Childhood Chronic Illness: The Role of Parenting Intervention

Alina Morawska
Parenting and Family Support Centre
The University of Queensland
alina@psy.uq.edu.au
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Collaborators
Jennifer Batch
Scott Burgess
Rachel Calam
Dianne Campbell
Ania Filus
Jennifer Fraser
Amy Mitchell
Matt Sanders
Kate Sofronoff

Students
Kah Yen Cheah
Paige Ebersohn
Lindsey Franklin-Browne
Caroline Gregory
Brenda Hughes
Adela Kiveric
Aditi Lohan
Roslyn Pay
Katie Sillar
Jenny Stelzer

Research Staff
Phoebe Cooper
Stacey Freebody
Mary-Cait Hunter
Adela Kiveric
Rachel Law
Shania Leung
Morgan Spence
Agnes Sumargi
Cassie Tellegen
Katie Vivian
Overview

• What is the problem
• Why parents matter
• What has been done to date
• Questions we are trying to answer
• Conclusions and future directions
Childhood Chronic Illness

Ongoing impairment characterised by a physical condition causing use of health services beyond routine care

Asher, et al. (2006)
A significant problem

- Burden of illness is greatest in childhood (AIHW, 2005)
- Impact on child and family (Halterman, et al., 2004; Moore, et al., 2006)
- Adherence is low (50-75%) (Morton et al., 2014)
- Treatment is expensive and complicated
Children with chronic health conditions have more emotional and behavioural problems (Hysing, et al., 2007; 2009; Pinquart & Shen, 2011)
Parenting and the family environment impact on children’s health directly and indirectly

Family Stress

Parenting Practices

Child health and wellbeing

Wood, et al., 2007
Why parents matter

• parenting factors and family stress can predict illness onset and disease course (Gustafsson, et al., 2002; Mrazek, et al., 1999)

• positive, confident and effective parenting associated with better management of chronic health conditions, and better child adjustment (Davis, et al., 2001)
Daily parenting tasks

Need to integrate parenting strategies for general behaviour and tasks relating specifically to their child’s condition.
Common parenting traps

- Different expectations for behaviour (Walker, et al., 1995)
- Discipline child less often and more inconsistently (Walker, et al., 1995; Wilson, et al., 1993)
- Disagreement between parents about severity and management (Eiser, et al., 1991)
- Reluctant to discipline their child to prevent distress that results worsening of the condition (Daud, et al., 1993)
What about treatment adherence?

- child behaviour problems
- parenting practices
- family stress (Burgess et al., 2014; Santer et al., 2014)
So what has the focus been to date?

- Medical adherence and health outcomes
- Most interventions focus on knowledge (Warschburger, et al., 2003)
- Limited effects of existing adherence interventions (Dean et al., 2010; Ersser et al., 2014)
- Psychological interventions have had small effects (Pai et al., 2014) – but these don’t target parenting
Some questions

• Can parenting interventions:
  o improve parenting?
  o reduce levels of emotional and behavioural problems?
  o improve family functioning?
  o impact on adherence?
  o impact on children’s health and wellbeing?

• What are the mechanisms involved in this process?
• Does it matter what the health condition is?
• How parents may best be engaged in interventions?
The evidence so far...

- **Parenting interventions for diabetes:** (Lohan, Morawska, & Mitchell, 2015)
  - Meta-analysis identified 7 studies
  - Mixed methodology, interventions
  - Some effects on parenting, child behaviour etc
  - No effects on metabolic control
Self-directed Triple P and Asthma

- Aim: evaluate the feasibility of self-directed, web-based Triple P with families of children with asthma

- Home page views: 668
- Information sheet views: 195
- Consent form views: 140
- Consents: 14
- Baseline completion: 13
- Drop out: 12 families by week 1

Clarke, Calam, Sanders, & Morawska (2013)
Teen Triple P and Diabetes

- Parents of 11-17 year olds
- Self-directed Teen Triple P program
- N=90
- Significant improvements in:
  - family conflict about diabetes
  - parenting practices
  - parenting confidence
  - child behaviour
- No change in parental stress

