



Institute for Applied  
Health Research

# A systematic review of the effectiveness of interventions for parents of children with chronic illness

**Dr Kerri McPherson, Dr Lisa Kidd, Dr Susan Kerr & Mr John Niven**

**Parenting and Family Support Research Programme  
Glasgow Caledonian University**

# Parenting of children with chronic illness

## **A chronic or long term illness is:**

- long in duration, last >12m
- slow in progression
- incurable
- manageable through tailored care

## **Self-management**

- The role of the parent
- The role of the young person

# Parenting of children with chronic illness

## **Quality of life** (Hatzmann et al, 2008; Halterman et al, 2004)

- Reduced QoL
  - social and daily functioning
  - sleep
  - less positive and more negative emotions
- Inversely associated with symptom severity
- Positively associated with perceptions of control

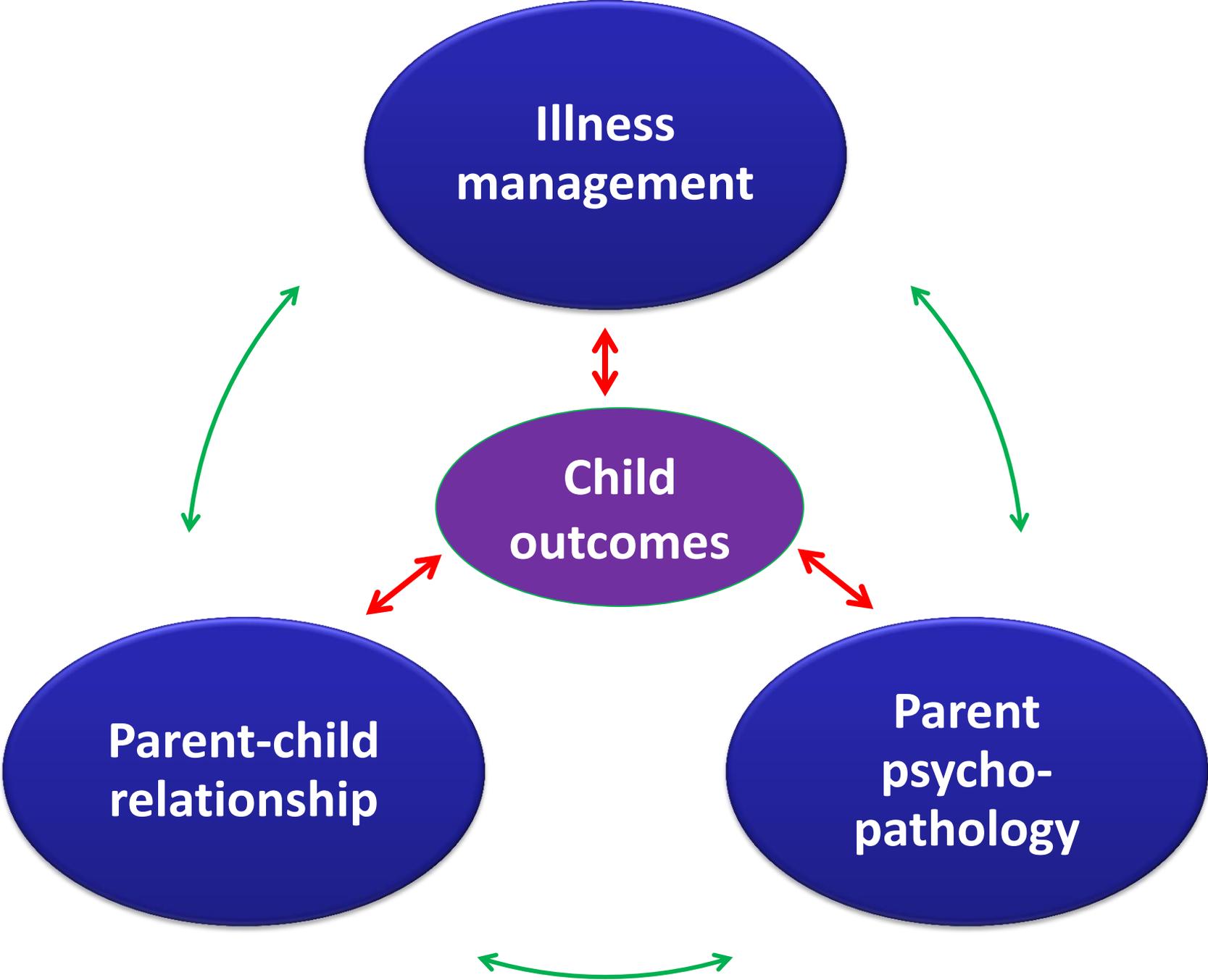
## **Stress, anxiety and depression**

- Diagnosis (Streisand et al, 2008)
- Condition management (Monaghan et al, 2009; Streisand et al, 2005)

## **Financial disadvantage** (De Rigne, 2012)

- Impact on employment

## **Social isolation** (Kratz et al, 2009)



# Aims

## Existing reviews

- Child/adolescent-focused
- No review of parent-focused interventions (Barlow & Ellard, 2004)

## To:

- Describe the characteristics, components and delivery of existing parent-focussed interventions
- Report on the effectiveness of parent-focussed interventions
- Make future recommendations for parent-focussed interventions for children with chronic or long-term conditions

# Parent-focussed intervention

## An intervention that aims to:

- Directly educate or impart knowledge to parents about a child's chronic/long-term illness and their management of this
- Enhance a parent's role in their child's illness management
- Helps parents to develop self-/illness management skills
- Helps parents to help their child develop self-management skills
- Helps parents to optimise their ill child's development
- Helps parents to adapt to life parenting a child with a chronic/long-term illness
- Helps parents to maintain their own physical and psychosocial wellbeing

# Inclusion criteria

## Population

- Parents: mothers, fathers, step-mothers, step-fathers
- Children: 2-12 years, diagnosed with a chronic/long term illness

## Intervention

- Studies of effectiveness
- Psycho-educational, behavioural, counselling, health promotion, self-management etc
- Individual, group, self-help, telephone etc

