



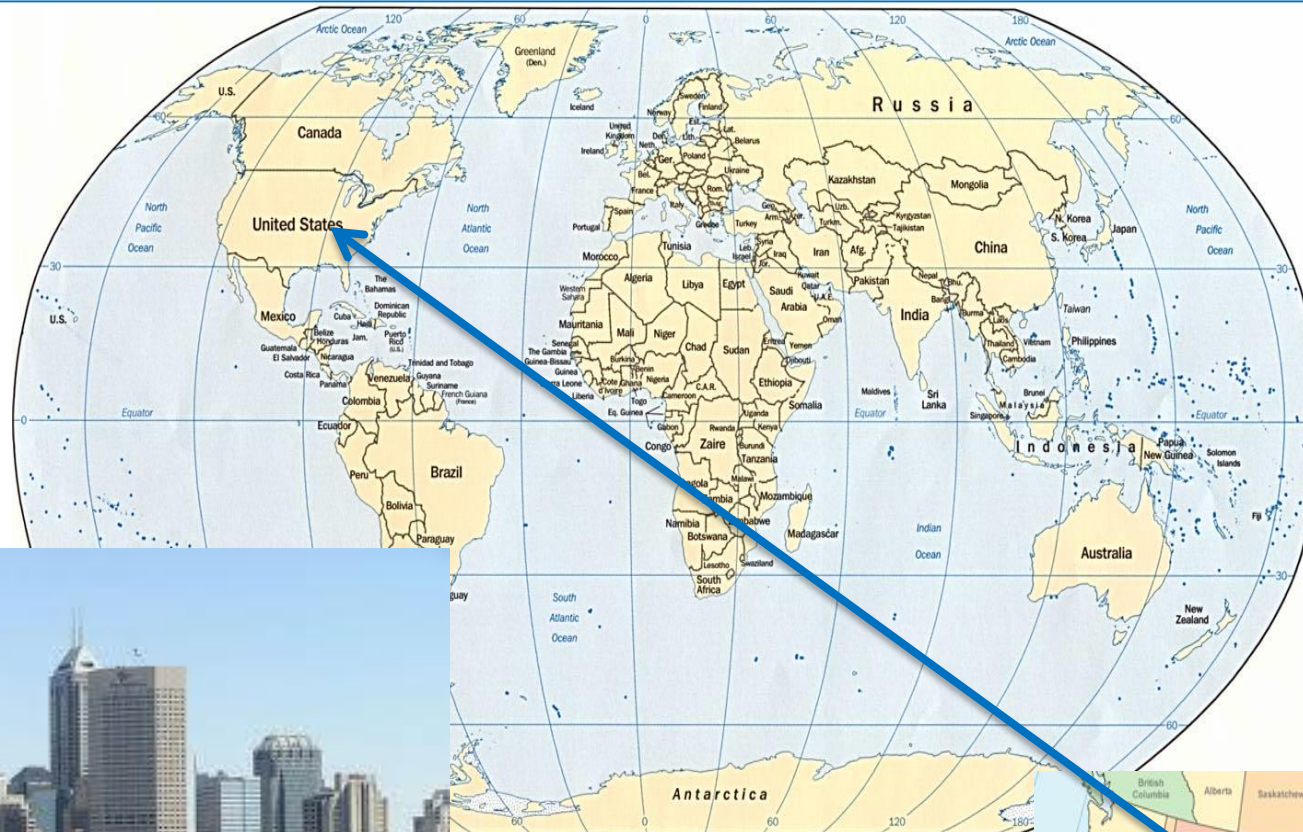
The Resilience in Illness Model: Dialogue on Across-Illness Conditions and Difficult/Traumatic Life Circumstances

Joan E. Haase, PhD, RN, FAAN

Holmquist Professor in Pediatric Oncology Nursing

Science of Clinical Care Department, School of
Nursing, Indiana University, Indianapolis, IN, USA

Greetings from Indiana University School of Nursing



Indianapolis
Indiana, USA



24 July, 2014



Haase, Chen, Wu 6.24.2014

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
- Singer B, Ryff, CD. *New horizons in health: An integrative approach*. Washington, DC: National Academy Press; 2001.

