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

Qian Liu, RN, MSN, Joan E Haase, PhD, RN, FAAN,
Michin Hong, PhD, Li-Min Wu, PhD, RN,
Yvonne Yueh-Feng Lu, PhD, RN, FGSA, Kiyoko Kamibeppu
Overview of the Symposium

- In this symposium we will tell the story of AREA Cooperative Group
  - How we came together
  - Our vision & mission
  - Our first two year goals
  - Our structure
  - Our accomplishments and planning for the future
Why we established the Adolescents and Young Adults with Cancer (AREA) Cooperative Group

- Adolescents and Young Adults (AYA) with Cancer
  - Poorer cancer outcome.
  - Significant interruptions in developmental milestones.
  - Multiple concerns:
    - infertility
    - body image dissatisfaction
    - difficulty establishing relationships
    - many other aspects of physical, emotional, and social well-being.
- Very few psychosocial/behavioral interventions.
The Resilience in Illness Model (RIM): Positive Health Approach to Improve AYA Outcomes.

- Adapted as guiding framework: Children’s Oncology Group (COG) Nursing Discipline Committee
- A well-confirmed model: a series of qualitative and quantitative studies.
- RIM includes
  - Risk factors (Illness-related Risk and Defensive Coping),
  - protective factors (Spiritual Perspective, Social Integration, Hope-derived Meaning, Family Environment, and Courageous Coping);
  - 3 outcomes (Resilience Resolution, Self-transcendence and Sense of Well-being).

Effective guide for intervention research aimed to:
- enhance AYA protective factors
- diminish illness-related distress and defensive coping
- foster positive health outcomes of resilience, self-transcendence and well-being.
Why Resilience in Asian Countries?

- Cancer: Leading cause of death in Asia.
- High interest in positive health and resilience research.
- Components of RIM successfully used.
- A critical mass of researchers studying RIM
- Lack of research on cultural “fit” of RIM.
Our Story of Coming Together

• The beginning idea, May, 2018
  • Dr. Haase’s Spring, 2019 sabbatical
  • Critical mass of researchers
  • Doctoral students from Asia studying resilience
    • 2006 Jan.-July Dr. Chin-Mi Chen, Professor Fu-Jen University, Taipei, Taiwan
    • 2008 Dr. Li-Min Wu, Professor Kaohsiung University, Taiwan
    • 2016-Heeyeon Son from Korea, PhD student at Duke University
    • 2017 Qian Liu, PhD Student and Faculty, Wuhan University;
    • 2019 Sho Murata, PhD Student, University of Tokyo.

• AREA Cooperative Group Faculty
  • USA, Indiana University: Drs. Yvonne Lu (from Taiwan), Michin Hong (from Korea), Dr. Celeste Phillips;
  • Korea: Dr. Sungsil Hong (Nursing);
  • Japan: University of Tokyo, Drs Akiko Ishibashi and Kiyoko Kamibeppu.
Our Vision & Mission

**Vision**
To foster resilience in all children, AYA with chronic illness worldwide

**Mission**
To improve resilience in AYA with cancer in Asia using the RIM as the guide
AREA Organization Chart and Members

Executive Council Chair: Joan Haase

Administrative Research Assistant: TBD

AVA Expert and Co-PI: Celeste Phillips

PhilD Students/Mentees: Oladele Oyede, Michelle Mravec

Biostatistics Team (Co-PIs): Patrick Monahan, Timothy Stump

Country Co-PIs

IU Co-PIs: Michin Hong (Korea) Yvonne Lu (China & Taiwan)

Korea Co-PIs: Heeyeon Son Sungil Hong

Medical Advisors: Jungwoo Han (Severance Hospital) Lee Jaryong (Severance & St. Mary’s Hospitals)

Local Team: Shin yoon jung Jung (Severance) Jin Jung (St. Mary’s)

China PI: Qian Liu

Medical Advisor: Di Deng (Zhongnan Hospital)

Local Team: He Rao (Zhongnan Hospital) Wei Cai (Wuhan Children’s Hospital) Hui-Fen Wang (Hubei Cancer Hospital) Liu-Qing Shi (Hubei Cancer Hospital)

Taiwan Co-PIs: Li-Min Wu Chin-Mi Chen

Medical Advisors: Shinn-Tang Jou (National Taiwan University Hospital) Gion Yi Hung (Taipei Veterans General Hospital)

Local Team: Hsin-Lan Su (Kaohsiung) Chia-Wen Hung (Kaohsiung) Hsiang-Hui Chen (Fujen Catholic University) Shinn-Tang Jou (National Taiwan University) Gion Yi Hung (Taipei Veterans General Hospital)

Japan Co-PIs: Kiyoko Kaminbeppu Akiko Ishibashi Sho Murata

Medical Advisor: TBD

Evaluators Hospital 1 (TBD) Hospital 2 (TBD)
Our Two-Year Goals

- Translate RIM measures
- Human Subjects approvals
- Develop multi-language RedCap
- Evaluate usability of multi-country data bases
- Data collection using RedCap
- Evaluate RIM measures for validity, reliability and cultural sensitivity
- Evaluate the measurement and structural equation model in and across all 5 countries and in comparison, with the American RIM
What Makes Our Work Feasible and Fun

What makes our working together feasible.

► Common research interests
► One common language
► Commitment of time and resources
► Real-time communication via ZOOM
► University and hospital partners in each country

What makes our work fun and meaningful.

► Working with and learning from each other.
► Meeting together at Sigma and other travel between countries.
► Rich discussions: ideas, commonalities, insights.