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Manuscript title: Parent education programs for special health care needs children: A systematic review

Running Head: Parent education programs for families with CSHCN

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Parent education programs for special health care needs children: A systematic review

ABSTRACT

Aims and objectives: The aim of this review was to examine parent education programs for families with children with special health care needs (CSHCN), in order to better design interventions focusing on the psychosocial aspects of living with a child's chronic condition.

Background: Studies of familial coping with CSHCN indicate high levels of parenting stress, with families with CSHCN at risk of major psychological and social disturbances and financial strain. Despite increased knowledge of the factors affecting CSHCN themselves, evidence for the effectiveness of preventative and treatment interventions in the form of parent education programs remains limited.

Design: Systematic review using PRISMA guidelines.

Method: Multi database Boolean searches in EBSCO Discovery Services using the search terms 'complex/ special health care needs children', 'child/pediatric/congenital heart disease', 'chronic illness (including diabetes, cancer and cystic fibrosis)', 'family coping', 'siblings' AND 'parenting/family support programs' were conducted.

Results: Analysis of thirteen included studies showed evidence for the effectiveness of both mixed-health condition and condition-specific parenting programs delivered in a variety of modes. Three common core intervention approaches were: use of narrative therapy enabling families to tell their own stories, thus facilitating emotional processing and (co-) construction of meaning; a focus on strengthening protective factors such as enhancing parents' skills in communication, and behavioural management; and provision of psycho-education to deepen parents' understanding of their child's condition and associated developmental challenges.

Conclusion: Irrespective of the type of outcome measures used in the studies, the review showed that there were positive gains and improvements across a range of areas of family functioning such as mental health, parenting, communication and problem-solving skills post-program.

Relevance to clinical practice: Identification of what program characteristics enhance functioning for families with CSHCN should encourage the design of effective interventions.

Keywords: special health care needs children, chronic illness, parenting education, family support

Word length: 2380 excluding tables and references

Summary Box

What does this paper contribute to the wider global clinical community?

- **Families can be challenged by parenting children with special health care needs (CSHCN).**
- **Our analysis of parent education programs for families with CSHCN showed evidence for the effectiveness of programs using both mixed health condition and health condition-specific parenting programs delivered in a variety of modes.**
- **Irrespective of the type of outcome measures used in the studies, there were positive gains and improvements for families across a wide range of functioning such as mental health, parenting, communication and problem-solving skills post-program.**

INTRODUCTION

Several decades of research has shown the importance of the family environment for children's and adolescents' healthy development (Mahoney et al., 1999; Brown, 2005). Since parenting style, in particular, shapes the quality of a child's development as well as parents' wellbeing, parent education can be instrumental in creating safe and supportive environments for children's development by promoting caring, consistent, and positive parenting (Seligman & Csikszentmihalyi, 2000; Sanders &

Cann, 2002). The Parenting Research Centre (PRC) in Australia describes parent education as parenting interventions, programs or services in which parents, caregivers or guardians receive direct/targeted education, training or support to improve child outcomes. The aim of parent education programs is to assist families through enhancing parent's knowledge, behaviour or cognition as a caregiver, and improving parent-child interactions, parent outcomes such as parent wellbeing, or family outcomes such as family relationships (Sanders, Markie-Dadds, Tully, & Bor, 2000; Bunting, 2004; PRC, 2012).

Parenting education programs are useful in supporting and strengthening the role of families in their everyday parenting. This is particularly pertinent to families of children with special health care needs (CSHCN) – defined as 'those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally' (McPherson, 1998, p. 138). Research has indicated that the wellbeing of families with CSHCN is at risk as the burden of care increases vulnerability to major psychological and social disturbances and increased financial strain (Woods, Haberman & Packard, 1993; Martin & Nisa, 1996; van Dyck et al, 2004; Newacheck & Kim, 2005). A review of familial coping with child heart disease indicated that a high level of parenting stress is prevalent for parents of children with severe heart diseases as they continue to experience repeated hospitalizations and accommodate the uncertainties and challenges that arise from the journey of children with cardiac conditions (Jackson, Frydenberg, Liang, Higgins & Murphy, 2015). Moreover, several studies have reported that family factors such as maternal adjustment, parental functioning, along with the nature of parent-child relationships, play a central role in the emotional functioning and behavioural outcomes in CSHCN (DeMaso, Twente, Spratt & O'Brien, 1995; Bruce, Lilja & Sundin, 2014). Despite increased knowledge of the factors affecting individual health, cognitive and behavioral outcomes of CSHCN, evidence for the effectiveness of interventions in the form of parent education programs remains limited (Beale, 2006; PRC, 2012).

AIMS

Following on an earlier review of familial coping with child heart disease (Jackson et,al. 2015), we wished to see if there were any specific targeted programs for these families or whether they were supported by more general parenting education programs, and what the impact of these programs was. The purpose of this systematic review was to examine the design, implementation and evaluation of parent education programs for families with CSHCN, whether condition-specific or generic, in order to better design interventions that focus on the psychosocial aspects of living with a chronic condition, for both the child and the family.

METHOD

This systematic review was conducted as part of a larger study, the Heart Child Family Project partly funded by HeartKids Australia which aimed to assess the impact of childhood heart disease on families and how they coped with this. Ethics approval for the project was granted by the University of Melbourne Humanities and Applied Sciences Human Ethics Committee on 17 June 2014 (Approval No: 1441631.1).

Procedure

Multi database Boolean searches in EBSCO Discovery Services (include databases such as CSA Illumina, PsychInfo, PubMed, JSTOR etc.) using the search terms 'complex/ special health care needs children', 'child/pediatric/congenital heart disease', 'chronic illness (including diabetes, cancer and cystic fibrosis)', 'family coping', 'siblings' AND 'parenting/family support programs' were conducted. The data base search was limited to English-language scholarly articles of peer-reviewed journals published from January 1990 onwards to discover the most contemporary approaches in designing and delivering interventions for families with CSHCN. A large body of research was screened for relevance by title with most relevant 250 results imported into EndNote X7. An initial review of the titles, keywords and abstracts resulted in 173 articles being rejected as they were either duplicates or deemed irrelevant for the purpose of the review, or there was no full-text report available, leaving 77 articles. An additional 11 studies were identified from manual searches of the reference lists of key studies identified. The resulting 88 articles were subjected to detailed assessment based on the following inclusion and exclusion criteria:

Sample

Studies were considered for the current review if they met the following inclusion criteria:

1. The study sample comprised families of children aged up to 16 years with clearly identified complex or special health care needs.
2. Explicit program or intervention(s) description.
3. Studies that provided the theoretical underpinning of the program/ intervention(s) outlined.
4. Explicit methodological design (qualitative, quantitative and/or observational) with clear measurement instruments and study design reported.
5. Full-text report was available in English.

Studies were excluded if:

1. The study sample comprised families with only late adolescents or young adults.
2. The articles were reviews, editorials or commentaries.
3. They were not deemed relevant to the primary focus on families of CSHCN (e.g. focused on children with developmental, intellectual or physical disabilities but not chronic illness)

Data extraction

One author independently evaluated and extracted the data. The accuracy of extraction of each study was assessed against the original document by two other authors. The following data were extracted from included studies: (a) name of program/intervention, including authors and date; (b) sessions/mode of delivery of the program; (c) sample characteristics including sample size and the jurisdiction where data were collected; (d) method, including program objectives and evaluation measures; (d) statistical analyses employed and key findings on program outcomes; and (e) strengths and limitations of the program.