Two Models of Care

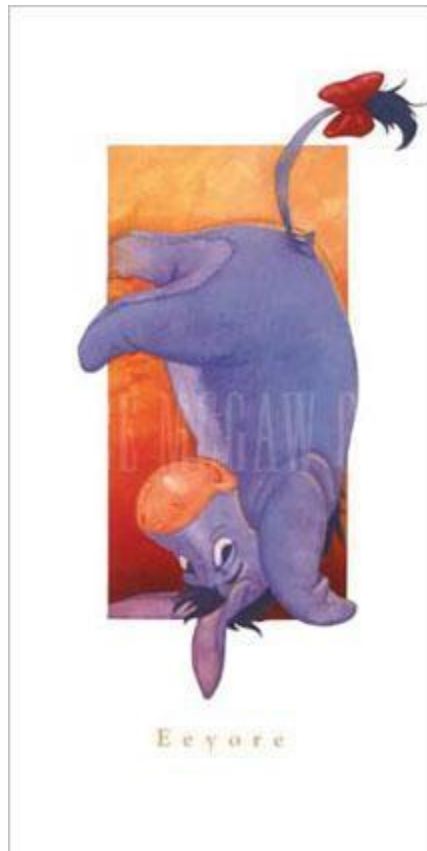
- Common Goals

BUT

- Different approaches and emphases



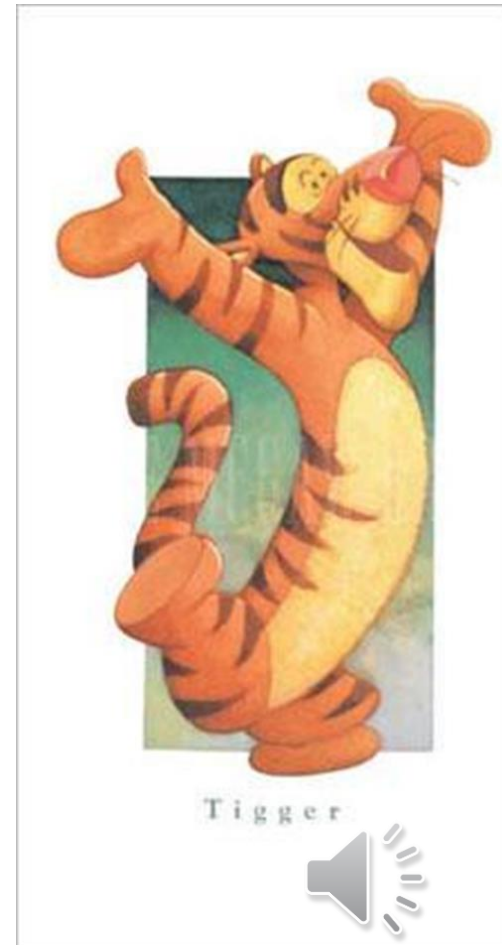
An Eeyore Perspective



10/8/2014



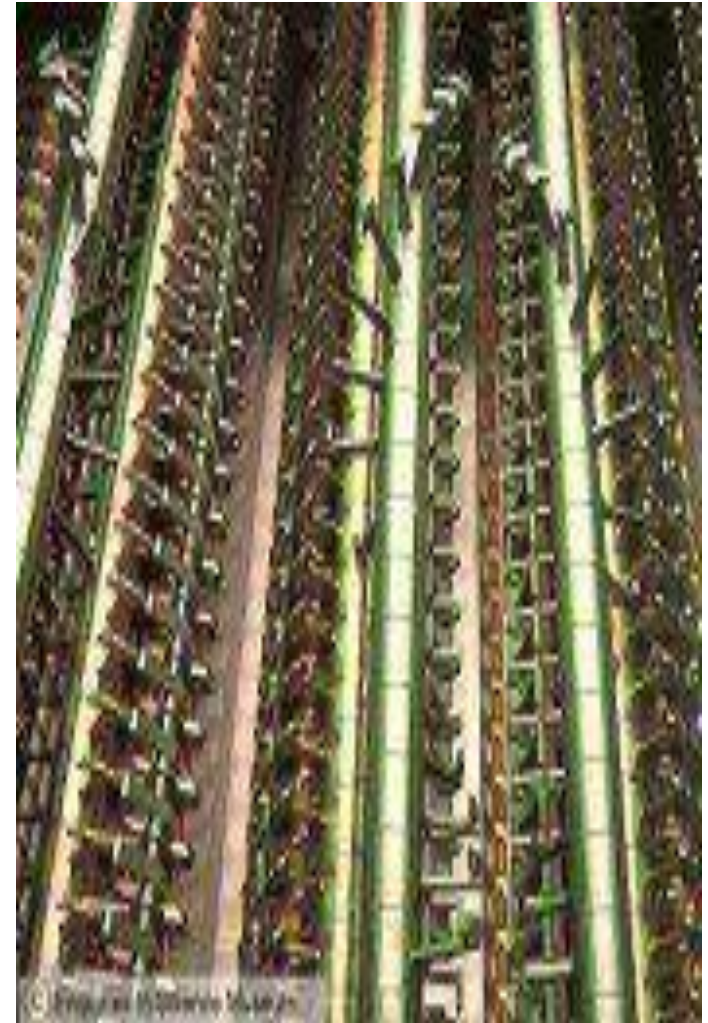
A Tigger Perspective



Haase

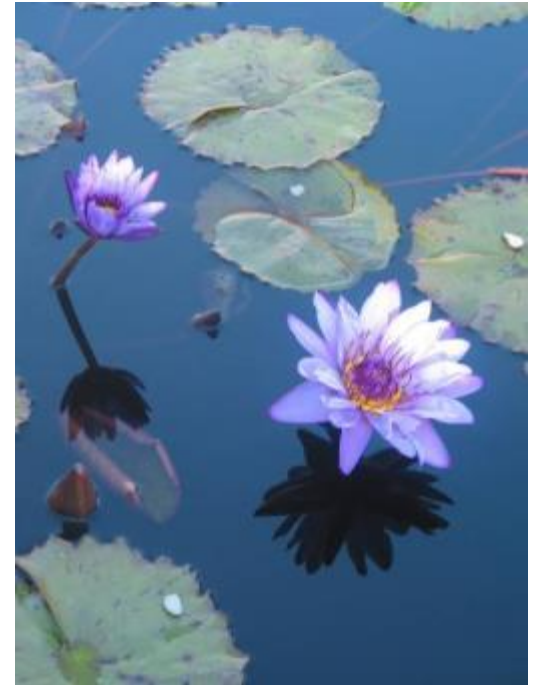
Function-based Model

- 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



-Costain, K., Hewison, J. & Hawes, M. (1993) Comparison of a function-based model and a meaning-based model of quality of life in oncology: Multidimensionality examined. Journal of Psychosocial Oncology. vol. 11(4)17-37.

-Haase, J. & Rostad, M. (1994a). Experiences of completing cancer treatments: Child perspectives. Oncology Nursing Forum, 21(9), 1483-1494.

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
1. Haase, J.E. (1987). The components of courage in chronically ill adolescents. *ADVANCES IN NURSING SCIENCE*, 9(2), 64-80.
 2. Haase, J.E., Heiney, S., Ruccione, K., & Stutzer, C. (1999). Research triangulation to derive meaning-based quality-of-life theory: Adolescent resilience model and instrument development. *INTERNATIONAL JOURNAL OF CANCER*, SUPP. 12, 125-131.
 3. Haase, J.E. (2004). The adolescent resilience model as a guide to interventions. Special Section: Proceedings from the 5th Annual State of the Science Workshop on Resilience and Quality of Life in Adolescents. *JOURNAL OF PEDIATRIC ONCOLOGY NURSING*. 21(5) 289-299.
 4. Haase, J. E., Kintner, E. K., Monahan, P.O., Robb, S.L. (2013). The Resilience in Illness Model, Part 1: Exploratory Evaluation in Adolescents and Young Adults with Cancer. *CANCER NURSING*. DOI: 10.1097/NCC.0b013e31828941bb.
 5. Robb, S., Burns, D., Stegenga, K., Haut, P., Monahan, P., Meza, J., Stump, T., Cherven, B., Docherty, S., Hendricks-Ferguson, V., Kintner, E., Haight, A., Wall, D., Haase, J.E. (In Press). Randomized Clinical Trial of Therapeutic Music Video Intervention for Resilience Outcomes in Adolescents/Young Adults Undergoing Hematopoietic Stem Cell Transplant: A Report from the Children's Oncology Group. *CANCER*.

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.

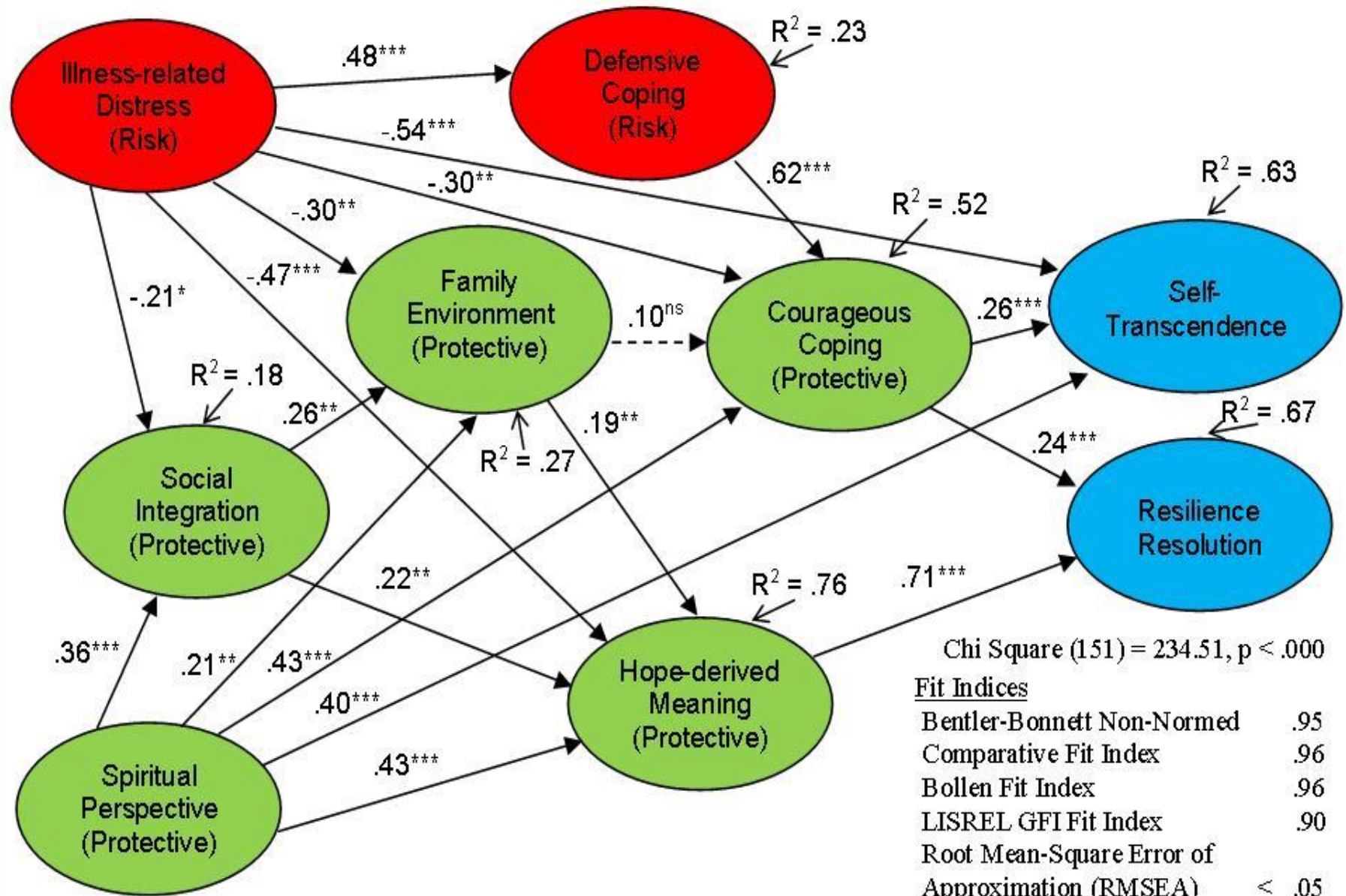
Definition:

