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The Nature of Family Engagement in Interventions for Children with Chronic Conditions

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Abstract

Recognizing the bi-directional relationship between family functioning and child wellbeing in the context of childhood chronic conditions, researchers have tested family-focused interventions aimed at promoting both child and family well-being through improving the family's condition management capacity. Based on a sample of 70 interventions for families in which there was a child with a chronic physical condition, this analysis examined the nature of family engagement in the interventions. Data were extracted from the intervention reports using a standardized template; conventional content analysis was used to describe family engagement. Interventions varied in focus, structure, and level of family engagement. Investigators most often sought to improve condition control or management, with parent engagement focused on improving capacity to manage the treatment regimen. Few investigators addressed capacity building in the context of family functioning. Recommendations are made for reporting standards for family-focused interventions and for enhancing the family systems grounding of interventions.

Keywords

family; intervention; chronic condition; child

An estimated 15% to 20% of children under the age of 18 have special healthcare needs (Bethell et al., 2014). These are children “who have or are at increased risk for a chronic

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physical, developmental, behavioral, or emotional condition and who also require health-related services of a type or amount beyond that required by children generally” (McPherson et al., 1998, p. 138). Close to one-quarter of U.S. households have one or more children with special healthcare needs (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2013), and a substantial percentage of these children have a chronic physical condition (CPC) such as asthma or diabetes (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2013). Children with a CPC experience a higher incidence of adjustment problems and lower educational attainment than healthy peers (Champaloux & Young, 2015; Pinquart & Shen, 2010; Pinquart & Shen, 2011; Pinquart & Teubert, 2011). Research findings on the intersection of family life and childhood CPCs point to the influence of family variables on children’s adaptation to the condition (Coffey, 2006; Herzer et al., 2010; Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). A compelling body of evidence also exists that childhood chronic conditions affect the functioning of families and individual family members (Barlow & Ellard, 2006; Cabizuca, Marques-Portella, Mendlowicz, & Coutinho, 2009; Holmbeck et al., 2006; Pai et al., 2007). Reviews of research on parents whose children had kidney disease (Aldridge, 2008), cancer (Pai et al., 2007), and spina bifida (Holmbeck et al., 2006) concluded that parents (especially mothers) were at increased risk for adjustment problems, and Herzer and colleagues (2010) found that across conditions, approximately one-quarter of families of children with chronic conditions evidenced areas of poor family functioning.

Family-focused Interventions

Recognizing the important contribution of family variables to the well-being of children with a CPC and the adjustment risks experienced by these children and families, researchers have turned their attention to developing and testing family-focused interventions, which are defined as “non-medical interventions that are psychologically, socially or behaviorally oriented and that involve members of the patient’s family or both the patient and family member” (Martire, Lustig, Schulz, Miller, & Helgeson, 2004, p. 601). In the case of children with a CPC, such interventions typically involve the child’s parents and are aimed at promoting physical and psychological well-being through improving capacity to adapt to and manage condition-related challenges. Family-focused interventions have been differentiated further as being either psychoeducational or relationship-focused (Chesla, 2010; Martire et al., 2004). Psychoeducational interventions are directed toward increasing family members’ knowledge of the condition and ability to manage the demands of the treatment regimen; relationship-focused interventions address improving family relations or overall family functioning by changing selected aspects of family life (e.g., communication, problem solving).

Reviews of family-focused intervention research have provided evidence of their efficacy with regard to improving condition knowledge (Armour, Norris, Jack, Zhang & Fisher, 2005; Carr & Springer, 2010; Fisher & Weihs, 2000), condition management and adherence (Carr & Springer 2010; Fisher & Weihs, 2000), child health (Armour et al., 2005; McBroom & Enriquez, 2009), and family/family member functioning (Armour et al., 2005; Carr & Springer 2010; Fisher & Weihs, 2000; Law, Fisher, Fales, Noel & Eccleston, 2014). In

developing family-focused interventions, researchers typically have conceptualized family system or family role variables such as conflict, cohesion, or parenting competence as contributing to patient, family, or family member risk or resilience. Accordingly, investigators may target reducing family conflict because it is conceptualized as contributing to poor child adaptation or may seek to increase family cohesion, which is hypothesized to enhance child resilience. Family variables are also conceptualized as mediating or moderating the effect of the intervention. For example, changes to parental role performance may mediate (i.e., cause) the effects that a family-focused intervention has on condition management. Differences in family structure may moderate (i.e., explain) variations in an intervention's effectiveness in one group versus another, for example single versus two parent families. Guidelines (Craig, Diepp, Macintyre & Michie, 2008; Drotar, 2005) for the development and testing of behavioral interventions emphasize the importance of specifying the link between the clinical problem being addressed and the conceptual underpinnings and content of the intervention. For family-focused interventions, this entails considering the intent of family engagement in the intervention and the nature of family participation.

Purpose

Although the differentiation of psychoeducational and relationship-focused interventions highlights important differences in the investigator's approach to intervention development, it does not address specific aspects of family engagement. The purpose of this analysis was to examine the focus, structure, and level of family engagement in interventions. Better understanding of these key dimensions of family-focused interventions will foster more informed decision making by future investigators about how to engage family members in the intervention to achieve desired outcomes.

