Envisioning the Future of the AREA Cooperative Group: Meeting Goals and Addressing Challenges

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In this presentation we describe our process of forming AREA, our progress to-date and our vision and potential challenges for the future. This symposium was submitted to STTI just seven months following the conceptualization of the AREA Cooperative Group, and only six months since our first Executive Committee meeting. In that time, we have accomplished much, including: 1) coming together as the Executive/Core team; 2) reaching out to investigators and clinicians in each country to collaborate on this work; 3) assuring we have all RIM measures translated into each country’s language; and 4) beginning dialogue on cultural and linguistic differences across cultures. We attribute our progress to the enthusiasm, dedication, persistence, and knowledge of our founding members. We are very determined to make a difference in the lives of children with chronic illnesses in Asia and world-wide by fostering a paradigm shift wherein the strengths children and families bring to their illness experience are maximized. We also know that sustaining this work requires wisdom, thoughtful planning, and additional expertise to achieve our goals, fulfill our mission, and obtain sustainable resources. So, we dream big.
Preparing this symposium was an excellent way for us to think deeply about who we are and want to be, what we have achieved, and how we will reach our goal to foster resilience in the midst of illness. Our list of short-term goals is well on the way to being accomplished by 2021. These goals are to: 1) complete translation of measures into Japanese; 2) complete and evaluate the RedCap database; 3) complete recruitment and data collection within each country; 4) analyze the RIM psychometric properties and publish findings; 5) evaluate the RIM Measurement and Structural Equation Model for each country and publish outcomes; 6) compare the RIM outcomes across Asian countries and publish outcomes; 7) compare similarities and differences in the ways RIM works in Western and Eastern cultures and publish; 8) let the world know about our work by publishing papers on our research and also on development of the AREA Cooperative Group; 8) obtain funding to support development and maintenance of the web-based data base; 9) establish a quality assurance monitoring system. We know this list is not complete, yet we also know it is important to stay focused. Within our Executive Committee it will be important for us to continue to have time for open dialogue about our current and future work.

Our longer-term research goals for 2021-2024 are to develop and test culturally appropriate interventions for AYA with cancer across collaborating countries and publish. We already have several scientists and clinicians who are interested in developing RIM interventions for children, AYA, and families with other chronic conditions. Because RIM was initially developed with children with a variety of chronic conditions (i.e., cancer, cystic fibrosis, asthma, and cardiac conditions), we already have these measures adapted for each disease in English and plan to extend our work to other chronic illnesses. As the work in each country moves forward, we plan to develop resilience training programs to foster young scientists and clinicians to engage in developing, evaluating, and implementing RIM guided interventions. By the end of 2024, our goal is to be ready to begin globally expanding use of RIM.

In addition to our research goals, we generated a "must-do" list of other goals/activities we know must occur to be successful—some need to occur sooner and some later. We will present our efforts and progress formalizing the AREA Cooperative Group as a sustainable entity. These efforts include documenting our philosophy and mission statement, identifying and attaining sustainable sources of funding within countries and for the ongoing work of the AREA Cooperative Group, deciding on and establishing an organizational structure (e.g. Non-profit Organization, Foundation, Association, a Center for Resilience Enhancement). To sustain our work, we will need to: partner with universities and other entities; establish guidelines, strategies and timelines for adding countries in Asia and then in other parts of our world; extend our membership to include a wider interprofessional network of scientists and clinicians. We are already beginning partnerships with physicians, social workers, psychologists, and others to conduct studies in our four Asian countries. We also will need to obtain legal advice to establish formal agreements (e.g. intellectual property, data use, and copyright agreements) and formalize policies and processes for timely, meaningful and consistent dissemination of AREA Cooperative Group project processes and outcomes (e.g. dissemination and authorship guidelines).

We also recognize we have significant challenges. Some challenges are to establish sustainable resources over time, implement and monitor best practices to assure
sustained enthusiasm and effort, assure we keep pace with communication
technologies. Lastly and most importantly, we need to assure that we consistently focus
on our mission to globally foster resilience in children, adolescents, and young adults
with chronic illness by developing efficacious RIM interventions and implementing them
into clinical practice.
The opportunity to prepare this a symposium for STTI provided our Executive
Committee with a perfect and timely opportunity to think about the current and future
work of the AREA Cooperative Group. Our work is just beginning, and we have much to
learn. During the last part of this session, we plan to engage our audience in dialogue
about this work and seek their own knowledge and expertise on our plans.