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)



Resilience in Illness Model

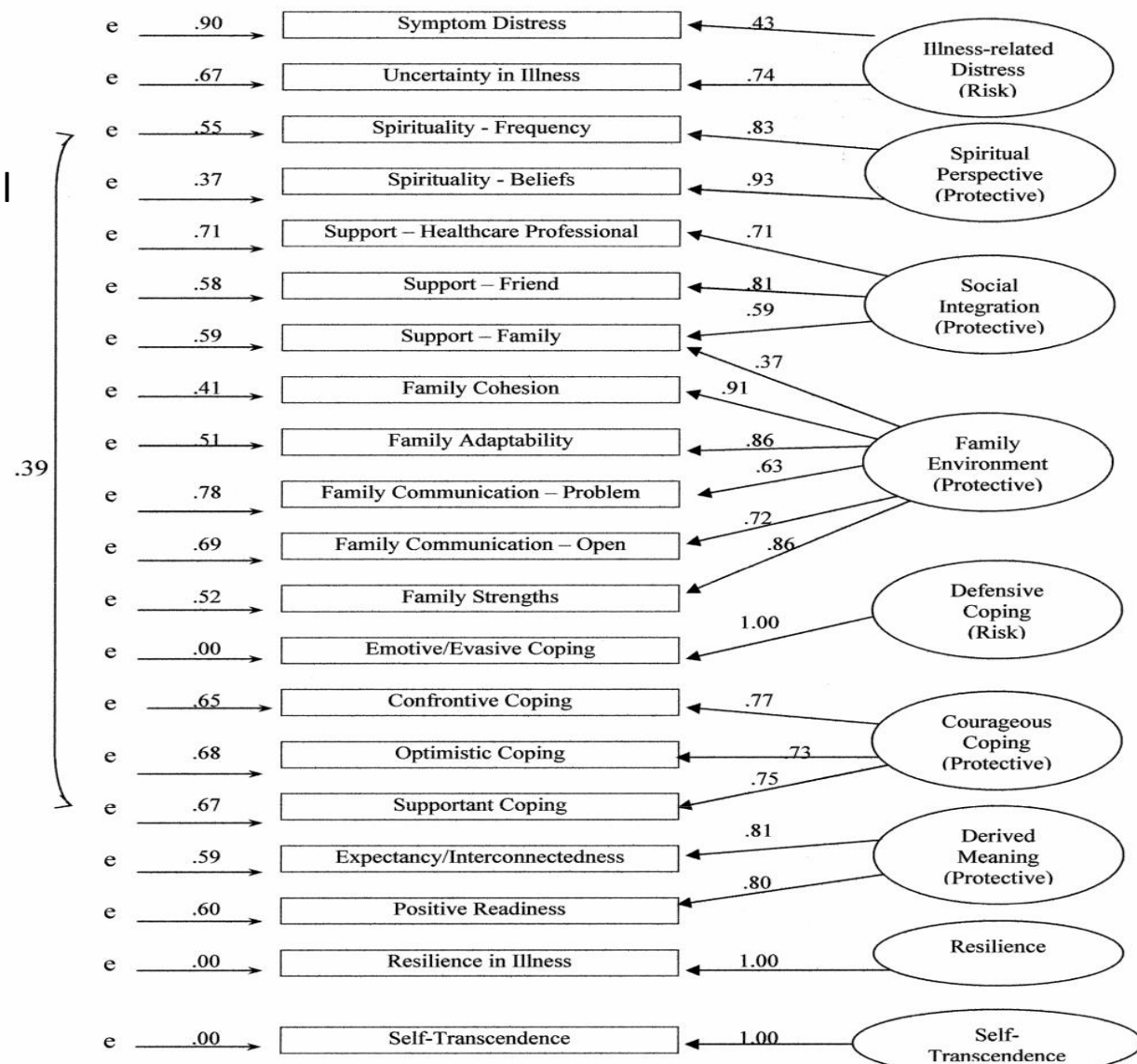
Latent Factors and Manifest Variables

	Latent Factors	Manifest Variables
1	Illness-related distress	Uncertainty in illness Symptom-related distress
2	Defensive coping	Evasive Emotive Fatalistic
3	Positive coping	Confrontive Optimistic Supportant
4	Family support	Family adaptability/cohesion Family communication
5	Social Integration	Perceived social support from family Perceived social support from healthcare providers
6	Hope-Derived meaning	Expectancy, Interconnectedness, Positive Readiness
7	Spiritual Perspective	Spiritual Beliefs Frequency of Spiritual Practices
8	Self-Transcendence	Self-Transcendence
9	Resilience	Resilience in Illness Confidence Sense of Well-being

Latent Variables	Manifest Variables	Measures	Item n, Range, Mean (SD)	Cronbach's Alpha
Illness-related distress	<ul style="list-style-type: none"> Symptom distress Uncertainty in illness 	<ul style="list-style-type: none"> McCorkle Symptom Distress Scale Mishel Uncertainty in Illness Scale 	<ul style="list-style-type: none"> 11 1-5 1.8 (0.6) 28 1-5 2.3 (0.5) 	.82 .89
Coping-defensive	<ul style="list-style-type: none"> Emotive/evasive coping 	Jalowiec Coping Scale Revised: <ul style="list-style-type: none"> Emotive & Evasive Subscales 	<ul style="list-style-type: none"> 18 0-3 1.2 (0.5) 	.79
Spiritual Perspective	<ul style="list-style-type: none"> Spirituality-frequency Spirituality-beliefs 	<ul style="list-style-type: none"> Reed Spiritual Perspective Scale-Practices Reed Spiritual Perspective Scale-Beliefs 	<ul style="list-style-type: none"> 4 1-6 4.0 (1.5) 6 1-6 4.5 (1.3) 	.87 .94
Social integration	Perceived Social Support: <ul style="list-style-type: none"> Healthcare provider Friends Family 	Perceived Social Support (PSS) <ul style="list-style-type: none"> PSS: Healthcare provider Scale PSS: Friends Scale PSS: Family Scale 	<ul style="list-style-type: none"> 20 1-5 3.7 (0.6) 20 1-5 4.1 (0.6) 20 1-5 4.0 (0.7) 	.90 .91 .91
Family Environment	<ul style="list-style-type: none"> Family Cohesion Family Adaptability Family Communication-Open Family Communication-Problem Family Strengths 	<ul style="list-style-type: none"> Family Adaptability Cohesion Scale Family Adaptability Cohesion Scale Parent-AYA Communication Scale Parent-AYA Communication Scale Family Strengths Scale 	<ul style="list-style-type: none"> 16 1-5 3.7 (0.6) 14 1-5 3.4 (0.6) 10 1-5 3.2 (0.7) 10 1-5 4.0 (0.7) 12 1-5 3.7 (0.6) 	.89 .83 .82 .90 .83
Courageous Coping	<ul style="list-style-type: none"> Confrontive Coping Optimistic Coping Supportant Coping 	Jalowiec Coping Scale-Revised <ul style="list-style-type: none"> Confrontive Subscale Optimistic Subscale Supportant Subscale 	<ul style="list-style-type: none"> 10 0-3 1.4 (0.6) 9 0-3 2.1 (0.6) 5 0-3 1.7 (0.6) 	.80 .75 .60
Hope-derived	<ul style="list-style-type: none"> Expectency/ 	Herth Hope Index Subscales		