## Comparison

- Usual care/standard care
- Wait-list control

## Outcomes

- Parents physical, psychosocial and emotional wellbeing
- Child outcomes

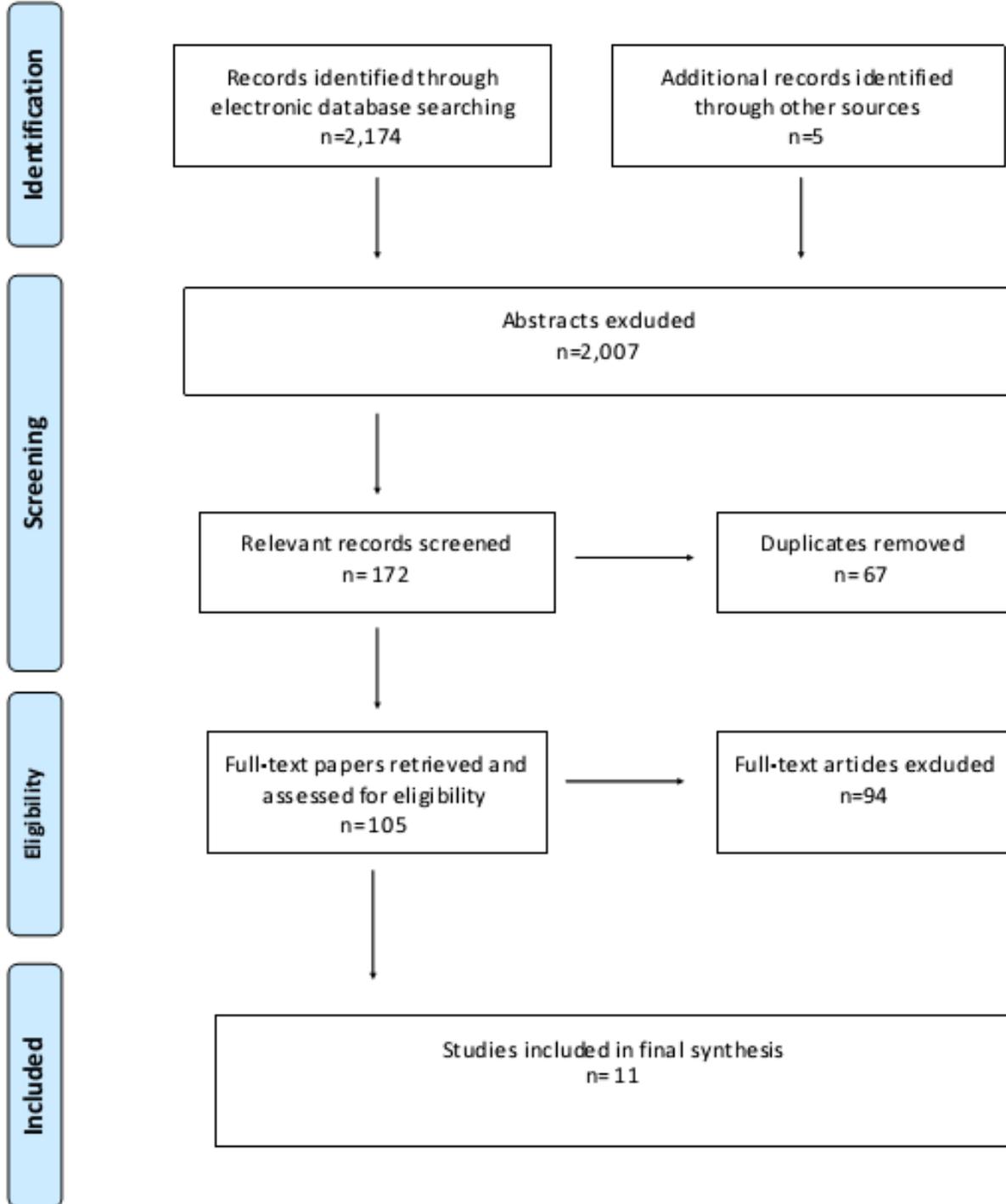
# Search strategy

## Electronic search

- Medline
- EMBASE
- PsycINFO
- CINAHL
- Cochrane Central Register of Controlled Trials

## Hand search of appropriate reference lists

# Search results



# Results

## Aim 1:

Describe the characteristics, components and delivery of existing parent-focussed interventions

<b>Study</b>	<b>RCT</b>	<b>Intervention</b>				<b>Session(s)</b>	
		<b>Sample</b>	<b>Focus</b>	<b>Type</b>	<b>Location</b>	<b>Number</b>	<b>Duration</b>
<b>Bergmo et al 2008</b> Norway	✓	<b>50 Parents</b>	<b>Parents</b>	<b>Condition specific</b>	<b>Internet</b>	<b>No limit</b>	<b>n/a</b>
<b>Burke et al 1997</b> Canada	✓	<b>25 Families</b>	<b>Parents + Child</b>	<b>Generic</b>	<b>Community</b>	<b>≥ 4</b>	<b>n/s</b>
<b>Burke et al 2001</b> Canada	✓	<b>45 Families</b>	<b>Parents + Child</b>	<b>Generic</b>	<b>Community</b>	<b>≥ 4</b>	<b>n/s</b>
