The Resilience in Illness Model: Dialogue on Across-Illness Conditions and Difficult/Traumatic Life Circumstances

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Science of Clinical Care Department, School of Nursing, Indiana University, Indianapolis, IN, USA
Greetings from Indiana University School of Nursing
During our time together...

• Describe the Positive Health Perspective
• Discuss the Resilience in Illness Model (RIM)
  – RIM development for adolescents/young adults with chronic illness
  – What hinders and fosters resilience: Protective, risk and outcome factors
  – Interventions and potential
  – RIM as organizing framework for nursing research and practice
• Dialogue among session attendees regarding
  – Positive health concepts in research and clinical practice
  – how the RIM may be useful and/or adapted for research on other illness conditions and/or traumatic life situations.
What is Positive Health?

• Efforts to gain understanding of ways individuals sustain or regain optimal health.
  – Salutogenic: Presence of wellness as well as absence of disease
  – Emphasis on primary prevention and positive health promotion
  – Consider strengths to address problems
  – Holistic Perspective

Two Models of Care

• Common Goals

BUT

• Different approaches and emphases
Function-based Model

• Problem Focused
• Pathology and deficits perspective
  – Risk
  – Morbidity
  – Adjustment problems
  – Developmental Delays
• Additive Approach
Meaning and Values-based Model

• The importance of meaning
  – Patterns and experiences of illness
  – Subjective and holistic
  – Meanings based on patient's understanding of situation, autonomy, beliefs, choices, and relationships.
  – Function viewed within meaning-based models


Research-based “Doing Well” Concepts

• Resilience
• Quality of Life
• Courage
• Courageous Coping
• Connectedness
• Spiritual Perspective
• Derived Meaning
• Hope
Development of the Haase Resilience in Illness Model

- Mixed Methods Approaches
  - Model Generation
  - Model Evaluation
  - Intervention Evaluating

- Focused on Adolescents/Young Adults with Chronic illness

Definition: Resilience as Process

• Ways individuals
  – identify, develop and use protective resources
    • (e.g., spiritual perspective, social integration, family environment, courageous coping, and hope-derived meaning)
  – to flexibly deal with illness-related stressors
    • (e.g. symptom distress, uncertainty in illness and defensive coping)

• in order to achieve positive health outcomes.
Definition: Resilience as Outcome

- Resilience resolution and self-transcendence

Characterized by:

- Mastery, accomplishment and competency;
- Motivation;
- Acknowledgement and acceptance;
- Ability to rise above the illness;
- Desire to reach out and help others.
Haase Resilience in Illness Model (RIM)

Illness-related Distress (Risk) → Defensive Coping (Risk)
  0.48***
  0.54***
  0.30**

Defensive Coping (Risk) → Family Environment (Protective)
  0.62***

Family Environment (Protective) → Courageous Coping (Protective)
  0.10ns

Courageous Coping (Protective) → Self-Transcendence
  0.26***
  0.24***

Courageous Coping (Protective) → Resilience Resolution
  0.71***

Social Integration (Protective) → Family Environment (Protective)
  0.26**

Social Integration (Protective) → Hope-derived Meaning (Protective)
  0.36***

Hope-derived Meaning (Protective) → Resilience Resolution
  0.21**

Spiritual Perspective (Protective) → Hope-derived Meaning (Protective)
  0.43***

Spiritual Perspective (Protective) → Family Environment (Protective)
  0.40***

R² Values:
- Illness-related Distress (Risk): 0.18
- Defensive Coping (Risk): 0.23
- Family Environment (Protective): 0.27
- Courageous Coping (Protective): 0.76

Chi Square (151) = 234.51, p < .000

Fit Indices:
- Bentler-Bonnett Non-Normed: .95
- Comparative Fit Index: .96
- Bollen Fit Index: .96
- LISREL GFI Fit Index: .90
- Root Mean-Square Error of Approximation (RMSEA): < .05
# Resilience in Illness Model