RESULTS

The review covers 13 studies with over half from the United States of America (n =7), four from the United Kingdom and two from Australia. All studies provided details of various intervention/support programs for families of CSHCN, including those with cardiac conditions. Some studies advocated for a non-categorical approach when recruiting family participants, that is, programs for parents of children with a variety of chronic conditions. This non-categorical approach is based on the assumption that regardless of the specific condition, families have similar experiences caring for an individual with serious ongoing disability or illness, which limits functional or communication abilities, and may require extra medical care or ongoing treatment (Giallo & Gavidia-Payne, 2008). Other studies focused solely on families of children with a specific chronic condition such as congenital heart disease or Type 1 diabetes. Each program described in the reviewed studies had its own theoretical underpinning – cognitive behavioural therapy, filial therapy, transactional model of stress, family system therapy etc. A PRISMA flow diagram shows the selection of papers for inclusion and exclusion (Fig. 1) (Moher, Liberati, Tetzlaff & Altman, 2009; PRISMA, 2012).

Seven of the 13 studies included a control or comparison group for evaluating the efficacy of the program implemented. A majority of the studies employed quantitative measures (n=8) incorporating at least one validated tool for measuring program outcomes. Five qualitative studies involved an exploratory inquiry using semi-structured interviews and field notes. Details of studies examined are presented in Table 1.

Insert Figure 1 about here

Fig.1 PRISMA Flow Diagram of Study Selection Process

Insert Table 1 about here

Table 1: Details of studies that met the inclusion criteria for reviewing parenting/family programs for children with special health care needs

DISCUSSION

Parent education and family support programs for CSHCN come in many forms (e.g. home-based, group-based, web-based, or provided through community services). It has been a common practice for many years to research and test programs for children with similar diagnoses, such as diabetes (Ridge et al., 2014) or cardiac conditions (Dengler, Scarfe, Redshaw, & Wilson, 2011), however over one-third of the reviewed studies advocate for and adopt a non-condition specific approach to assess and meet the common needs of families by delivering universal programs/interventions (Glazer-Waldman et al., 1992; Williams et al., 2003; Lobato & Kao, 2005; Giallo & Gavidia-Payne, 2008; Kieckhefer et al., 2014). This approach seems to be adopted increasingly in today's pediatric health services system as it can provide accessible and cost effective models of care in the face of increased rates of paediatric chronic conditions and disabilities by encouraging development of core resources to meet common family needs (Kieckhefer et al., 2014). The findings of non-significant differences between diagnoses and program outcome variables in one of the reviewed studies (Williams et al.2003) appear to provide preliminary evidence in supporting this non-condition specific approach.

Program/Intervention Characteristics

Underpinned by theories of cognitive and behavioural change, social learning principles and family-focused care, three core therapeutic or intervention approaches common to all of the parenting/family programs reviewed were identified. First, a number of studies utilised narrative therapy in their program design to emphasise the importance of allowing individuals and families the opportunity to tell their own stories, through metaphors, journaling or tactile objects (e.g. beads), to facilitate emotional processing and (co-) construction of meaning and thereby increasing their sense of wellbeing (DeMaso et al., 2000; Ridge et al., 2014). Second, a common thread amongst the studies was the focus on strengthening family level protective factors such as enhancing the relationships of parents, with spouses, children and treatment staff, through providing and strengthening parents' skills in communication, stress and behavioural management, problem-solving, showing affection and managing emotional reactions (Lobato & Kao, 2005; Giallo & Gavidia-Payne, 2008; McCusker et al., 2010, 2012; Dutreil et al., 2011; Doherty et al., 2013; Kieckhefer et al., 2014). Third, an essential component of all the parenting/family programs reviewed was psycho-education. This was aimed at normalising the parent-child interaction through deepening parents' understanding of the child's chronic condition and specific developmental challenges. It also aimed at facilitating family information exchange beyond the sick child – parent to include all parties in the family such as siblings of the child (Glazer-Waldman et al., 1992; Doherty et al.; Drazen et al., 2014; Ridge et al.).

Program timing and delivery

A variety of program delivery methods were reported in the studies depending on participant needs, age of child and program goals. The most common form was group-based family-centred programs which comprised six to ten weekly sessions delivered by -trained, professional staff for families, with occasional homework and supervision and/or telephone support (e.g. filial therapy group (Glazer-Waldman et al., 1992), Sibstars (Giallo & Gavidia-Payne, 2008)). These group-based programs are common as they are often less expensive and can provide the opportunity for participants to share ideas and similar experiences and the chance for modelling and social reinforcement (Ridge et al., 2014). Other types of delivery method include a one-off workshop (McCusker et al., 2012), a residential camp (Williams et al., 2003), home-based visits (Drazen et al., 2014) and an online forum (DeMaso et al., 2000). Despite the differences in the mode of program delivery, all studies emphasised the importance of early intervention and timely delivery at point of diagnosis to set the stage for positive parent-child relationships throughout the treatment process and into the future. Some of the more recent programs offered concurrent parent or joint sibling-parent sessions for siblings of CSHCN because it is widely acknowledged that any risk of adjustment difficulties for siblings is best to be addressed within the context of the family (Williams et al., 2003).

Program efficacy

Evaluations of the effectiveness of parenting education and family support programs typically assess program outcomes using a range of measures, both qualitative and quantitative, which closely aligned with the program features and processes (e.g. self-efficacy scale for a self-efficacy enhancement based program). In general, irrespective of the type of outcome measures, there were positive gains and improvements for families across a range of functioning such as mental health, parenting competencies, communication and problem-solving skills post-program. Some of the superior evaluation approaches included: randomised controlled design (e.g. McCusker et al., 2010; Kieckhefer et al., 2014), assessment of both the clinical and statistical significance of the intervention (e.g. Giallo & Gavidia-Payne, 2008; McCusker et al., 2012) and long-term follow-up (e.g. Williams et al., 2003). Studies with qualitative reports complemented quantitative evaluation by offering in-depth insights as to what intervention or program features were deemed most relevant for individual families (e.g. Glazer-Waldman et al., 1992; Redshaw et al., 2011). The best practices from these evaluations can be used to better understand and replicate successful family or parenting programs for special health care needs children.

RELEVANCE TO CLINICAL PRACTICE

At the conclusion of this systematic review, we have identified several successful elements of effective parenting or family support programs for children with special health needs:

- Provision of opportunities for parents/families to tell and share their unique stories
- Support for the wellbeing and strengths of the family as a unit (e.g. strengthening relationships between parents, the CSHCN and siblings)

- Focus on generic skills in relation to parenting (e.g. problem-solving, stress management)
- Having input from trained professional staff (e.g. expert on chronic illness management)

References

Beale, I. L. (2006) Scholarly literature review: efficacy of psychological interventions for pediatric chronic illnesses. Journal of Pediatric Psychology, 31, 437–451.

Brown, M. B. (2005). Parent education and support literature review 2005. University of Delaware Cooperative Extension. Retrieved from http://ag.udel.edu/extension/fam/professionalresources/parentEd/2005litreview.htm

Bruce, E., Lilja, C., & Sundin, K. (2014). Mothers' lived experiences of support when living with young children with congenital heart defects. Journal For Specialists In Pediatric Nursing, (1), 54.

Bunting, L. (2004). Parenting programmes: The best available evidence. Child Care in Practice, 10(4), 327-343.

