International Study of Adaptation and Resilience in Families of Individuals with Down Syndrome

Marcia Van Riper, RN, PhD, FAAN
Professor
Chair Family Health Division
University of North Carolina at Chapel Hill
Fulbright Scholar Ireland 2012-2013
Past President, International Family Nursing Association

Co-authors
- George Knafl – UNC-Chapel Hill
- Maria do Céu Barbieri Figueiredo
- Maria João Silva
  - Escola Superior de Enfermagem do Porto
- Maria Caples
  - University College Cork

Down Syndrome
- Most common genetic cause of intellectual disabilities
  - 1 in every 800-1000 live births
- Complex Disorder
  - Multigene/Multisystem
- High degree of variability

Worldwide,
- There are over 7 million people living with Down syndrome
- Families of individuals with Down syndrome are from all races, religions, ethnic backgrounds and socioeconomic status

Growing evidence,
- Some families of individuals with Down Syndrome are:
  - Resilient and thrive
  - While others remain vulnerable
  - And some deteriorate
Few studies have compared the experiences of families living in different countries.

**Purpose**

- To examine the influence of culture and family factors on adaptation and resilience in families of individuals with Down Syndrome.

**Methods:**

- Cross-Cultural (10 or more countries)
- Cross-Sectional, Descriptive, Mixed Methods
  - All participants complete a packet of self-report questionnaires designed to assess key dimensions of the Resiliency Model of Family Stress, Adjustment & Adaptation
    - Hard copy or Online version
  - Participants are given the option of being interviewed
    - In-person or Telephone

**Resiliency Model of Family Stress, Adjustment, and Adaptation**

**Family Measures**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Index of Regenerativity and Adaptation (FIRA-G)</td>
<td>74 item measure/7 scales</td>
</tr>
<tr>
<td>Family Management Measure (FaMM)</td>
<td>53 item measure/6 scales</td>
</tr>
<tr>
<td>Family Problem Solving Communication Index (FPSC)</td>
<td>10 item measure</td>
</tr>
<tr>
<td>Family Member Well-Being (FMWB)</td>
<td>8 item measure</td>
</tr>
<tr>
<td>Brief Family Assessment Measure General (BFAM-G)</td>
<td>14 item measure</td>
</tr>
<tr>
<td>Background Information</td>
<td>Demographic information Questions about how they were informed of diagnosis of Down Syndrome</td>
</tr>
</tbody>
</table>

**Family Variables/Measures**

<table>
<thead>
<tr>
<th>Category</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Demands</td>
<td>Family Stressor Index (14 items FIRA-G)</td>
</tr>
<tr>
<td></td>
<td>Family Strains Index (15 items FIRA-G)</td>
</tr>
<tr>
<td></td>
<td>Condition Management Effect Scale (6 items FaMM)</td>
</tr>
<tr>
<td>Family Appraisal</td>
<td>Child’s Daily Life (5 items FaMM)</td>
</tr>
<tr>
<td></td>
<td>Condition Management Ability (2 items FaMM)</td>
</tr>
<tr>
<td></td>
<td>Family Life Difficulty (4 items FaMM)</td>
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<tr>
<td></td>
<td>View of Condition Impact Scale (10 items FaMM)</td>
</tr>
<tr>
<td></td>
<td>Essential Mutuality Scale (8 items FaMM)</td>
</tr>
<tr>
<td>Family Type</td>
<td>Family Hardiness Index (20 items FIRA-G)</td>
</tr>
<tr>
<td>Family Resources</td>
<td>Relative and Family Support (8 items FIRA-G)</td>
</tr>
<tr>
<td></td>
<td>Social Support Index (17 items FIRA-G)</td>
</tr>
<tr>
<td>Family Problem Solving &amp; Coping</td>
<td>Family Problem-Solving Communication Index (1 item FaMM)</td>
</tr>
<tr>
<td></td>
<td>Family Coping-Coherence (4 items FIRA-G)</td>
</tr>
<tr>
<td>Family Adaptation</td>
<td>Brief Family Assessment Measure (14 items B-FAM)</td>
</tr>
<tr>
<td></td>
<td>Family Distress (5 items FIRA-G)</td>
</tr>
<tr>
<td></td>
<td>Family Member Well-Being (8 items FMWB)</td>
</tr>
</tbody>
</table>
Resiliency Model of Family Stress, Adjustment, and Adaptation

Critical Event Stresser

Family Hardiness

Family Functioning

Family Distress

Parental Well-Being

Well Adapted

Maladapted

Vulnerability/Tile Up

Family Type

Family Appraisal

Family Resources

Family Problem Solving & Coping

Progress to Date

- Over 1200 parents have completed the self-report questionnaires (Brazil, Ireland, Japan, Korea, Malaysia, Netherlands, Portugal, Thailand, United Kingdom, United States)
- Over 600 parents have expressed interest in being interviewed
- Data collection will begin in other countries next spring (Italy, Spain, and hopefully Sweden and Denmark)

For this study

- Data from 802 parents living in 4 countries:
  - Ireland (79 Mothers/18 Fathers)
  - Portugal (63 Mothers/10 Fathers)
  - USA (425 Mothers/119 Fathers)
  - United Kingdom (77 Mothers/11 Fathers)

Approach Used to Analyze Data

- Linear Mixed Modeling
  - 13 Predictors
  - 3 Outcomes
  - All models accounted for:
    - Gender of parent
    - Partner status (partnered or non-partnered)
    - Country
    - Intra-familial correlation and constant variance in families where 2 parents participated