Latent Variables	Manifest Variables	Outcome Measures	Items n, Range, Mean (SD)	Cronbach's Alpha
Self-Transcendence	<ul style="list-style-type: none">Self-transcendence	<ul style="list-style-type: none">Reed Self-transcendence Scale	<ul style="list-style-type: none">15 1-4 3.3 (0.4)	.75
Resilience in Illness	<ul style="list-style-type: none">Resilience in Illness	<ul style="list-style-type: none">Haase Resilience in Illness Scale	<ul style="list-style-type: none">15 1-6 5.1 (0.6)	.81

Resilience in Illness Measurement Model



Chi Square (142) = 233.09, $p < .000$		Root Mean-Square Error Of Approximation (RMSEA)	
Bentler-Bonnett Non-Normed	.94		.05
Comparative Fit Index	.95	90% Confidence Interval	.04, .07
Bollen Fit Index	.96		
LISREL GFI Fit Index	.90		

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.”

Puchalski, C., B. Ferrell, et al. (2009). "Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference." J Palliat Med **12**(10): 885-904.

Puchalski, C. & Ferrell, B. (2010) Making Healthcare Whole: Integrating Spirituality into Patient Care. West Conshohocken, PA: Templeton Press

Spiritual Distress

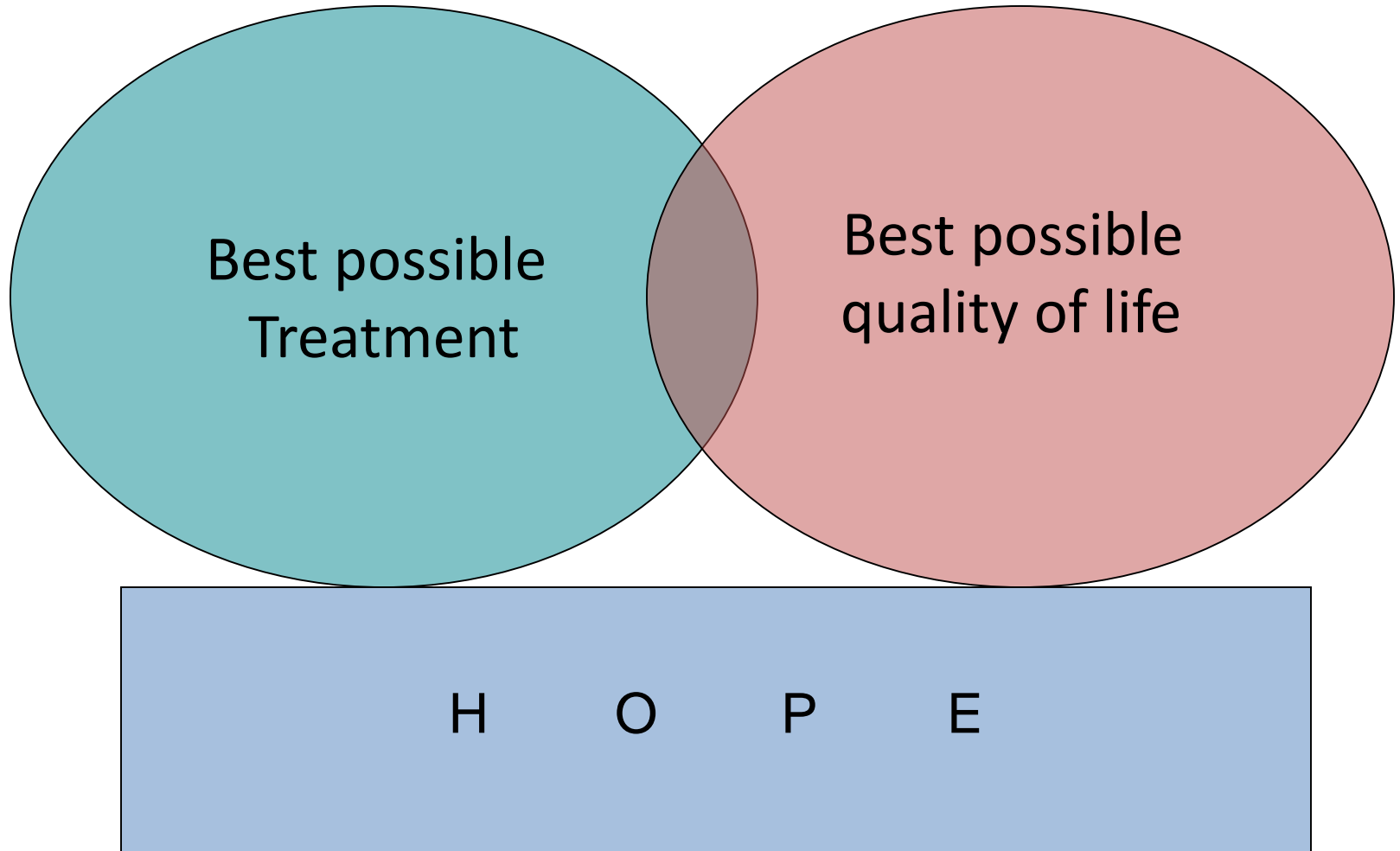
- **Existential**
- **Abandonment**
- **Anger**
- **Concerns about relationship with deity**
- **Conflicted or challenged belief systems**
- **Despair / Hopelessness**
- **Grief/loss**
- **Reconciliation**
- **Isolation**
- **Religious / Spiritual Struggle**