Method

This analysis is based on a subsample of 93 published reports from 70 different intervention studies included in a larger, ongoing mixed-methods synthesis of the intersection of family life and CPCs (Mixed Methods Synthesis of Research on Childhood Chronic Conditions and Family - R01 NR012445; hereafter referred to as the Family Synthesis Study).

Sample

Intervention studies were included in the sample if they met the following criteria: 1) randomized clinical trial design (RCT), 2) published in an English-language journal between January 1, 2000 and March 31, 2014, and 3) intervention included families in which a child less than 19 years old had a CPC. Consistent with the definition presented previously (Martire et al., 2004), the intervention had to be psychologically, socially, or behaviorally oriented and include participation by the child's parent(s) or primary caregiver(s) (hereafter referred to as parents). Research reports were located through a search of nine databases (Academic Search Premier, CINAHL, EMBASE, ERIC, Family & Society Worldwide, PsychInfo, PubMed, Social Work Abstracts, and Sociological Abstracts) and screening of the reference lists of reports retained in the sample. More detailed accounts of the methodological underpinnings of the study have been reported elsewhere (Authors, 2015).

Data Extraction

Using a structured template, the investigators extracted the following information from each report: research purpose, sample characteristics, data collection methods, and findings. For the current analysis, an additional summary template was completed that included detailed information about the intervention: 1) theoretical underpinnings, 2) focus of family engagement in relation to hypothesized intervention outcomes, and 3) structure and level of family participation. Two members of the research team completed the extraction of data from each report. A research assistant completed the initial extraction, which was reviewed for accuracy and completeness by one of the investigators who edited the extraction as needed.

Analysis

Conventional content analysis (Hsieh & Shannon, 2005) was used to identify and code the nature of family engagement in the interventions. Consistent with the approach we identified categories based on our review of authors' descriptions of the interventions rather than applying a preconceived set of categories. Interventions varied in terms of the focus, structure, and level of family engagement. The scheme used to categorize interventions along these three dimensions is summarized in Table 1, with further description of how these dimensions varied across interventions reported in the results section. The first two authors independently categorized characteristics of the interventions and met to discuss disagreements and reach consensus on the appropriate categorization. Our unit of analysis was the 70 interventions on which the 93 reports were based.

Results

Description of the Sample

A description of the 70 interventions included in the review is provided in Table 2. Most were condition specific, with only seven including children with different conditions. Slightly over half (53%) of the interventions included families in which the child had asthma, followed by diabetes (16%). Relatively few interventions were directed toward families of children with other conditions including cancer, cystic fibrosis, blood disorders, fibromyalgia, and heart conditions. Although reports of children with arthritis, end-stage renal disease, epilepsy, and muscular dystrophy were included in the larger Family Synthesis Study, there were no interventions in our sample developed for families of children with these conditions. For the most part, the RCTs were carried out in the US (68%), though studies from Europe (20%), Asia (5.5%), and Australia/New Zealand (5.5%) were also in the sample. Based on credentials, it was possible to identify the authors' disciplinary affiliations (nursing, medicine, or social science) for 67 of the interventions. In 47 studies (74%) the team was comprised of a physician and/or nurse and a social scientist, with most collaborations between physicians and social scientists (n=34). In 10 studies, the team included a nurse, physician, and social scientist.

Across interventions, the mean number of study participants was 180, with a range of 7 to 1014. It was not always clear who the family member participants in the study were, since the sample sometimes was described only in terms of number of families enrolled. In the 36

studies (51%) specifying family member participants, mothers were the majority of participants in 23 studies and the only family member participant in nine. In four interventions, parent dyads were recruited. In the majority of studies, the mean age of the child with the CPC was 10 years or less.

Overview of Interventions

Interventions were predominantly psychoeducational ($n = 55$; 79%), with only 15 (21%) also addressing family relationships or family systems functioning (labeled as Relationship-Focused on Table 2). The percentage of interventions including a relational component varied across conditions. Comparing the two conditions with the largest number of interventions in the sample, 55% of the diabetes interventions had a relational component, but only 11% of the asthma interventions did. The interventions that included a relationship focus, addressed both specific aspects of family life, such as conflict resolution and teamwork, as well as the quality of overall family functioning and relationships.

Authors specified the theoretical underpinnings of 24 interventions (34%), with most ($n = 16$) grounded in a framework addressing individual adaptation or coping and relatively few ($n = 6$) referencing a family systems framework. An additional 10 interventions (14%) were based on practice guidelines. For 36 interventions (51%), authors did not identify the conceptual grounding of the intervention or described the intervention as based on a general orientation or tradition, such as cognitive behavioral.

Investigators hypothesized that interventions would lead to improvements in condition control (e.g., metabolic control, lung function), condition management (e.g., adherence, management competence), child and parent well-being (e.g., quality of life, depression), and family functioning (e.g., cohesion, communication), with the majority of interventions (84%) having been developed to yield improvements in multiple areas. Interventions most often targeted improvements in condition control (73%), followed by improvements in condition management ability (69%). Fewer investigators anticipated improvements in child (53%), parent (47%), or family (27%) functioning. Nine of the asthma interventions addressed only condition control and management, and one addressed only control. In contrast, investigators testing 10 of the 11 diabetes interventions targeted improvements in child, parent, or family functioning as well as condition control or management. Neither condition control nor management was assessed in any of the interventions directed to families of children with multiple conditions or cancer. In these cases, the interventions focused on child, parent, or family functioning.

