Parenting interventions for childhood chronic illness

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Overview

- Introductions & Goals
- Background
- Existing Interventions
- Triple P Research & Development Cycle
- Positive Parenting for Healthy Living
- Evidence of effectiveness
- Future directions

Childhood Chronic Illness

- Ongoing impairment characterised by a physical condition causing use of health services beyond routine care
- Common & rates on the rise
  - Asthma affects 14% of children
  - Eczema affects 17% of children
  - Prevalence in Australian children is among the highest in the world Asher, et al. (2006)

- Burden of illness is greatest in childhood (AIHW, 2005)
- Prescribed medical regimen; but adherence is low (AIHW, 2005)
- Impact on child and family (Halterman, et al., 2004; Moore, et al., 2006)

Childhood Chronic Illness & Emotional and Behavioural Problems

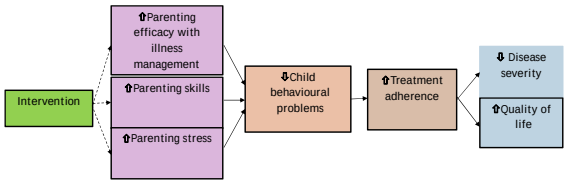
More behavioural and adjustment problems (Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Hysing, Elgen, Gillberg, & Lundervold, 2009)

Existing interventions

- Meta-analytic data for interventions to improve adherence
  - moderate effect sizes
  - combinations of behavioural and educational interventions highest effect size
  - significant variability between studies in outcomes (Graves, et al., 2010)

Existing Interventions II

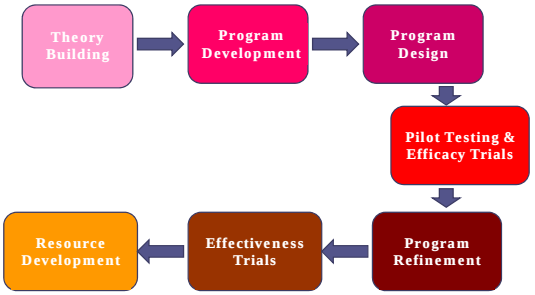
- Most focused on medical adherence and health outcomes
- Most interventions focus on knowledge (Warschburger, et al., 2003)
- Behavioural interventions more effective than educational interventions (Cushing & Steele, 2010)
- Limited data on parenting interventions for chronically ill children:
  - single case studies (Bagner, et al., 2004; Gorski, et al., 2004)
  - interventions for adolescents (Bruzzese et al 2008)
  - single disorder studies (Applegate et al., 2003).



A common approach?

- diagnostic category does not predict adjustment → factors such as the family environment, illness severity and chronicity more important (Bennett, 1994; Frank, et al., 1998; Stein & Jessop, 1989; Svavarsdottir & Arlygsdattir, 2006)
- communities are more likely to have children with a range of conditions

Triple P Research & Development Cycle

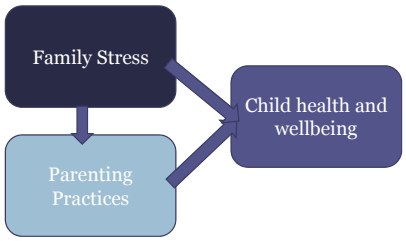


Theory Building

Role of parents in illness management

- 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)

Pathways of Impact



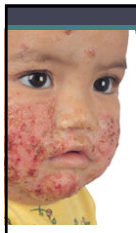
Wood, et al., 2007

Daily parenting tasks

- need to integrate parenting strategies for general behaviour and tasks relating specifically to their child's condition
  - close monitoring of daily activities
  - administering medication and other medical interventions
  - responding quickly and effectively to medical emergencies
  - providing child with developmentally appropriate play and social experiences
  - helping children to manage their emotions
  - developing effective home-school communication and partnerships

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)



Program Development

Intervention targets

- Increase positive parenting practices
- Reduce ineffective, coercive and inconsistent strategies
- Fewer child behaviour problems, and better child adjustment
- Empower parents to develop better daily routines
- Encourage children to carry out health related activities that they might otherwise resist
- Reduce child and family stress
- Improve the quality of life for the child and family
- Improve medical adherence and child health

Intervention elements Morawska et al 2014

1. brief psychoeducation component
2. strategies for effective illness management
3. information to assist parents to understand the link between illness and behavioural and emotional adjustment and impact of family environment
4. strategies to prevent emotional and behavioural problems
5. strategies to assist parents in preventing and managing their child's anxiety
6. strategies to prevent and manage child behavioural difficulties