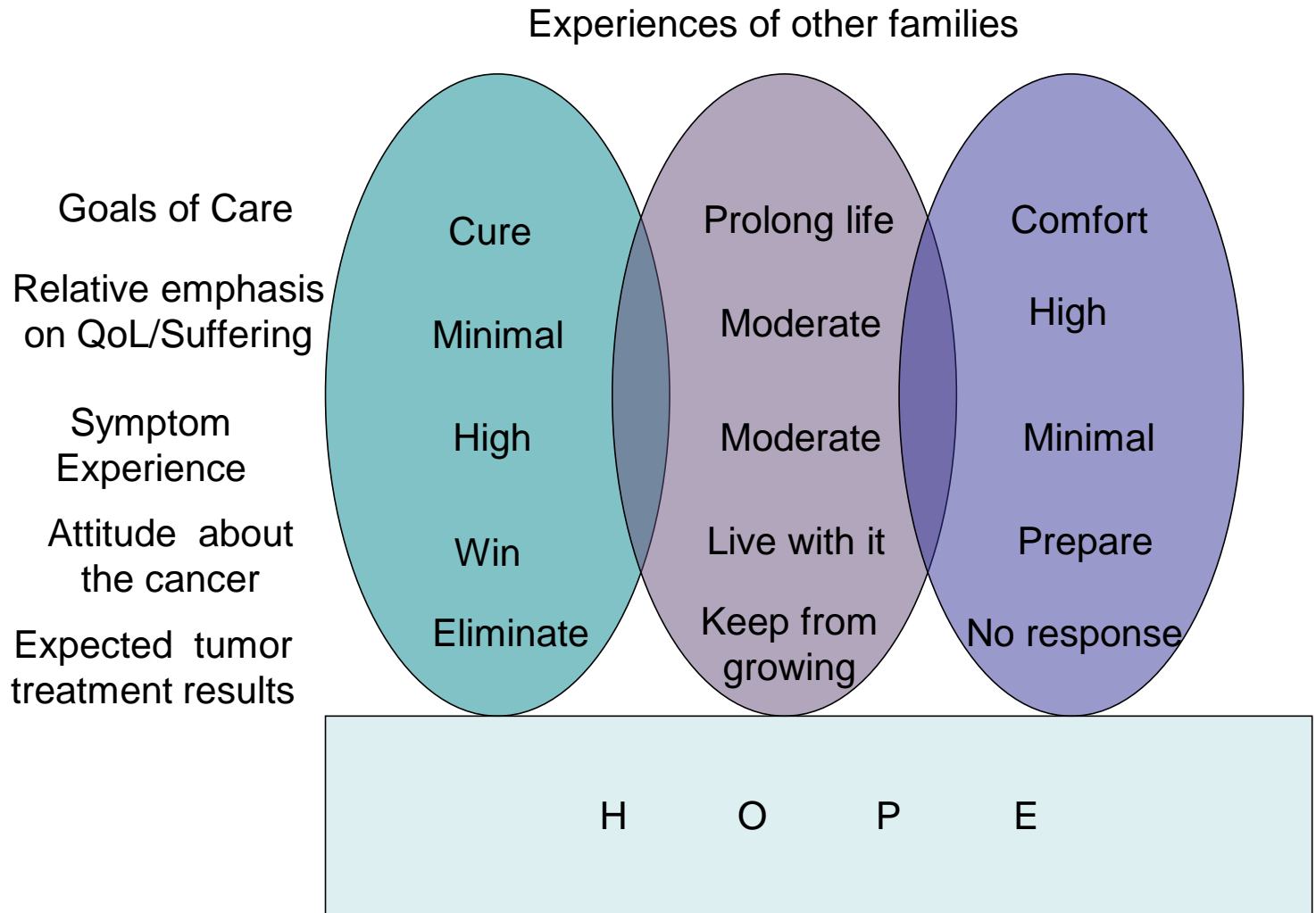
Spiritual Care

- 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

Hope-Derived Meaning

Forming a Team to care for your child





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

- Phillips-Salimi, C. R., Haase, J. E., & Kooken, W. C. (2011). Connectedness in the Context of Patient-Provider Relationships: A Concept Analysis. J ADV NURS. DOI: 10.1111/J.1365-2648.2011.05763.X.

Family Environment (Protective)

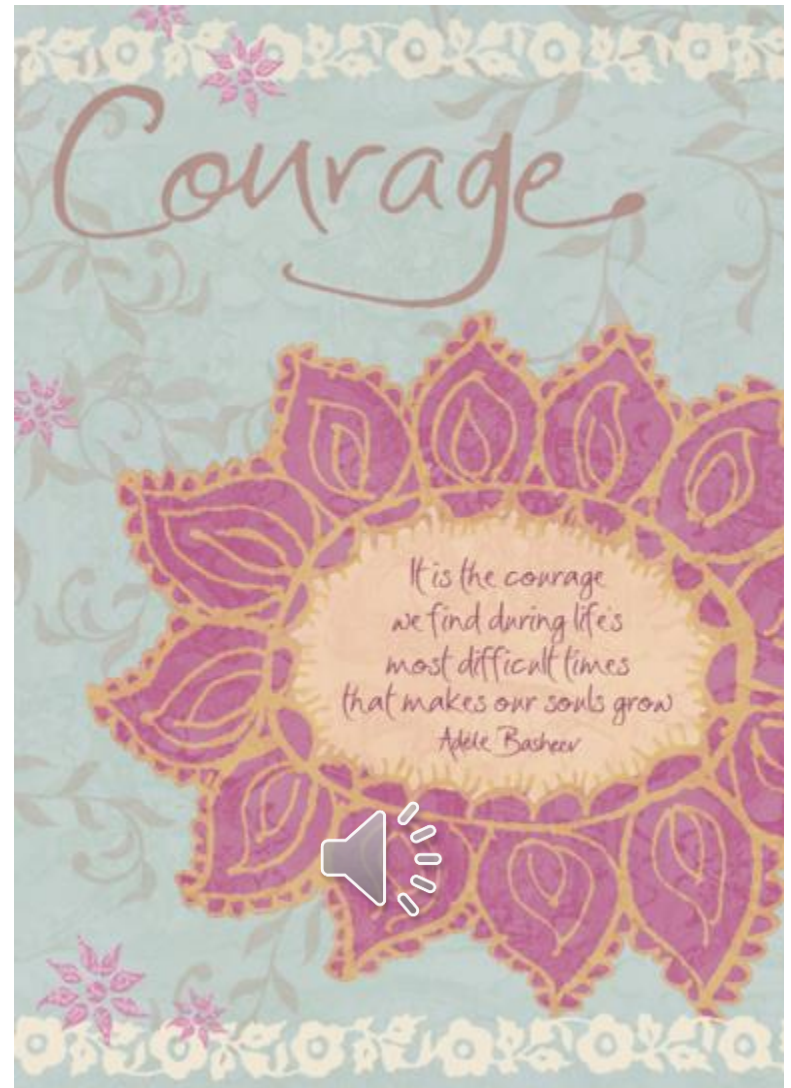
- The degree to which the patient/family member perceives the family as adaptable, cohesive, effectively communicating, and having family strengths.
- Family
 - Adaptability
 - Cohesion
 - Communication
 - Perceived Strengths
- Example: Adolescent/Young Adult Profile

Courageous Coping (Protective)

The degree to which the AYA **uses and finds effective:**

- confrontive
- optimistic
- supportant

copmg strategies to deal with the illness experience



Resilience and Self-Transcendence

“Chemo Kid Rock” by Heather (age 12)

Verse 3

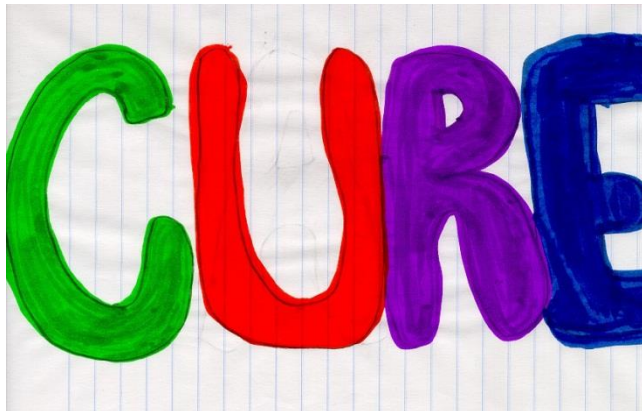
Somebody once asked, “How can you do this task?”

I said, “You just have to do it yourself...”