DeMaso, D. R., Twente, A. W., Spratt, E. G., & O'Brien, P. (1995). Impact of psychological functioning, medical severity, and family functioning in pediatric heart transplantation. The Journal Of Heart And Lung Transplantation, 14(6 Pt 1), 1102-1108

DeMaso, D. R., Gonzalez-Heydrich, J., Erickson, J. D., Grimes, V. P., & Strohecker, C. (2000). The experience journal: a computer-based intervention for families facing congenital heart disease. Journal Of The American Academy Of Child And Adolescent Psychiatry, 39(6), 727-734.

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.

Drazen, C. H., Abel, R., Lindsey, T., & King, A. A. (2014). Development and feasibility of a home-based education model for families of children with sickle cell disease. BMC Public Health, 14.

DuTreil, S., Rice, J., Merritt, D., & Kuebler, E. J. (2011). Parents Empowering Parents (PEP) Program: understanding its impact on the bleeding disorders community. Haemophilia, 17(5), e895-e900. doi: 10.1111/j.1365-2516.2011.02512.x

Giallo, R., & Gavidia-Payne, S. (2008). Evaluation of a family-based intervention for siblings of children with a disability or chronic illness. AeJAMH (Australian e-Journal for the Advancement of Mental Health), 7(2), 1-13. Retrieved from: http://pandora.nla.gov.au/pan/24225/20081003-015/www.auseinet.com/journal/vol7iss2/index.html

Glazer-Waldman, H. R., Zimmerman, J. E., Landreth, G. L., & Norton, D. (1992). Filial therapy: An intervention for parents of children with chronic illness. International Journal of Play Therapy, 1(1), 31-42. doi: 10.1037/h0090233

Jackson, A., Frydenberg, E., Liang, R. T., Higgins, R., & Murphy, B. (2015). Familial Impact and Coping with Child Heart Disease: A Systematic Review. Pediatric Cardiology, 1-18. doi: 10.1007/s00246-015-1121-9

Kieckhefer, G. M., Trahms, C. M., Churchill, S. S., Kratz, L., Uding, N., & Villareale, N. (2014). A randomized clinical trial of the building on family strengths program: an education program for parents of children with chronic health conditions. Maternal And Child Health Journal, 18(3), 563-574. doi: 10.1007/s10995-013-1273-2

Lobato, D. J., & Kao, B. T. (2005). Brief Report: Family-Based Group Intervention for Young Siblings of Children with Chronic Illness and Developmental Disability. Journal Of Pediatric Psychology, 30(8), 678-682.

Mahoney, G., Kaiser, A., Girolametto, L., MacDonald, J., Robinson, C., Safford, P., & Spiker, D. (1999). Parent Education in Early Intervention: A Call for Renewed Focus. Topics In Early Childhood Special Education, 19(3), 131-40.

Martin, C. & Nisa, M. (1996) Meeting the Needs of Children and Families in Chronic Illness and Disease: A Greater Role for the G.P.? Australian Family Physician, 25 (8), 1273-1281.

McCusker, C. G., Doherty, N. N., Molloy, B., Rooney, N., Mulholland, C., Sands, A., . . . Casey, F. (2010). A controlled trial of early interventions to promote maternal adjustment and development in infants born with severe congenital heart disease. Child: Care, Health and Development, 36(1), 110-117. doi: 10.1111/j.1365-2214.2009.01026.x

McCusker, C. G., Doherty, N. N., Molloy, B., Rooney, N., Mulholland, C., Sands, A., . . . Casey, F. (2012). A Randomized Controlled Trial of Interventions to Promote Adjustment in Children With Congenital Heart Disease Entering School and Their Families. Journal of Pediatric Psychology 37(10), 1089-1103.

McPherson, M. B. (1998). A new definition of children with special health care needs. Pediatrics, 102(1), 137 -140.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. Annals of Internal Medicine, 151 (4), 264–269. doi: 0000605-200908180-00135.

Newacheck, P. W., Kim, S. E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. Arch Pediatr Adolesc Med. 159 (1), 10-17. doi: 10.1001/arcpedi.159.1.10.

Parenting Research Centre. (2012) Evidence review: An analysis of the evidence for parenting interventions in Australia. Retrieved from http://www.parentingrc.org.au/index.php/resources/parenting-interventions-in-australia

PRISMA. (2012). PRISMA endorsers. Retrieved from: http://www.prisma-statement.org/statement.htm

Redshaw, S., Wilson, V., Scarfe, G., & Dengler, L. (2011). Narratives of the heart: telling the story of children with a cardiac condition through a bead program. Journal of Clinical Nursing, 20(19/20), 2802-2811. doi: 10.1111/j.1365-2702.2011.03780.x

Ridge, K., Thomas, S., Jackson, P., Pender, S., Heller, S., Treasure, J., & Ismail, K. (2014). Diabetes-Oriented Learning Family Intervention (DOLFIN): a feasibility study evaluating an intervention for carers of young persons with Type 1 diabetes. Diabetic Medicine, 31(1), 55-60.

Sanders, M., & Cann, W. (2002). Promoting positive parenting as an abuse prevention strategy. In K. D. Browne, H. Hanks, P. Stratton & C. Hamilton (Eds.), Early prediction and prevention of child abuse: A handbook (pp. 145-163). West Sussex, England: John Wiley & Sons.

Sanders, M., Markie-Dadds, C., Tully, L. A., & Bor, W. (2000). The Triple P-Positive Parenting Program: A comparison of enhanced, standard, and self-directed behavioural family intervention for parents of children with early onset conduct problems. Journal of Consulting and Clinical Psychology, 68(4), 624-640.

Seligman, M. P. & Csikszentmihalyi, M. (2000). Positive Psychology: An introduction. American Psychologist 55(1), 5–14.

Van Dyck, P.C., Kogan, M.D., McPherson, M.G., Weissman, M.A., Newacheck, P. W. (2004). Prevalence and characteristics of children with special health care needs. Arch Pediatr Adolesc Med. 158 (9), 884-890. doi: 10.1001/arcpedi.158.9.884.

Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., . . . Sanders, S. (2003). A community-based intervention for siblings and parents of children with chronic illness or disability: the ISEE study. The Journal of Pediatrics, 143(3), 386-393. doi: http://dx.doi.org/10.1067/S0022-3476(03)00391-3

Woods, N.F., Haberman, M.R. & Packard, N.J. (1993). Demands of Illness and Individual, Dyadic, and Family Adaptation in Chronic Illness. Western Journal of Nursing Research, 15 (1), 10-30.

Supplementary Material

References for theoretical underpinning of interventions and measures used in the reviewed studies

Building on Family Strengths (BFS) (Kieckhefer et al., 2014)

Bandura, A. (2004). Health promotion by social cognitive means. Health Education and Behavior, 31(2), 143–164.

Lorig, K., Stewart, A., Ritter, P., Gonzales, V., Laurent, D., & Lynch, J. (1996). Outcome measures for health education and other health care interventions (p. 109). Thousand Oaks, CA: Sage Publications.

McQuaid, E., Penza-Clyve, S., Nassau, J., Fritz, G., Klein, R., O'Connor, S., et al. (2001). The asthma responsibility Questionnaire: Patterns of family responsibility for asthma management. *Children's* Health Care, 30(3), 183–199.

McCubbin, H., & Thompson, A. (1991). Family assessment inventories for research and practice. Madison, WI: University of Wisconsin System.

Andresen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). American Journal of Preventive Medicine, 10(2), 77–84.

Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385–401.

Stein, R. E., & Jessop, D. J. (1985). Tables documenting the psychometric properties of a measure of the impact of chronic illness on a family (PACTS Papers/AECOM). Bronx, NY: Albert Einstein College of Medicine.

