		
> Borderline	16.3	15.8
> Clinical	10.5	8



Results – Adherence

Parents report problems with:

- **Physiotherapy adherence 50.4%**
- Enzyme and electrolyte adherence 6%



Results – Primary Caregiver

	CF	Population Data
Mental health		
Depression %	33.3	8.5
Median (IQR)	6 (0-10)	2 (0-8) ¹
Anxiety %	16.4	5.8
Median (IQR)	2 (0-6)	2 (0-6) ¹
Stress %	34.2	10.7
Median (IQR)	12 (0-16)	8 (2-14) ¹
Sleep quality		
Bad or very bad	37.6%	(30.6 - 32%) ²

1. TWT data 2. LSAC data



Logistic regression

Only harsh parenting was associated with internalizing problem behaviours

(Adjusted 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



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