



HHS Public Access

Author manuscript

Fam Process. Author manuscript; available in PMC 2016 March 01.

Published in final edited form as:

Fam Process. 2015 March ; 54(1): 173–184. doi:10.1111/famp.12101.

Delimiting Family in Syntheses of Research on Childhood Chronic Conditions and Family Life

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Abstract

Synthesis of family research presents unique challenges to investigators who must delimit what will be included as a family study in the proposed review. In this paper, the authors discuss the conceptual and pragmatic challenges of conducting systematic reviews of the literature on the intersection between family life and childhood chronic conditions. A proposed framework for delimiting the family domain of interest is presented. The framework addresses both topical salience and level of relevance and provides direction to future researchers, with the goal of supporting the overall quality of family research synthesis efforts. For users of synthesis studies, knowledge of how investigators conceptualize the boundaries of family research is important contextual information for understanding the limits and applicability of the results.

Keywords

Research Synthesis; Family Research; Childhood Chronic Conditions

The investigation of the intersection of family life and childhood chronic conditions has been an especially fertile area of inquiry for researchers from multiple disciplines. Varying considerably in their conceptual and methodological underpinnings, studies have addressed varied topics, including the contribution of family factors to child adaptation, the nature and predictors of family response to the child's condition, and the testing of interventions to improve child and family outcomes. Despite the breadth and quantity of this research, investigators continue to seek more precise answers to the question of which factors contribute to optimal outcomes for children and their families.

The volume and diversity of research on family and childhood chronic conditions make it difficult to assess the body of knowledge in the field, and state with confidence "this is what we know about these children and families." The quantity of work in the field points to the importance of undertaking syntheses of this rich but unwieldy body of research and provides an ample data base for doing so.

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The significant contributions of research synthesis studies to the scientific basis for practice have received increasing recognition (Cooper, 2010b; Hardin & Thomas, 2010; Pope, Mays, & Popay, 2007; Sandelowski, Voils, Crandell, & Leeman, 2013), but synthesis of family research presents unique challenges to investigators who must delimit what will be included as a “family study” in the synthesis. This paper is grounded in our experiences undertaking a large scale study entitled “Mixed-Methods Synthesis of Research on Childhood Chronic Conditions and Family” (hereafter referred to as the Family Synthesis study) and issues encountered in delimiting the boundaries of family research to be included in the sample. The overall objective of the study, which is in progress, is to complete a series of syntheses of findings from studies on the intersection of family life and childhood chronic conditions. Through multiple analyses addressing specific research questions, we will map the relationships found among family system, family member, condition management, demographic, and healthcare system variables to explain how these factors contribute to variations in child and family/family member functioning (Havill et al., 2014; Leeman, Sandelowski, Havill, & Knafl, in press; Sandelowski, Leeman, Knafl, & Crandell, 2013).

Regardless of scope, the quality of synthesis research is dependent on the investigator’s ability to generate a sample of research reports inclusive of a conceptually defined domain of interest. Because of the volume of health-related family research, investigators are likely to identify more studies that are potentially relevant to the proposed synthesis than practically feasible to include. Pragmatic challenges related to the volume of available research are especially likely in mixed-methods syntheses that include studies with varied research designs. In this article, we examine conceptual and pragmatic challenges that investigators are likely to encounter when defining what constitutes a “family study”. We also describe a framework to guide the specification of search criteria and sample selection in family synthesis research that includes both identification of relevant content areas and assessment of the level of relevance of individual research reports. The framework was developed to be applicable to both large and small scale syntheses of family research and provides a systematic strategy for managing the conceptual boundaries and size of the final sample.

CHALLENGES IN SYNTHESIZING FAMILY RESEARCH

The body of knowledge in the field, and not the individual study, increasingly is viewed as the optimal source of evidence for guiding clinical practice and intervention development (Cooper, 2010b; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012; Pope et al., 2007). Rigorously conducted reviews also provide direction for ongoing research in the field and allow investigators to address questions that could not be addressed in a single study. Substantial advances have been made in recent years in the development of methods for conducting reviews, with multiple options available (Grant & Booth, 2009; Sandelowski & Barroso, 2007).

