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# Interventions aimed at the parents/caregivers of children with long term respiratory conditions

## **Cochrane Airways Scoping Search Report**

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## Introduction to the scoping search report

This scoping search report describes the methods and results of scoping activities undertaken by Cochrane Airways on interventions aimed at parents or caregivers of children with long term respiratory conditions. This topic was identified as priority by the Cochrane Airways Priority Setting Group (CAPSG) as part of the Cochrane Airways ‘whole of scope’ priority setting exercise conducted in 2019/2020. The question prioritised by the CAPSG was “Interventions to improve engagement/adherence to routine care for parents of children with long term respiratory conditions”.

This scoping search report does not attempt to appraise or synthesise the included studies. It provides a summary of the existing evidence on this topic.

## Purpose

The purpose of this scoping search report is:

- to assess what evidence exists for this topic
- to inform the development of future Cochrane Review titles
- to provide a transparent record of scoping work undertaken by Cochrane Airways

## Study inclusion criteria

Population: parents or caregivers of children with long term respiratory conditions e.g. asthma, bronchiectasis

Intervention: any intervention aimed at parents/caregivers, including family interventions

Comparator: any

Outcomes: any

Study design: systematic reviews, randomised controlled trials (RCTs), quasi-RCTs

## Literature search

A limited literature search was conducted to identify relevant systematic reviews and trials. A search limited to the last 10 years was conducted in the [Cochrane Airways Trials Register](#) to identify relevant RCTs and quasi-RCTs. A search of the [Epistemonikos](#) database was conducted to identify relevant systematic reviews published in the last 10 years. The search strategies can be found in the [appendix](#). Searches were conducted on 17 April 2020.

## Assessment of search results

The search of the Cochrane Airways Trials Register retrieved 185 references and the search of Epistemonikos retrieved 55 references. These were imported into Rayyan for title and abstract screening. One member of the Cochrane Airways team (LS) screened the titles and abstracts and checked full-text if necessary to identify relevant study reports.

## Included studies

The search identified 4 related systematic reviews and 30 RCTs (36 references). The reviews and studies are summarised in **Table 1** and **Table 2**. The primary reference for each review and study is listed in the [References](#) section.

**Table 1: Summary of reviews**

<b>Study ID</b>	<b>Review type</b>	<b>Population</b>	<b>Intervention/theme</b>	<b>Comparison</b>	<b>Outcome</b>	<b>No. included studies</b>
Archibald 2014	'state-of-the-science' review of the literature	North American parents of children with asthma	-	-	Parental information needs taxonomy	11
Fawcett 2019	Qualitative	Parents and carers caring for a child aged 0-18 years with asthma	Management of asthma	-	Experiences of parents and carers caring for a child with asthma, wheeze or bronchiolitis and managing their condition	77
Santer 2014	Qualitative	Parents and caregivers of children with a range of long-term conditions.  Long-term conditions included; asthma, cystic fibrosis, HIV, diabetes and juvenile arthritis	Treatment adherence	-	Views of parents and caregivers of children with a range of long-term conditions on their treatment adherence	17
Walter 2016	Systematic review of RCTs	Children aged five to 18 with diagnosis of asthma, and their caregivers	School-based family asthma educational programs		Quality of life; number of asthma exacerbations measured by either missed days from school or work; physical activity intolerance; emergency hospital visits	5

**Table 2: Summary of studies**

Study ID	Trial Registration	Population	Intervention(s)	Comparator	No. participants randomized	Country
Bender 2014		Parents of children with asthma	Automated telephone reminder about medication to parent	usual care	1187	USA
Botngard 2013		Parents of children with breathing difficulties in a pediatric acute ward	Multimedia intervention	verbal health information	101	Norway
Bruzzese 2010		Parents of pre-adolescents	Asthma: It's a Family Affair (school-based, family-focused intervention)	control	393	USA
Chen 2013		Caregivers of children with asthma	Self-management interactive support (SMIS) program for caregivers	usual care	83	Taiwan
Chong 2019		Parents of children with asthma	Acceptance and Commitment Therapy	Asthma education talk	168	China (Hong Kong)
Clarke 2014		Families of children with asthma	Positive Parenting Programme	wait list	14	UK
Divecha 2020		Parents of children with asthma	Education	Control	75	India
Duncan 2013		Parent & youth (9-15)	Parent-youth teamwork intervention	Asthma education; standard care	48	USA
Edwards 2019		Parents of children with asthma or wheeze	Videos on identifying asthma triggers	children viewed video on asthma medications	63	USA
Farooqui 2017		Primary caregiver and child	AsthmaCare (application providing medication/trigger reminders and electronic treatment plan)	online asthma information	193	USA
Garbutt 2010		Parents of children with asthma	Structured telephone coaching program	control	362	USA
Garbutt 2012	NCT00860834	Families of children with asthma	Telephone-based peer coaching for parents	usual care	950	USA
Gustafson 2012		Parents & children	Web-based eHealth with telephone nurse case management	usual care	301	USA