CHIP-Infant (C. G. McCusker et al., 2010)

Bayley, N. (1993) Bayley Scales of Infant Development, 2nd edn. The Psychological Corporation, Harcourt Brace & Company, San Antonio, TX, USA.

Carver, C. S., Scheier, M. F. & Weintraub, J. K. (1989) Assessing coping strategies: a theoretically-based approach. Journal of Personality and Social Psychology, 56, 267–283.

De Vet, K., & Ireys, H. (1998). Psychometric properties of the maternal worry scale for children with chronic illness. Journal of Pediatric Psychology, 23, 257–266.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. & Jacobs, G. A. (1983) Manual for the State-Trait Anxiety Inventory. Consulting Psychologists Press, Palo Alto, CA, USA.

Thompson, R. J., Gustafson, K. E., Hamlett, K.W. & Spock, A. (1992) Stress, coping and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology, 17, 573–585.

CHIP-School (Christopher G. McCusker et al., 2012)

Achenbach, T. M. (1991). Manual for the Child Behavior Checklist/4-18 and (1991) Profile. Burlington, VT: University of Vermont.

Derogatis, L. R. (1993). Brief symptom inventory: Administration, scoring and procedures manual. Minneapolis, MN: National Computer Systems.

De Vet, K., & Ireys, H. (1998). Psychometric properties of the maternal worry scale for children with chronic illness. Journal of Pediatric Psychology, 23, 257–266.

Stein, R., & Reissman, C. (1980). The development of an impact-on-family scale: Preliminary findings. Medical Care, 18, 465–472.

Thompson, R. J., Gustafson, K. E., Hamlett, K.W. & Spock, A. (1992) Stress, coping and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology, 17, 573–585.

DOLFIN (Ridge et al., 2014)

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. Psychotherapy: Theory, Research & Practice, 19(3), 276-288. doi:10.1037/h0088437

Treasure, J., Sepulveda, A. R., Whitaker, W., Todd, G., Lopez, C., & Whitney, J. (2007). Collaborative care between professionals and non-professionals in the management of eating disorders: a description of workshops focussed on interpersonal maintaining factors. European Eating Disorders Review, 15(1), 24-34. doi:10.1002/erv.758

Experience Journal (EJ) (DeMaso, Gonzalez-Heydrich, Erickson, Grimes, & Strohecker, 2000)

Shapiro, D. E., & Koocher, G. P. (1996). Goals and practical considerations in outpatient medical crises intervention. Professional Psychology, Research And Practice, (2), 109.

Filial therapy (Glazer-Waldman et al., 1992)

Gillis, J. S. (1980). Child anxiety scale. Champaign, IL: Institute for Personality and Ability Testing.

Levant, R. F. (1983). Client-Centered Skills-Training Programs for the Family: A Review of the Literature. Counseling Psychologist, 11(3), 29. doi:10.1177/0011000083113003

Porter, B. R. (1954). Measurement of parental acceptance of children. Journal of Home Economics, 46(3), 176-182.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. & Jacobs, G. A. (1983) Manual for the State-Trait Anxiety Inventory. Consulting Psychologists Press, Palo Alto, CA, USA.

ISEE (Williams et al., 2003)

Eyberg, S. A. (1983). Conduct Problem Behavior: Standardization of a Behavior Rating Scale with Adolescents. Journal Of Clinical Child Psychology, 12(3), 347.

Harter S. (1985).Manual for the self-perception profile for children. Denver (CO) University of Denver

Harter S. (1985) Manual for the social support scale for children. Denver (CO) University of Denver

Patterson, G. R., & Reid, J. B. (1975). A Social learning approach to family intervention. Eugene, Or. : Castalia Pub. Co., c1975-<82 >.

Robinson, E. W. (1980). The Standardization of an Inventory of Child Conduct Problem Behaviors. Journal Of Clinical Child Psychology, 9(1), 22.

Sahler, O., & Carpenter, P. (1989). Evaluation of a camp program for siblings of children with cancer. American Journal Of Diseases Of Children, 143(6), 690-696.

Williams, P. D., Hanson, S., Karlin, R., Ridder, L., Liebergen, A., Olson, J., & ... Tobin-Rommelhart, S. (1997). Outcomes of a nursing intervention for siblings of chronically ill children: a pilot study. Journal Of The Society Of Pediatric Nurses: JSPN, 2(3), 127-137.

Williams, P. D., Williams, A. R., Hanson, S., Graff, C., Ridder, L., Curry, H., & ... Karlin-setter, R. (1999). Maternal Mood, Family Functioning, and Perceptions of Social Support, Self- Esteem, and Mood Among Siblings of Chronically Ill Children. Children's Health Care, 28(4), 297-310.

SibLink (Lobato & Kao, 2005)

Harter, S., & Pike, R. (1983). The pictorial scale of perceived competence and acceptance for young children. Denver, CO: University of Denver.

SIBSTARS (Giallo & Gavidia-Payne, 2008)

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. Journal of Health and Social Behaviour, 24, 385-396.

Giallo, R. & Gavidia-Payne, S. (2005). The Development of the Daily Events Scale for Siblings of Children with a Disability or Chronic Illness.

Unpublished Manuscript. RMIT University, Melbourne.

Goodman, R., Meltzer, H., & Bailey, V. (1998). The Strengths and Difficulties Questionnaire: A pilot study on the validity of the self-report version. European Child & Adolescent Psychiatry, 7, 125-130.

Gordon, D. (1994). Parent Behaviour Questionnaire. Unpublished measure. Ohio University, Athens.

Kearney, C., Drabman, R., & Beasley, J. (1993). The trials of childhood: the development, reliability and validity of the Daily Life Stressors Scale. Journal of Child and Family Studies, 2, 371-388.

McCubbin, H., Thompson, A., & McCubbin, M. (1996). Family Assessment: Resiliency, Coping and Adaptation. Wisconsin: University of Wisconsin Publishers.

Teen Triple P workbook (Doherty et al., 2013)

Arnold, D. S., O'Leary, S. G., Wolff, L., & Acker, M. M. (1993). The Parenting Scale: A measure of dysfunctional parenting in discipline situations. Psychological Assessment, 5, 137–144.

Eyberg, S. M., & Robinson, E. A. (1983). Conduct problem behavior: Standardization of a behavioral rating scale with adolescents. Journal of Clinical Child Psychology, 12, 347–354.

Hood, K. K., Butler, D. A., Anderson, B., & Laffel, L. M. (2007). Updated and revised diabetes family conflict scale. Diabetes Care, 30, 1764–1769.

Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. Journal of Clinical Child Psychology, 18, 167–175.

Sanders, M.R. (1999). The Triple P—Positive Parenting Program: Towards an empirically validated multilevel parenting and family support strategy for the prevention of behavior and emotional problems in children. Clinical Child and Family Psychology Review, 2, 71–90.

Streisand, R., Braniecki, S., Tercyak, K. P., & Kazak, A. E. (2001). Childhood illness-related parenting stress: The pediatric inventory for parents. Journal of Pediatric Psychology, 26, 155–162.