Previous reviews of research on family life and childhood chronic conditions have made substantial contributions to our understanding of the intersection of family life and children’s chronic conditions. They provide strong evidence of the contribution of family processes to child adaptation as well as evidence that a child’s health-related condition

influences the nature of family and family member functioning (Berge & Patterson, 2004; Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006; McClellan & Cohen, 2007; Swallow, Macfadyen, Santacroce, & Lambert, 2012; Vermaes, van Susante, & van Bakel, 2012). Across reviews, however, authors have provided little information on their underlying conceptualization of their domain of interest and used varied selection criteria to identify a final sample of reports.

This variation is reflected in Table 1, which provides a synopsis of eight reviews addressing some aspect of the intersection of family life and childhood chronic conditions. In addition to specifying a publication timeframe for inclusion of reports, the search terms and inclusion criteria for these reviews typically defined the three primary aspects of the intersection of childhood chronic conditions and family life—child, chronic condition, and family. Child usually was defined in terms of age (< 18 years). Chronic condition was defined in terms of specific diagnoses or as a condition expected to continue for a prolonged length of time. Family was defined in terms of the aims of the synthesis. Reviews addressed how the condition influenced family life and/or family member functioning (Aldridge, 2008; Berge & Patterson, 2004; Holmbeck et al., 2006; McClellan & Cohen, 2007; Pai et al., 2007; Swallow et al., 2012; Vermaes et al., 2012) or the contribution of family variables to the functioning of the child with the chronic condition (Drotar, 1997). In several studies, researchers further operationalized “family study” by specifying the inclusion of a family-related variable or quantitative measure of family functioning (Drotar & Bonner, 2009; McClellan & Cohen, 2007; Pai et al., 2007; Vermaes et al., 2012). The family-related search terms used in prior reviews also varied considerably. Authors reported using search terms that specified family variable(s) of interest (e.g., adaptation, coping) (Aldridge, 2008; McClellan & Cohen, 2007), family member(s) of interest (e.g., sibling) (Vermaes et al., 2012), or both (Holmbeck et al., 2006; Pai et al., 2007; Swallow et al., 2012).

Despite the strengths of these reviews with regard to clearly formulated aims and search criteria, researchers provided minimal information about their approach to conceptualizing the family domain of interest. Our intent in this article is to provide investigators with an approach to conceptualizing and refining their targeted domain of family research that will both streamline and strengthen the rigor of the search and selection process.

PROBLEM FORMULATION IN LITERATURE SEARCHING

Despite variations in their purpose and strategies, all synthesis approaches emphasize the importance of a sound research plan. The design of a synthesis study should include problem formulation, literature searching based on explicit criteria, data extraction and evaluation, data analysis and interpretation, and presentation of results (Cooper, 2010b; Whittemore & Knafl, 2005). Drawing on examples from the Family Synthesis study, in this article we focus on the interplay of problem formulation and search criteria in family synthesis research.

Guidelines for problem formulation and literature searching typically are broad and applicable to a wide array of topics. As part of the problem formulation stage of a synthesis study, Cooper (2010b) recommended defining the conceptual domain of interest, the breadth of one’s interest within the conceptual domain, and how the conceptual domain will be

operationalized in the search. In family synthesis research, this entails conceptually defining family research in a way that reflects the aims of the proposed study. The conceptual definition of family research is then the basis for specifying inclusion and exclusion criteria to determine whether a research report will be included in the final sample.