Horn 2014		Parents of children with asthma (urban, minority ethnic groups)	Face-to-face education on effective communication	usual care	150	USA
Iio 2014		Caregivers of young children with asthma	Tailored education program	Booklet education	47	Japan
Iio 2017		Caregivers of young children with asthma	Tailored education program using touch-screen computers	Booklet education	53	Japan
Kashaninia 2018		Parents & children	Family empowerment program	Control	45	Iran
Lin 2019		Parents of children with asthma	Parents attended tai chi training, home practice & social media platform	control	53	Taiwan
Macy 2011		Parents of children with asthma presenting at the ED	Video education	written education	129	USA
Naar-King 2014		African-American adolescents with asthma & family	Multisystemic Therapy adapted for health care settings (MST-HC)	in-home family support	170	USA
O'Neil-Pirozzi 2012		Parents of children with asthma (low socioeconomic status)	Language literacy adjusted education program	control	24	?
Rastogi 2013		Caregivers & children (Hispanic & African American)	In-hospital educational intervention	control	268	USA
Roach 2019		Mothers of children with asthma	Education (information booklet & video)	Routine care	80	India
Saini 2014		Parents & children	Audio-visual education session & child-friendly workbook was provided to the child	standard information pack	40	India
Seid 2010	NCT00250588	Primary caregivers of child children with asthma	Care Coordination+Problem-Solving Skills Training	Care Coordination; wait list	252	USA
Sigurdardottir 2013		Families of children with asthma	Theory-based family therapeutic conversation intervention	control	31	Iceland
Swerczek 2013		Parents of children with asthma	Telephone coaching intervention	control	?	USA
Szczepanski 2010		Parents of children with asthma (2-5)	Family-oriented psycho-educational asthma training program	Wait list; instruction group	338	Germany

Terpstra 2012		Caregivers & adolescents	group-based skills training for the adolescents followed by 6-weekly targeted newsletters for caregivers and others	group-based skills training for adolescents only	51	USA
Zarei 2017		Parents of children with asthma	Multimedia Education (CD)	control	50	Iran

## References

### *Systematic Reviews*

Archibald Mandy M, Scott Shannon D. The information needs of North American parents of children with asthma: a state-of-the-science review of the literature *Journal of pediatric health care* 28 ( 1) ; 5-13.e2

Fawcett R, Porritt K, Stern C, Carson-Chahhoud K. Experiences of parents and carers in managing asthma in children: a qualitative systematic review *JB I database of systematic reviews and implementation reports* **2019**: 17 ( 5) ; 793-984

Walter H, Sadeque-Iqbal F, Ulysse R, Castillo D, Fitzpatrick A, Singleton J. Effectiveness of school-based family asthma educational programs on quality of life and asthma exacerbations in asthmatic children aged five to 18: a systematic review *JB I database of systematic reviews and implementation reports* **2016**: 14 ( 11) ; 113-138

Santer M, Ring N, Yardley L, Geraghty AW, Wyke S. Treatment non-adherence in pediatric long-term medical conditions: systematic review and synthesis of qualitative studies of caregivers' views *BMC pediatrics* **2014**: 14 ( 1) ; 63

### *Randomized controlled trials*

Bender BG, Cvietusa P, Goodrich G, Lowe CR, Nuanes H, Shetterly S, Tacinas CR, Wagner N, Wamboldt FS, Xu S, Magid D. A 24-month randomized, controlled trial of an automated speech recognition program to improve adherence in pediatric asthma *Journal of allergy and clinical immunology* **2014**: 133 ( 2 Suppl) ; AB166