## Latent Factors and Manifest Variables

<table>
<thead>
<tr>
<th>Latent Factors</th>
<th>Manifest Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong> Illness-related distress</td>
<td>Uncertainty in illness</td>
</tr>
<tr>
<td></td>
<td>Symptom-related distress</td>
</tr>
<tr>
<td><strong>2</strong> Defensive coping</td>
<td>Evasive</td>
</tr>
<tr>
<td></td>
<td>Emotive</td>
</tr>
<tr>
<td></td>
<td>Fatalistic</td>
</tr>
<tr>
<td><strong>3</strong> Positive coping</td>
<td>Confrontive</td>
</tr>
<tr>
<td></td>
<td>Optimistic</td>
</tr>
<tr>
<td></td>
<td>Supportant</td>
</tr>
<tr>
<td><strong>4</strong> Family support</td>
<td>Family adaptability/cohesion</td>
</tr>
<tr>
<td></td>
<td>Family communication</td>
</tr>
<tr>
<td><strong>5</strong> Social Integration</td>
<td>Perceived social support from family</td>
</tr>
<tr>
<td></td>
<td>Perceived social support from healthcare providers</td>
</tr>
<tr>
<td><strong>6</strong> Hope-Derived meaning</td>
<td>Expectancy, Interconnectedness, Positive Readiness</td>
</tr>
<tr>
<td><strong>7</strong> Spiritual Perspective</td>
<td>Spiritual Beliefs</td>
</tr>
<tr>
<td></td>
<td>Frequency of Spiritual Practices</td>
</tr>
<tr>
<td><strong>8</strong> Self-Transcendence</td>
<td>Self-Transcendence</td>
</tr>
<tr>
<td><strong>9</strong> Resilience</td>
<td>Resilience in Illness</td>
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<tr>
<td></td>
<td>Confidence</td>
</tr>
<tr>
<td></td>
<td>Sense of Well-being</td>
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<tr>
<td>Latent Variables</td>
<td>Manifest Variables</td>
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<td>---------------------</td>
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<tr>
<td><strong>Illness-related distress</strong></td>
<td>• Symptom distress</td>
</tr>
<tr>
<td></td>
<td>• Uncertainty in illness</td>
</tr>
<tr>
<td><strong>Coping-defensive</strong></td>
<td>• Emotive/evasive coping</td>
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<td><strong>Spiritual Perspective</strong></td>
<td>• Spirituality-frequency</td>
</tr>
<tr>
<td></td>
<td>• Spirituality-beliefs</td>
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<tr>
<td><strong>Social integration</strong></td>
<td>Perceived Social Support: Healthcare provider</td>
</tr>
<tr>
<td></td>
<td>• Friends</td>
</tr>
<tr>
<td></td>
<td>• Family</td>
</tr>
<tr>
<td><strong>Family Environment</strong></td>
<td>• Family Cohesion</td>
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<tr>
<td></td>
<td>• Family Adaptability</td>
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<td>• Family Communication-Open</td>
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<td>• Family Communication-Problem</td>
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<td>• Family Strengths</td>
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<tr>
<td><strong>Courageous Coping</strong></td>
<td>• Confrontive Coping</td>
</tr>
<tr>
<td></td>
<td>• Optimistic Coping</td>
</tr>
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<td></td>
<td>• Supportant Coping</td>
</tr>
<tr>
<td><strong>Hope-derived</strong></td>
<td>• Expectancy/Interconnectedness</td>
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<tr>
<td>Latent Variables</td>
<td>Manifest Variables</td>
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</tr>
<tr>
<td><strong>Self-Transcendence</strong></td>
<td>• Self-transcendence</td>
</tr>
<tr>
<td><strong>Resilience in Illness</strong></td>
<td>• Resilience in Illness</td>
</tr>
</tbody>
</table>
Resilience in Illness Measurement Model

Chi Square (142) = 233.09, p < .000
Bentler-Bonett Non-Normed = .94
Comparative Fit Index = .95
Bollen Fit Index = .96
LISREL GFI Fit Index = .90