<b>Ireys et al 2001</b> USA	✓	<b>86 Families</b>	<b>Parents</b>	<b>Generic</b>	<b>Community</b>	<b>10 face-to-face Bi-weekly call</b>	<b>60-90min 5min</b>
<b>Jerram et al 2005</b> NZ	✓	<b>41 Parents</b>	<b>Parents</b>	<b>Generic</b>	<b>Community</b>	<b>6</b>	<b>n/s</b>
<b>Liu et al 2001</b> Australia		<b>125 Parents</b>	<b>Parents</b>	<b>Condition specific</b>	<b>Clinical + Community</b>	<b>2</b>	<b>40min</b>
<b>Magyary et al 1996</b> Canada		<b>29 Families</b>	<b>Parents + Child</b>	<b>Generic</b>	<b>Community</b>	<b>1 family 3 parent-only 12 child-only</b>	<b>2h 90min 75min</b>
<b>McCarthy et al 2002</b> Canada		<b>29 Families</b>	<b>Families</b>	<b>Condition specific</b>	<b>N/S</b>	<b>3 group 6 x monthly call</b>	<b>2-3h n/s</b>
<b>Staab et al 2002</b> Germany	✓	<b>93 Families</b>	<b>Parents</b>	<b>Condition specific</b>	<b>N/S</b>	<b>6</b>	<b>2h</b>
<b>Staab et al 2006</b> Germany	✓	<b>446 Families</b>	<b>Parents + Child</b>	<b>Condition Specific</b>	<b>N/S</b>	<b>6</b>	<b>2h</b>

