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Resilience in Illness Model Research: Potential for Guiding Asian Resilience Enhancement for Adolescents/Young Adults Studies

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The Resilience in Illness Model (RIM) is the guiding framework for AREA cooperative research. RIM was developed from a positive health perspective to evaluate positive health processes and outcomes in AYA with chronic illness, primarily in AYA with cancer (Haase et al., 2014). RIM was developed through a series of qualitative and quantitative studies conducted over 33 years. These studies used phenomenology, simultaneous concept analysis and instrumentation methods to understand and measure AYA experiences of dealing with chronic illnesses (I.e., cancer, cystic fibrosis, asthma, and cardiac diseases) (Haase, 1987; Haase, Britt, Coward, Leidy, & Penn, 1992; Haase, Heiney, Ruccione, & Stutzer, 1999; Haase & Phillips, 2004). The confirmed RIM includes 2 risk factors (Illness-related Risk and Defensive Coping), 5 protective factors (Spiritual Perspective, Social Integration, Hope-derived Meaning, Family Environment, and Courageous Coping) and 3 outcomes (Resilience Resolution, Self-transcendence and Sense of Well-being). (Haase et al, 2016).

Evaluation of the RIM was first done using exploratory latent variable structural equation modeling in a combined sample from two studies of young patients with cancer ages 10-26 years (n=202). In this preliminary evaluation, RIM explained 67% of variance for resilience resolution and 63% of variance for self-transcendence. Variance explained for proximal outcomes ranged from 18% to 76% (Haase et al., 2014). To increase confidence in the ability of RIM to predict and guide the intervention research, we then conducted a confirmatory model evaluation to determine how well RIM is replicated in a different sample. This study was done with 113 AYA with cancer, aged 11-24 years who were at the beginning of treatment for the hematopoietic stem cell transplant. Findings indicated that the data fit well with the confirmatory structural equation model. The comparative fit index (CFI) =0.92, standardized root mean square residual (SRMR) =0.07, and root mean square error of approximation (RMSEA) =0.07 with a 90% confidence interval between 0.06 and 0.09 (Haase et al., 2016). The confirmatory model accounted for 72%

of variance for the outcomes of resilience resolution, and 62% of variance for self-transcendence (Haase et al., 2016).

RIM was used in several descriptive and experimental studies.

- A randomized clinical trial (RCT) of the “Stories and Music for Adolescent/Young Adult Resilience during Transplant” (SMART I) was guided by the RIM (Robb et al., 2014). In this study AYA with cancer and undergoing a hematopoietic stem cell transplant developed a therapeutic music video intervention. AYA selected a song from 10 options within 5 genres; wrote lyrics to the song, recorded the song, and selected pictures for the music video. At T2, the TMV group reported significantly better courageous coping (ES=0.505; P=0.030). At T3, the TMV group reported significantly better social integration (ES=0.543; P=.028) and family environment (ES=0.663; P=0.008), as well as moderate non-significant effect sizes for spiritual perspective (E=0.450; P=0.071) and self-transcendence (ES=0.424; P=0.088). Conclusion: The TMV intervention improves positive health outcomes of courageous coping, social integration, and family environment during a high-risk cancer treatment.
- In a follow-up RCT, “Stories and Music for AYA and Parents” (SMART II), parents of AYA with high risk cancer participated in a family communication intervention delivered by nurses. The intervention, delivered in 3 1-hour sessions, included 3 components: parent self-care strategies to be able to be present for their AYA; distinguishing teaching, comforting and listening to open dialogue, and, active listening to open dialogue with their AYA. Primary results will be submitted for publication and presented at the symposium in 2019.
- We will provide brief descriptions of insights obtained from post-intervention qualitative interviews with study AYA and parent participants and nurse intervenors in these studies will also be presented. (Docherty et al., 2013; Landon et al, in Press; Haase et al, in Review).
- A third intervention study, Drs Phillips and Haase developed and are pilot testing the “Resilience Enhancement between AYA with Cancer, Parents and Healthcare Providers (REACH). This intervention provides the AYA and parent with a RIM profile based on AYA and parent scores on RIM measures. AYA and parent scores depicted by the location of an avatar located on a soccer field in relation to shaded areas depicting the mean and standard deviation of other AYA the same age and gender. Results are then discussed with the AYA and parent with the aim to increase awareness, use, and enhancement of AYA protective factors as a way to reduce illness related distress and foster resilience outcomes through the cancer journey. In the future, using the profile, we will explore ways to help healthcare providers gain an evidence-based understanding of the AYA and family resilience profile.
- Several studies focused on one factor in the model are being conducted. For example, the RIM Social Integration factor which includes connectedness with healthcare providers as a manifest variable, was the impetus for Dr. Phillip’s research program on connectedness with healthcare providers. Her publications, “A Primer of Connectedness” and “Like Prisoners in a War Camp: AYA experiences of Disconnected with Healthcare providers” describe ways interactions with their providers can foster resilience or provide long-lasting negative memories of poor cancer care experiences. (Phillips, Haase, Broome, Carpenter, & Frankel, 2017).
In 2014, the Nursing Discipline Committee of Children’s Oncology Group adapted the RIM as the guiding framework for all research accomplished through the Nursing Discipline based on the RIM. Their framework, the “Resilience in Individuals and Families Affected by Cancer” is used by Nursing Committee’s research in North America, Australia, New Zealand, and parts of Europe to guide research on ways to promote resilience and well-being for the