I have to be strong, I have to be tough

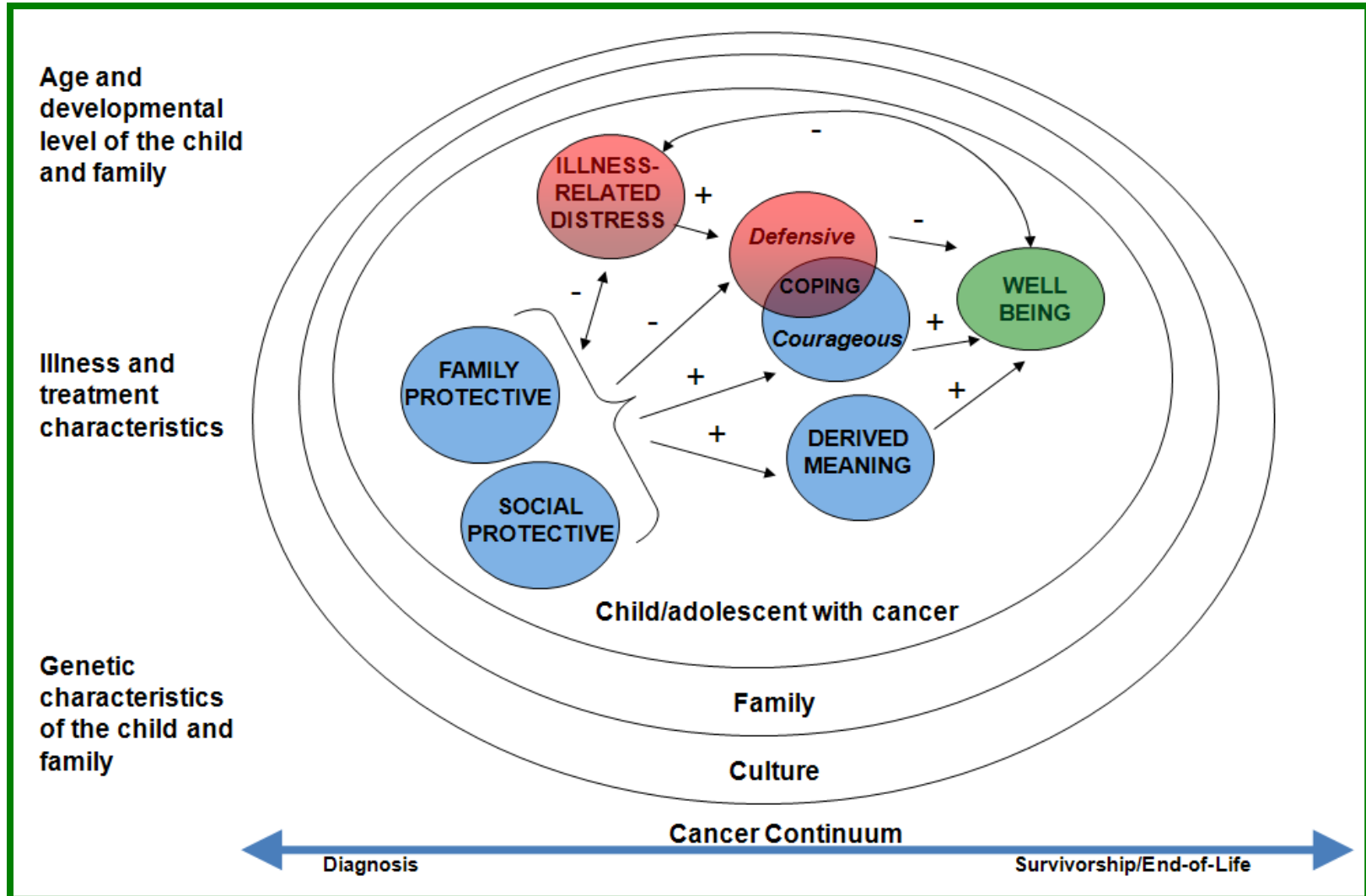
And I’ll know when I’ve had enough

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



Stories and Music for Adolescent and
Young Adult Resilience during Transplant

- 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)



Stories through Music for AYA Resilience
during Treatment and Parents

- 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

Robb, S.L. (2000). The effect of therapeutic music interventions on the behavior of hospitalized children in isolation: Developing a contextual support model of music therapy. *Journal of Music Therapy*, 37, 118-146.

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.

TMV Intervention Components	TMV Process Outcomes	RIM Latent Variables
Predictability <ul style="list-style-type: none"> Familiar, predictable music Song scripts Storyboards Leveled Involvement Autonomy Support <ul style="list-style-type: none"> AYA-Directed Choices (music, lyrics, visual images, vocalists, involving others) Quality Product Supportive Relationships <ul style="list-style-type: none"> Music to communicate unspoken thoughts, feelings, dreams for future AYA-Centered Family, peer, healthcare provider involvement 	Predictable structure supports active engagement in the intervention by choosing/creating contents of music video (music, photos, lyrics)	Courageous coping Defensive coping Illness-related distress
	Reflect on their experiences; Identify what is important to them	Spiritual perspective Social integration Family environment
	Identify hopes/desires for the future	Hope-derived meaning
	Involve family, peers, and/or healthcare providers in project as desired	Social integration Family environment
	Communicate their ideas to others	Social integration Family environment Courageous Coping Defensive Coping

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)*

Albert's Video: *My Fight*

Age 15

Melody: *My Girl* by the Temptations



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)

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

- 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

Effect Sizes for Latent Variable Outcomes

	TMV n	Con- trol n	Tx effect	Cohen effect size	P value	TMV n	Con- trol n	Tx effect	Cohen effect size	P value
Illness-Related Distress	36	40	-0.686	-0.160	0.493	31	36	-0.487	-0.121	0.626
Coping-Defensive	36	40	0.855	0.199	0.393	31	36	-0.328	-0.082	0.743
Spiritual Perspective	40	40	1.283	0.291	0.199	30	37	1.805	0.450	0.071
Social Integration	39	40	1.015	0.231	0.310	31	37	2.197	0.543	0.028
Family Environment	40	40	1.374	0.311	0.169	30	37	2.659	0.663	0.008
Hope-Derived Meaning	40	40	-1.154	-0.261	0.248	30	37	0.734	0.183	0.463
Coping-Courageous	36	40	2.167	0.505	0.030	31	36	1.096	0.273	0.273
Self-Transcendence	36	40	0.737	0.172	0.461	31	36	1.706	0.424	0.088
Resilience	40	40	0.936	0.212	0.349	30	37	1.05	0.262	0.294

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)



Original article

Parental Perspectives on a Behavioral Adolescent/Young Adult Resilience D the Children's Oncology Group

Sharon L. Docherty, Ph.D., C.P.N.P.^{2,4}, Sheri L. R. Celeste Phillips-Salimi, Ph.D., R.N.², Brooke Chervin, Verna Hendricks-Ferguson, Ph.D., R.N.², Lona R. Joan Haase, Ph.D., R.N.²

¹Duke University School of Nursing, Durham, North Carolina

²School of Nursing, Indiana University, Indianapolis, Indiana

³College of Nursing, University of Kentucky, Lexington, Kentucky

⁴Adult Cancer Center and Blood Disorders Service, Children's Healthcare of Atlanta

⁵Children's Mercy Hospital, Kansas City, Missouri

⁶School of Nursing, Saint Louis University, St. Louis, Missouri

⁷The University of Texas Health Science Center at San Antonio, San Antonio, Texas

Article history: Received October 5, 2011; Accepted May 9, 2012

Keywords: Adolescent health services; Behavioral intervention; Qualitative evaluation; Targeted intervention

ARTICLE

Recruitment Strategies and Rates of a Multi-Site Behavioral Intervention for Adolescents and Young Adults With

Research Article

Engaging Nurses in Research for a Randomized Clinical Trial of a Behavioral Health Intervention

Verna L. Hendricks-Ferguson, M. CPON, Debra S. Burns, PhD, M (AC/PC), Celeste R. Phillips-Salimi, Kristin A. Stegenga, PhD, RN, C & Joan E. Haase, PhD, RN, FAA

Lona Roll,¹ Kristin Stegenga,² Verr Brooke Chervin,³ Sharon L. Doch

¹The University of Texas Health Science Center at

²Children's Mercy Hospital, 2401 Gillham Road, K

³St. Louis University School of Nursing, 3525 Carr

⁴Washington University School of Medicine, One C

⁵Children's Healthcare of Atlanta, 2015 Uppergate

⁶Duke University School of Nursing, D104C.322

⁷Indiana University School of Nursing, 1111 Middle

ABSTRACT

Introduction: To provide an overview of factors i treatment of adolescents and young adults (A search and recruitment rates and reasons for i a multicenter study entitled "Stories and Music c on Young Adult Resilience during Transplant" **Methods:** A randomized clinical trial study desig The settings included 9 hospitals. The sample in aged 11–24 years who were undergoing a ste plant. Several instruments were used to measu