Guidance on search strategies for locating studies within the conceptual domain of a review includes topics such as the specification of search criteria and terms, effective use of computerized databases, strategies for supplementing use of these databases, and the advantages and disadvantages of including unpublished reports (Cooke, Smith, & Boothe, 2012; Cooper, 2010b; Papaioannou, Sutton, Carroll, Booth, & Wong, 2010; Pope et al., 2007; Whittmore & Knafl, 2005). Experts in the field (Cooper, 2010b; Papaioannou et al., 2010) acknowledge that investigators may need to modify their conceptualization of the area of interest if initial search yields are excessively large as they were in the Family Synthesis study. In other cases, there may be a poor or ambiguous fit between the investigator's initial area of interest and what is reported in the literature. It is the investigator's responsibility to determine when modifications are needed and to provide a rationale for any changes to the initial conceptualization of the domain of interest or search plan.

DELIMITING THE BOUNDARIES OF RELEVANT FAMILY RESEARCH

In the Family Synthesis study, delimiting the domain of interest was completed in two phases (Table 2). During the initial phase, we completed a scoping study (Arksey & O'Malley, 2005) to assess the range of research related to families in which there is a child with a chronic condition and to provide evidence of the feasibility of our research aims. Following identification of a large group of topically relevant reports, the second phase of screening focused on further specifying the breadth of our interest across topical areas, and refining inclusion criteria to address level of relevance as well as topical focus.

Phase 1—Initial Conceptualization of Relevant Family Research

In Phase 1 of delimiting our sample, we conducted a scoping study (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010) of approximately 350 research reports published between January 2000 and June 2010. As described by Levac et al. (2010), "researchers can use scoping studies to clarify a complex concept and refine subsequent research inquiries" (p. 1). The scoping study resulted in a conceptualization of relevant topical areas of family research. The scoping study was guided by our initial conceptualization of family research, which was grounded in a definition of family as "a group of intimates living together or in close geographic proximity with strong emotional bonds and a history and a future" (Fisher et al., 1998). Consistent with study aims, this definition focused our attention on the internal functioning of the family system (e.g., roles, relationships, processes) rather than its structure. We were interested in the relationship of family functioning to other child, family member, condition, demographic, and health care system factors. Our goal was to identify a sample of research reports that was diverse in terms of family structures, chronic conditions, and methodology.

Through the scoping study, we developed a heuristic categorization of topical areas of research on the intersection of family life and childhood chronic conditions and more

specific areas of inquiry within each topical category (see Table 3). The topical categories (family systems functioning, functioning of the child with the condition and other family members, condition management and control, relationship with healthcare system) delimited the initial conceptual boundaries of our synthesis, and the areas of inquiry further defined the categories and provided direction for specifying search terms and assessing the relevance of research reports. The breadth of research across categories provided evidence of a sufficient body of literature to achieve the aims of the study. The results of the scoping study provided a topical map of areas of research relevant to the Family Synthesis study. It did not, however, address how topically relevant content was incorporated into a study or the extent to which it was central or peripheral to the study's research aims.

Phase 2—Refining the Conceptualization of Family Research and Inclusion Criteria

Once a target domain of family research has been specified, the investigator must identify all reports meeting inclusion criteria. Ideally, this leads to a final sample that is large enough to address the aims of the synthesis, but is not so large that it exceeds available resources. Using the topical domains identified in the scoping study, we screened over 40,000 research reports and identified 3716 “possibly relevant” reports based on their fit with one or more of the topical categories summarized in Table 3 (Havill et al., 2014). This number far exceeded the resources of a grant budgeted for a final sample of 750–800. Through an iterative process, focused on assessing the relevance of reports to the study aims, we narrowed the initial pool of 3716 “possibly relevant” research reports to a final sample of 801. In the process of doing so, we developed a framework for determining the degree of relevance that specific research studies had for the Family Synthesis study.