Family Engagement in Interventions

Family engagement in interventions varied in terms of its focus, structure, and level (Table 1). In the following sections, the dimensions of engagement are described, highlighting commonalities and differences across conditions.

Focus of family engagement—The logic underlying most interventions was that changes in selected aspects of parent or family functioning were fundamental to realizing improvements in condition control, condition management, or child functioning, and family

members were engaged in interventions to realize these improvements. Based on the analysis of authors' descriptions of the interventions and hypothesized outcomes, investigators focused on family engagement to produce change in one or more of the following: condition management capacity, parent role performance, or family functioning. In interventions addressing parents' condition management capacity, the focus was on improving knowledge, skills, or self-efficacy for adhering to the treatment regimen or managing condition-related problems. Interventions that focused on parent role performance were directed to the nature of parent-child interactions, with the intent of changing those interactions in a way that would improve the child's well-being or ability to participate in condition management. Interventions focusing on family functioning targeted changing family roles, relationships, or processes. In 90% of the interventions, changes in these areas were linked to improved condition control, adherence, or child well-being. In eight (11%) interventions, the intent of family engagement focused solely on improving parent well-being or family functioning, and condition control, condition management, and child well-being were neither measured nor targeted for change.

The majority (76%) of interventions engaged parents with the intent of improving their capacity to manage the treatment regimen and resolve problems related to condition control and management through knowledge and skill development. For example, in a sample of parents of children with asthma, Butz and colleagues (2005b) sought to improve the parents' ability to identify symptoms and initiate appropriate nebulizer use in order to decrease child morbidity. Slifer and colleagues (2009) tested the efficacy of a distraction intervention administered by parents during injection procedures that was hypothesized to decrease child distress. In 33 (89%) of the asthma interventions, improving the parents' capacity to manage the condition was the sole focus of their engagement. In the 33 interventions addressing other conditions, capacity building was more likely to be one of multiple forms of family engagement, with only 33% of non-asthma interventions focusing solely on improving management capacity.

Only 11 (16%) interventions targeted supporting or changing parent role performance or family functioning. For example, an intervention developed by Scholten and colleagues (2013) provided parents with information and strategies for addressing their child's special needs and supporting the child's coping efforts, with the intent of improving the child's psychosocial functioning. Three of the five interventions with families in which there was a child with cystic fibrosis (Janicke et al., 2008; Opiari-Arrigan, Powers, Quittner & Stark, 2010; Stapleton et al., 2001; Stark et al., 2003) focused on developing parenting strategies that would increase the child's caloric intake during mealtime and promote weight gain. In 14 (20%) interventions, parent engagement included efforts to strengthen family relationships or functioning. In these interventions, family member involvement focused on clarifying or altering family roles or optimizing family relationships. The intervention was directed to producing improvements in family communication, problem solving, conflict resolution, or teamwork related to condition management. For example, the Coping Skills Training intervention (Ambrosino et al., 2008; Grey et al., 2009; Grey et al., 2011) was intended, among other things, to engage parents in activities that would decrease family conflict related to diabetes management and therein improve condition control and the quality of life of children with diabetes. Duncan and colleagues (2013) engaged parents and

children with asthma in an intervention designed to promote teamwork in condition management, with the goal of maintaining adherence to the treatment regimen as children assumed increasing responsibility for their own care. Interventions for families of children with diabetes stood out as engaging parents through addressing family relations and processes that put the child, parents, or the family system at risk for poor outcomes. On the other hand, only two asthma interventions involved parents in interventions addressing family processes and relationships.

Structure of family engagement—The structure of family engagement varied in terms of family members participating in the intervention and whether or not family members were jointly engaged. Parents and children were included in 47 (67%) interventions: separately (20%), jointly (30%), and sometimes with a combination of individual and joint participation (17%). Parents were the sole family participants in 23 (33%) interventions. Based on reports of child's mean age there was evidence of a relationship between the child's age and the structure of the intervention. In 9 of the 14 interventions (64%) engaging parents and children together or together and separately mean child age was 9 years old or older. In contrast, only 3 (16%) of the 19 interventions engaging parents alone reported a mean child age of 9 years old or older and only 4 (28%) of the 14 interventions engaging parents and children separately did so. The structure of family engagement also varied across conditions. Parents were the sole participants in 13 (35%) of the asthma interventions, but no cystic fibrosis and only two diabetes interventions included only parents. Structure also varied in terms of the focus of family engagement. In most (82%) interventions involving only parents, management capacity building was the sole focus of family engagement. In contrast, 57% of interventions engaging both parents and child focused only on improving management capacity. Twenty-eight interventions engaging parents and children aimed to enhance parent role performance or family functioning; eight of these also addressed management capacity.

