Coming Together: Formation of the Asian Resilience Enhancement for Adolescents/Young Adults (AREA) Cooperative Group

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The purpose of this presentation is to provide an overview of the AREA Cooperative Group. Our group was formed in May 2018, when a critical mass of researchers from three Asian countries (i.e., China, Korea, and Taiwan) were studying resilience in adolescents and young adults with cancer using the Resilience in Illness Model (RIM) to guide their research. The RIM is a well-confirmed model developed by Dr. Joan Haase through a series of qualitative and quantitative studies (Haase, 1987; Haase, Britt, Coward, Leidy, & Penn, 1992; Haase, Heiney, Ruccione, & Stutzer, 1999; Haase & Phillips, 2004; Haase et al., 2014; Haase et al., 2016; Docherty et al., 2013; Robb et al., 2014). RIM was adapted as the guiding framework for the Children’s Oncology Group (COG) Nursing Discipline Committee. COG is the primary cooperative group; they are conducting research on cancer in > 80% of children with cancer in North America, Australia, New Zealand, and parts of Europe (Kelly et al., 2014). Through COG, the adapted RIM is used to guide research and clinical practice in North America and parts of Europe.

In this presentation we discuss how our group began—the “glue” which binds us together to accomplish the work, including developing our vision, mission, goals,
organizational structure and feasibility of our work. To begin, several members of our
current Executive Committee convened a Zoom internet meeting to discuss working
together on common projects and formed the AREA Cooperative Group. Additional
researchers from Japan were subsequently added. The organizational structure of the
AREA Cooperative Group is comprised of an Executive Committee, including 11
interdisciplinary healthcare clinicians and scientists from each country and the United
States, and country teams of researchers and clinicians located in hospital and
university settings.
Our vision is to foster resilience in all children with chronic illness worldwide, and our
first mission is to improve resilience in adolescents/young adults (AYA) with cancer in
Asia. Our two-year goals are to foster resilience in AYA with cancer across the four
Asian countries. In this symposium we describe our process for identifying translated
versions and, when necessary, conducting forward/back translation of any RIM
measures not already translated into Chinese Mandarin, Korean, and Taiwanese
Mandarin. We also will describe ways we are connecting with faculty and clinicians at
universities and hospitals in China, Korea and Taiwan to join with us to evaluate the
RIM measures for validity, reliability and cultural sensitivity in each country. We are
beginning this same work in Japan, with a June, 2018 target date for completion. In our
third abstract, we further discuss insights gained from evaluating the measurement and
structural equation model in and across countries with AYA with cancer.
Our work to date is feasible because of our common research interests, use of English
as a common language, availability of time and resources to communicate in real time
to discuss our work, resources for developing a common RedCap database that can
manage internet input of data across around the world, and having university and
hospital support for recruiting AYA and parents, collecting and managing data and
funding the efforts.

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Keywords:
Adolescents/Young Adults with Cancer, International Cooperative Group and Resilience
Enhancement for Adolescents/Young Adults

References:
concept analysis of spiritual perspective, hope, acceptance and self-
transcendence. Journal of Nursing Scholarship, 24(2), 141-147.
triangulation to derive meaning-based quality-of-life theory: Adolescent Resilience
Abstract Summary:
Researchers from five countries came together to foster positive health outcomes, especially resilience in children, adolescents, and young adults with cancer and other chronic illnesses. In this presentation, we describe formation of the AREA Cooperative Group, including our vision, mission, goals, organizational structure, resources and progress to date.

Content Outline:
The AREA Cooperative Groups’ Formation, Vision, Mission, Goals and Structure.
1. The Story of our formation: Who we are, how we became connected and came together to collaborate across 4 countries in Asia (China, Japan, Korea, and Taiwan) and the United States.
2. Our Vision is to foster resilience in all children, adolescents/young adults with chronic illness worldwide.
3. Our Mission is to improve resilience in AYA with cancer in Asia
4. Our 1-2 year Goals:
   a. Translate the Resilience in Illness Model measures into Chinese Mandarin, Korean, Japanese, and Taiwan Mandarin (Now completed in 3 of 4 Countries)
   b. Human Subjects within each country/site.
   c. Complete development of the RedCap data base at Indiana University.
   d. Evaluate all 13 RIM measures for validity, reliability and cultural sensitivity in the 4 Asian countries with AYA with cancer.
   e. Evaluate the measurement and structural equation model in and across all 5 countries.
5. Our Structure:
   a. Executive Committee comprised of 11 interdisciplinary healthcare clinicians and scientists from each country and the United States.
   b. Within country teams of researchers and clinicians located in hospital and university settings.
6. What is necessary to make our work feasible: common research interests, using a common language, resources for communicating, sharing our work in real time, collecting and managing data, and funding the efforts.
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**Author Summary:** The author is the director and associate professor in school of nursing, Kaohsiung Medical University. Specializing in pediatric nursing and palliative care, nursing research, nursing education, and evidence-based nursing.

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**Author Summary:** Qian Liu is a PhD candidate and a faculty in Wuhan University in China, and her PhD dissertation project focuses on evaluating the cultural sensitivity of the Resilience in Illness Model in Adolescents/Young Adults with cancer in mainland China.

Third Secondary Presenting Author

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**Author Summary:** Heeyeon Son is a second year Ph.D student at Duke University School of Nursing. Based on her clinical experience, she has developed interest in improving the quality of life of pediatric cancer patients and their families. Her current research focuses on improving family communication in the context of childhood cancer.

Fourth Secondary Presenting Author

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Author Summary: Her research topics focus on the survivorship of children and AYA with cancer. She is one of the developers of the interdisciplinary seminar program of Lifetime Care and Support for Child, Adolescent, and Young Adult Cancer Survivors (LCAS) entrusted from the Japanese Ministry of Health, Labour, and Welfare.

Author Summary: I got PhD degree in 2007 at Department of Nursing, College of Medicine, in National Taiwan University, Taipei, Taiwan. I majored in pediatric nursing, especially adolescent health, pediatric oncology nursing. My research interests are promoting positive health outcomes of adolescents and young adults with cancer.

Author Summary: Dr. Hong got PhD degree in 2015 at College of Nursing, in Catholic University, Seoul, Korea. Sungsil majored in pediatric nursing, especially pediatric oncology nursing. Sungsil’s research interests are promoting positive health outcomes of children and adolescents with cancer.
Author Summary: Dr. Michin Hong is an Assistant Professor of the Indiana University of Social Work. Her research focuses on long-term care for older adults from family caregiving, home and community-based services to end-of-life care. In particular, she is interested in ethnic/racial disparities in long-term care. She received her BSW and MSW from Ewha Womans University in Korea and a PhD in social work from the University of Maryland.

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Author Summary: Dr. Yvonne Lu is an Associate Professor at the IU School of Nursing. She has over 10 year experience in academia in Colleges/Schools of Nursing that offer doctoral education (DNP and PhD). She is also co-faculty of NIH, NIA, Indiana University Alzheimer Disease Center, Outreach Recruitment and Education Core (P30AG10133).

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Author Summary: Dr. Haase's research focuses on improving the resilience and quality of life of children, adolescents/young adults, and families with cancer. Her Resilience in Illness Model is used internationally to guide research interventions. She is the Co-director of the RESPECT Center that focuses on improving Palliative and End-of-Life Communication and Training.