

# Discovering What We Know – Innovations in Family Synthesis Research

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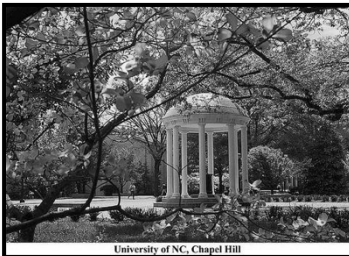
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Mixed Methods Synthesis of Research on Childhood Chronic Conditions and Family  
Funded by the National Institute of Nursing Research (1R01NR012445)



## Greetings from Our Research Team at University of North Carolina at Chapel Hill



## Background

- **Synthesis research – summary of all pertinent studies on a specific question or topic**
  - Contributes to evidence-based practice & knowledge development
  - Multiple approaches (e.g., systematic review, meta-analysis, mixed-methods)
  - Importance of a sound research plan
    - Problem formulation
    - Literature searching
    - Data extraction
    - Data evaluation
    - Data analysis & interpretation

Cooper, H. (2010). *Research synthesis and meta-analysis: A step-by-step approach* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage.

Whittemore, R., et al. (2014). Methods for knowledge synthesis: An overview. *Heart & Lung*, 43, 453-461.

## Family Synthesis Research

- **Sufficient body of research for undertaking syntheses in multiple areas of health-related family research**
- **Key issues**
  - Determining the conceptual domain of interest - what will “count” as a family study for the synthesis?
  - Specifying the breadth of interest within the conceptual domain – Are there limits on the family domain of interest?

## Purpose

- **Examine the conceptual and pragmatic challenges of family synthesis research**
- **Describe a framework for delimiting the family domain of interest**
  - Establishing feasibility
  - Assessing topical salience
  - Assessing level of relevance



## Basis for Framework Development

- ***Mixed Methods Synthesis of Research on Childhood Chronic Conditions and Family***  
**(1R01NR012445, 09/01/11 - 06/30/16)**
- **Map the relationships found among family system, family member, condition management, demographic, & healthcare system variables**
- **Describe the nature of interventions involving families of children with CPCs and their effects on child and family outcomes.**



## Delimiting the Target Sample in Family Research

- **Phase 1 – Develop initial conceptualization of family research domain of interest**
  - Conduct **scoping study** to examine the volume of research addressing aims (feasibility);
  - Categorize **topical focus** of research (delimiting conceptual boundaries)
- **Phase 2 – Refine conceptualization and specify search criteria**
  - Define **levels of relevance** across topical areas (positioning of family)
  - **Assess relevance** of search yields (sample selection)



## Phase 1: Scoping Study – feasibility

- **Method**
  - Guided by definition family used in proposal
  - Published 2000-2010
  - 10 data bases searched
  - Comparison of yields using different search terms (general vs. condition-specific search terms)
- **Outcome**
  - Identified  $\approx$  900 English language research reports
  - Evidence of a sufficient body of evidence to address research aims
  - Further refinement of search strategies & targets



Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19-32.

Levac, D., et al. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5:69.

## Phase 1: Scoping Study – conceptual boundaries

### Method

- Sub-sample of scoping study
  - ≈300 reports of qualitative & quantitative research
  - ≈35 reports of intervention studies
- Extraction of information using a structured template
  - Qualitative/quantitative reports: Aims, sample, design, measures/themes
  - Intervention reports: Also included intervention profile

### Outcome

- Topical map of content relevant to proposed aims
- Delimitation of initial conception boundaries of synthesis



### Initial Conceptualization of Study Variables (excerpt from larger table Included in proposal)

Topical Category	Example Areas of Inquiry
Family system functioning	<ul style="list-style-type: none"> <li>• Family relationships (e.g., satisfaction, attachment)</li> <li>• Family structure (e.g., division of labor, routines)</li> <li>• Family processes (e.g., communication, conflict)</li> </ul>
Affected child functioning	<ul style="list-style-type: none"> <li>• Health status (e.g., general health, condition control)</li> <li>• Wellbeing and functioning (e.g., quality of life)</li> </ul>
Family member functioning (parents, siblings)	<ul style="list-style-type: none"> <li>• Wellbeing and functioning (e.g. quality of life)</li> <li>• Performance of parenting role (e.g., parenting stress)</li> </ul>
Condition management & control	<ul style="list-style-type: none"> <li>• Symptom management</li> <li>• Regimen management (e.g., adherence, monitoring)</li> </ul>

## Reviewer Response to Addition of Scoping Study in Resubmission

- **First submission**

“The proposed research questions and guiding framework contain a plethora of variable/constructs. Although a “scoping study was performed, it only addressed the number of reports that included family as a variable or topic” (reviewer #3)

- **Resubmission**

“The initial search provides data that confirms the study data base is sufficiently large to move forward with the project”(reviewer #1).

“Preliminary investigations have been utilized to design the study and provide key feasibility data” (reviewer #3).



## Phase 2: Addressing a Pragmatic Challenge

- More potentially relevant reports than resources
- Screened  $\approx 40,000$ ; identified 3716 “potentially relevant” reports based on fit with topical categories; budgeted for final sample of 800
- Variation across reports in how family variables/factors positioned
  - Focus of study (e.g., relationship of family functioning and parenting competence to child adaptation)
  - Minor aspect of study (e.g., family income a covariate in analysis)



## Phase 2: Assessing Level of Relevance

- **Identified three relevance levels based on study aims**
  - **High Relevance:** Addressed families' efforts to manage the condition, family functioning, performance of family roles, or family members' perceptions of family life.
    - Descriptive
    - Relationship testing
  - **Low Relevance:** Did not address relationship of family or parenting variables to child functioning or condition management (e.g. studies of health care utilization)
  - **Qualified Relevance:** Consistent with initial conceptualization of family research, **but retained only if** reporting a relationship among family system, family member & condition management variables.

## Phase 2 – Examples of Qualified Relevance

Included studies of ...	Excluded studies of ...
The relationship between parents quality of life & children's quality of life	The quality of life of parents of children with a chronic condition & parents of healthy children
The relationship of differences between parents and children's perceptions of the seriousness of the condition and treatment adherence.	Comparisons of parents' and children's perceptions of the condition.
The relationship between family SES and parenting self-efficacy.	Descriptions of the demographic characteristics of families of children with a chronic condition.

## Phase 2: Make Final Sample Decisions

- **Based on assessment of conceptual fit and level of relevance**
  - Included all high relevance reports
  - Excluded all low relevance reports
  - Included qualified relevance reports addressing relationships among family system, family member, & condition management variables.
- **Final sample** (including update sample)  
NEED NUMBERS

## Discussion

- **Advantages of 2-phase process**
  - Systematically addresses both conceptual and pragmatic issues
    - Scoping study to expand or further limit initial conceptualization of domain of interest
    - Relevance assessment to refine conceptualization & sample selection criteria
    - Provides replicable, systematic strategy for managing conceptual boundaries & size of final sample.
- **Application of the framework**
  - Levels of relevance could vary across synthesis studies
  - Important to link relevance assessment to study aims
  - If scoping study reveals low volume of eligible reports, relevance assessment may not be necessary



# Questions