Title:
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oncology. Seminars in Oncology Nursing, 34(4), 402-408.
doi:10.1016/j.soncn.2018.09.009
Understanding the culture of Chinese children and families. The Journal of School
Nursing, 21(1), 3-9.
Dycus, P., & McKeon, L. (2009). Using QSEN to measure quality and safety knowledge,
skills, and attitudes of experienced pediatric oncology nurses: an international
doi:10.1097/QMH.0b013e3181aea256
practice Nursing Management - UK, 19(7), 14-19.
doi:10.1097/NCC.0000000000000433
Casado, B. L., Negi, N., & Hong, M. (2012). Culturally-competent social work research:
Methodological consideration for research with language minorities. Social Work, 57, 1-10.
doi: 10.1093/sw/swr002

Abstract Summary:
This presentation focuses on our plans for the AREA Cooperative Group's future. We
discuss our short/long-term goals and challenges. Short-term research goals:
completing recruitment, data collection, and data analysis across countries and
compare Eastern and Western similarities and differences. Long-term goals include expansion to other chronic illness and world-wide AREA expansion.

**Content Outline:**
- The purpose of this presentation is to describe our plans for the future. We will discuss our short- and long-term goals and anticipated challenges over time and also allot time for audience discussion and feedback about this global initiative.
  - Our short-term research goals (2019-2021)
    - Complete translation of measures into Japanese
    - Complete and evaluate the RedCap database
    - Complete recruitment and data collection within each country
    - Analyze the RIM psychometric properties and publish results
    - Analyze of the RIM Measurement and Structural Equation Model and publish results
    - Compare the RIM outcomes across Asian Countries and publish results
    - Compare RIM: Western and Eastern Similarities and Differences and publish
    - Publish papers on development of the AREA Cooperative Group and on RIM's psychometric properties, fit of the model and cultural appropriateness outcomes
    - Obtain funding to support development and maintenance of the web-based data base
    - Establish a quality assurance monitoring system. Others to be determined
  - Our longer-term research goals (2021-2024)
    - Develop and test culturally appropriate interventions for AYA with cancer across collaborating countries and publications
    - Develop resilience training programs to foster young scientist development
    - Develop training program to implement evidenced-based research findings into clinical practice
    - Globally expand use of RIM into clinical practice
  - Other “must do” goals/activities
    - Finalize the AREA Cooperative Group’s Philosophy and Mission Statement.
    - Identify sustainable sources of funding within countries and for the ongoing work of the AREA Cooperative Group
    - Develop a business model, including guidelines, strategies and timelines for adding additional countries in Asia and other parts of our world.
    - Expand our membership to include a wide interprofessional network of scientists and clinicians.
    - Develop data use and copyright agreements
    - Meaningful and Consistent dissemination of AREA Cooperative Group project processes and outcomes
    - Establish dissemination and authorship guidelines
    - STTI as a perfect first effort
  - Anticipated challenges over time
    - Developing sustained funding sources
    - Establishing strategies to assure sustained enthusiasm and effort
    - Monitoring established communication, cooperative, and time management strategies and adjust as needed
    - Monitoring and addressing data management and safety
    - Implementing efficacious RIM interventions into clinical practice
Expanding AREA to new countries and on-boarding new within-country recruitment sites

- Responses, feedback, and ideas of attendees related to AREA Cooperative as a global initiative

First Primary Presenting Author

**Primary Presenting Author**
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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.

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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.

Tenth 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.

Eleventh Secondary Presenting Author

Corresponding Secondary Presenting Author

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Author Summary: My research is on Resilience in Adolescents/Young Adults with Cancer. My research focuses on resilience of AYAs with cancer. I am conducting interviews the AYA about psychosocial thoughts, feeling, hope and purpose in future. I am also studying parents of AYA.