Root Mean-Square Error Of Approximation (RMSEA) = .05
90% Confidence Interval = .04, .07
A Closer Look at Risk and Protective Factors

Clinical and Research Implications and Potential Mechanisms of Interventions
Illness-related Distress (Risk)

• The degree of perceived illness-related uncertainty and disease and symptom-related distress

• Focus:
  – Uncertainty in Illness
    • Ambiguity
    • Complexity
  – Symptom Distress
Defensive Coping (Risk)

• The degree to which the patient/family member uses evasive and emotive coping strategies to deal with the cancer experience.

• Use/ Effectiveness of strategies:
  – Evasive/avoidant
  – Emotive
  – Fatalistic
Derived Meaning (Protective)

• The degree to which the patient/family member uses spiritual perspective and hope to derive meaning from the cancer experience.

• Spiritual Perspectives
  – Beliefs
  – Practices

• Hope-Derived Meaning
Spiritual Perspective

• “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”

Spiritual Distress

- Existential
- Abandonment
- Anger
- Concerns about relationship with deity
- Conflicted or challenged belief systems
- Despair / Hopelessness
- Grief/loss
- Reconciliation
- Isolation
- Religious / Spiritual Struggle
Spiritual Care

• Compassionate presence
• Reflective listening/query about important life events
• Support patient sources of spiritual strength
• Open ended questions
• Inquiry about spiritual beliefs, values and practices
• Life review, listening to the patient’s story
• Targeted spiritual intervention
• Continued presence and follow up
• Guided visualization for “meaningless pain”
• Progressive relaxation
• Meaning-oriented-therapy
• Referral to spiritual care provider as indicated
• Dignity-conserving therapy
Forming a Team to care for your child

- Best possible Treatment
- Best possible quality of life

Hope-Derived Meaning

H O P E
Experiences of other families

Goals of Care
- Cure
- Prolong life
- Comfort

Relative emphasis on QoL/Suffering
- Symptom Experience
  - High
  - Moderate
  - Minimal

Attitude about the cancer
- Win
- Live with it

Expected tumor treatment results
- Eliminate
- Keep from growing
- Prepare
- No response

Expected tumor treatment results
- HOPE

Symptom Experience
- High
- Moderate
- Minimal

Attitude about the cancer
- Win
- Live with it

Goals of Care
- Cure
- Prolong life
- Comfort

Relative emphasis on QoL/Suffering
- Symptom Experience
  - High
  - Moderate
  - Minimal
Social Integration (Protective)

• Degree to which
  – patient/family perceive a sense of connectedness with and support from friends and health care providers in the midst of having cancer.

• Perceived Social Support
  – Friends
  – Healthcare Providers

• Example: Profile Based Intervention

Family Environment (Protective)

- The degree to which the patient/family member perceives the family as adaptable, cohesive, effectively communicating, and having family strengths.
- Family
  - Adaptability
  - Cohesion
  - Communication
  - Perceived Strengths
- Example: Adolescent/Young Adult Profile
Courageous Coping (Protective)

The degree to which the AYA uses and finds effective:
• confrontive
• optimistic
• supportant coping strategies to deal with the illness experience
Resilience and Self-Transcendence

“Chemo Kid Rock” by Heather (age 12)

Verse 3

Somebody once asked, “How can you do this task?”
I said, “You just have to do it yourself…”
I have to be strong, I have to be tough
And I’ll know when I’ve had enough
And we could all use some kind of CURE…
Children’s Oncology Group Nursing Discipline Committee
Organizing Framework
Resilience in Individuals and Families Affected by Cancer

COG Nursing Discipline Guiding Values

– Child and adolescent/young adult (AYA) at the core
– Directly solicit child’s perspective
– Cancer a family experience
– Social/ecological features important
– Positive health approaches
– Strengths-based perspective -- focus on meaning of the cancer experience
– Importance of the child’s symptom experience
– Distal outcome of care = sense of wellbeing in context of illness
– Goal: help children and their families transcend the illness
Two Randomized Control Trials
In AYA with Cancer