Level of family engagement—The level of family member engagement in the interventions ranged from being relatively passive recipients of information about the condition and its management to active involvement in tailoring the intervention to the family's preferences and needs. In seven (10%) interventions, six of which were with families with an asthmatic child, the focus of family engagement was conveying information to parents and providing instruction about how to carry out selected aspects of the treatment regimen. Although education sessions included opportunities for parents to ask questions, they did not include other activities such as role playing and problem solving exercises, and there was limited one-to-one interaction with the intervener. For example, one tested intervention entailed a single clinic visit with an asthma educator and physician during which parents received instruction on asthma self-monitoring and management, environmental modification and trigger control, and linkages and referrals to ongoing primary care provider (Teach, Crain, Quint, Hylan & Joseph, 2006).

More often ($n = 55/81\%$), families were engaged as active participants in the intervention. Active participation was primarily between the parent and the interventionist and included opportunities for parents to practice skills or engage in problem solving exercises related to

condition management in 44 interventions (63%). The specific content of the intervention was determined by interventionists based on their assessment of the of family's needs. For example Fedele and colleagues (2013) tested an intervention delivered by a psychologist and a nurse that was designed to be highly interactive, with solicitation of feedback about personal experiences coping with uncertainty. In eight (11%) interventions, active engagement included parent-child interactions and participation in joint activities. For example, children were expected to include parents in "homework" activities or parents and children were expected to practice new ways of resolving problems or conflicts. Other forms of active participation included parent record keeping of the child's daily symptoms (Collandra et al., 2004) and group sessions where parents shared their experiences with one another (Hederos, Janson, & Hedlin, 2005; Hederos, Janson, & Hedlin, 2007; Hederos, Janson, & Hedlin, 2009).

In eight (11%) interventions parents helped determine the specific content of the intervention by identifying a particular management problem they wanted to address or the specific skills or information they wanted to learn. For example, Sahler and colleagues (2002) asked mothers of children with brain tumors to identify current problems they were experiencing, which became the basis for the problem solving intervention. Similarly, in an intervention involving parent mentors developed by Sullivan-Bolyai (2010), parents determined the number and timing of mentor visits and the focus of the discussion during each interaction.

Discussion

Through this analysis, three key dimensions of the positioning of families in family-focused interventions were identified and described. The 70 interventions varied in the focus, structure, and level of family engagement and their overall emphasis on family variables and family member involvement. Investigators most often sought to improve condition control or management, with parent engagement in the intervention focused on enhancing capacity to manage the treatment regimen. Comparatively few investigators addressed capacity building in the context of family roles or relationships. In this sense, the family emphasis of the interventions was limited.

The dimensions of family engagement—focus, structure, and level—extend existing guidelines for intervention reporting (Colquhoun et al., 2014; Davidson et al., 2003) to include key aspects of family engagement that should be addressed in reports of family-focused interventions. Although the three dimensions are relevant to all family focused interventions, there is likely more variability in how they are manifested than what has been described herein based on the current sample. While dimensions of family engagement could be identified and described, basic information related to theoretical underpinnings of the intervention and family member participants as well as the investigators' theoretical rationale for their design choices related to the focus, structure, and level of family engagement were rarely discussed, despite prior critiques of family-focused interventions pointing to the need for more explicit reporting of the conceptual grounding of the intervention (Martire et al., 2004; Wood, 2005).

Although parents were included in the intervention, comparatively few were done from a family systems perspective. This may reflect the condition-specific nature of most interventions, which contributed to an emphasis on enhancing parents' capacity to manage specific aspects of the treatment regimen, with limited consideration of the family context for developing and carrying out management skills. The focus on enhancing management capacity was especially apparent in interventions for families of children with asthma which comprised over half of the interventions and were characterized by a singular focus on improving parents' management capacity. While this focus is understandable, given the implications of non-adherence to the treatment regimen for condition control and child well-being, an exclusive focus on management capacity ignores the family context in which it occurs. In contrast to asthma interventions, those directed to families of children with diabetes and multiple conditions were more likely to focus on capacity building in concert with enhancing parental role performance or family functioning.

The limitations of the current study, similar to other synthesis efforts, are related to our sample selection criteria, which specified that only randomized clinical trials would be included in the analysis. Thus studies addressing intervention development, which might have included additional information about the theoretical grounding of intervention content or the rationale for the nature and focus of family involvement, were not included in the analysis. The analysis was based solely on information from the reports included in the sample. We did not contact the developers of the interventions for more detailed information about the intervention nor did we ask them to confirm our categorization of the intervention. Moreover, the predominance of interventions directed toward families in which the child had asthma limited our ability to examine condition-specific variations in family involvement.

Prior syntheses of family focused interventions have provided evidence of the efficacy of including family members. Multiple authors (Drotar, 2005; Meyler et al., 2010; Wood, 2005) have addressed the merits of adopting a family systems perspective when developing family-focused interventions in order to realize fully the benefits of family engagement. Nonetheless, relatively few of the interventions in the current analysis were grounded in a family systems perspective. When developing family-focused interventions, future researchers are encouraged to ground their interventions in theoretical frameworks that incorporate family system constructs and expand the psychosocial content of the intervention to address the family roles and relationships in which the treatment regimen is managed. To fully understand how family engagement contributes to intervention outcomes, investigators need to make purposeful, theoretically driven decisions about their intent in engaging families and provide an explicit rationale for the nature of family engagement.

