

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

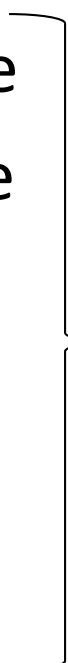
Joyce Yi-Frazier, Katy Fladeboe, Victoria Klein,
Lauren Eaton, Claire Wharton, Elizabeth McCauley,
Abby R. Rosenberg

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?**

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”

External

- Social Support
- Community

Internal

- Inherent Traits
- Learned Skills

Existential

- Meaning-making
- Faith

Designing an Intervention: evidence-based “modifiable” resilience resources

Internal

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

Existential

- Meaning-making
- Benefit-Finding



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

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?”***

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

Thank you to the inspiring and resilient parents who participated in this project.

Thank you to our funders:

- NIH/NCATS KL2TR000421
- SCH Center for Clinical & Translational Research (CCTR) CRSP award
- CureSearch for Children's Cancer Foundation