- National Institute of Nursing Research R01 NR008583 (Haase, PI; Robb, Co-PI)
- Children’s Oncology Group ANUR0631 National Cancer Institute U10 CA098543 & U10 CA095861 (Co-chairs: Haase & Robb)

- Children’s Oncology Group ANUR0631 National Cancer Institute U10 CA098543 & U10 CA095861 (Co-chairs: Haase & Robb)
Robb’s Contextual Support Model of Music Therapy

Motivational Theory of Coping (Skinner & Wellborn, 1994)

• Coping as a function of behavior regulation
• Fundamental Psychological Needs
  – Competence
  – Autonomy
  – Relationships
• Drives influence and direct human behavior
• Attributes of environment & self interact
  – Influences the appraisal process
  – Influences resulting action

SMART I Study Design

- Phase II randomized control trial
- Two groups:
  - TMV (experimental)
  - Audiobooks (low dose control)
  - Stratified by site and age (11-13, 14-17, 18-24)
- Six intervention sessions delivered by board certified music therapist over 3 weeks
- Outcomes measured at baseline, post-intervention, and 100 days post-transplant
- Brief symptoms measured pre- & post-sessions 2, 4, and 6.
Contextual Support Model of Music Therapy (CSM-MT)

TMV designed to improve positive health outcomes via multiple RIM paths. Elements of structure, autonomy support, and relationship support essential to active AYA involvement in song writing & video production.

<table>
<thead>
<tr>
<th>TMV Intervention Components</th>
<th>TMV Process Outcomes</th>
<th>RIM Latent Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predictability</strong></td>
<td>Predictable structure supports active engagement in the intervention by choosing/creating contents of music video (music, photos, lyrics)</td>
<td>Courageous coping</td>
</tr>
<tr>
<td>• Familiar, predictable music</td>
<td></td>
<td>Defensive coping</td>
</tr>
<tr>
<td>• Song scripts</td>
<td></td>
<td>Illness-related distress</td>
</tr>
<tr>
<td>• Storyboards</td>
<td></td>
<td></td>
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<tr>
<td>• Leveled Involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Autonomy Support</strong></td>
<td>Reflect on their experiences; Identify what is important to them</td>
<td>Spiritual perspective</td>
</tr>
<tr>
<td>• AYA-Directed</td>
<td></td>
<td>Social integration</td>
</tr>
<tr>
<td>• Choices (music, lyrics, visual</td>
<td></td>
<td>Family environment</td>
</tr>
<tr>
<td>images, vocalists, involving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>others)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Quality Product</td>
<td></td>
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<tr>
<td><strong>Supportive Relationships</strong></td>
<td>Identify hopes/desires for the future</td>
<td>Hope-derived meaning</td>
</tr>
<tr>
<td>• Music to communicate unspoken</td>
<td></td>
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<tr>
<td>thoughts, feelings, dreams for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>future</td>
<td></td>
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<tr>
<td>• AYA-Centered</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family, peer, healthcare provider involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Involve family, peers, and/or</td>
<td></td>
<td>Social integration</td>
</tr>
<tr>
<td>healthcare providers in project</td>
<td></td>
<td>Family environment</td>
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<tr>
<td>as desired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Communicate their ideas to</td>
<td></td>
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<tr>
<td>others</td>
<td></td>
<td>Social integration</td>
</tr>
<tr>
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<td></td>
<td>Family environment</td>
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<tr>
<td></td>
<td></td>
<td>Courageous Coping</td>
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<tr>
<td></td>
<td></td>
<td>Defensive Coping</td>
</tr>
</tbody>
</table>
Why a music video?