Table 1: Details of studies that met the inclusion criteria for reviewing parenting/family programs for children with special health care needs

Program/ Intervention	Sessions/mode of delivery	Population/ sample size	Objectives, measures/ Theoretical underpinnings*	Key Findings	Strengths/Limitations
Building on Family Strengths (BFS) (Kieckhefer et al., 2014)	Using a non-condition-specific and extensive participatory family-centred approach, the parent education curriculum of BFS is delivered over 7weekly 2-hour sessions.	110 parents with children 2-11 years with a variety of chronic conditions (intervention group, n=69; control group, n=41) USA	BFS is a derivative of the adult version of the Chronic Disease Self-Management Program which both have self-efficacy enhancement as the theoretical grounding of the curriculum. 5 pre-specified outcome (measures): -Self-efficacy (Self-efficacy Scale, Lorig et al.) -Shared management (P-C SM, McQuaid et al.) - Coping (F-COPES, McCubbin & Thompson) -Depression (CES-D 10, Andresen et al., Radloff) -Quality of life (Family Impact Scale, Stein & Jessop) *Bandura's (2004) self-efficacy enhancement	T-tests results revealed that the five pre-specified outcomes significantly improved across 6 months for the intervention group: higher scores on self-efficacy to manage the child's condition (p = .049), coping with childhood chronic illness (p < .001), Non-significantly higher scores on parent–child shared management of the condition (p = .097), family quality of life (p = .010), and significantly lower scores on a measure of depressive symptoms (p = .046). Average effect-sizes were modest across outcomes (7–11% improvement) with intervention participants having baseline scores in the least favourable quartile improving the most (12–41%).	Strengths: first systematic study to assess the effectiveness of a non-disease-specific approach parenting program; control group; random allocation to group; standardised protocols and pre-specified measures. Limitation: no information on specific types of physical conditions/ sibling health; data based on participant report; homogeneous sample.

Congenital Heart Disease Intervention Programme (CHIP)-Infant (C. G. McCusker et al., 2010)	Psychosocial intervention program for families following the birth of a child with severe congenital heart disease (CHD). The CHIP-Infant program is delivered in 6 x (1-2 hour) sessions	70 families (intervention group, n=35; standard care control group, n=35) of infants (mean age: 2.9 months) born with CHD. UK	CHIP was underpinned by Thompson's transactional stress and coping framework. This psychosocial intervention programme for infants and their primary caregivers (mostly mothers) incorporated psycho education, parent skills training & emotional processing using narrative therapy techniques. Outcome measures: 1. Infant development – The Bayley Scales of Infant Development (BSID-II; Bayley) 2. Feeding 3. Maternal coping & adjustment – - The state anxiety subscale of the Spielberger State-Trait Anxiety Inventory (Form Y) (Spielberger et al). - Maternal Worry Scale (De Vet & Ireys) - Four subscales from the multidimensional coping	Parametric analyses including mean difference scores, confidence intervals, effect sizes and ANCOVA revealed both clinical and statistical significant gains: Mothers in the intervention group reported reduced levels of anxiety and worry and increased use of positive appraisal strategies compared with control group (p = .04). They also reported reduced difficulties with introducing solids and breastfeeding rates were higher at 6-month follow-up. Intervention infants demonstrated statistically and clinically significant advantages over the Control infants on the mental development scale of the Bayleys-II (p = .02). The findings of no between-group differences on the psychomotor index, and that these scaled scores were 1-2 standard deviations below the normative mean, may suggest particularly delays of clinical significance which could not be circumvented by the relatively brief interventions.	Strengths: a controlled trial program with clinically significant findings for the inclusion of early psychosocial interventions into the clinical care of infants with CHD and their mothers. Limitation: Reliance on self-report data for maternal adjustment; the non-blind status of the Bayley's tester; integrated intervention package makes it difficult to discern which particular programme elements were more efficacious.

			inventory (COPE, Carver et al.) *Transactional stress and coping framework (Thompson, Gustafson, Hamlett, & Spock, 1992).		
Congenital Heart Disease Intervention Programme (CHIP)-School (Christopher G. McCusker et al., 2012)	A set of psychological interventions formed by a multi-disciplinary team to provide a 1-day workshop for parents, and a follow-up session (1-4 week after workshop) with families individually.	90 families (intervention group, n=45; control group, n=45) of children (mean age: 4.6 years) with congenital heart disease (CHD). UK	CHIP-School was underpinned by Thompson’s transactional stress and coping framework and has three components to it: Problem Prevention Therapy, Psychoeducation & Parenting skills. It focused on bolstering parenting skills in relation to both general developmental challenges and those specific to parenting a child with CHD. Outcome measures: 1. Child Adjustment - The Child Behavior Checklist (CBCL, Achenbach) 2. Family functioning – • Maternal Mental Health – Brief Symptom Inventory (BSI, Derogatis) • Maternal Worry Scale (De Vet	A 2x2 mixed analysis of variance was used to test for the statistical and clinical significance of any differential changes between baseline assessment (T1) and final analyses (T2) with mean time between T1 and T2 = 10.1 months (range 9-14 months). Findings show positive gains on measures of maternal mental health (p = .005) and perceived personal strain in the family (p = .01). Although no differences were found on measures of child behaviour at home or school, children in the intervention group were perceived as “sick” less often by their mother and missed fewer days of school. A regression model, using baseline measures as predictors, highlighted the importance of child cognitive functioning, maternal mental health and maternal worry for long term child behavioural outcomes.	Strengths: first major randomised controlled trial design of a psychological intervention for children with CHD and their families; intervention promoted clinically significant gains for both the child and family Limitation: Participants were not blind to group status; delivery of the program was from research team. Insufficient response rate from father for analyses.

			& Ireys) • Impact on Family Scale (Stein & Reissman) 3. Program Acceptability 4. A bicycle exercise stress test (1-4 week after workshop) *Transactional stress and coping framework (Thompson, Gustafson, Hamlett, & Spock, 1992).		
Diabetes Oriented Learning Family Intervention (DOLFIN) (Ridge et al., 2014)	A pilot diabetes-oriented carer-based group intervention for families with children with Type 1 diabetes. The program was delivered over 6 1.5 hour sessions by trained diabetes healthcare professionals.	17 parents/carers of young persons (10-18 years of age) with Type 1 diabetes UK	DOLFIN was a modified version of a collaborative care intervention originally used in eating disorders (Treasure et al.). This intervention focused on teaching carers motivational interviewing skills in order to reduce expressed emotion in parents and increase positive interactions in the home. Parenting styles were expressed in animal metaphors to illustrate adaptive and maladaptive relationship patterns. Information collected for this exploratory study:	Most parents/carers found DOLFIN valuable. Content analysis revealed three clinical themes and suggested that carers wanted (1) to talk about their experiences, (2) skills for managing and reacting to challenges in diabetes, and (3) support in exploring the impact that having a child with diabetes has on their lives and their children's lives. Paired t-tests that compared attending group's baseline vs. follow-up biomedical and psychological data revealed positive trends (e.g. slight fall in average glycaemia for patients) but authors noted these should be interpreted with caution given the small sample size and pilot nature of the program.	Strengths: in-depth description of clinical themes; identified key components in designing an intervention for this group of service users. Limitation: small sample size; no control group; different attrition rates for families from different backgrounds.