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Table 1

Dimensions of Family Engagement Across 70 Interventions

Dimension	Variations in Family Engagement
Focus of Engagement : Purpose of including family members in the intervention; parent and/or family characteristics intervention was intended to change	<ul style="list-style-type: none"> • Parent condition management capacity • Parent role performance • Family functioning - roles, relationships, and processes
Structure of Engagement: Family member(s) included in the intervention and form of engagement	<ul style="list-style-type: none"> • Parent only • Parent and child separately • Parent and child together • Combination of separate and together
Level of Engagement: Ways in which family members participated in the intervention	<ul style="list-style-type: none"> • Recipient of information • Active participant; problem solving • Active participant and tailoring

Table 2

Overview of 70 Interventions

Reports	# Families (Intervention/control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
ASTHMA (n = 37)				
Bonner et al., 2002	56/63	9.95/ 4 –19.	Readiness to Learn Model/P	Condition control; Management/Adherence
Borrelli, Novak, McQuaid, Hammond, & Becker, 2010	68/65	6.9/ na	Behavioral Action Model/P	Condition control
Butz, 2010	121/110	8.13/na	NR ³ /P	Condition control; Management/Adherence
Butz et al., 2005a	131/91	8.02/ na	NR/P	Condition control; Child well-being; Parent well-being
Butz et al., 2005b; 2006	105/105	4.5/ 2–8	Symptom Management Model/P	Condition control; Management/Adherence
Canino et al., 2008	110/111	7.3/ 5–12	Practice guidelines/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Cano-Garcinuno et al., 2007	182 (across 3 groups/63	11/ 9–13	NR/P	Condition control; Management/Adherence; Child well-being; Parent Well-being
Chen, Huang, Yeh, & Tsai, 2013	33/32	7.45/ 5–12	General orientation/P	Condition control; Management/Adherence
Chiang, Ma, Huang, Tseng, & Hsueh, 2009	22/26	Na/ 6–14	Relaxation-based behavioral therapy/P	Condition control; Child well-being
Christakis et al., 2012	283/320	6.15/ 2–10	Social Cognitive Theory/P	Condition control Management/Adherence
Clark et al., 2004	416/419	na/ 7–10	NR/P	Condition control; Management/Adherence; Child well-being
Collanda et al., 2004	14/15	6.5y/ 4–11	NR/P	Condition control; Management/Adherence; Parent well-being
Duncan et al., 2013	38 (2 groups)/17	11.1/ 9–15y	General orientation/R	Condition control; Management/Adherence; Family functioning

Reports	# Families (Intervention/control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
Evans, Clark, Levison, Levin, & Mellins, 2001	239 (total sample)	9.1/ na	Reference previous description of the program/P	Condition control; Management/Adherence; Child well-being
Flores et al., 2009	112/108	7.3/7.1/ 2–18	NR/P	Condition control; Management/Adherence; Child well-being; Parent well-being;
Garbutt et al., 2010	190/172	8.0/7.1/ 5–13	Practice guidelines/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Gustafson et al., 2012	148/153	7.9/1/ na	Self-determination theory/P	Condition control; Management/Adherence; Parent well-being
Hederos, Janson, & Hedlin, 2005; 2007; 2009)	32/28 couples	2/ <1–6	NR/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Horner & Brown, 2014	101/82	8.78/ grades 2–5	Bruh's Theoretical Model of Asthma Management/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Hung, Chen, Mao, & Chiang, 2002	41/41	na/ 5–12	General orientation/P	Condition control; Management/Adherence; Parent well-being
Hussain-Rizvi, Kunkov, & Crain, 2009	40/46	3/ 1.5–4.5/y/o	Social Cognitive Theory/P	Condition control; Management/Adherence
Khan, O'Meara, Stevermuer, & Henry, 2004	155/155	4.9/1–14	Theory of Empowerment Family; Social System Theory; Social Support Theory/P	Condition control; Management/Adherence; Parent well-being
Kliment et al., 2005	90/91	1.4/ 9–24 months	NR/R	Condition control; Management/Adherence; Parent well-being; Family functioning
Krieger, Takaro, Song, Beaudet, & Edwards, 2009	156/153	8/ 3–13	Social Cognitive Theory; Trans-theoretical Model of Change/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Krishna et al., 2003	107/121	na/ 0–18	Practice guideline/P	Condition control; Management/Adherence; Child well-being; Parent well-being
Mandhane et al., 2010	125/162	8.6/ 6–13	Social Cognitive Theory/P	Condition control; Management/Adherence; Child well-being
Nelson et al., 2011	120/121	5.1/2–10	Trans-theoretical Model of Change/P	Condition control; Management/Adherence; Parent well-being
Ng et al., 2008	23/23	9.24/ 7–12	Self-efficacy Theoretical Framework/R	Condition control; Management/Adherence; Child well-being; Parent well-being

