Promoting Resilience in Parents of Children with Serious Illness: a pilot intervention study

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Disclosures

• No financial or other disclosures
Caregiver Concerns in Pediatric Illness

- Nurture, Protect, Advocate
- Logistical and Physical care
- Financial Responsibilities
- Sibling Care
- Spousal Care
- Self Care

Serious Pediatric Illness changes all of these
Parent Stress and Distress

• Parent well-being → Child (& family) well-being

• Disease-specific examples:
  – Diabetes: ~25% PTSD
  – Cancer: >40% “high” psychological distress

• Implication for interventions?

Robinson J Ped Psych 2007; Landolt J Ped Psych 2002; Rosenberg JAMA Peds 2014
A Novel Approach: Promoting Resilience?

Resilience = an individual’s capacity to maintain psychological and physical well-being in the face of stress

• Candidate to buffer impact of serious illness?
“Resilience is a process to harness resources to sustain well-being”

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<tr>
<th>External</th>
<th>Internal</th>
<th>Existential</th>
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<td>• Social Support</td>
<td>• Inherent Traits</td>
<td>• Meaning-making</td>
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<td>• Community</td>
<td>• Learned Skills</td>
<td>• Faith</td>
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Southwick., Eur J Psychotraumatology, 2014
Designing an Intervention: evidence-based “modifiable” resilience resources

**Internal**
- Learned Skills
- Stress management
- Problem solving
- Goal-setting
- Mindfulness

**Existential**
- Meaning-making
- Benefit-Finding

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<th>Part 1: Managing Stress</th>
<th>Managing Stress</th>
<th>Mindfulness, stress-management techniques</th>
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<td>Setting Goals</td>
<td>Setting realistic, concrete goals, dealing with pitfalls</td>
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<td>Part 2: Building Resilience</td>
<td>Positive Reframing</td>
<td>Recognizing negative self-talk, identifying positives</td>
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<td>Making Meaning</td>
<td>Identifying benefit/meaning from current experience</td>
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PRISM studies among teens/young adults

• Pilot: n=24 with diabetes or cancer
  • Feasible & Acceptable

• “Phase II” efficacy RCT: n=100 with cancer
  • Preliminary results: ↑resilience, ↑quality of life

• “My mom needs this too.”
• “Do you have a version for parents?”

Rosenberg and Yi-Frazier, J Pediatric Psych 2015
Pilot Study of Adapted PRISM for Parents ("PRISM-P")

• **Objectives:**
  – Feasibility (80% completion)
  – Acceptability (qualitative feedback)

• **Participants:**
  – English speaking parents of teens with Type 1 Diabetes or Cancer

• **Format:** Iterative (based on teen pilot)
Results – Feasibility

Type 1 Diabetes
• 12/24 (50%) enrolled
• Mean age 48.1 (SD 5.6)
• 83% mothers
• 9/12 (75%) completed
• All opted for 2 long sessions

Cancer
• 13/15 (87%) enrolled
• Mean age 48.4 (SD 7.0)
• 85% mothers
• 9/13 (69%) completed
• All opted for 4 shorter sessions
Results – Acceptability

Successes:

• “Using those techniques helped me gain my ground back again...that was life-changing for me...”

• “This should be part of every parent’s toolbox...it helps us take better care of our kids.”

• “Not having it be cancer-specific, but having it be skills to take home, was helpful to me.”
Results – Acceptability

**Pitfalls:** High attrition/delays ("Too hard to get away")

“I’m realizing as I sit here talking about this with you that this it is the first time I’ve taken any time to myself since [patient name’s] diagnosis. So much of my day is all about taking him to and from his appointments or keeping up my professional commitments whenever I get a free moment. It’s got to have been over 2 years since I last recall just sitting in silence with my thoughts. ... This is so valuable to me, you have no idea. I really must try to find the time for this more often”
Limitations

• Too much heterogeneity:
  – Disease experiences
  – Iterative design

• Not enough heterogeneity:
  – Small sample sizes
  – Mostly moms
  – No family-level variables
Lessons Learned

• PRISM-P was well-accepted and impactful among parents who completed it.
• Attrition higher than anticipated.

• Future directions:
  – Other formats to allow participation
  – Efficacy studies
  – Family-level interventions
Acknowledgements

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