Program Design

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

Rationale for Triple P Discussion Groups

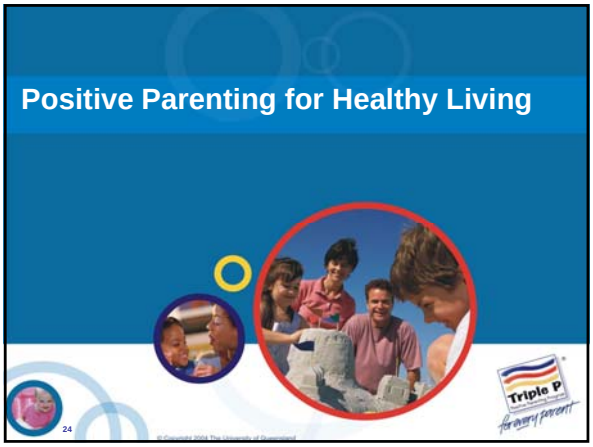
- Specifically targeted
- Based on Triple P principles of positive parenting
- Includes relevant Triple P strategies for preventing and managing specific problems
- Uses minimally sufficient approach
- Level 3 Intervention

Rationale of Triple P Discussion Groups

- Can be used to manage waiting lists or as a first step to engage high needs parents
- May increase parental engagement as Triple P Discussion Groups are topic specific for areas of identified needs for parents
- Cost and time effective (for parents and practitioners) especially in illness context
- Parents may also generalise skills to other problem behaviours

Overview of Triple P Discussion Groups

- Two 2-hour group sessions
- Small group format (8-15 people)
- Various teaching methods employed
  - PowerPoint slides and teaching
  - DVD clips
  - Group exercises and discussions
- Parents are encouraged to keep track and try new strategies



Program Overview

- Session 1:
  - What is chronic illness?
  - Preventing illness problems
  - Managing your child's illness
- Session 2:
  - Why do children have problems with behaviour or emotions?
  - Managing treatment routines
  - Assertive discipline

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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

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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

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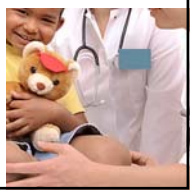
Pilot Testing and Efficacy Trials



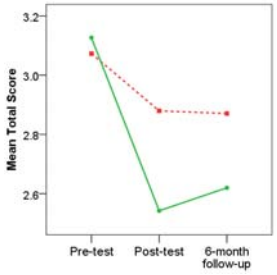
Efficacy Trial Morawska et al

- Randomised controlled trial
- 107 parents of 3-10 year old children suffering asthma and/or eczema
- Assessment: self-report, monitoring, observation
- Random allocation to discussion group or care as usual

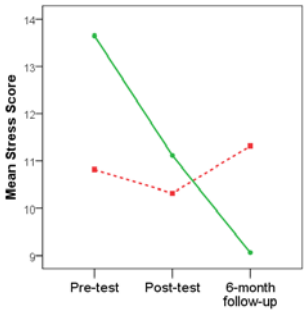
Assessment

Domain of Assessment	Children with Asthma
Sociodemographic	Family Background Questionnaire
Parenting efficacy	Asthma Parent Tasks Checklist
Child illness behaviour	Asthma Behaviour Checklist
Parenting behaviour	Parenting Scale
Child behaviour & adjustment	Eyberg Child Behavior Inventory CAPES, Emotional subscale
Child quality of life	PedsQL4.0 Generic Core Scale
Family quality of life	PedsQL Family Impact Module
Parent adjustment & stress	DASS-21
Illness severity (monitoring)	Asthma Diary
Child & parent behaviour	Home Observation

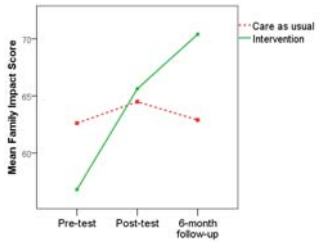
Use of ineffective parenting strategies (Parenting Scale) p=.006



Parent stress (DASS-21) p=.041



Impact of child's illness on family (PedsQL FIM) p=.001



Triple P for Asthma

Clarke, S.-A., Calam, R., Sanders, M. R., & Morawska, A. (2013). Developing web-based Triple P 'Positive parenting programme' for families of children with asthma. (Short communication). *In Press: Child: Care, Health and Development*. doi: 10.1111/cch.12073

- 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

Triple P for Diabetes

Doherty, F. M., Calam, R., & Sanders, M. R. (2013). Positive Parenting Program (Triple P) for Families of Adolescents With Type 1 Diabetes: A Randomized Controlled Trial of Self-Directed Teen Triple P. *Journal of Pediatric Psychology, 38*(8), 846-858. doi: 10.1093/jpepsy/jst046

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

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

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

What's next?

- Adherence measurement
- Health outcomes
- Other illnesses & acute illnesses
- Service delivery & training