Reports	# Families (Intervention/ control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
Seid, Varni, Gidwani, Gelhard, & Slymen, 2010	250/152	7.37/ 2–14	Problem Solving Interventional Approach/P	Condition control; Child well-being
Szczepanski, Jaeschke, Spindler, Ihorst, & Forster, 2010	222 (2 groups)/116	3.9/ 2–5	Practice guidelines/P	Condition control; Management/Adherence; Parent well-being
Teach et al., 2006	244/244	na/ 1–17	Health Belief Model/P	Condition control; Management/Adherence; child well-being
Walders et al., 2006	89/86	7.3/ 4–12	NR/P	Condition control; Child well-being
Watson et al., 2009	201/197	7.4/ 3–16	Practice Guidelines/P	Condition control; Management/Adherence; Parent well-being
Wilson, Farber, Knowles, & Lavori, 2011	178/174	7.9/ 3–12	NR/P	Condition control; Management/Adherence
Wilson et al., 2001	44/43	7.2/ 3–12	NR/P	Condition control; Management/Adherence; Child well-being
Yoos, Kitzman, McMullen, Henderson, & Sidora, 2002	168 (3 groups)	Na/ 6–19	NR/P	Condition control; Management/Adherence
Zivkovic, Radic, Cerovic, & Vukasinovic, 2008	267/121	10/ 5–18	Stress Adaptation Model/R	Condition control; Management/Adherence
DIABETES (n = 11)				
Ambrosino et al., 2008; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Grey et al., 2009	65/46	9.9/ 8–12	Stress Adaptation Model/R	Condition control; Management/Adherence; Child well-being; Parent well-being; Family functioning
Cakan, Ellis, Templin, Frey, & Naar-king, 2007; Ellis, Frey, et al., 2005; Ellis, Naar-King, et al., 2005; Ellis, Templin, et al., 2007; Ellis, Yopp, et al., 2007	64/63	13.2/ 10–17	Systems Theory/R	Condition control, Management/Adherence; Child well-being; Family functioning
de Wit et al., 2008, 2010	46/45	14.8/ 13–17	NR/P	Condition control; Management/Adherence; Child well-being; Family functioning

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Reports	# Families (Intervention/control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
Forsander, Sundelin, & Persson, 2000	19/19 (51% mothers)	9.7/ 3–14	Systems Theory/P	Condition control: Family functioning
Harris, Greco, Wysocki, & White, 2001; Wysocki, Greco, Harris, Bubb, & White, 2001; Wysocki et al., 2000	(2 groups)/40	14.3/ 12–17	Family Systems/R	Condition control; Management/Adherence; Child well-being; Family functioning
Lafiel et al., 2003	50 parent dyads/50 parent dyads	12.1/ 8–16	NR/R	Condition control; Management/Adherence; Child well-being; Family functioning
Murphy et al., 2012	158/147	13/ 1–16	NR/R	Condition control; Management/Adherence; Child well-being
Sullivan-Bolyai et al., 2010	30/28 (100% mothers)	6/ 1–12	Irey's Social Support Model/P	Parent well-being; Family functioning
Tiberg, Katarina, Carlsson, & Hallstrom, 2012	58/58	8.7/ 3–15	NR/P	Condition control; Parent well-being
Toscos et al., 2012	27/27 families; na parents	8.5/ na	NR/P	Condition control; Management/Adherence; Child well-being; Parent well-being
(Wysocki et al., 2006; 2007; 2008	72 families (2 groups)/32 families	14/ 11–16	Systems Theory/R	Condition control; Management/Adherence; Family functioning
MULTIPLE CONDITIONS (n = 7)				
Burke, Harrison, Kauffman, & Wong, 2001	41 families/67 families	7.3/ 1–15	Calgary Family Assessment Model and Intervention Model/R	Family functioning
Chernoff, Ireys, DeVet, & Kim, 2002; Ireys, Chernoff, DeVet, & Kim, 2001	86/75	9/ 7–11	NR/P	Child well-being; Parent well-being
Cloutier, Manion, Walker, & Johnson, 2002	16 parent dyads/16 parent dyads	6.1/ na	Emotion-focused couple therapy/R	Parent well-being; Family functioning
Jerram, Raeburn, & Stewart, 2005	41/17	na; 1–9	NR/R	Parent well-being; Family functioning
Scholten et al., 2013	120/74	11.52/ 8–18y/o	NR/P	Child well-being

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Reports	# Families (Intervention/control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
Slifer et al., 2009	23/24	6.25/ 2–10	NR/P	Child well-being; Family functioning
Svavarsdottir, Tryggvadottir, & Sigurdardottir, 2012	45/45	na; 0–18	Calgary Family Assessment and Intervention Model/R	Family well-being
CANCER (n = 6)				
Askins et al., 2009; Dahlquist & Pendley, 2005	197 (2 groups)/104	8.1/ na	Cognitive Behavioral Approach/P	Parent well-being
Dahlquist & Pendley, 2005	18/12	3.5/ 2–5	NR/P	Child well-being
Fedele et al., 2013	29/28	8/ 2–17	Cognitive Behavioral Approach/P	Child well-being; Parent well-being
Genc & Conk, 2008	30/30	9.3/ 7–12	NR/	Child well-being
Kazak et al., 2004	76/74	14.32/ 11–19	Cognitive-behavioral and family systems/R	Child well-being; parent well-being
Sahler et al., 2002; 2005	217/213	7.6/ 3–14	Problem Solving Therapy/P	Parent well-being
CYSTIC FIBROSIS (n = 5)				
Downs, Roberts, Blackmore, Le Souef, & Jenkins, 2006	33/29	8.4/ 6–11	Social Cognitive Theory/P	Management/Adherence; Child well-being; Parent well-being
Grasso, Button, Allison, & Sawyer, 2000	10/10	13.3 mo/ 4.5–23 mo	NR/P	Condition management; Child well-being; Parent well-being
Janicke, Mitchell, Quittner, Piazza-Waggoner, & Stark, 2008; Opiipari-Arrigan, Powers, Quittner, & Stark, 2010)	78 (both groups)	7.8/ 4–12	NR/P	Condition control; Management/Adherence; Family functioning
Stapleton et al., 2001	30/29	na/ 2–11	NR/P	Management/Adherence
Stark et al., 2003	15 (both groups)	10/ 6–12y/o	NR/P	Condition control; Management/Adherence; Family functioning
BLOOD DISORDERS (n = 2)				