• Expressing the “unspoken”
  – “…very deep things like what she’s been going through with this illness – there was silence about that. With the video...she is talking now.” (parent)

• Music as a non-threatening and appealing medium
  – “My favorite was writing...the music. Writing the words.” (adolescent)

• Using the process to explore and “make sense” of the cancer experience
  “Watching the video after transplant helps me remember...Just the hard times and the fun times I had.” (adolescent)

• Sharing the video with others as a way to communicate and connect
  – “So I was trying to go in depth there in the words. So people could hear [my] song and maybe understand it better.” (adolescent)
Verse 1
I’ve got courage on a painful day. When it’s hard at times, I’ve still got joy in the day.

Chorus
I guess y’all would say what would make me feel this way. My courage, my heart, my God—talkin’ bout my fight, my fight.

Verse 2
I’ve got so much faith, the angels protect me.
I’ve got positivity and it runs through me.

Verse 3
I’ve got all the support that one child needs; I’ve got all the love from my friends and family.
SMART Sample (N = 113)

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
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<tbody>
<tr>
<td>Oncology condition requiring SCT</td>
<td>Cognitive impairment precluding completion of measures/intervention</td>
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<tr>
<td>Both allogeneic and autologous</td>
<td>Cancer diagnoses not usually occurring in childhood/AYA populations</td>
</tr>
<tr>
<td>Ages 11 to 24 years inclusive</td>
<td>Married or Having Children</td>
</tr>
</tbody>
</table>

- Mean Age: 17.3 (3.8)
- Gender: 42.5% female; 57.5 male
- Autologous: 40.2%; Allogeneic: 59.8
- Groups equivalent at baseline; exception religious activity
<table>
<thead>
<tr>
<th>Factor</th>
<th>TMV n</th>
<th>Control n</th>
<th>Tx effect</th>
<th>Cohen effect size</th>
<th>P value</th>
<th>TMV n</th>
<th>Control n</th>
<th>Tx effect</th>
<th>Cohen effect size</th>
<th>P value</th>
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<tbody>
<tr>
<td><strong>Illness-Related Distress</strong></td>
<td>36</td>
<td>40</td>
<td>-0.686</td>
<td>-0.160</td>
<td>0.493</td>
<td>31</td>
<td>36</td>
<td>-0.487</td>
<td>-0.121</td>
<td>0.626</td>
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<td><strong>Coping-Defensive</strong></td>
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<td>40</td>
<td>0.855</td>
<td>0.199</td>
<td>0.393</td>
<td>31</td>
<td>36</td>
<td>-0.328</td>
<td>-0.082</td>
<td>0.743</td>
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<td><strong>Spiritual Perspective</strong></td>
<td>40</td>
<td>40</td>
<td>1.283</td>
<td>0.291</td>
<td>0.199</td>
<td>30</td>
<td>37</td>
<td>1.805</td>
<td><strong>0.450</strong></td>
<td><strong>0.071</strong></td>
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<td><strong>Social Integration</strong></td>
<td>39</td>
<td>40</td>
<td>1.015</td>
<td>0.231</td>
<td>0.310</td>
<td>31</td>
<td>37</td>
<td>2.197</td>
<td><strong>0.543</strong></td>
<td><strong>0.028</strong></td>
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<tr>
<td><strong>Family Environment</strong></td>
<td>40</td>
<td>40</td>
<td>1.374</td>
<td>0.311</td>
<td>0.169</td>
<td>30</td>
<td>37</td>
<td>2.659</td>
<td><strong>0.663</strong></td>
<td><strong>0.008</strong></td>
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<tr>
<td><strong>Hope-Derived Meaning</strong></td>
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<td>40</td>
<td>-1.154</td>
<td>-0.261</td>
<td>0.248</td>
<td>30</td>
<td>37</td>
<td>0.734</td>
<td>0.183</td>
<td>0.463</td>
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<tr>
<td><strong>Coping-Courageous</strong></td>
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<td>40</td>
<td>2.167</td>
<td><strong>0.505</strong></td>
<td><strong>0.030</strong></td>
<td>31</td>
<td>36</td>
<td>1.096</td>
<td>0.273</td>
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<tr>
<td><strong>Self-Transcendence</strong></td>
<td>36</td>
<td>40</td>
<td>0.737</td>
<td>0.172</td>
<td>0.461</td>
<td>31</td>
<td>36</td>
<td>1.706</td>
<td><strong>0.424</strong></td>
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<tr>
<td><strong>Resilience</strong></td>
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<td>40</td>
<td>0.936</td>
<td>0.212</td>
<td>0.349</td>
<td>30</td>
<td>37</td>
<td>1.05</td>
<td>0.262</td>
<td>0.294</td>
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</table>
Summary & Next Steps: ANUR 1131