Botnård A, Skranes LP, Skranes J, Døllner H. Multimedia based health information to parents in a pediatric acute ward: a randomized controlled trial *Patient education and counseling* **2013**: 93 (3); 389-393

Bruzzese J-M, Stepney C, Gallagher R, Wang J, Petkova E, Evans D. Reducing Morbidity And Urgent Health Care Utilization In Urban Pre-adolescents With Asthma: Results Of A Randomized Control Trial Of Asthma: Its A Family Affair [Abstract] *American journal of respiratory and critical care medicine* **2010**: 181 ( Meeting Abstracts) ; A2250

Chen Sue-Hsien, Huang Jing-Long, Yeh Kuo-Wei, Tsai Yun-Fang. Interactive support interventions for caregivers of asthmatic children *Journal of asthma* **2013**: 50 ( 6) ; 649-657

Chong YY, Mak YW, Leung SP, Lam SY, Loke AY. Acceptance and commitment therapy for parental management of childhood asthma: an RCT *Pediatrics* **2019**: 143 ( 2) ; 1-16

Clarke S-A, Calam R, Morawska A, Sanders M. Developing web-based Triple P 'Positive Parenting Programme' for families of children with asthma *Child* **2014**: 40 ( 4) ; 492-497

Divecha CA, Tullu MS, Jadhav DU. Parental knowledge and attitudes regarding asthma in their children: impact of an educational intervention in an Indian population *Pediatric pulmonology* **2020**: 55 ( 3) ; 607-615

Duncan CL, Hogan MB, Tien KJ, Graves MM, Chorney JM, Zettler MD, Koven L, Wilson NW, Dinakar C, Portnoy J. Efficacy of a parent-youth teamwork intervention to promote adherence in pediatric asthma *Journal of pediatric psychology* **2013**: 38 ( 6) ; 617-628

Edwards JE, Garro AC, Tourangeau J, Congdon EA, Frackiewicz LM, Hipolito ER. A randomized controlled trial of a point-of-care computerized intervention to improve family knowledge of environmental triggers for children with asthma *Pediatrics* **2019**: Conference: National Conference on Education 2018. United States. 144 ( 2)

Farooqui N, Stukus DR, Strothman KR, Ryan K, Cohen DM, Stevens JH. Improvement in asthma outcomes through a mobile application may be dependent upon health literacy *Journal of allergy and clinical immunology* **2017**: 139 ( 2 Suppl 1) ; AB178

Garbutt JM, Banister C, Highstein G, Sterkel R, Epstein J, Bruns J, Swerczek L, Wells S, Waterman B, Strunk RC, Bloomberg GR. Telephone coaching for parents of children with asthma: impact and lessons learned *Archives of pediatrics & adolescent medicine* **2010**: 164 ( 7) ; 625-630

Garbutt JM, Highstein G, Yan Y, Strunk RC. Partner randomized controlled trial: study protocol and coaching intervention *BMC pediatrics* **2012**: 12 ; 42-42

Gustafson David, Wise Meg, Bhattacharya Abhik, Pulvermacher Alice, Shanovich Kathleen, Phillips Brenda, Lehman Erik, Chinchilli Vernon, Hawkins Robert, Kim Jee-Seon. The effects of combining web-based eHealth with telephone nurse case management for pediatric asthma control: a randomized controlled trial. *Journal of medical Internet research* **2012**: 14 ( 4) ; e101

Horn IB, Mitchell SJ, Gillespie CW, Burke KM, Godoy L, Teach SJ. Randomized trial of a health communication intervention for parents of children with asthma *Journal of asthma* **2014**: 51 ( 9 // ) \*National Center for Research Resources\*) ; 989-995

Iio M, Takenaka K, Narita M, Futamura M, Hamaguchi M, Fukushima K, Yamano O, Haraguchi J, Sakai H, Ishiguro A, Ohya Y. Development and effectiveness of a tailored education program for caregivers of asthmatic children. *Japanese journal of allergology* **2014**: 63 ( 2) ; 187-203

Iio M, Hamaguchi M, Narita M, Takenaka K, Ohya Y. Tailored education to increase self-efficacy for caregivers of children with asthma: a randomized controlled trial *Computers, informatics, nursing* **2017**: 35 ( 1) ; 36-44

Kashaninia Z, Payroovee Z, Soltani R, Mahdavian SA. Effect of family empowerment on asthma control in school-age children *Tanaffos* **2018**: 17 ( 1) ; 47-52