In screening the “possibly relevant” reports, it became apparent that there was considerable variation across topical areas in how family factors were incorporated in the report. In some, family system functioning or its relationship to child functioning was the focus of the inquiry, and the report clearly was relevant to the aims of the Family Synthesis study and the topical areas of interest summarized in Table 3. For example, in a study focusing on the contribution of family variables to condition management, Miller and Drotar (2007) examined the relationship between quality of parent–adolescent communication (a family process variable) and adolescent treatment adherence and decision-making competence (condition management variables). However, in other reports, the inclusion of family variables was limited to demographic variables such as family income or parents' educational status as covariates in the analysis. Investigators also addressed topics such as the functioning of individual family members and family utilization of health care services apart from their relationship to other family, child, or condition factors. Although we identified 3716 reports that included results relevant to one or more topical content categories, the reports varied widely in their level of relevance to our study aims. We recognized that the decision to include or exclude a study should take into account both the topical focus of the family content and how that content was incorporated into the report.

GUIDELINES FOR FURTHER DELIMITING THE DOMAIN OF FAMILY RESEARCH

Building on our initial specification of relevant topics, further refinement of inclusion criteria entailed assessing the level of relevance of research reports to the aims of the Family Synthesis study. We developed criteria for determining relevance level and differentiated research reports as having high, qualified, or low relevance (see Table 4). All high-relevance reports were included in the sample. Qualified-relevance reports were included only if they reported results on relationships involving child or family variables. Low-relevance reports were excluded. Specification of level of relevance provided a systematic strategy for managing sample size. It guided the exclusion of additional reports and contributed to a final sample that was manageably sized and optimally aligned with study aims.

In the Family Synthesis study, reports were classified as high relevance if the report focused on the functioning of the family system and/or study aims addressed relationships among family system, family member, and condition management variables. High-relevance reports addressed some aspect of families' efforts to manage the condition, family functioning (e.g., relationships, processes), performance of family roles (most often parenting), or family members' perceptions of family life. These reports were considered high relevance whether or not they examined relationships among family and other variables. In high-relevance reports, the primary aim of the study was to generate knowledge of the intersection of family life and childhood chronic conditions. They included qualitative and quantitative descriptions of family members' perceptions of family life and condition management. For example, Kelly and Ganong (2011) examined how parent relationships and family boundaries were changed in stepfamilies following a child's cancer diagnosis. Reports of the association among family variables and child well-being and condition management such as a study of the relationship between family functioning during mealtime and dietary adherence in children with cystic fibrosis (Mitchell, Powers, Byars, Dickstein, & Stark, 2004) also were classified as high relevance. Because of their focus on family system, family role, and condition management experiences and variables, high-relevance reports were relatively straightforward to screen.

In contrast, low-relevance reports, even though they addressed one of the topical areas summarized in Table 3, were a marginal fit with our conceptualization of the target domain of family research. Low relevance reports did not include findings on the functioning of the family system in relation to child or condition management variables. Low-relevance reports often were large-scale, population-based surveys describing such things as the demographic characteristics of families of children with a chronic condition, the economic consequences of having a child with a chronic condition, or families' level of health care utilization. Also deemed as low relevance were reports of the efficacy of treatments unrelated to families' condition management efforts and reports in which family variables such as income or parents' education were included only as covariates in the analysis.

Considerable discussion accompanied our decision to exclude reports focusing on the functioning of children with a chronic condition and their families in comparison to healthy children and their families. Although these reports highlighted areas of resilience and risk

for children and families, they were classified as low relevance because they did not address factors related to the nature or quality of functioning in children and families other than the presence of the condition. Typical of these studies was De Clercq, De Fruyt, Koot, and Benoit's (2004) comparison of the quality of life of childhood cancer survivors to healthy referents. The report was excluded since it did not relate the child's quality of life to family or condition management variables. Reports of instrument development or assessments of the appropriateness of different data collection approaches also were considered low relevance. In these reports the investigator's primary aim was to advance the methodological underpinnings of family research rather than generate knowledge of the intersection of family life and childhood chronic conditions. Similar to the high-relevance studies, those in the low-relevance category were relatively straightforward to screen.