			-Qualitative data from first session's discussion and information exchange -Feedback evaluation on carer's satisfaction and experiences with DOLFIN -Pilot biomedical and psychological data at baseline and 13 weeks after completion of the intervention. *Transtheoretical model of change (Prochaska & DiClemente,1982).		
Experience Journal (EJ) (DeMaso, Gonzalez-Heydrich, Erickson, Grimes, & Strohecker, 2000)	A computer-based, narrative therapy, intervention for families of children with congenital heart disease (CHD) to narrate stories about living and coping with a medical condition or	40 mothers of children (ages 3-16 years) with CHD and hospitalised for cardiac surgery or for cardiac medical reasons. Mothers were asked to use the EJ for at least half an hour while in the	The EJ is based upon a narrative model involving the sharing of personal stories about an illness in cyberspace to promote self-understanding and shared-understanding with the construction of meaning as a central concept and goal. Semi-structured interviews were conducted to elicit both quantitative ratings (7-point likert scale) and qualitative data prior to EJ utilization	Descriptive statistics were computed for each of the rating scales and open-ended responses were coded based on similarity and frequency. Results show that EJ had high satisfaction ratings along with very low ratings of harmfulness. Mothers found EJ helpful through expanding their perspective, decreasing social isolation, improved understanding of feelings and behaviour of children with heart conditions, and increased hopefulness. Some mothers found EJ less helpful in understanding specific cardiac illness or specific	Strengths: one of the few interventions that utilise a computer-based preventative program which provides families with a virtual support system through providing psychoeducational & medical information closely connected to "one's own story" and

	illness. Contributions were organised by the EJ software and accessible to users anytime.	hospital. USA	and 2-4 weeks after hospital discharge: • Satisfaction and safety • Coping response • Attitude change • Illness-related concerns • Family functioning *Narrative therapy in outpatient medical crisis intervention (Shapiro & Koocher, 1996)	coping skills.	could supplement traditional types of interventions. Limitation: No control group; homogenous sample; EJ only made accessible to mothers but not to other family members which could have contributed different perspectives.
Filial therapy (Glazer-Waldman, Zimmerman, Landreth, & Norton, 1992)	Client-centered family skills training program using role-playing, demonstration, homework and supervision offered over 10 2-hour weekly sessions.	6 parents (5 mothers + 1 father) with children 4-8 years with a range of chronic illness. USA	Program based on a 10-session filial therapy training guide with a major focus to increase parental responses that reflect feelings and to increase acceptance of all emotions, concurrently decreasing the focus on the chronic illness. Qualitative reports from group leaders and observers + 3 quantitative outcome measures (administered pre & post-program): - Parent's anxiety/general distress	Wilcoxin matched-pairs signed-rank tests revealed no significant pre-post differences on the 3 quantitative outcome measures. However, there was a trend in increased parental acceptance of their children. There was also a significance decrease in the difference between child and parent CAS raw scores indicating parents were better able to accurately judge their child's level of anxiety (p = .043). Qualitative reports from parents on the other hand highlights many of the positive outcomes of the filial group – parents believed that the group had a	Strengths: Program paid special attention to group dynamics and relationship building to normalise the parent-child interaction. Limitation: one group, no control, small sample size.

			(State-Trait Anxiety Inventory –STAI, Spielberger) - Children's anxiety (Child Anxiety Scale – CAS, Gillis) - Parent's acceptance of children (Porter Parental Acceptance Scale, Porter) *Filial therapy: client-centered family skills training program (Levant, 1983)	positive impact on their relationships with their children	
Heart Beads Program (Redshaw, Wilson, Scarfe, & Dengler, 2011)	A person-centered care where each family at pre-admission is given a set of beads and an information flyer outlining the purpose of the program and specifying what each of the distinct beads are for and how their child will access	11 families with a child (baby – 15 years) with cardiac conditions. Australia	The Heart Beads Program was developed based on principles of person centred care where the child and their family are able to construct a coherent narrative/story of the experiences with the medical journey and to help make sense of it and deal with the stressors related to such traumatic life events. Semi-structured interviews were conducted with families on their experiences of participating in the Heart Beads Program (post-program interviews – no time frame mentioned).	Content analyses of the semi-structured interviews revealed Heart Beads provided an opportunity to review and understand the processes and procedures involved in the child's condition and recovery. Parents felt that the beads had provided them a tangible, visual tool to show family and friends in a substantial way what their experience had involved. This also helped the parent and the child to communicate in a shared language. There were five subthemes and characteristics stemming from storytelling: -Symbolism -Encouraging/uplifting -Acknowledgement -Connecting with others	Strengths: child and parent perspectives; qualitative in-depth data. Limitation: small sample size; one group; no demographic data on parents' cultural background which might have been a factor in constructing the narrative.

	the beads and help them to tell the story throughout their treatment process.		*No explicit theoretical underpinning but emphasised on person centered care with a narrative component to the program	-Imagining the future	
Intervention for Siblings: Experience Enhancement (ISEE) (Williams et al., 2003)	A community-based intervention for siblings and parents of children with chronic illness or disability. The intervention comprised a 5-day residential summer camp with a 2-2.5 hours teaching and psychosocial session each day for siblings and a 2-hour parent session plus a 2-hour booster	252 parent-sibling dyads (well sibling 7-15 years old) of children with chronic illness or disability. A randomized, three-group repeated-measures design was used: full intervention (n = 79), partial intervention (n = 71), and a waiting list control group (n = 102).	ISSE was developed consistently with learning theory as well as family systems and role theories to address non-categorical needs of siblings and families. Topics covered include: sibling educational & psychosocial sessions, parental awareness training on sibling needs, child behaviour management. Assessments of the performance of groups were conducted at baseline and at 4 post intervention periods: 5 days, 4, 9 and 12 months after baseline. Outcome measures: 1. Sibling Knowledge About Illness (SKNOW) – Knowledge test (Williams, et al.)	An estimate population-average generalised estimating equations panel-data model was used for statistical analyses. Separate panel analyses provided estimates of coefficients of the independent variables on each of the six outcome variables. Findings show that the full treatment group showed significant improvements on all six outcomes over most periods ($p < .05$), the partial treatment group on three outcomes (SSELF, SSUP & SATT), and the control group on two outcomes (SSUP & SATT). Improvements in outcomes ranged from 5% to 25% increases over baseline measures.	Strengths: randomized, three-group design; with follow-up study illustrating long term outcomes; provided estimated cost for full treatment to each parent-child dyad; Limitation: homogenous population, expense of intervention

	session for both parents and siblings 4 and 9 months after camp provided by research staff and nurse clinicians.	USA	2. Sibling Social Support (SSUP) – Social Support Scale for Children (Harter) 3. Sibling Self-Esteem (SSELF) – Self-Perception Profile for Children (Harter) 4. Sibling Mood (SMOOD) – Sibling Perception Questionnaire Revised-Mood Scale (Sahler & Carpenter; Williams et al.) 5. Sibling Behavior Problems (SBEHV) – Eyberg Child Behavior Inventory (Eyberg & Robinson; Robinson, Eyberg & Ross) 6. Sibling Attitude Towards Illness (SATT) – Sibling Perception Questionnaire – Attitude Scale (Sahler & Carpenter; Williams et al.) *Social learning theory, family system theory and role theories (Patterson, & Reid, 1975)		
Parents Empowering	A parenting program	301 parents (31 fathers, 258	The PEP Program was introduced internationally in 1996 to parents of	Descriptive analyses and chi-square tests were used to evaluate the survey data. Results indicated that	Strengths: control group; targeted

