Well Siblings in the Context of Childhood Chronic Illness: A Research Synthesis Using Existing Grounded Theory

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• Parent study: 1028 English Language research reports published between 1.1.2000 and 3.31.2014
• Purpose: Examine the relationships found among family system, family member, condition management, demographic, & healthcare system variables.
**Purpose: Sibling Analysis**

**Compare:**

- Well siblings’ report of their own emotional responses.
- Parents’ perceptions of well siblings’ emotional responses.

**Background: Sibling Analysis**

- In a review of research focused on well siblings of children with cancer, autism, or Down’s Syndrome the authors found a sizable variation in sibling emotional response and adjustment difficulties.
- Based on a meta-analysis of reports detailing siblings’ internalizing problems, externalizing problems and/or positive attributes, the authors found that siblings of ill children had greater internalizing problems, externalizing problems and less positive self-attributes than comparison children.


Sample: Sibling Analysis

- 90 reports with findings about siblings
  - Siblings were the focus of the research (n=24)
  - Family was focus of research but report included individual findings on siblings (n=66)

Data Extraction & Coding

- Results written as stand alone sentences
  “Among well siblings of children with chronic renal failure, their parents”

- All results sentences coded using codes developed specifically for Family Synthesis Project
  - demographic
  - family
  - parent & child
    - sibling well-being
Sibling Wellbeing

- 241 results statements coded as Sibling Wellbeing
- Identified an existing framework to organize the statements

Creating a Tenuous Balance

Realizing the seriousness of cancer

- Knowing Something is Seriously Wrong
- Not Knowing what is Wrong
- Enduring Uncertainty
- Having the “Right” Information
- Recalling Cancer-Related Events

Figuring Out the Meaning of Cancer

- Understanding What Cancer Means
- Coming to Terms with Cancer
- Thinking Now About Mortality
- Losing a Sense of Security

Adapting to Changes in Personal and Family Life

- Losing Family Normalcy
- Assuming a Parent-Like Role
- Losing a Sense of Self as Separate from Cancer
- Relying on Others

Handling Emotional Reactions to Cancer

- Experiencing Strong Feelings
- Riding the Roller Coaster
- Employing Coping Strategies
- Accepting Social Support

Sample: Experiencing Strong Feelings Sub-analysis

- 34 reports from 33 studies
- 803 siblings (6-27 y.o.) & 702 parents
- 9 countries
- Cancer, CF, Diabetes, Epilepsy, ESRD, Muscular Dystrophy, Sickle Cell, Fanconi Anemia, Spina Bifida, Multiple
- 52 results statements: 31 from siblings & 21 from parents
- 29 emotions plus dealing with parents’ emotions

Circumplex Model of Emotions

Sibling Emotions

Parents’ Emotions
- Suppressed Emotions
- Conflicting Emotions
- Unspecified Negative Emotions
- Anger
- Sadness
- Guilt
- Loneliness
- Shame
- Conflicting Emotions
- Suppressed Emotions
- Parents’ Emotions

Questions?
For more information of the Family Synthesis Project visit:
http://familysynthesis.unc.edu/home