The most challenging reports to screen were those in the qualified relevance group. As reflected in Table 4, reports in this group addressed content that was consistent with our initial conceptualization of family research in the following areas: congruence of family members' perceptions of their situation, family member well-being and functioning (other than parental role functioning), demographic characteristics, knowledge of the condition, ability to carry out treatments, and interactions with health care providers. The pragmatic necessity of narrowing the sample to a manageable size led us to specify an additional qualifier for retention of reports in these content-relevant areas.

Because one of the primary aims of the study was to map the relationships among family system, family member, and condition management variables, reports in the qualified-relevance group were retained only if they addressed at least one such relationship. For example, we screened many reports comparing different family members' perceptions of the same thing (e.g., child's quality of life, condition severity), but relatively few were included in the final sample. In most of these reports, the investigators did not link level of agreement among family members to other family/family member or condition management variables. Similarly, reports of the well-being and functioning of individual family members were retained in the sample only if results about the individual were linked to results about the family system, other family members, or condition management. For example, the report by Anthony, Bromberg, Gil, and Schanberg (2011) of parental perceptions of child vulnerability and parental stress was retained in the sample because it linked these variables to the child's adjustment, but a study of psychological distress in parents of children with congenital heart disease (Spijkerboer et al., 2007) was excluded because it did not relate parental distress to other family, child, or condition management variables. Most reports focusing on the demographic characteristics of the family and family members were excluded because they did not examine the relationship between demographic characteristics and other family or condition management variables. The addition of an added qualifier for some topically relevant reports was grounded in our study aims and conceptualization of the target domain of family research. The consistent application of this qualifier contributed to the systematic screening of reports and a final sample that was consistent with both study aims and resources.

DISCUSSION

With the growing recognition of the importance of synthesis research to knowledge development and evidence-based practice have come increasingly sophisticated methods for undertaking reviews (Cooper, 2010a; Grant & Booth, 2009; Hardin & Thomas, 2010; Sandelowski, Voils, Leeman, & Crandell, 2012). In this article, we have addressed two key issues often encountered when doing a health-related family synthesis study—conceptualizing the family domain of interest and managing pragmatic issues related to the volume of available research. We provide a framework for delimiting the family domain of interest that takes into account both target areas of content and their level of relevance to study aims. The proposed framework provides guidelines for determining the conceptual boundaries of the family research to be included in the synthesis while also managing the volume of literature in the final sample.

As summarized in Table 2, we undertook and recommend to others a 2-phase process for determining the family research to be included in a synthesis study. In Phase 1, the researcher completes a scoping study (Arksey & O'Malley, 2005; Levac et al., 2010) to identify the topical areas addressed in the domain of interest. Scoping studies typically are based on broad research questions with the intent of examining the breadth of research in the field. The results of the initial scoping study are used to exclude certain topical areas from the final sample and to either expand or further limit search criteria and terms. In Phase 2 of sample selection, the investigator assesses the level of relevance of reports identified in Phase 1 for their fit with the aims of the synthesis. In the family synthesis study, we identified three levels of relevance, but this number could vary across syntheses. Following the assessment of relevance, the investigator is positioned to decide which reports will be retained in the final sample. This decision entails balancing the desired comprehensiveness of the final sample with pragmatic considerations related to feasibility and resources.

Application of the proposed framework would vary considerably across studies, but the importance of addressing both content areas of interest and level of relevance is applicable to a broad array of health-related family synthesis studies. Syntheses always address a topical area of interest, with the volume and nature of family research varying across topical areas. Based on a conceptualization of family that focused on internal family processes and relationships, our topical focus was broad and required a more restrictive delimitation of the boundaries of family research than would have been necessary if our research aims had been narrower. For example, if our aims had focused on synthesizing research on fathers of children with a chronic condition, the body of research would have been considerably more limited, and it would have been both appropriate and feasible to include studies that reported anything related to fathers' experiences, well-being, or functioning whether or not it was linked to other family or family member variables.