Lin HH, Hung YP, Weng SH, Lee PY, Sun WZ. Effects of parent-based social media and moderate exercise on the adherence and pulmonary functions among asthmatic children *The Kaohsiung journal of medical sciences* **2019**:

Macy ML, Davis MM, Clark SJ, Stanley RM. Parental health literacy and asthma education delivery during a visit to a community-based pediatric emergency department: a pilot study *Pediatric emergency care* **2011**: 27 ( 6) ; 469-474

Naar-King Sylvie, Ellis Deborah, King Pamela S, Lam Phebe, Cunningham Phillippe, Secord Elizabeth, Bruzzese Jean-Marie, Templin Thomas. Multisystemic therapy for high-risk African American adolescents with asthma: a randomized clinical trial *Journal of consulting and clinical psychology* **2014**: 82 ( 3) ; 536-545

O'Neil-Pirozzi TM, Heydt M. Benefit of parent participation in a program emphasizing asthma health literacy *Journal of medical speech-language pathology* **2012**: 20 ( 1) ; 35-46



Rastogi D, Madhok N, Kipperman S. Caregiver asthma knowledge, aptitude, and practice in high healthcare utilizing children: Effect of an educational intervention *Pediatric allergy, immunology, and pulmonology* **2013**: 26 ( 3 ) ; 128-139

Roach EJ, Bhaskaranand N. Effectiveness of an educational package on health promotion behaviours of mothers of asthmatic children in Karnataka, India: a quasi experimental study *Indian journal of public health research and development* **2019**: 10 ( 8 ) ; 231-236

Saini B, Grover C, Armour C, Van Asperen P, Moles R, Goel N, Gaur S. To assess asthma medication education programme in Indian children *Respirology (Carlton, Vic.)* **2014**: Conference: 2014 Annual Scientific Meetings of the Thoracic Society of Australia and New Zealand and the Australian and New Zealand Society of Respiratory Science Adelaide, SA Australia. 84 [TP 084]

Seid M, Varni JW, Gidwani P, Gelhard LR, Slymen DJ. Problem-solving skills training for vulnerable families of children with persistent asthma: report of a randomized trial on health-related quality of life outcomes *Journal of pediatric psychology* **2010**: 35 ( 10 ) ; 1133-1143

Sigurdardottir AO, Svavarsdottir EK, Rayens MK, Adkins S. Therapeutic conversations intervention in pediatrics: are they of benefit for families of children with asthma? *Nursing clinics of North America* **2013**: 48 ( 2 ) ; 287-304

Swerczek LM, Banister C, Bloomberg GR, Bruns JM, Epstein J, Highstein GR, Jamerson PA, Sterkel R, Wells S, Garbutt JM. A telephone coaching intervention to improve asthma self-management behaviors *Pediatric nursing* **2013**: 39 ( 3 ) ; 125-130, 145

Szczepanski R, Jaeschke R, Spindler T, Ihorst G, Forster J, ASEVStudy Group. Preschoolers' and parents' asthma education trial (P2AET)--a randomized controlled study *European journal of pediatrics* **2010**: 169 ( 9 ) ; 1051-1060

Terpstra JL, Chavez LJ, Ayala GX. An intervention to increase caregiver support for asthma management in middle school-aged youth *Journal of asthma* **2012**: 49 ( 3 ) ; 267-274

Zarei AR, Jahanpour F, Alhani F, Razazan N, Ostovar A. The Impact of Multimedia Education on Knowledge and Self-efficacy among Parents of Children with Asthma: a Randomized Clinical Trial *Journal of Caring Sciences* **2014**: 3 ( 3 ) ; 185-192

## Appendix: Database search strategies

*Cochrane Airways Register of Trials via The Cochrane Register of Studies*

- #1 (parent\* or carer\* or mother\* or father\*):ti,ab AND INREGISTER
- #2 (educat\* or support\* or information):ti,ab AND INREGISTER
- #3 #1 AND #2
- #4 (2020 OR 2019 OR 2018 OR 2017 OR 2016 OR 2015 OR 2014 OR 2013 OR 2012 OR 2011 OR 2010):YR AND INREGISTER
- #5 #3 AND #4

*Epistemonikos*

(asthma OR bronchiectasis) AND (parent\* OR carer\*) AND (educat\* OR support\* OR information)