• TMV efficacious for positive growth in courageous coping, social integration, family environment
• RIM working as hypothesized to guide intervention design and evaluation
• Parent interview data indicate parents also derived benefit, but may need help to open/sustain dialogue about DVD content
• Testing Parent Intervention – TMV Standard of Care for AYA
  - National Cancer Institute R01 CA162181 (Haase/Robb, MPIs)
  - Children’s Oncology Group ANUR1131 National Cancer Institute; U10 CA098543 & U10 CA095861 (Haase/Robb, Co-Chairs)
Recruitment Strategies and Rates of a Multi-Site Behavioral Intervention Among Adolescents and Adults With Adenoma

Verna L. Hendricks-Ferguson, PhD, COPN, Debba S. Bums, PhD, ACNP, Celeste R. Phillips-Salit, PhD, Kristin A. Wogenga, PhD, RN, C, and Joan E. Haase, PhD, RN, FA

Abstract

Purpose To evaluate recruitment strategies and rates of participation in a multi-site, randomized clinical trial for adults and adolescents with adenoma.

Methods Participants for the trial were recruited at four academic medical centers across the United States. Recruitment strategies included face-to-face interviews, phone calls, and electronic mail. Participants were mailed a recruitment letter, followed by an invitation to participate in the trial.

Results A total of 200 participants were enrolled in the study, with 100 participants in each group (adolescents and adults). The recruitment rate was 10%, with 20% of participants being new to clinical trials.

Conclusion Recruitment strategies were effective in recruiting participants for the multi-site trial.

Keywords: Recruitment, Adolescents, Adults, Adenoma, Behavioral Intervention.
SMART II Rationale

• By adding a parent intervention component, to our already efficacious TMV we hypothesize that:
  – Parents will have less distress
  – Parents and AYA will perceive better family environment, that will lead to additional significant benefits for AYA not observed in previous trial
SMART Aims and Study Design

• Test efficacy of a therapeutic music video (TMV) intervention for adolescents/young adults during the acute phase of SCT
• Qualitatively evaluate the effectiveness of the TMV
• Two group, randomized, control design with 114 AYA with cancer, 11-24 years undergoing SCT for cancer
Figure 1. Conceptual Framework for Proposed Study (Includes AYA Outcomes from Current R01)

Footnote: All loadings are in the anticipated direction except for the negative loading (-.37) from Social Integration to Hope-Derived Meaning which should not be overly interpreted because it was not significant.

Figure 2. Conceptual Framework for Parent Intervention Component and its proposed interaction with AYA perceived Family Environment and Related Outcomes
SMART II Design

- Two-group randomized control trial
- AYA/Parent Dyads
  - 198 enrolled for 128 accrued
- Dyads randomized to TMV or TMV+P
  - All AYA receive the TMV as standard care
  - Parents in TMV group receive low dose control
  - Parents in TMV+P receive the parent intervention component
Program B Parent Intervention

• Tailored 60-minute sessions with a trained nurse
• Session content focuses on:
  – Managing the Chaos: Self-care as the First Step to Caring for Your AYA
  – Relationship Support: How to listen to and Encourage your AYA to Talk
  – Strategies for AYA Autonomy Support: Understanding AYA’s Ways of Coping
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• American Cancer Society
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Dialogue? Questions?

- Positive Health Perspective?
- Cross-cultural Perspectives of Resilience in Illness?
- Adaptations?
- Measurement?