

Identifying Family Stress, Coping Strategies and Strengths: Using the Impact on Family Scale (IFS) with Parents of Children with Spina Bifida

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Background on the IFS

- Developed in 1985 by Ruth Stein (pediatrician) and Dorothy Jessop (social worker) in New York
- Adequate reliability, good content and construct validity - responsiveness unknown
- Used with parents of various groups of children, e.g., asthma, ventilator-dependent children, low-birthweight children, acquired brain injury, cancer, behaviour difficulties, children in special education

Structure of the IFS

- Contains 33 items
- Parent report: completed independently by parents with social worker sitting nearby, and some took it away and returned it
- 10 to 20 minutes to complete
- 5 impact subscales: Financial (5 items), Familial/social (9), Personal (8), Mastery (5), and Sibling (6)

Sample items from the IFS

STRESSES

- **Financial (F)**: Additional income is needed in order to cover my child's medical expenses
- **Financial (F)**: Time is lost from work because of hospital appointments for my child.

Sample items from the IFS

- **Familial/social (F/S)**: Sometimes I wonder whether my child should be treated “specially” or the same as an able-bodied child.
- **Familial/Social (F/S)**: People in the neighbourhood treat us differently because of my child’s condition

Sample items from the IFS

- **Personal Strain (PS)**: I worry about what will happen to my child in the future (when he/she grows up, when I am not around).
- **Personal Strain (PS)**: I live from day to day and don’t plan for the future.
- **Sibling impact (S)**: It is hard to give much attention to the other children because of the needs of my child.

Sample items from the IFS

STRENGTHS:

- **Mastery (M):** Learning to manage my child's condition has made me feel better about myself
- **Mastery (M):** Because of what we have shared we are a closer family

Scoring of the IFS

- Parents use a 4-point Likert scale: Strongly Agree, Agree, Disagree, Strongly Disagree
- Respondent must commit to one score for each item!
- Higher scores reflect more of an issue, e.g., greater financial stress, greater personal stress, less mastery

The Respondents

- 66 parents of children with Spina Bifida
- Parents completed IFS once from April 2000 ...
- Children's mean age = 10.1 years
 - Ages 6m to 6 yrs: 20
 - 7 to 12 yrs: 37
 - 12 to 18 yrs: 23

The Children's Lesion Levels

- T10 - L2 MMC: **21**
- L3 - L4 MMC: **24**
- L5 - S2 MMC: **17**
- MC, SB Occulta, dermal cysts: **6**
- LipoMMC: **11**
- Sacral agenesis, caudal regression **1**
- SCI, tumour: **1**

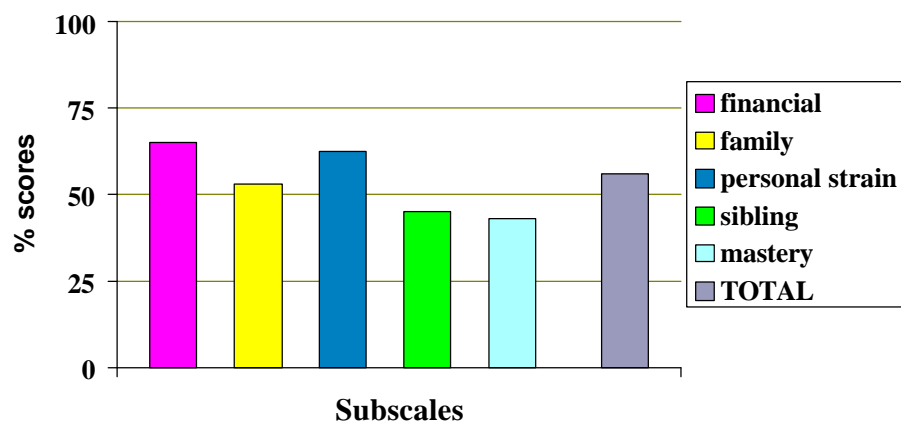
Summary Score Results

- Summary scores can be calculated for the 5 Subscales and the Total Score (vary from 25% to 100%)
- Median scores $\geq 50\%$ would indicate agreement on average with the stress statements and therefore greater issues

