Background

- IBD affects basic daily family routines
- Supportive family environment predicts
  - Psychological adjustment
  - Treatment adherence
- IBD “Family” research = Parent, Child, and IBD
- What about Siblings?
  - Siblings are fundamental to family life
  - Sibling roles in IBD care has been ignored

Objective: to examine

- Healthy sibling support in IBD care and its relation to
  - IBD Quality of Life
  - IBD Medication adherence

Method

Participants

- 16 children and adolescents diagnosed with IBD > one yr
  - 69% Crohn’s
  - 31% UC
  - 75% had not experienced flare-up in over a year
  - One randomly selected healthy sibling referenced

<table>
<thead>
<tr>
<th>IBD Child</th>
<th>Healthy Sib</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>11-18 yrs (M=14 yrs)</td>
</tr>
<tr>
<td>Sex</td>
<td>50% Male</td>
</tr>
<tr>
<td>Birth Order</td>
<td>50% IBD Child Older than Sib</td>
</tr>
<tr>
<td>Race</td>
<td>87.5% White</td>
</tr>
</tbody>
</table>

Procedures

- IRB approved / Assent and consent obtained
- Recruitment through Pediatric GI Clinic
- Interviews scheduled at IBD follow-up appointment
- Patients & parents interviewed separately & jointly

Measures

Demographics: Parents reported household members’ age, sex, medical hx, ethnicity/race, and SES.

IBD Sibling Support: This 23 item (α = .90) questionnaire assesses sibling IBD support behaviors including medication use, hospitalization, bathroom use, and emotional support. The child with IBD rated a 5-point Likert scale re the frequency and helpfulness of each sib support behavior.

Quality of Life: IBD patients completed the IMPACT II (Loonen et al., 2002), comprised of 35 questions in 6 domains of IBD impact: IBD sx, systemic sx, emotional function, social function, body image, and treatment. Domain-specific scale scores and a Total QoL score were computed.

IBD Medication Adherence: Parents and children jointly rated how often the child missed doses of their IBD meds and their level of difficulty with treatment management on a 5-point Likert scale. Mean IBD Medical Adherence score was computed by averaging ratings of missed doses of 3 types of oral meds (anti-inflammatories, antimetabolites, and immunosuppressants).

Results

Demographic variables

One-way ANOVA revealed no effects of IBD child & sib sex, age, birth order on Sib Support, Quality of Life, or IBD Med Adherence

Sib support

- Sibs “sometimes” participate in IBD care (M=2.59, SD=.66)
- Sib IBD care is perceived as supportive (M=3.06, SD=.59)

Most Common IBD Sib Support Behaviors

<table>
<thead>
<tr>
<th>Behavior</th>
<th>M (1-5)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit or call in hospital</td>
<td>3.67</td>
<td>1.44</td>
</tr>
<tr>
<td>Show discretion re IBD</td>
<td>3.44</td>
<td>1.96</td>
</tr>
<tr>
<td>Help out at home during hospital</td>
<td>3.28</td>
<td>1.42</td>
</tr>
<tr>
<td>Give extra time in bathroom</td>
<td>3.13</td>
<td>1.46</td>
</tr>
</tbody>
</table>

Frequency of Sib Support X Quality of Life

<table>
<thead>
<tr>
<th>IMPACT-II Scale</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Quality of Life</td>
<td>.55</td>
<td>.03</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>.50</td>
<td>.05</td>
</tr>
<tr>
<td>Body Image</td>
<td>.56</td>
<td>.03</td>
</tr>
<tr>
<td>IBD treatment concerns</td>
<td>.52</td>
<td>.04</td>
</tr>
</tbody>
</table>

Quality of Sib Support X Med Adherence

IBD patients who reported a positive attitude toward sibling support reported fewer difficulties with treatment management (r = -.605, p = .01); however sibling support was not related to ratings of how often IBD medication doses were missed.

Summary and Conclusions

Summary

- Siblings participate in IBD care
- Sibs involved most with active IBD
- Sibling care is perceived as helpful & supportive
- Sibling IBD support may be associated with
  - Better Quality of Life
  - Less difficulty with medication adherence

Study Limitations

- Small sample size
- Self-report measure of adherence

Implications

- Siblings are rarely included in IBD educational & family support services, despite role in IBD care
- Attend to siblings in family-based IBD care