

# The Contribution of Family Variables to the Wellbeing of Children with Arthritis



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## Background

- Juvenile idiopathic arthritis (JIA) affects an estimated 59,000 children in Europe & 294,000 in the US.
- Treatments include drug & physical therapies entailing considerable effort by the child & parents.
- Children experience pain, joint damage, & impaired mobility, putting them at risk for decreased quality of life & poor psychosocial functioning.
- Family response to JIA influences child well-being, but the precise nature of the relationship is unknown.

Borchers, et al. (2006). Juvenile idiopathic arthritis. *Autoimmunity Reviews* 5, 279-298.

Thierry, S., et al., (2010). Prevalence and incidence of juvenile idiopathic arthritis: A systematic review. *Joint Bone Spine*, 81, 112-117.



## Purpose

- Provide overview of research on intersection of family life and childhood arthritis.
- Examine the relationship between parent and family variables and child well-being.
- Identify aspects of parents' experiences that enhance or impede their capacity to parent a child with arthritis.

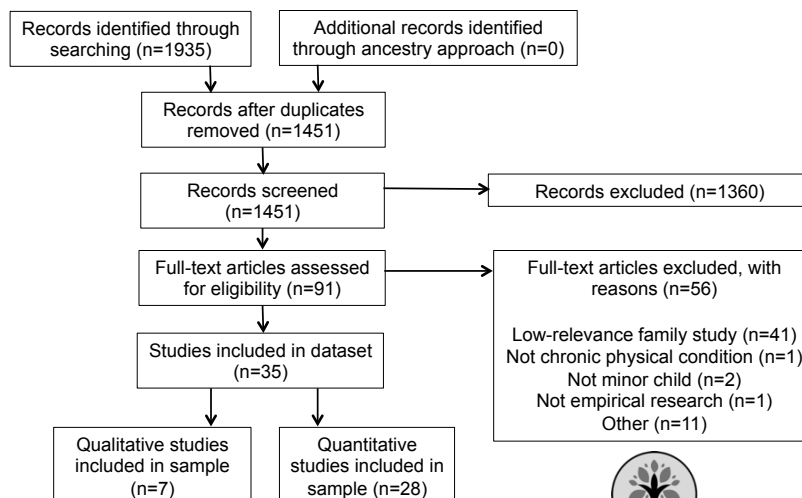


## Study Design & Sample

- Mixed-methods research synthesis
- Sample
  - English language research reports published between 1/1/00 to 3/31/14 addressing families of children with arthritis
  - Subsample of reports from larger Family Synthesis Study (R01NR012445)  
<http://familysynthesis.unc.edu/home>



## Arthritis PRISMA Flow Chart



## Method – Data extracted from each report

- Key features of report & study methods (e.g. sample, conceptual underpinnings, measures)
- Study results relevant to study aims
- Quality assessment; no study excluded based on quality

Sandelowski, et al., 2013. Text-in-Context: A method for extracting findings in mixed-methods mixed research synthesis studies. *Journal of Advanced Nursing*, 69, 1428-1437.



## Method - Format for extracting results

- Stand alone statements
  - In children with JRA, higher levels of parental depression & anxiety were significantly related to lower child psychosocial functioning. (*Effect size calculated for all relationships in quantitative reports*)
  - In families of children with arthritis, mothers & fathers reported that becoming a caregiver was entirely different from just being a parent because it included vigilant monitoring, responsibility for difficult daily treatments, & dealing with professionals in health, social service, & education. (*Qualitative result*)



## Method – Coding results statements

### CONDITION & DEMOGRAPHIC CODES

- Condition Characteristics
- Condition Management
- Condition Perceptions
- Demographics
- Diagnosis

### FAMILY - SYSTEM CODES

- **Family Functioning**
- **Family Relationships**
- **Family Resources**
- **Family Structure**



### PARENT & CHILD CODES

- **Child Well-being**
- **Parent Experience**
- **Parent Role Performance**
- Parent View of Child Identity
- **Parent Wellbeing**
- Sibling Wellbeing

## Method – Quantitative analysis

- Strength of relationship between family/parent & child well-being variables
  - Second level coding grouped results statements based on Dekovic's conceptualization family factors
    - **Proximal** – Parent-child relationship
    - **Distal** – Characteristics of parents; perception of condition
    - **Contextual** – Characteristics of the family

Dekovic, M., et al. (2003). Family predictors of antisocial behavior in adolescents. *Family Process*, 42, 223-235.



