



The 2014 National Nursing Research Roundtable: The science of caregiving

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ABSTRACT

The National Nursing Research Roundtable (NNRR) meets annually to provide an opportunity for the leaders of nursing organizations with a research mission to discuss and disseminate research findings to improve health outcomes. In 2014, the NNRR addressed the science of caregiving, a topic of increasing importance given that more people are living with chronic conditions and that managing chronic illness is shifting from providers to individuals, their families, and the communities where they live. The NNRR consisted of scientific presentations in which leading researchers discussed the latest advances in caregiving science across the life span and breakout sessions where specific questions were discussed. The questions focused on the policy and practice implications of caregiving science and provided an opportunity for nursing leaders to discuss ways to advance caregiving science. The nursing community is ideally positioned to design and test caregiver health interventions and to implement these interventions in clinical and community settings.

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The mission of the National Nursing Research Roundtable (NNRR) is to serve the public's health through the development of a strong, research-based nursing practice. As a collaborative of nursing organizations, the NNRR provides clinicians, scientists, educators, scholars, and policy leaders an opportunity to come together to discuss priorities in science, practice, and policy; to envision the future; and to act on this vision with prescience and ingenuity.

The NNRR is committed to fostering research excellence, which provides the scientific foundation for improvements in health and health care. The NNRR seeks to promote and protect the health and well-being of all people, including unrepresented, underrepresented, at-risk, and vulnerable populations. In this sense, scientific excellence and excellence in practice

are matched by leadership that reflects compassion and connection to the constituencies they serve.

Since 1987, leaders from the health sciences have joined leaders in the health care community at the annual meeting of the NNRR. Together, they share advances in science and practice as they work to identify, enhance, and leverage research resources; assess research challenges, gaps, redundancies, and opportunities; and pinpoint and support strategies, innovations, and policy initiatives that fuel new discoveries in science driving the translation of these discoveries into improvements in our nation's health.

The 2014 NNRR was cosponsored by the Oncology Nursing Society (ONS) and the National Institute of Nursing Research (NINR), part of the National Institutes of Health. Representatives from over a dozen

professional nursing societies met with colleagues from other disciplines and professions to discuss the science of caregiving, a topic of increasing importance as the number of people living with chronic conditions grows. One of the outputs from the meeting will be a scholarly paper describing the role of caregiving in advancing health care and offers suggestions to advance research (Grady & Rosenbaum, in preparation).

The NNRR is a mix of formal scientific presentations, roundtable discussions, and breakout sessions. In her opening remarks, ONS President Dr. Mary Gullatte described current ONS activities, including the ONS Foundation's ongoing support of research funding for nurse scientists and young investigators. A recently launched ONS initiative focuses on an innovative campaign, "Get Up, Get Moving," to encourage cancer nurses to teach patients about evidence-based use of physical exercise as an intervention for cancer and cancer treatment-related fatigue. Dr. Gullatte stated the meeting's goal—to identify opportunities for future interprofessional research collaborations and partnerships across organizations to guide outcomes for patients and caregivers across the life span.

NINR Director Dr. Patricia Grady provided an NINR update in which she summarized the NINR-supported studies focused on caregiving. Dr. Grady noted that the management of chronic illness is shifting from health care providers to individuals, their families, and the communities where they live, and there is an increasing awareness that the responsibilities of caring for family members and friends can have a significant impact on the health of informal caregivers. She added that caregiver health is an area in which the nursing community is ideally positioned to design and test caregiver health interventions and translate research findings into clinical and community health practices.

The keynote address was presented by Dr. Michael Irwin of the University of California, Los Angeles, who discussed health issues of dementia caregivers. He noted that there are more than 10 million dementia caregivers, and they have a 63% higher mortality risk than noncaregivers (Schulz & Beach, 1999), with some of this increased risk associated with increased inflammation (Frasure-Smith et al., 2007; Ko et al., 2012; Ridker, Hennekens, Buring, & Rifai, 2000).

Dr. Irwin also focused on sleep as a modifiable risk factor that contributes to fatigue, depression, and other health issues. More than 60% of older adult caregivers report sleep disturbances (McCurry, Logsdon, Teri, & Vitiello, 2007), and the rate of sleep disturbance in dementia caregivers is twice that of the general population. Uniting these two areas, Dr. Irwin's research has pursued a possible causal link between sleep disturbance and inflammation and subsequent behavioral outcomes that may be relevant to caregivers. Findings from Dr. Irwin's team and others have identified potential molecular markers of inflammation that correlate with depression (Eisenberger, Inagaki, Mashal, & Irwin, 2010; Eisenberger, Inagaki, Rameson,

Mashal, & Irwin, 2009; Gimeno et al., 2009; Raison et al., 2013; Slavich & Irwin, 2014).

Dr. Irwin concluded by recommending future research directions, such as further studies addressing the association between sleep disturbance and inflammation that may contribute to cardiovascular disease and increased mortality. Dr. Irwin suggested that caregiver assessments should include behavioral (e.g., sleep), emotional (e.g., depression), and biological (e.g., inflammation) domains.

Drs. Kathleen Knafl, Laurel Northouse, and Laura Gitlin provided scientific presentations about caregiving across the life span. Topics included parenting and caregiving for children with chronic conditions, caregiving when illness happens at midlife (e.g., cancer diagnosis), and caregiving in the elderly (e.g., persons with dementia).

Dr. Knafl (School of Nursing, University of North Carolina at Chapel Hill) cited family research as a primary approach for addressing parental caregiving of children with chronic conditions, noting that families' experiences vary, even when the pediatric patients have the same condition. To understand the factors contributing to these differences and the outcomes for patients, parents, and families, major lines of inquiry in family research involve the family response to the patient's condition, the effect of parenting behaviors and the parent-child relationship on the child's response, and the effectiveness of family-oriented interventions.

Knafl et al. (2013) have developed and tested a new family management assessment tool. It incorporates several measurement scales, covering a spectrum of family behaviors, and yields four patterns of family response to a child with a chronic condition.

Dr. Knafl described the following effective family-oriented interventions in the context of chronic pediatric conditions: building knowledge and skills (psychoeducational), improving family relations, and addressing family dysfunction. Promising areas of inquiry include the characterization of common psychosocial challenges across conditions that can be implemented in tailored interventions and the use of systematic mixed methods analyses to address research questions.

In her presentation, Dr. Northouse (School of Nursing, University of Michigan and ONS's 2013 Distinguished Researcher) noted that recovery from cancer treatment occurs in the home, and family caregivers often feel unprepared to take on these responsibilities. Studies have revealed a number of adverse symptoms in cancer caregivers such as elevated rates of depression, sleep problems, and alcohol use; decreased physical activity; and weight gain (Beesley, Price, & Webb, 2011; Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007). Also, caregivers are more likely to forget to take their own medications.

Dr. Northouse's ongoing FOCUS program is a psychoeducational intervention for cancer patient-caregiver dyads that includes nurse-facilitated

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