Correspondence should be addressed to Lona R Received 23 April 2013; Revised 10 July 2013; Acc Academic Editor: Kate Khair

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Nurse involvement in research is essential to it participation challenges encountered by nurses p with research, adjusting to fluctuating staff and pi with their knowledge of the research process. T the Stories and Music for Adolescents/Young Ad multiple, randomized, behavioral clinical trial a stem cell transplant for an oncology condition. T direct care nurses, advanced practice nurses, an coordinators, and physicians. Efforts to include disciplines in both academic and clinical settings

FEATURE

ARTICLE

Psycho-Oncology
Psycho-Oncology 20: 1193–1201 (2011)

Published online 29 September 2010 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.1845

Development an of a Web-Based Management System for a Randomized Clinical Trial of Adolescents and Young Adults

Ensuring treatment fidelity in a multi-site behavioral intervention study: implementing NIH behavior change consortium recommendations in the SMART trial

Sheri L. Robb¹*, Debra S. Burns², Sharon L. Docherty³ and Joan E. Haase¹
¹Indiana University, Indianapolis, Indiana
²Purdue University, Indianapolis, Indiana
³Duke University, Durham, North Carolina

Research in Nursing & Health, 2011, 34, 362–371

BEVERLY S. MUSICK, MS
SHERI L. ROBB, PhD, MT-BC
DEBRA S. BURNS, PhD, MT-BC
KRISTIN STEGENGA, PhD, RN
MING YAN, MS
KATHY J. MCCORKLE, MPH
JOAN E. HAASE, PhD, RN, FAA

*Correspondence to: Indiana University School of Nursing, 1111 Middle Drive, Indianapolis, IN 46202. E-mail: shrobbs@iupui.edu

Abstract

The Stories and Music for Adolescent/Young Oncology Group randomized clinical trial intervention for adolescents/young transplant. Treatment fidelity at Institutes of Health (NIH) Beh (BCC) recommendations and in implementation in a large, multi-20 specific treatment fidelity stra correspond with NIH BCC recom providers, (3) delivery of treatme skills. Increased use and reporting reliability and validity of behavior model for the application of fidelity absence of published literature, behavioral intervention studies. Copyright © 2010 John Wiley & keywords: behavioral intervention assurance monitoring; treatment fi

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Revised 21 July 2010
Accepted 24 July 2010

Principles and Strategies for Monitoring Data Collection Integrity in a Multi-Site Randomized Clinical Trial of a Behavioral Intervention

Celeste R. Phillips-Salimi,¹ Molly A. Do Melissa Lee,² Jo

¹University of Kentucky, 315 College of Nursing B
²Indiana University School of
³Children's Mercy Hosp
⁴Indiana University School of
Accepted 11 /

Abstract: Although treatment fidelity of behavioral interventions have been written about monitoring data collect the principles and strategies developed of the "Stories and Music for Adolescents Transplant" study (R01NR008583, U multi-site Children's Oncology Group i therapy intervention for adolescents i cell transplant. The principles and provide one model for development c integrity monitoring plan for beha adopted by investigators and may be u application reviewers in evaluating pr Inc. Res Nurs Health 34:362–371, 2011

Randomized Clinical Trial of Therapeutic Music Video Intervention for Resilience Outcomes in Adolescents/Young Adults Undergoing Hematopoietic Stem Cell Transplant

A Report From the Children's Oncology Group

Sheri L. Robb, PhD, MT-BC¹; Debra S. Burns, PhD, MT-BC²; Kristin A. Stegenga, PhD, RN³; Paul R. Haut, MD⁴; Patrick O. Monahan, PhD⁵; Jane Meza, PhD⁶; Timothy E. Stump, MA⁶; Brooke O. Chervin, MPH, RN⁶; Sharon L. Docherty, PhD, CPNP-AC/PC, RN⁷; Verna L. Hendricks-Ferguson, PhD, RN⁸; Ellen K. Kintner, PhD, RN⁹; Ann E. Haight, MD¹⁰; Donna A. Wall, MD¹⁰; and Joan E. Haase, PhD, RN, FAAN¹

BACKGROUND: To reduce the risk of adjustment problems associated with hematopoietic stem cell transplant (HSCT) for adolescents/young adults (AYAs), we examined efficacy of a therapeutic music video (TMV) intervention delivered during the acute phase of HSCT to: 1) increase protective factors of spiritual perspective, social integration, family environment, courageous coping, and hope-derived meaning; 2) decrease risk factors of illness-related distress and defensive coping; and 3) increase outcomes of self-transcendence and resilience. **METHODS:** This was a multisite randomized, controlled trial (COG-A040603) conducted at 8 Children's Oncology Group sites involving 183 AYAs aged 11–24 years undergoing myeloablative HSCT. Participants, randomized to the TMV or low-dose control (audiobook) group, completed 6 sessions over 3 weeks with a board-certified music therapist. Variables were based on Haase's Resilience in Illness Model (RIM). Participants completed measures related to latent variables of illness-related distress, social integration, spiritual perspective, family environment, coping, hope-derived meaning, and resilience at baseline (T0), post-intervention (T2), and 100 days posttransplant (T3). **RESULTS:** At T2, the TMV group reported significantly better courageous coping (Effect Size (ES), 0.505, $P = .030$). At T3, the TMV group reported significantly better social integration (ES, 0.543, $P = .028$) and family environment (ES, 0.663, $P = .008$), as well as moderate nonsignificant effect sizes for spiritual perspective (ES, 0.450, $P = .071$) and self-transcendence (ES, 0.424, $P = .088$). **CONCLUSIONS:** The TMV intervention improves positive health outcomes of courageous coping, social integration, and family environment during a high-risk cancer treatment. We recommend the TMV be examined in a broader population of AYAs with high-risk cancers. **Cancer 2015;000:000–000.** © 2013 American Cancer Society

KEYWORDS: resilience, adolescents, young adult, cancer, music therapy, music, courageous coping, self-transcendence, family relations, social environment.

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)