Reports	# Families (Intervention/ control)	Child Age (mean/range; years unless otherwise indicated) ¹	Conceptual Underpinnings or Evidence Base/Intervention Approach ²	Hypothesized Area(s) of Improvement
Applegate et al., 2003	122 (2 groups)/32	11.52/na	NR/P	Management/Adherence
Barakat, Schwartz, Salamon, & Radcliffe, 2010	27/26	14/na	Cognitive Behavioral Therapy/P	Condition control, Management/Adherence; Child well-being; Parent well-being; Family functioning
FIBROMYALGIA (n = 1)				
Kashikar-Zuck, Swain, Jones, & Graham, 2005	15/15	15.8/ 13–17	NR/P	Condition control
HEART (n = 1)				
McCusker et al., 2012	45/45	5.5/ na	Transactional Stress and Coping Framework/P	Child well-being; Parent well-being; Family functioning

¹ For studies for which there were multiple articles, the sample size reflects the largest N across reports; sample size at time of allocation to group

² Psychoeducational (P) or Relationship-Focused (R)

³ Not reported – NR

Table 3

Nature of Family Engagement in 70 Interventions

Reports	Focus of Engagement	Structure of Engagement	Level of Engagement
ASTHMA (n = 37)			
Bonner et al., 2002	Condition management capacity	Parent/child separately; parent-child together	Active participant
Borrelli, Novak, McQuaid, Hammond, & Becker, 2010	Condition management capacity	Parent only	Active participant
Butz, 2010	Condition management capacity	Parent/child separately; parent-child together	Active participant
Butz et al., 2005	Condition management capacity	Parent/child separately	Active participant
Butz et al., 2005; 2006	Condition management capacity	Parent/child separately	Recipient of information
Canino et al., 2008	Condition management capacity	Parent only	Recipient of information
Cano-Garcinuno et al., 2007	Condition management capacity	Parent/child separately; parent-child together	Active participant
Chen, Huang, Yeh, & Tsai, 2013	Condition management capacity	Parent/child separately	Active participant
Chiang, Ma, Huang, Tseng, & Hsueh, 2009	Condition management capacity	Parent-child together	Active participant
Christakis et al., 2012	Condition management capacity	Parent only	Active participant & tailoring
Clark et al., 2004	Condition management capacity	Parent/child separately; parent-child together	Active participant
Collanda et al., 2004	Condition management capacity	Parent/child separately	Active participant
Duncan et al., 2013	Family functioning	Parent-child together	Active participant & tailoring
Evans, Clark, Levinson, Levin, & Mellins, 2001	Condition management capacity	Parent/child separately	Active participant
Flores et al., 2009	Condition management capacity	Parent-child together	Active participant
Garbutt et al., 2010	Condition management capacity	Parent only	Active participant
Gustafson et al., 2012	Condition management capacity	Parent/child separately	Active participant

Reports	Focus of Engagement	Structure of Engagement	Level of Engagement
Hederos, Janson, & Hedlin, 2005; 2007; 2009)	Condition management capacity	Parent only	Active participant
Horner & Brown, 2014	Condition management capacity	Parent/child separately	Active participant
Hung, Chen, Mao, & Chiang, 2002	Condition management capacity	Parent only	Active participant
Hussain-Rizvi, Kunkov, & Crain, 2009	Condition management capacity	Parent only	Active participant
Khan, O'Meara, Stevermuer, & Henry, 2004	Condition management capacity	Parent only	Recipient of information
Klennert et al., 2005	Parent role performance	Parent only	Active participant
Krieger, Takaro, Song, Beaudet, & Edwards, 2009	Condition management capacity	Parent only	Active participant
Krishna et al., 2003	Condition management capacity	Parent-child together	Active participant
Mandhane et al., 2010	Parent role performance	Parent/child separately	Recipient of information
Nelson et al., 2011	Condition management capacity	Parent only	Active participant
Ng et al., 2008	Condition management capacity Family functioning	Parent/child separately; parent-child together	Active participant
Seid, Varni, Gidwani, Gelhard, & Slymen, 2010	Condition management capacity	Parent/child separately	Active participant & tailoring
Szczepanski, Jaeschke, Spindler, Ihorst, & Forster, 2010	Condition management capacity	Parent/child separately	Active participant
Teach et al., 2006	Condition management capacity	Parent-child together	Recipient of information
Walders et al., 2006	Condition management capacity	Parent only	Active participant
Watson et al., 2009	Condition management capacity	Parent-child together	Active participant
Wilson, Farber, Knowles, & Lavori, 2011	Condition management capacity	Parent only	Active participant
Wilson et al., 2001	Condition management capacity	Parent-child together	Active participant
Yoo, Kitzman, McMullen, Henderson, & Sidora, 2002	Condition management capacity	Parent-child together	Active participant
Zivkovic, Radic, Cerovic, & Vukasinovic, 2008	Condition management capacity	Parent-child together	Recipient of information