The proposed framework is meant to provide direction to future researchers, with the goal of supporting the overall quality of family research synthesis efforts. For consumers of synthesis studies, knowledge of how the investigator has conceptualized the boundaries of family research is important contextual information for understanding the limits and applicability of the results of the synthesis.

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Table 1

Problem Formulation and Search Criteria in Prior Reviews of Family Research

Citation	Purpose of study	Search criteria based on...
Aldridge (2008)	Review studies of family adjustment to childhood kidney failure	<ul style="list-style-type: none"> • Publication date: 1980–2007 • Child: <18 years at diagnosis • Condition(s): Chronic renal failure • Family focus: Family system adjustment to condition • Family study: Not defined • Family related search terms: Adaptation, adjustment
Berge and Patterson (2004)	Understand how cystic fibrosis affects family systems and subsystems	<ul style="list-style-type: none"> • Publication date: 1980–2002 • Child: Birth to 18 years • Condition(s): Cystic fibrosis • Family focus: Impact of condition on family system • Family study: Family variables included in analysis; not an intervention • Family related search terms: Not reported
Drotar (1997)	Review research on relationship of parent and family functioning to the psychological adjustment of children with chronic health conditions	<ul style="list-style-type: none"> • Publication date: 1976–1995 • Child: 18 years • Condition(s): Ongoing chronic condition • Family focus: Contribution of family/parent variables to child functioning • Family study: Inclusion of validated measure of family/parent and child functioning • Family related search terms: Not reported
Holmbeck et al. (2006)	Examine how spina bifida impacts family and family member (parents, siblings) functioning	<ul style="list-style-type: none"> • Publication date: 1986–2002 • Child: Not defined • Condition(s): Spina bifida • Family focus: Impact of condition on family/family member functioning • Family study: Not specified • Family related search terms: Family, parent, adjustment
McClellan and Cohen (2007)	Review research on functioning of families with children with chronic illnesses compared with healthy controls	<ul style="list-style-type: none"> • Publication date: Not reported • Child: Not defined

Citation	Purpose of study	Search criteria based on...
Pai et al. (2007)	Summarize and examine the impact of pediatric cancer on parent and family functioning	<ul style="list-style-type: none"> • Condition(s): Cystic fibrosis, juvenile rheumatoid arthritis, type 1 diabetes, asthma, hemophilia, sickle cell disease • Family focus: Impact of condition on family/family member functioning • Family study: Inclusion of family measure • Family related search terms: Family functioning, family coping, family adjustment
Swallow et al. (2012)	Review the literature on fathers' involvement in the management of their child's condition	<ul style="list-style-type: none"> • Publication date: 1967–2005 • Child: Age 18 • Condition(s): Cancer—Any type • Family focus: Impact of cancer on family and parents • Family study: Objective measure of parent psychological, family, or marital functioning • Family related search terms: Parent, mother, father, family, system, marital, adaptation, coping
Vermaes et al. (2012)	Examine the psychological functioning of siblings of children with chronic health condition compared to siblings of healthy children	<ul style="list-style-type: none"> • Publication date: 1995–2008 • Child: 0–18 years • Condition(s): Long-term condition • Family focus: Impact of condition on father; fathers' involvement in condition management • Family study: Not specified • Family related search terms: Coping, management/intervention, compliance, adherence, and treatment, concordance, provision of information, information and treatment, role and illness self-care (all in conjunction with father) • Publication date: December 2010 and earlier • Child: Not defined • Condition(s): Multiple • Family focus: Impact of condition on siblings • Family study: Not specified • Family related search terms: Sibling, brother, sister

Table 2

Delimiting Target Sample for Family Research

Phase 1—Develop initial conceptualization of family and family research
Specify definition of family
Conduct scoping study to examine extent, range, and nature of research on family and childhood chronic conditions
Categorize topical focus of research
Delimit boundaries of conceptual area of interest
Identify initial search terms
Phase 2—Refine conceptualization of family research and search criteria
Define levels of relevance across topical areas
Assess search yields for relevance
Retain all high relevance studies; exclude all low relevance studies; selectively retain qualified relevance studies