child/adolescent/young adult with cancer and their family members across the cancer trajectory (Kelly et al., 2014).

In Taiwan, RIM was the guiding framework, for Dr. Wu's research. The Haase Adolescent Resilience Scale (HARS) was used to confirm the convergent and discriminate validity of the Pediatric Cancer Coping Scale (PCCS). The results showed that cognitive coping and problem-oriented coping were highly correlated with the resilience (Wu, Chin, Chen, Lai & Tseng, 2011). The cognitive coping and defensive coping were found to predict resilience significantly in a step-wise multiple regression analysis and accounted for 46.5% of total variance. The regression equation for resilience was $39.413 + 0.745$ (cognitive coping) -0.165 (defensive coping) (Wu, Sheen, Shu, Chang, & Hsiao, 2013). RIM was one of the theoretical frameworks for Dr. Chen's dissertation. This study used a cross-sectional, case-control design to compare adolescent survivors of brain tumors (ASBT) with healthy adolescents in terms of resilience and how it is affected by various health problems. The 2 groups did not differ significantly in resilience, but survivors without emotional problems had a higher mean resilience score than did healthy adolescents and survivors with emotional problems ($F = 8.65$, $P < .01$). The results found emotional problems as a risk factor for resilience in both adolescent survivors of brain tumors and healthy adolescents and the effect of emotional problems on resilience was greater for brain tumor survivors than healthy adolescents. (Chen, Chen, & Wong, 2014).

As an example of RIM-focused research in Korea, Hong's dissertation was based on RIM (Haase, Kintner, Monahan, & Robb, 2014). The purpose was to identify the factors relating to resilience for adolescents with leukemia and examine the relationship between these factors in physical, psychosocial and spiritual aspects. The design was a cross-sectional and descriptive study. To verify the predictors and the effects of resilience, uncertainty, symptom distress, perceived social support, spiritual perspective, defensive coping, courageous coping, hope, and self-transcendence were measured. The final regression model showed that courageous coping, hope, and self-transcendence were significant predictors related to resilience in adolescents with leukemia (Hong & Park, 2015).

These studies indicate the potential usefulness of using RIM to guide research in Asia and at the same time, it is clear that cultural differences (e.g. the communication patterns of parents and AYA with in Western and Eastern cultures and differences in spiritual perspectives in China) need further research.

Title:

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Keywords:

Adolescents/Young Adults, Chronic Illness and Resilience

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Abstract Summary:

We describe the Resilience in Illness Model (RIM) research, including: 1) an overview of the RIM development; 2) RIM's risk and protective factors, positive and negative paths influencing the outcomes; 2) RIM multi-site intervention and descriptive research with adolescents/young adults (AYA) with chronic illness in the US and Asia.

Content Outline:

1. Overview of RIM Development: Aims, Framework, Development of the RIM
2. Overview of RIM Risk Factors, Protective Factors, and Outcomes
3. The Importance of obtaining AYA perspectives via qualitative research
4. Overview of the RIM Development and Evaluation: Mixed Method Approaches
5. Studies using RIM as the guiding framework for intervention research
 1. Overview of RIM research in the United States.
 1. A multi-site, randomized clinical trial (RCT) of a Therapeutic Music Therapy for AYA with Cancer Intervention including process and outcome reports.
 2. A multi-site RCT of an AYA with cancer and parent communication intervention.
 3. Adaptation of RIM as the guiding framework for the Children's Oncology Group.
 4. Resilience Enhancement for AYA with Cancer and Caregivers (REACH), a profile-based intervention for newly diagnosed AYA and Parent Overview of Studies in Asia.
 2. Overview of RIM studies Asian Countries
 1. Descriptive studies
 2. Potential Cultural Differences in RIM factors

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