Parents (PEP) (DuTreil, Rice, Merritt, & Kuebler, 2011)	designed by a social worker practising in the bleeding disorders community for parents. The program is delivered in group meetings over weekends or in 10 weekly 1-hour sessions.	mothers) were recruited from 11 haemophilia treatment centres (HTC) that had provided PEP. Participants were divided into those who did attend PEP (n=62) and those who did not attend (n=235) – which were further divided into 3 groups based on their reasons for not attending: (Not offered (as control – n=50), Bad time – n=57 and Don't need – n=40). USA	children with bleeding disorders, HTC social workers, and nurses. The core messages of PEP attempt to increase parents' understanding of their child's bleeding disorder, heighten parents' ability to respond objectively and consistently to bleeding episodes, provide parenting skills to parents, and enhance relationships of parents, with spouse, children and treatment staff. An evaluation survey (post-program) was used to assess the efficacy of PEP in terms of parents' evaluation of the content and outcomes of the program: - Changes in spouse/partner relationship - Value of the PEP program - Effects of PEP concepts on important relationships - Parenting technique usage *No explicit theoretical underpinning mentioned but focus on psychoeducation and core	parents who attended PEP reported less use of yelling, spanking, slapping and giving-in after attending PEP. Those not offered the program by their HTC used praising, natural consequences, being consistent, ignoring, distracting, setting limits, giving choices, being consistent and distracting less than all other groups. Those for whom the intervention had been offered at a 'bad time' used time-out and ignoring more than the other groups that did not attend PEP. Those who did not think they needed the program used spanking, time-out and yelling less than all other groups (all p <.05). Attending PEP decreased the use of negative parenting techniques, improved communication, listening and problem solving skills.	disorder; well established program. Limitation: unspecified age of children; Descriptive study – no causal effect can be established.

			communication, relationship-building and problem-solving skills.		
Parents as Teachers™ (PAT) Born to Learn (Drazen, Abel, Lindsey, & King, 2014)	A home based parent education program targeting parenting skills and typical developmental milestones for parents of children with sickle cell disease (SCD). An occupational therapist who was certified as a PAT provider visited the family's home each at least once for an hour over a 26 month period) to deliver the program content and to	39 African American families of children (age 2-35 months) with SCD USA	Parents as Teachers™ PAT is a home-based parent education curriculum that aims to provide information, support and encouragement for families to help children reach developmental milestones during the first few years of life. Outcome measures: - Feasibility: acceptance and the number who participated in a home visit. - A satisfaction survey after completing a minimum of four home visits. - Field notes from each home visit (e.g. topics discussed and the child's current level of functioning in intellectual, language, motor and social-emotional development) *No explicit theoretical underpinning mentioned but focus on psychoeducation.	39 families participated in at least one home visit. 41% of families had between 1-5 visits, 33% had between 6-12 visits and 26% families had over 13 visits to the home. This participation rate is a two-fold increase in the poor attendance (20%) for a previous hospital-based program. Parents of younger infants were more likely to commit to the parenting program. Of the 23 families who completed more than four visits, 13 evaluated the program. All agreed or strongly agreed that they liked PAT visits and all strongly agreed that PAT visits helped the caregiver understand development and engage with their child. Qualitative observance of parenting practices revealed at least three common needs across many of the families: (1) lack of appropriate toys, (2) failure to read/talk to the child, and (3) inability to deal with challenging child behaviours during mealtime and bedtime. Intervention strategies provided by therapists	Strengths: A program focusing on SCD demonstrating that home-based visits were a feasible method for reinforcing clinic education. Limitation: Recruitment and participation from a single centre; a single arm intervention with no control group.

	provide additional handouts as appropriate for each family's needs (specific to SCD).			during each home visit were effective in helping these families to overcome adverse environmental conditions that are compounded by the complexities of a chronic health condition.	
SibLink (Lobato & Kao, 2005)	A family-based group intervention for healthy siblings of children with chronic illness (CI) or developmental disability (DD) and their parents. Siblings and parents participated in six 90-minute sessions of concurrent and integrated sibling-parent groups. Activities	43 well siblings (age 4-7 years) and their 40 parents of children (mean age = 6.1 years) with CI/DD. USA	Building on the evidence that sibling and parent adjustment are interrelated, SibLink was designed to develop and evaluate an integrated group intervention for siblings and parents of children with CI/DD. The six sessions aimed to improve sibling knowledge and family information exchange; identify and manage sibling emotions with problem-solving around challenging situations; and balance siblings' individual needs. Evaluation measures (each coded on a rating scale): 1. Sibling knowledge of CI/DD (scale of 1-4/ 1-5) 2. Sibling Connectedness (scale of	Repeated measures ANOVAs were conducted to assess the main effects of time (pre/post treatment + 3-month follow-up) on the evaluation measures: Siblings' knowledge of the child's disorder and sibling connectedness increased significantly from pre- to post-treatment for both boys and girls, regardless of the nature of the brother or sister's condition ($p < .05$). On the Pictorial Scale, siblings' cognitive competence and physical competence scores increased from pre- to post-treatment ($p < .01$) whereas parent reports of sibling behavioral functioning remained within the normal range. Improvements in sibling knowledge and connectedness were maintained at follow-up. Parents' high satisfaction, excellent attendance, and 100% program completion rates indicated the family-based intervention addressed a need	Strengths: one of the few family-based interventions targeted at young siblings of children with CI/DD. Limitation: No control group; homogenous demographic background of families; no specific measure for young siblings' adjustment to CI/DD.