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Table 3

Initial Conceptualization of Topically Relevant Family Studies

Topical category	Example areas of inquiry
Family system functioning	<ul style="list-style-type: none"> • Family relationships (e.g., satisfaction, attachment) • Family structure (e.g., division of labor, routines) • Family processes (e.g., communication, problem solving, coping) • Family system characteristics (e.g., resilience, environment) • Family resources (e.g., social support, health care system)
Affected child functioning	<ul style="list-style-type: none"> • Health status (e.g., general health, condition control) • Well-being and functioning (e.g., school performance, psychosocial adjustment) • Perceptions of experience (e.g., family life, condition management)
Family member functioning (parents, siblings)	<ul style="list-style-type: none"> • Well-being and functioning (e.g. quality of life, psychosocial adjustment) • Performance of parenting role (e.g., parenting style, parenting stress) • Perceptions of experience (e.g., family life, condition management)
Family/family member demographics	<ul style="list-style-type: none"> • Age/developmental stage • Gender • Race/ethnicity • Socio-economic status • Parent's education • Location (urban, rural)
Condition management and control	<ul style="list-style-type: none"> • Symptom management • Regimen management (e.g., adherence, monitoring) • Condition trajectory • Condition status
Family/family member interaction with healthcare system	<ul style="list-style-type: none"> • Health and social services utilization • Healthcare costs • Needs/satisfaction • Family/professional provider relations

Table 4

Assessing Level of Relevance across Categories of Family Research

Topical category	Relevance to study aims		
	High relevance—Include all reports with this content focus	Qualified relevance—Include if report relationship between content focus and child/family/family member functioning	Low relevance—Exclude all reports with this content focus
Family system functioning	<ul style="list-style-type: none"> Family relationships Family structure Family processes Family system characteristics Family resources 	<ul style="list-style-type: none"> Family member perceptions and congruence across family members 	<ul style="list-style-type: none"> Economic burden of condition to families Methods/ measures development
Affected child functioning	<ul style="list-style-type: none"> Perception of family experience 	<ul style="list-style-type: none"> Health status Well-being and functioning 	<ul style="list-style-type: none"> Comparisons to healthy children Methods/ measures development
Family member functioning (parents, siblings)	<ul style="list-style-type: none"> Performance of parenting role Perception of parenting and family experience 	<ul style="list-style-type: none"> Well-being and functioning 	<ul style="list-style-type: none"> Comparisons to parents of healthy children Methods/ measures development
Family/family member demographics		<ul style="list-style-type: none"> Age/developmental stage Gender Race/ethnicity Socio-economic status Parent's education Geographic location 	<ul style="list-style-type: none"> Population-based descriptions of demographic characteristics of families in which a child has a chronic condition Demographic variable as control variable Methods/ measures development
Condition management and control	<ul style="list-style-type: none"> Regimen management (e.g., adherence, symptom monitoring, incorporating regimen into family life) 	<ul style="list-style-type: none"> Family members' knowledge, beliefs, and/or concerns about the condition or treatments Family members' ability to carry out treatments or use medical equipment 	<ul style="list-style-type: none"> Comparative efficacy of treatments Risks for condition or risk reduction Incidence of condition

Topical category	Relevance to study aims		
	High relevance—Include all reports with this content focus	Qualified relevance—Include if report relationship between content focus and child/family/family member functioning	Low relevance—Exclude all reports with this content focus
Family/family member interaction with healthcare system		<ul style="list-style-type: none"> • Health and social services utilization • Healthcare expenditures • Needs/satisfaction • Family/professional provider relations 	<ul style="list-style-type: none"> • Distributions of providers and services • Economic analyses of family caregiving

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