## Method – Qualitative analysis

- Aspects of parenting experience that could explain relationships between parent/family variables and child well-being
- Reviewed all **qualitative** result statements coded as parent experience
- Grouped using Dekovic's conceptualization of family factors
  - **Proximal** – Parent-child relationship
  - **Distal** – Characteristics of parent; perception of condition
  - **Contextual** – Characteristics of family



## Results – Sample

- 35 reports from 24 studies in arthritis sub-sample of Family Synthesis Study
- **29 reports from 19 studies contributed to current analysis**
  - 22 reports (14 studies) quantitative
  - 7 reports (5 studies) qualitative
- Reports from 21 journals (psychology, medicine, nursing, child development, family science, occupational therapy)



## Results – Sample\*

- o **Parents**

- o Total across studies: N=1209
- o Predominantly mothers; 9 studies reported including fathers; 7 studies did not specify which parent

- o **Children**

- o Total number of children across studies - 1143
- o Age: Mean age across studies 8.7 to 14.5 y/o
- o 50% or more female in all but 3 studies

\*Numbers based on 19 studies used in present analysis



## Results – Family measures

- o **Proximal – Parent-child relationship: n=4 measures** (e.g., Illness Behavior Encouragement Scale, Parenting Style)
- o **Distal – Characteristics of parents & perception of condition: n=12 measures** (e.g., Beck Depression Inventory, Arthritis Self-Efficacy, Symptom Checklist-SCL 90)
- o **Contextual – Characteristics of family: n=7 measures** (e.g., Family Relationship Scale, Family Environment Scale, Feeth – Family Functioning Scale)



## Results – Child measures\*

- **Psychological/Behavioral Functioning & Quality of Life:** N=22 measures (e.g., Child Depression Inventory, Children's Hope Scale, Child Behavior Checklist)
- **Health & physical status:** N=9 measures (e.g., Child Activity Limitations, JRA Symptom Rating Scale)
- 6 reports included both aspects of child wellbeing

\*Both parent & child report



## Coded Results Statements

- Results from 22 reports addressed relationships between a family &/or parenting variable & child well-being
- Results from 7 additional reports addressed parenting experience
- 3 reports judged low quality





## The Contribution of Family Variables to the Wellbeing of Children with Arthritis (Meta-Analysis)

- o 136 results of a relationship between a family factor & child well-being
- o 68% of these addressed a relationship between characteristic of parent & child well-being
- o Relatively few reports addressed relationship between family characteristics (27%) or parent-child relationship (23%) & child well-being



## Significant Relationships between Family Factors & Child Well-being

- o Seven reports addressed the relationship of **parental depression/anxiety to child's psychological status**; pooled correlation **.35** (95% CI .26 to .43, **p < .01**)
- o Four reports addressed relationship of **family conflict to child's psychological functioning**; pooled correlation **-.29** (95% CI -.40 to -.18, **p < .001**)
- o Three reports addressed the relationship between **parental depression or anxiety and the child's physical functioning**, yielding a significant medium pooled correlation of **.23** (95% CI .09 to .35, **p < .001**)

Correlation effect size – small  $\leq .10$ ; medium = .25; large  $\geq .40$



## Themes Characterizing Parenting Experience – Parent-child relationship

- Caregiving activities are the focus of time with child and viewed as distinct from parenting (6 reports)
- Inability to control child's pain and caregiving activities that inflict pain undermine relationship (5 reports)
- Relationship with child is viewed as unlike usual parent-child relationships (4 reports)



## Themes Characterizing the Parenting Experience – Personal impact & perceptions of condition

- Having a child with JIA and its associated caregiving demands is a highly emotional, distressful experience for parents, which can interfere with other aspects of their lives (4 reports)
- JIA is an unpredictable, poorly understood condition (4 reports)



## Themes Characterizing the Parenting Experience – Family impact

- Condition management limits time for other activities and results in altered family roles and relationships (6 reports)
- Management of JIA is the focus of family life and impacts the entire family system (5 reports)



## Discussion

- Evidence of relationship between multiple parent/ family factors and child well-being in the context of arthritis.
- Qualitative results furthered understanding of the unique challenges of parenting a child with arthritis that potentially put parents and families at risk.
- Limited attention to positive parent characteristics; overreliance on general measures of family functioning
- Research has focused on relationship between characteristics of parents & child well-being; fewer studies addressing family system variables or parent-child relationship



## Discussion

- Results point to the importance of assessing parents' perceptions of their care management efforts and how those efforts influence the parent/child relationship and family functioning.
- Interventions to enhance parenting competence, especially with regard to pain management, and reduce the role strain associated with being both a parent and a caregiver are promising avenues for improving parents' and thereby children's mental health.



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