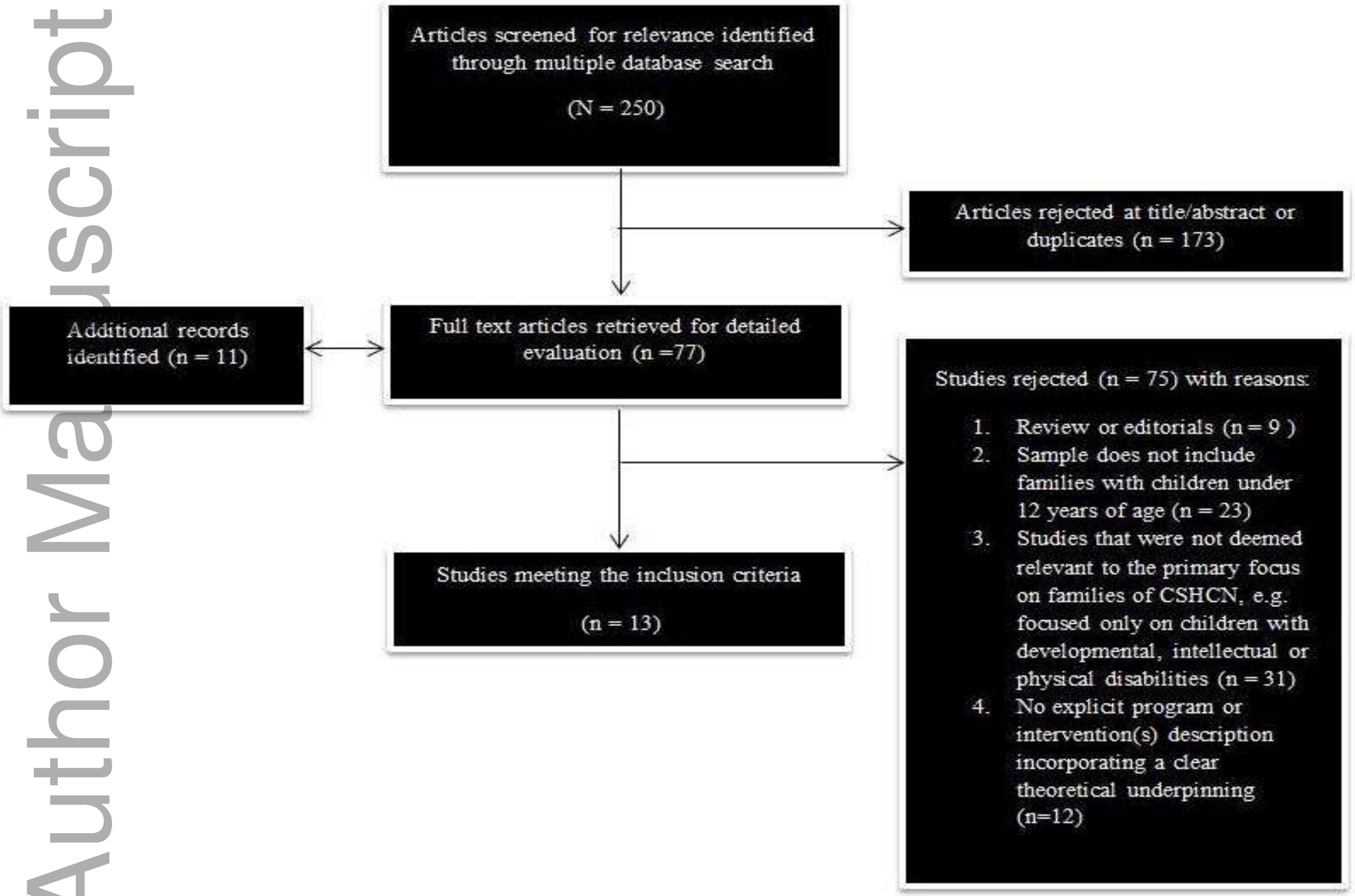
	were detailed in separate parent and sibling group treatment manuals.		1-4) 3. Sibling Global Functioning – Pictorial Scale of Perceived Competence and Social acceptance for Young Children (Harter & Pike) 4. Participant Satisfaction (scale of 1-5) *No explicit theoretical underpinning mentioned	important to the families.	
SIBSTARS (Giallo & Gavidia-Payne, 2008)	Family-based psycho-educational intervention using written information with booklet activities and telephone support for siblings and parents. Following one face to face session, telephone support offered	21 families (intervention, n=12; waitlist, n=9) with siblings (aged 8-16 years) and mothers of children (mean age =10) with at least one chronic illness, residing at home (not restricted to a specific disability or illness).	SIBSTARS was underpinned by cognitive-behavioural research and effective family-based approaches to assist both parents and siblings to develop and strengthen their coping, communication and problem-solving (and parenting for parents) skills. Measures for parents: -The Strengths and Difficulties Questionnaire - Parent Version (SDQ, Goodman, Meltzer & Bailey); -The Perceived Stress Scale (PSS, Cohen, Kamarck & Mermelstein); -The Parent Behaviour Questionnaire (PBQ, Gordon);	ANCOVA using pre-test scores as a covariate were conducted to compare the intervention (measures completed 2 weeks after intervention) and waitlist groups (measures completed after 8 weeks of no contact from researcher) on the measures at post-intervention: Siblings outcomes: At post-intervention, the intervention group had significantly lower emotional symptoms subscales scores; significantly lower perceived intensity of daily hassles stress related to the child with a disability or illness; and less use of distancing coping than the waitlist group (all p <.05). Parent and family outcomes:	Strengths: randomised controlled trial design with a focus on siblings support; clinical significance of the intervention was assessed; treatment acceptability of the intervention was assessed. Limitation: small sample size; variability in sibling's age; no systematic trialling of different

	for 20-30 minutes per week for 6 weeks.	Australia	-The Family Hardiness Index (FHI, McCubbin,Thompson & McCubbin); -The Family Problem Solving Communication Index (FPSC, McCubbin et al.); -The Family Time and Routines Index (FTRI, McCubbin et al.); Measures for siblings: - The Sibling Daily Hassles and Uplifts Scale (Kearney, Drabman & Beasley; Giallo & Gavidia-Payne) - The Self-Report Coping Scale (SCS, Causey & Dubow) - The Participant Satisfaction Questionnaire for both parents and siblings * Referred generally to intervention programs utilising cognitive-behavioural research and effective family-based approaches	At post-intervention, the intervention group reported that they engaged in more family time and routine activities than the waitlist group (p =.025) Clinical significance of intervention outcome: Most salient are improvements on the SDQ total difficulties, family hardiness and family problem-solving communication, and reductions in perceived intensity of daily stress for siblings and perceived stress for parents as assessed by the Reliable Change Index (RCI) method. All parents and 78% of siblings agreed or strongly agreed that the life skills covered in SIBSTARRS were appropriate and useful.	intervention components to see which of these are most effective; no follow-up data.
Teen Triple P workbook (Doherty, Calam, &	A self-directed family intervention for	79 parents of 11–17-year-olds with diabetes were	The Teen Triple P workbook is a self-directed behavioural family intervention, based on social learning	Primary outcome ANCOVA analyses showed that participants in the intervention group reported significantly less conflict (rDFCS) post-	Strengths: two time points, standardised tests, first to report

Sanders, 2013)	parents of children with Type 1 diabetes. Parents received a self-directed Teen Triple P workbook and Chronic Illness Tip Sheet to work through over a 10-wk period (1 hour per wk).	randomized to usual care (n=37) or intervention (n=42) using computerized block randomization. UK	principles used to help parents build on their existing skills and information to practice positive parenting. Four main categories of skill building: (1) increase positive parent–teenager relations; (2) increase desirable behaviour; (3) teach new behaviours and skills; and (4) manage problem behaviours. The workbook builds on weekly exercises to help the family use and implement the suggested strategies. Measures (baseline data + post-intervention data[no timeframe specified]): 1. Family conflict around diabetes-related tasks: revised Diabetes Family Conflict Scale (rDFCS; Hood, Butler, Anderson, & Laffel) 2. Parental stress in relation to caring for a child with an illness: Paediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak)	intervention than parents in usual care (p = .008). No significant difference was found between groups on measure of parental stress (PIP total). ANCOVA analyses also showed that change on all secondary outcome measures were statistically significant. Decreased scores on ECBI and PS, and increased score on the PSOC all represented positive change. Participants in the intervention group reported significantly fewer disruptive behaviour problems (ECBI) (p =.008), more productive parenting strategies (PS) (p =.039), and higher self-confidence in parenting skills (PSOC) (p =.006) post intervention than usual care comparison. Higher module completion was associated with increased self-confidence in parenting skills (r = -.46, p =.03), but no correlation was found on the other outcomes.	outcomes of a web-based RCT of a self-directed intervention for families of children with Type 1 diabetes. Limitation: possibility of selection bias due to the recruitment method (e.g. online data collection); no future treatment control or attention control groups were in place.

			3. Parental perceptions of child's behaviour: Eyberg Child Behavior Inventory (ECBI; Eyberg & Robinson,) 4. Feelings about being a parent: Parenting Sense of Competence Scale (PSOC; Johnston & Mash) 5. Parenting style: Parenting Scale (PS; Arnold, O'Leary, Wolff, & Acker) *Behavioural family intervention system based on social learning principles (Sanders, 1999)		

Fig.1 PRISMA Flow Diagram of Study Selection Process



Articles screened for relevance identified through multiple database search
(N = 250)
Articles rejected at title/abstract or duplicates (n = 173)
Additional records identified (n = 11)
Full text articles retrieved for detailed evaluation (n =77)
Studies rejected (n = 75) with reasons:
1. Review or editorials (n = 9)
2. Sample does not include families with children under 12 years of age (n = 23)
3. Studies that were not deemed relevant to the primary focus on families of CSHCN, e.g. focused only on children with developmental, intellectual or physical disabilities (n = 31)
4. No explicit program or intervention(s) description incorporating a clear theoretical underpinning (n=12)
Studies meeting the inclusion criteria
(n = 13)