<table>
<thead>
<tr>
<th>13 Resiliency Model Predictors</th>
<th>Mothers (644)</th>
<th>Fathers (158)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Stressors (higher more stressors)</td>
<td>9.6 (0-40.2)</td>
<td>8.8 (0-41.7)</td>
</tr>
<tr>
<td>Family Strains (higher more strain)</td>
<td>9.1 (0-41.8)</td>
<td>7.7 (0-41.8)</td>
</tr>
<tr>
<td>Condition Management Ability (higher more manageable)</td>
<td>46.1 (26-60)</td>
<td>46.3 (28-60)</td>
</tr>
<tr>
<td>Child Daily Life (higher more normal life)</td>
<td>17.0 (5-25)</td>
<td>17.3 (8-25)</td>
</tr>
<tr>
<td>Family Life Difficulty (higher more difficulty managing)</td>
<td>30.6 (14-47)</td>
<td>31 (14-61)</td>
</tr>
<tr>
<td>View of Condition Impact (higher greater concern)</td>
<td>26.1 (10-44.4)</td>
<td>26.7 (12-39)</td>
</tr>
<tr>
<td>Condition Management Effort (higher more effort)</td>
<td>11.7 (4-20)</td>
<td>11.5 (4-20)</td>
</tr>
<tr>
<td>Family Hardiness (higher more hardy)</td>
<td>63.9 (37-78)</td>
<td>63.8 (39-78)</td>
</tr>
<tr>
<td>Relative &amp; Family Support (higher more support)</td>
<td>25.9 (8-40)</td>
<td>25.5 (8-37)</td>
</tr>
<tr>
<td>Affirming Communication (higher more affirming communication)</td>
<td>11.5 (0-15)</td>
<td>11.2 (2-15)</td>
</tr>
<tr>
<td>Incendiary Communication (higher more incendiary communication)</td>
<td>4.4 (0-13.8)</td>
<td>4.3 (0-14)</td>
</tr>
<tr>
<td>Family Coping (higher better coping)</td>
<td>15.7 (8-20)</td>
<td>15.5 (8-20)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3 Outcome Variables</th>
<th>Mothers (644)</th>
<th>Fathers (158)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjusted Family Functioning</td>
<td>45.2 (24-108)</td>
<td>45.4 (20-90)</td>
</tr>
<tr>
<td>Family Distress (higher more distress)</td>
<td>4.8 (0-33.6)</td>
<td>4.7 (0-27)</td>
</tr>
<tr>
<td>Family Member Well-Being (higher better well-being)</td>
<td>47.5 (5-78)</td>
<td>49.3 (8-74)</td>
</tr>
</tbody>
</table>
Results

- Each of the 13 predictors had a significant effect on each of the three outcomes (and the direction of the effect was as predicted)

- Adaptive Modeling was then used to reduce the model with all 13 predictors holding the predictors and the intercept in the model

Family Functioning

- Family functioning was worse with:
  - Greater Family Strains
  - More Incendiary Communication
  - Less Affirmative Communication
  - Lower Condition Management Ability
  - Lower Hardiness

- Family Functioning was worse in non-partnered families (p= 0.001)

- Fathers were not significantly different from mothers in terms of family functioning

Family Functioning (continued)

- Parents from Ireland (p= 0.577) and the UK (p= 0.412) were not significantly different from parents in the US in terms of family functioning.

- However, parents from Portugal were significantly different from parents in the US.
  - Parents from Portugal had lower family functioning (p= 0.001)

- Family Functioning changed significantly with child age (family functioning was worse in families of older children) (p= 0.008)

Parent Well-Being

- Parent Well-Being was worse with:
  - Greater Condition Management Effort
  - Greater Family Strains and Stressors
  - More Incendiary Communication
  - Lower Condition Management Ability
  - Lower Hardiness

- Fathers were not significantly different from Mothers in terms of Parent Well-Being (p= 0.722)

Parent Well Being Continued

- Parents from Ireland (p= 0.335), UK (p= 0.343), and Portugal (p= 0.428) were not significantly different from parents in the US in terms of Parent Well-Being
  - Parent Well Being did not change significantly with age (p=0.562)
  - Non-partnered parents were not significantly different from partnered parents in terms of Parent Well-Being (p= 0.106)

Family Distress

- Family Distress was greater with:
  - Greater family strains
  - More incendiary communication

- Families from Ireland (p=0.134), UK (p= 0.372), and Portugal (p = 0.792) were not significantly different from US families

- Fathers were not significantly differently from Mothers in terms of Family Functioning (p =0.357)
Family Distress Continued

- Families with non-partnered parents were significantly worse than families with partnered parents in terms of Family Distress ($p<0.001$)
- Family distress did not change significantly with child’s age ($p=0.214$)

Summary: Family Functioning

- FF was worse with:
  - Greater Family Strains
  - More Incendiary Communication
  - Less Affirmative Communication
  - Lower Condition Management Ability
  - Lower Hardiness

Summary: Parent Well-Being

- Parent Well Being was worse with:
  - Greater Condition Management Effort
  - Greater Family Strains and Stressors
  - More Incendiary Communication
  - Lower Condition Management Ability
  - Lower Hardiness

- Parent Well-Being did not vary significantly by
  - Country
  - Gender
  - Partner status
  - Age of Individual with DS

Summary – Family Distress

- Family Distress was worse with:
  - Greater family strains
  - More incendiary communication

- Family Distress was worse in Families with Non-partnered parents

Findings from this study contribute to our understanding of the underlying processes associated with differing outcomes in families of individuals with Down syndrome.

Efforts to intervene will be more effective if health care providers recognize how culture & family factors interact and shape how families respond.
Special Thanks

- Families who shared their stories with us
- Wonderful colleagues and students who have worked on this project
- Questions - contact me at vanriper@email.unc.edu