No Stone Unturned: How do families make treatment decisions?

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Factors Affecting Treatment Choices by Caregivers of Children with Autism

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Rational Action Theory

- Rational action theory
  - Individuals are rational actors (i.e., act in a manner that maximizes self-interest)

- All things being equal, caregivers of children with ASD will select treatments that are:
  - Empirically supported
  - Produce immediate effects
  - Are affordable
  - Are highly available

Participants

- Convenience sample
- 11 Caregivers of children with ASD diagnoses
  - Maintain custody at least 50% of the time for at least 1 year
  - Had an ASD diagnosis for at least 1 year
### Treatments

- Updated the list of treatments used in Green et al. (2006)
  - 206 treatments identified:

- Caregivers responded on a 5 point Likert-type scale
  - How knowledgeable they were about each treatment
  - How effective each treatment is
  - How much risk is involved in using each treatment
Part 1: Current Use of Treatments

- Participants were asked if they used each treatment
- Once all currently used treatments had been identified, they were asked to allocate tokens that represented the resources they expend on treatment

Participant 4

n=12
Part 2: Unconstrained Choice of Treatments

- Which treatments would they use if not constrained by cost/availability?

- Participants were asked if they would use each treatment if resources/availability were no object
Participant 4: Allocation of Current Resources

- Treatment
- n=12

Participant 4: Allocation of Unconstrained Resources

- Treatment
- n=58
Overall

- Average number of treatments with current resources: 9.7 (range: 1-21)
- Average number of treatments with unconstrained resources: 48.6 (range: 13-77)

Allocation of Resources: Informed

<table>
<thead>
<tr>
<th>Current</th>
<th>Unconstrained</th>
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<tbody>
<tr>
<td>Expert</td>
<td>34</td>
</tr>
<tr>
<td>I know many things</td>
<td>32</td>
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<tr>
<td>I know a few things</td>
<td>23</td>
</tr>
<tr>
<td>Have heard of, but don't have details</td>
<td>18</td>
</tr>
<tr>
<td>Never heard of treatment</td>
<td>11</td>
</tr>
<tr>
<td>Never heard of treatment</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
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1/2/2013
Allocation of Resources: Effective

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<td>31</td>
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<td>7</td>
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<td>4</td>
<td>8</td>
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- Extremely Effective
- Very Effective
- Moderately Effective
- Slightly Effective
- Not Effective

Part 3: Empirical Support vs. Immediacy

- How do empirical support and immediacy interact?
- Eleven note cards (treatments)
- Each representing a hypothetical treatment
- Degree of empirical support
  - Range from 0% - 100% of the criteria used by the scientific community to prove effectiveness
- Immediacy
  - Range from 1 week - 5 years to achieve the caregiver's treatment goals
Participant 4

Overall
Future Directions

- More participants from a broader recruitment pool
- Classification and Regression Trees (CART)
  - Create decision making model

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