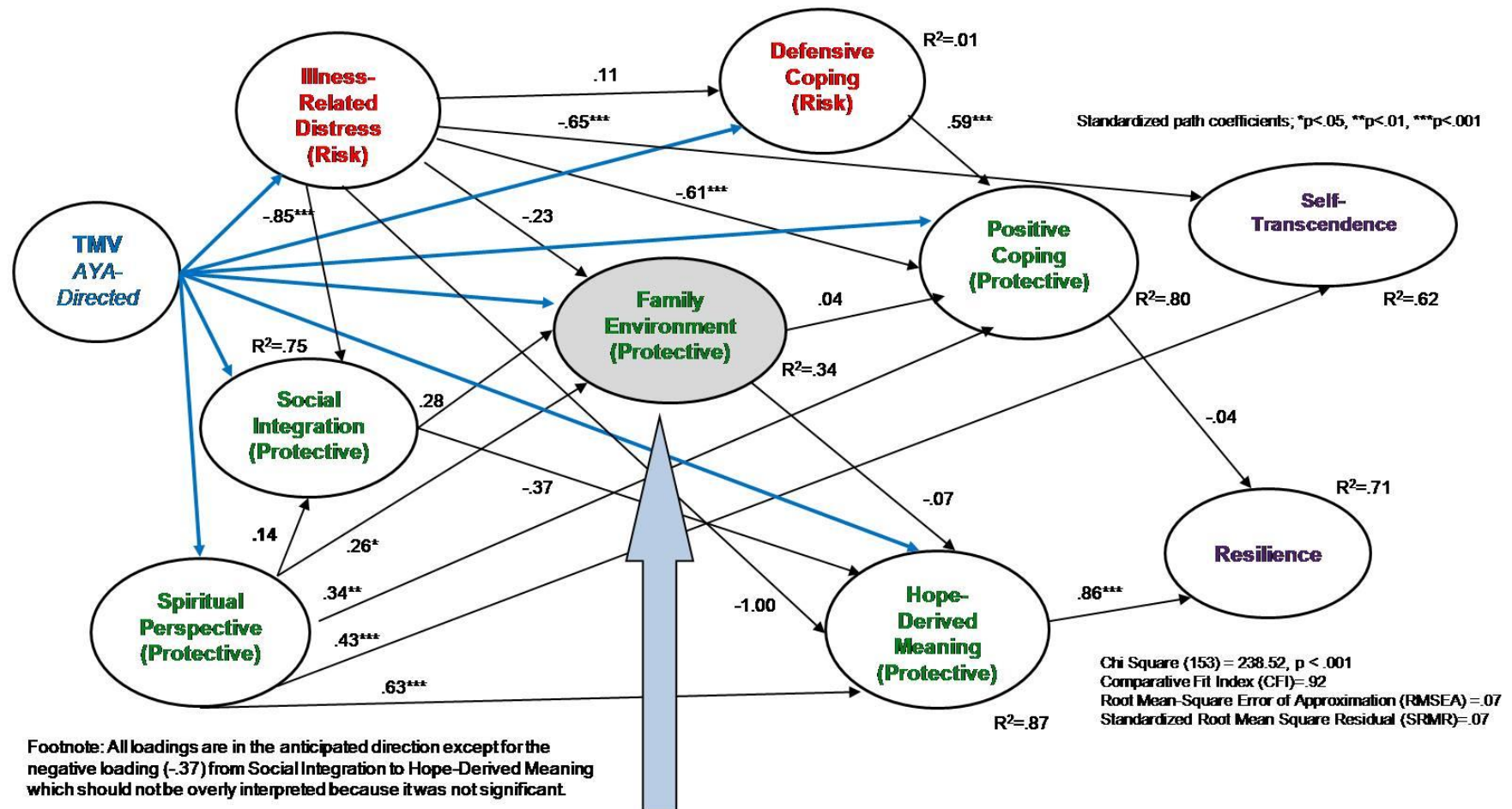
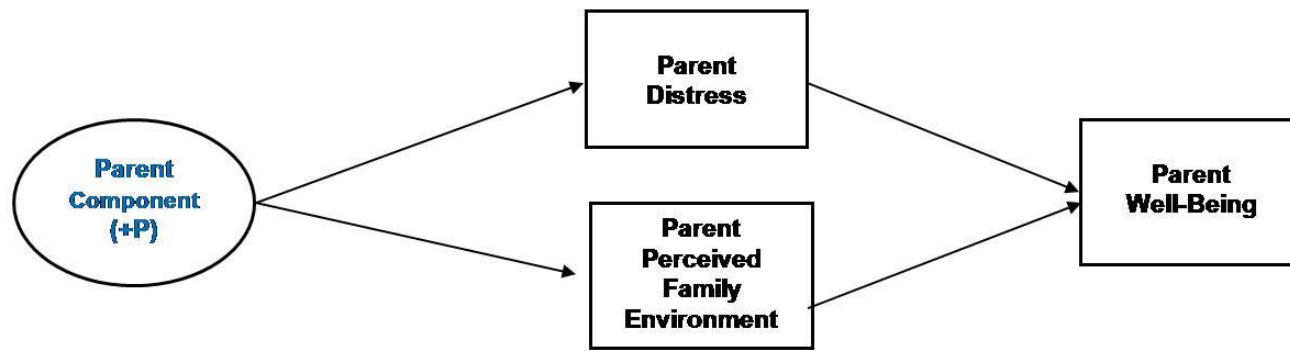


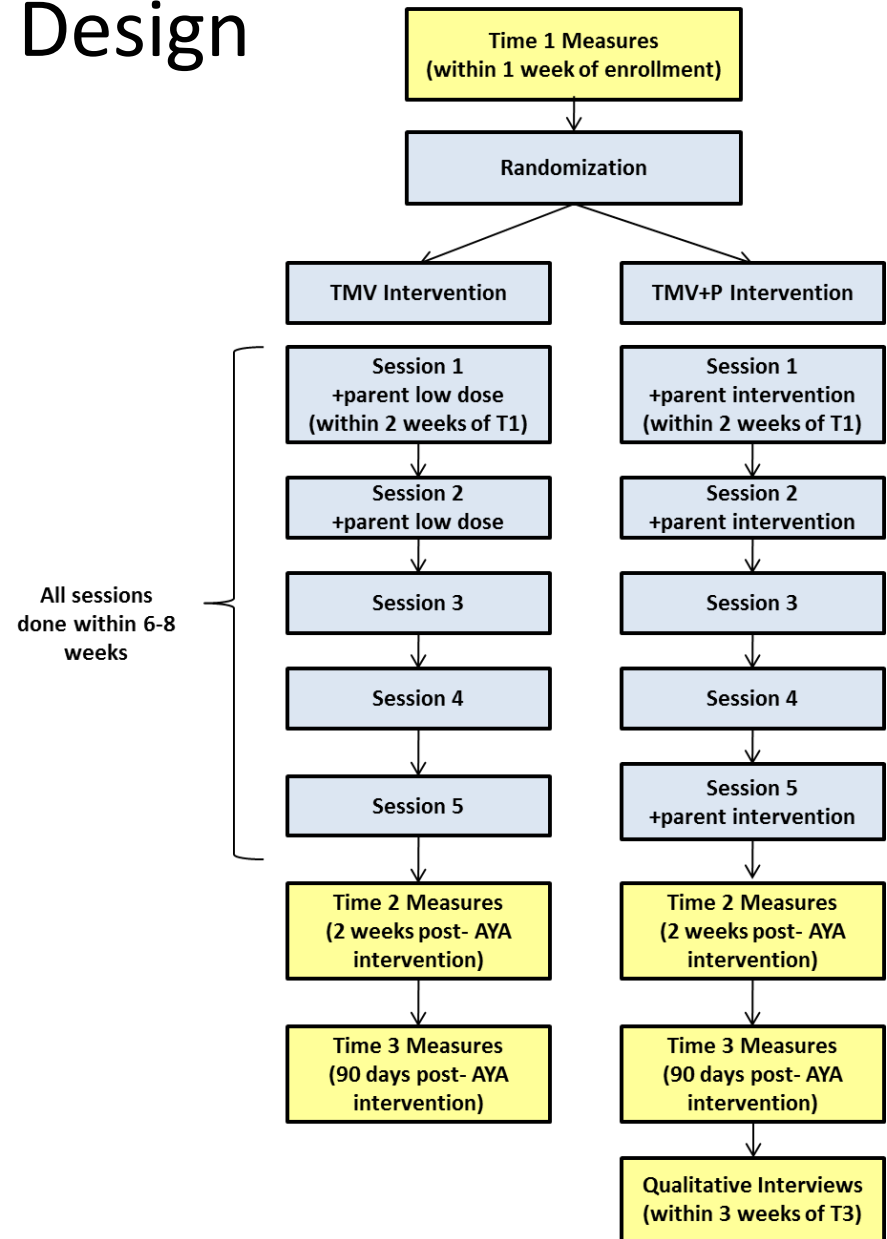
Figure 2. Conceptual Framework for Parent Intervention Component and its proposed interaction with AYA perceived Family Environment and Related Outcomes



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

Figure: Study Schema



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?