# Intervention content

## Generic

- developing parents' capacity to seek out and use family, social and professional support  
(Ireys et al, 2001; Jerram et al, 2005; McCarthy et al, 2002)
- goal setting  
(Jerram et al, 2005; Burke et al, 2001)
- improving communication  
(Jerram et al, 2005)
- Relaxation and stress/anxiety management  
(Magyary and Brandt, 1996; Jerram et al, 2005; Staab et al, 2002; Staab et al, 2006)

## Condition specific

- disease-specific management behaviours
  - avoidance of triggers  
(Staab et al, 2002; Staab et al, 2006)
  - symptom management  
(Staab et al, 2002; Staab et al, 2006; Bergmo et al, 2009)

# Results

## Aim 2:

Reported on the effectiveness of parent-focussed interventions

# Outcomes

## Parental

- condition management
- stress/anxiety/depression
- coping
- quality of life

## Child

- self-management
- avoidance of illness triggers
- condition severity
- condition morbidity
- development
- problem behaviours

## Generic

- family function
- health economics / resource use

# Parent outcomes

Study	Condition management	Stress/anxiety/Depression	Coping	QoL
Bergmo et al 2010	0			
Burke et al 1997		- / +	+	
Burke et al 2001			+	
Ireys et al 2001		+		
Jerram et al 2005	+	+	+	+
Liu et al 2001	+	+		
Magyary et al 1996	+			
McCarthy et al 2002	+			
Staab et al 2002	+		+	0
Staab et al 2006				+
Walker et al 1996				

# Child outcomes

Study	Self-management	Avoidance of illness triggers	Condition severity	Condition morbidity	Development	Problem behaviours
Bergmo et al 2010			0			
Burke et al 1997					+	0
Burke et al 2001						
Ireys et al 2001						
Jerram et al 2005						
Liu et al 2001			+	+		
Magyary et al 1996	+			+		
McCarthy et al 2002						
Staab et al 2002		+	0			
Staab et al 2006			+			
Walker et al 1996						

# Child outcomes

Study	Self-management	Avoidance of illness triggers	Condition severity	Condition morbidity	Development	Problem behaviours
Bergmo et al 2010			0			
Burke et al 1997					+	0
Burke et al 2001						
Ireys et al 2001						
Jerram et al 2005						
Liu et al 2001			+	+		
Magyary et al 1996	+			+		
McCarthy et al 2002						
Staab et al 2002		+	0			
Staab et al 2006			+			
Walker et al 1996						

# Generic outcomes

Study	Family functioning	Health economics / resource use
Bergmo et al 2010		0
Burke et al 1997	+	
Burke et al 2001	+	
Ireys et al 2001		
Jerram et al 2005	+	
Liu et al 2001		
Magyary et al 1996		
McCarthy et al 2002		
Staab et al 2002		+
Staab et al 2006		
Walker et al 1996	+	

# Results

## Aim 3:

Make future recommendations for parent-focussed interventions for children with chronic or long-term conditions

# Limitations in the evidence

- Lack information about intervention ‘active ingredients’ and ‘mechanisms of action’
- Heterogeneity in outcomes and length of follow up periods
- Description of the intervention recipients
  - Whole family ‘v’ parent(s) only
  - maternal ‘v’ paternal outcomes
- Limited information about the length of time since diagnosis and point in the care pathway

# Preliminary conclusions and recommendations

- Limited data with which to make clear recommendations that inform parenting interventions
- Existing interventions do not appear to cause harm
- Research needed to determine:
  - What works best
  - Who does it work for
  - What at the key age groups
  - What are the key stages in the illness/treatment pathways

**Thanks for listening!**

**[kerri.mcpherson@gcu.ac.uk](mailto:kerri.mcpherson@gcu.ac.uk)**