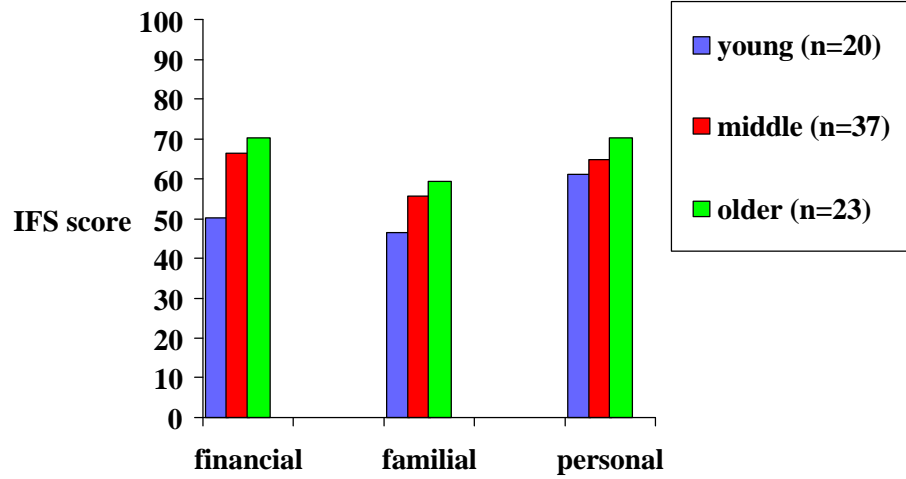
Impact on Family Scale Results

Median scores (n=66): **Higher scores indicate more negative impact or issues.**

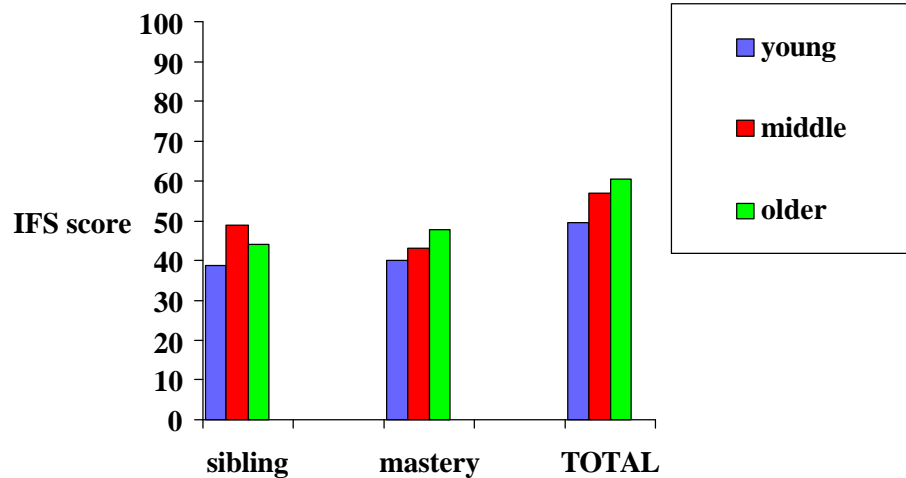
Scores ≥ 50 = Agree.



Age Group Differences on the IFS



Age Group Differences on the IFS



Individual IFS Item Scores

- Interested in items on which parents “agree” or “strongly agree” - identifies stress or issues in this client group
- Identification of items on which parents “strongly disagree” - not an issue for this client group!
- Median scores used since not an interval scale (Median = middle value of all scores reported)

Common stress across Families

“I Agree” (Median score =3)

3 of 5 Financial Items

- Child’s condition causing financial problems
- Time is lost from work for appointments
- Additional income is needed to cover child’s medical expenses

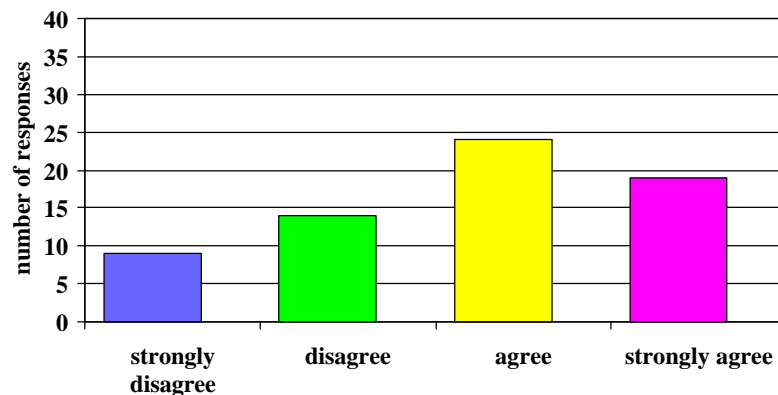
Common stress across Families

**"I Agree" (Median score =3)
3 of 8 Personal Strain Items**

- It is hard to find a reliable person to care of my child
- Fatigue is a problem for me because of my child's condition
- Sometimes I feel like we live on a roller coaster: in crisis when my child is ill, OK when things are stable