Doherty, Calam, & Sanders (2013)
Group Triple P and Diabetes

- Improvements in child behaviour at 3 months, but not sustained at 12 months
- For group with pre-existing problems:
  - Lower parent anxiety & stress at 12 months
  - Improved parent competence at 12 months
- No effect on glycemic control

Westrupp et al., 2014
Intervention Elements

1. brief psychoeducation component
2. strategies for effective illness management
3. assist parents to understand the link between illness and behavioural and emotional adjustment and impact of family environment
4. strategies to prevent & manage emotional and behavioural problems

Morawska et al 2014
Delivery Considerations

- in conjunction with appropriate medical management
- in the context of the child’s existing treatment
- burden of intervention for families
- viability and sustainability → effective for variety of chronic illnesses
- consideration of how illness specific information communicated to parents
Session Plan

• What is chronic illness?
  – Activity 1: Raising a child with a chronic illness
  – Children’s behaviour and emotions

• Preventing illness problems
  – Activity 2: Continue regular activities
  – Activity 3: Have realistic expectations
  – Reduce family stress
  – Reduce children’s stress and anxiety
  – Activity 4: Saying helpful things
  – Help siblings cope

• Managing your child’s illness
  – Activity 5: Keep informed and keep track
  – Activity 6: Involve your child
Session Plan

• Review of Session 1
• Why do children have problems with behaviour or emotions?
  – Activity 7: Parent traps
  – Activity 8: Preventing problems
• Managing treatment routines
• Assertive discipline
  – How to teach your child limits
  – Activity 9: Giving clear instructions
  – How to manage disobedience
  – If problems persist
Healthy Living Triple P & Asthma and Eczema

- Better parenting
- Better child behaviour
- Less parent stress
- More confidence with eczema management and with child behaviour
- Better child illness related behaviour (eczema)
- Better parent QoL
- Better family functioning
- Symptom diary measures approaching significance

Morawska et al. (2015a,b)
# Healthy Living Triple P & Diabetes

(Morawska, Sofronoff, Batch & Filus, ARC Discovery Grant 2014)

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<th>Domain of Assessment</th>
<th>Measures</th>
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<td>Family Background Questionnaire</td>
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<td>Parenting efficacy</td>
<td>Self-Efficacy for Diabetes Scale</td>
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<td>Child illness behaviour</td>
<td>Diabetes Behaviour Checklist</td>
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<td>Parenting behaviour</td>
<td>Alabama Parenting Scale (including child assessment)</td>
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<td>Child behaviour &amp; adjustment</td>
<td>Child Adjustment and Parent Efficacy Scale</td>
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<td>Child quality of life</td>
<td>PedsQL4.0 Generic Core Scale</td>
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<td>Family quality of life</td>
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<td>Parent adjustment &amp; stress</td>
<td>Parent Experience of Child Illness Scale</td>
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<td></td>
<td>Parenting Stress Index-Short Form</td>
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<tr>
<td>Illness severity (monitoring)</td>
<td>BG readings downloaded directly from the child’s BG meter; HbA1c levels</td>
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<td>Child &amp; parent behaviour</td>
<td>Home Observation</td>
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<td>Program satisfaction</td>
<td>Client Satisfaction Questionnaire (including child assessment)</td>
</tr>
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</table>
Some questions

- Can parenting interventions:
  - improve parenting ✔️
  - reduce levels of emotional and behavioural problems? ✔️
  - improve family functioning ✔️
  - impact on adherence?
  - impact on children’s health and wellbeing?

- What are the mechanisms involved in this process? ❔
- Does it matter what the health condition is? ❔
- How parents may best be engaged in interventions? ❔
What’s next?

• Adherence measurement
• Health outcomes
• Other illnesses & acute illnesses
• Mechanisms of change
• Parent engagement