Reports	Focus of Engagement	Structure of Engagement	Level of Engagement
DIABETES (n = 11)			
Ambrosino et al., 2008; Grey, Jaser, Whitemore, Jeon, & Lindemann, 2011; Grey et al., 2009	Family functioning	Parent/child separately; parent-child together	Active participant
Cakan, Ellis, Templin, Frey, & Naar-king, 2007; Ellis, Frey, et al., 2005; Ellis, Naar-King, et al., 2005; Ellis, Templin, et al., 2007; Ellis, Yopp, et al., 2007	Family functioning	Parent-child together	Active participant
de Wit et al., 2008, 2010	Unclear	Parent/child separately; parent-child together	Active participant
Forsander, Sundelin, & Persson, 2000	Condition management capacity Family functioning	Parent/child together	Active participant
Harris, Greco, Wysocki, & White, 2001; Wysocki, Greco, Harris, Bubb, & White, 2001; Wysocki et al., 2000	Family functioning	Parent-child together	Active participant
Laffel et al., 2003	Condition management capacity Family functioning	Parent-child together	Active participant
Murphy et al., 2012	Condition management capacity Family functioning	Parent-child together	Active participant
Sullivan-Bolyai et al., 2010	Condition management capacity	Parent only	Active participant & tailoring
Tiberg, Katarina, Carlsson, & Hallstrom, 2012	Condition management capacity	Parent-child together	Active participant
Toscos et al., 2012	Condition management capacity	Parent only	Recipient of information
Wysocki et al., 2006; 2007; 2008	Family functioning	Parent-child together	Active participant
MULTIPLE CONDITIONS (n = 7)			
Burke, Harrison, Kauffman, & Wong, 2001	Family functioning	Parent only	Active participant & tailoring
Chernoff, Ireys, De Vet, & Kim, 2002; Ireys, Chernoff, De Vet, & Kim, 2001	Condition management capacity Parent role performance	Parent/child separately; parent child together	Active participant
Cloutier, Manion, Walker, & Johnson, 2002	Family functioning	Parent only	Active participant

Reports	Focus of Engagement	Structure of Engagement	Level of Engagement
Jerram, Raeburn, & Stewart, 2005	Condition management capacity Parent role performance Family functioning	Parent only	Active participant
Scholten et al., 2013	Parent role performance	Parent/child separately	Active participant
Slifer et al., 2009	Condition management capacity Parent role performance	Parent/child separately; parent-child together	Active participant
Svavarsdottir, Tryggvadottir, & Sigurdardottir, 2012	Family functioning	Parent only	Active participant
CANCER (n = 6)			
Askins et al., 2009; Dahlquist & Pendley, 2005	Condition management capacity	Parent only	Active participant & tailoring
Dahlquist & Pendley, 2005	Condition management capacity	Parent-child together	Active participant
Fedele et al., 2013	Condition management capacity	Parent only	Active participant
Genc & Conk, 2008	Condition management capacity	Parent/child separately	Active participant
Kazak et al., 2004	Condition management capacity Family functioning	Parent/child separately; parent-child together	Active participant
Sahler et al., 2002; 2005	Condition management capacity	Parent only	Active participant & tailoring
CYSTIC FIBROSIS (n = 5)			
Downs, Roberts, Blackmore, Le Souef, & Jenkins, 2006	Condition management capacity	Parent-child together	Active participant
Grasso, Button, Allison, & Sawyer, 2000	Condition management capacity	Parent-child together	Active participant
Janicke, Mitchell, Quitner, Piazza-Waggoner, & Stark, 2008; Oipari-Arrigan, Powers, Quitner, & Stark, 2010)	Parent role performance	Parent/child separately	Active participant
Stapleton et al., 2001	Parent role performance	Parent/child separately; parent-child together	Active participant
Stark et al., 2003	Parent role performance	Parent/child separately	Active participant

Reports	Focus of Engagement	Structure of Engagement	Level of Engagement
BLOOD DISORDERS (n = 2)			
Applegate et al., 2003	Condition management capacity	Parent only	Active participant & tailoring
Barakat, Schwartz, Salamon, & Radcliffe, 2010	Parent role performance	Parent-child together	Active participant
FIBROMYALGIA (n = 1)			
Kashikar-Zuck, Swain, Jones, & Graham, 2005	Parent role performance	Parent/child separately; parent-child together	Active participant
HEART (n = 1)			
McCusker et al., 2012	Condition management capacity Parent role performance	Parent-child together	Active participant