Scores for:

"It is hard to find a reliable person to take care of my child"

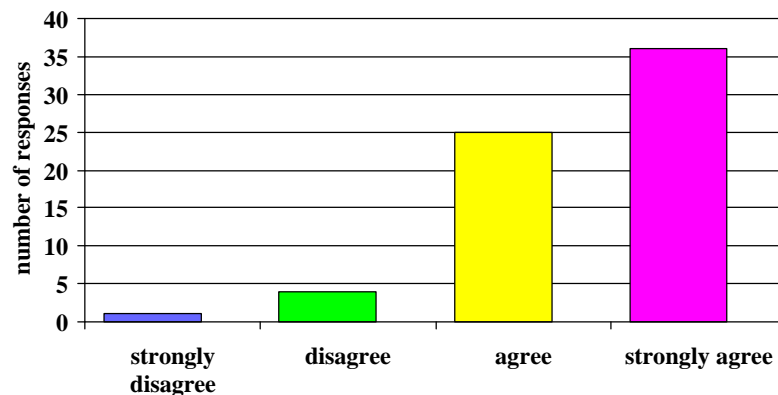


Common Stress Across Families “I Strongly Agree” (Median score = 4)

1 Additional Personal Strain Item

- I worry what will happen to my child in the future (when he/she grows up, when I am not around)

Scores for: “I worry what will happen to my child in the future”



Common Stress Across Families

"I Agree" (Median score = 3)

2 of 9 Familial/Social Impact Items

- Sometimes we change plans at the last minute because of my child's condition
- Sometimes I wonder if child should be treated specially or same as able-bodied child

Mastery Items

"I Agree" (Median score = 3)

- Learning to manage my child's condition has made me feel better about myself
- My relatives have been helpful and understanding of my child's condition

**Common Strengths Across Families - 3 of 5 Mastery Items:
"I Strongly Agree" (Median score = 4)**

- Because of what we have shared we are a closer family
- We try to treat my child as if he/she were able-bodied
- My partner and I discuss my child's problems together

**No Stress Identified
"I Strongly Disagree"
(The only items with Median score = 1) (n=46)**

3 Sibling Impact Items

- My other children seem to have more disabilities, aches and pains than most children their age
- My other children are frightened by my child's condition
- The school grades of my other children suffer because of my child's condition

Strengths of the IFS

- Normalizes issues/concerns
- Encourages discussion within the family
- Opens negotiations towards setting goals
- Points out what is helpful
- Identifies areas to be put on the “back burner”
- Parent report

Limitations of the IFS

- Verbal and written English needed-though could be read to parent
- Usually only one parent responds
- Not always contemporary language (from 1985), e.g., some items are victim-focused, use of spouse rather than partner
- Western values of independence and emancipation(items ‘e’, ‘t’)
- Professional assessment still required

Parents' Thoughts About the IFS

- “Often as a parent we do not take the time to reflect on areas of difficulty we are having. This questionnaire provides some thinking material that would be good to discuss with my spouse from time to time.”

Parents' Thoughts About the IFS

- “Time is also lost from other activities including volunteering or time spent with other children or from hobbies, education, not just work.”

Parents' Thoughts About the IFS ...

- “This questionnaire is written for parents and or guardians. We are legal guardians as well as his grandparents. We're learning that there are many people in the same situation as we are.”

Clinical Implications

- How can we use this information?
- Develop and reinforce areas of STRENGTH è
- Address STRESS →

Develop and Reinforce Strengths

- Talk/share with partner and relatives
- Provide opportunities for partners and relatives to learn more
- Encourage family events/socializing
- Focus on normal activities, peer groups, sports, skill training

Address Stress

- Acknowledge/normalize areas of stress
- Provide information, resources (\$, respite, family connections)
- Deal with personal fatigue and care
- Revisit back burner issues
- Talk about the future

Further Work with the IFS

- Have started work doing a follow-up IFS - rating against an external standard of change as judged by parents
- Does the IFS identifies different stresses, strengths and coping abilities in other pediatric client groups?
- Use in other programs at Bloorview MacMillan
- Development of contemporary language version
- Collaborative use across OACRS Centres?

Summary / Conclusions

- Appropriate measure with parents of children with Spina Bifida
- Parents enjoy participating/learning about themselves
- Common issues and strengths identified in this group of parents
- Judged clinically useful from both parents' and social worker's perspectives

