Promoting Resilience Among Patients and Families Facing Pediatric and Young Adult Cancer

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Career Goals

To develop clinical & translational research programs to promote positive psychosocial outcomes among adolescent and young adult (AYA) cancer patients and their families.
Why?

“…Cancer care today provides state-of-the-science biomedical treatment, but fails to address the psychological and social (psychosocial) problems associated with the illness. These problems, including patients’ lack of skills to manage the illness, emotional problems, disruptions in work, school, and family life, can cause additional suffering and threaten patients’ return to health.”
Why Adolescents and Young Adults (AYAs)?

- **Patients 15-39**
- Lack of improvement in survival
- Inferior psychosocial outcomes
- Reasons?
  - Biology
  - Enrollment in clinical trials
  - Limited access to care
  - Distinct developmental and psychosocial needs

*SEER AYA monograph, 2006*
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?
A challenge in psychosocial research

- Clinically recognized
- Poorly operationalized
- Resilience:
  - Divergent theories?
  - Surrogate markers?

Bonnano, J Traumatic Stress, 2004
Step 1: Studies with parents

- **Rationale:**
  - 1 in 7 have serious (debilitating) distress
  - Parent psychosocial well-being $\rightarrow$ patient (family) well-being
  - Understanding (and defining) parent resilience may help

Rosenberg AR, JAMA Pediatrics 2013
Understanding Resilience in Parents of Children with Cancer Study

- Retrospective, mixed-methods study
- Qualitative Interviews (n=18 bereaved parents/families)
- Survey (n=96 non-bereaved and n=24 bereaved parents)
- Objectives:
  1) Define parent-perceptions of resilience
  2) Describe relationship between resilience and “standard” outcomes
Results

• Resilience is self-defined
  • Related to personal resources, learned coping and perspectives

• Low self-perceived resilience associated with:
  • High psychological distress (OR 3.7, 95% CI 1.2, 11.7)
  • Poor overall HR-QOL (OR 6.8, 95% CI 2.5, 18.7)
  • Frequent sleep difficulties (OR 5.0, 95% CI 1.7, 15.4)
  • ?Drinking and driving? (OR 7.8, 95% CI 0.8, 80)
  • Inability to express hopes (OR 3.0, 95% CI 1.1, 8.4)
  • Inability to express worries (OR 4.1, 95% CI 1.4, 11.8)

Rosenberg AR, J Pall Med 2013
Rosenberg AR, Pediatric Blood Cancer 2014
Step 2: Define AYA Patient Perceptions

- Prospective, longitudinal, multi-site, mixed-methods cohort
- AYAs (ages 14-25 years) with new diagnosis of cancer & their parents
- Serial 1:1 interviews (n=17)
- Serial surveys (n=50)
- Objectives:
  1) Define (changing?) AYA perspectives of resilience over time
  2) Describe trajectories of coping, distress, resilience
  3) Inform intervention development
## Inhibiting Factors
- Overwhelming stress, worries, fear
- Not knowing what to expect
- Stuck in the negative
- Negative emotions (anger, sadness, shame)
- Isolation, being “different”

## Contributing Factors
- Managing stress, coping strategies
- Having goals, sense of Purpose
- Staying positive
- Benefit-finding, meaning-making
- Connection, social support, being “normal”

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**Resilience**

**Non-Resilience**

*Rosenberg AR et al., manuscript under review*
Step 3: Intervention Development

The Promoting Resilience In Stress Management (PRISM) intervention

• Development:
  • Background studies at SCH – cancer & diabetes
  • Literature
  • Expert opinions

• Format: Disease non-specific, skills-based, brief, patient-focused, parent-inclusive, cost-effective

• Goal: increase resilience, reduce distress → improve outcomes
# PRISM Details

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Step 4: PRISM pilot feasibility/acceptability study

- **Type 1 Diabetes patients:**
  - 15/26 (58%) enrolled
  - Mean age 15 yrs (13-17)
  - 1 drop-out
  - 12/14 (86%) completed

- **Cancer patients:**
  - 15/22 (68%) enrolled
  - Mean age 17 yrs (12-20)
  - 3 drop-outs
  - 10/12 (83%) completed, last two patients on-going

- 3 Interventionists trained/successful

- Qualitative feedback highly positive:
  - “This is so helpful, I wish we had done this sooner.”
  - “Yeah, I was actually telling [my friends] about it afterward and they said would try it out.”
  - “I think it’s good techniques to use, definitely. I am teaching my little sister. I am sure it can help her too.”
PRISM “pilot” – Lessons learned

• **Type 1 Diabetes patients:**
  • Prefer longer, fewer sessions; distance-based (phone)

• **Cancer patients:**
  • Prefer shorter, more frequent sessions; in person (in-pt)

• **Both:**
  • Parents should have separate intervention

• **Refinements built into protocol to modify based on differences in diagnostic groups**
Step 5: Future Directions and Impact - Research

- PRISM studies (RCT, PRISM-parent, other disciplines)
  - Funding: KL2 (NIH/NCATS)
- Invitations to collaborate:
  - AYA Risky Health Behaviors R01 (PI: Fainsilber-Katz)
  - AYA Stress and Bio-behavioral Outcomes R01 (PI: McLaughlin)
  - AYA Survivorship Cohort R01 (PI: Baker)
  - Parent Coping and Adjustment R01 (PI: Doorenbois)
  - End-of-life communication PCORI (PI: Mack)
  - Pediatric Palliative Care Network, Children’s Oncology Group, AYA communities
Step 5: Future Directions and Impact - Clinical

• Clinical Program:
  • First stand-alone AYA unit in the USA
  • Research opportunities available to all patients
  • Standard psychosocial care and assessments

• National Leadership:
  • Psychosocial Standards of Care Guidelines
  • Children’s Oncology Group
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