



Published in final edited form as:

Nurs Outlook. 2014 ; 62(5): 362–365. doi:10.1016/j.outlook.2014.05.007.

The 2014 National Nursing Research Roundtable: The science of caregiving

Patricia A. Grady, PhD, RN, FAAN^a and Mary Gullatte, PhD, RN, ANP-BC, AOCN, FAAN^b

^aNational Institute of Nursing Research, National Institutes of Health, Bethesda, MD

^bOncology Nursing Society, Pittsburgh, PA

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.

Keywords

Caregivers; Caregiver/psychology; Chronic illnesses; Nursing research

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 care-giving 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.

Knafl et al. 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 Distinguished Researcher 2013) 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 conversation and providing health information. It has been tested in patient-caregiver dyads who are managing different types of cancers at different stages of disease (Northouse et al., 2013; Northouse et al., 2002). The researchers found that caregivers at both low and high risk for distress benefited from the intervention. A feasibility study of a web-based translation of the FOCUS intervention yielded similar outcomes, such as improvements in quality of life, ability to cope, communication about illness, and reduced emotional distress (Zulman et al., 2012). In addition, the intervention was adapted for community distribution, and similar outcomes were achieved when it was implemented by social workers rather than researchers. Several meta-analyses have shown that caregiver interventions are effective in reducing burden, depression, and distress and in improving physical health, coping, and several other aspects of caregiver health (Candy, Jones, Drake, Leurent, & King, 2011; Hartmann, Bazner, Wild, Eisler, & Herzog, 2010; Martire, Schulz, Helgeson, Small, & Saghafi, 2010; Northouse, Katapodi, Song, Zhang, & Mood, 2010). However, few of these interventions have been implemented in practice.

Rounding out the formal presentations, Dr. Gitlin (Schools of Nursing and Medicine, Johns Hopkins University) noted that our understanding of caregiving is hampered by inconsistent data, the lack of a standard definition of caregiving, poor information on nonfamily caregivers, and the impact of attending health care visits and episodic care. The cost of dementia caregiving is much higher than for other conditions in terms of dollars as well as time. The caregiving tasks are incremental and cumulative through progression of the disease. Elderly patients are being discharged from health care facilities earlier, and families are taking on more nursing tasks (Reinhard, Levine, & Samis, 2012). With these increased health care responsibilities, family caregivers worry about making mistakes, and with more caregiving tasks, the prevalence of depression increases.

The bulk of caregiver research has been conducted during the moderate stages of dementia. These studies have identified effective interventions for family caregivers that improve caregiver knowledge, burden, self-efficacy, anxiety, and depression and delay institutionalization of the dementia patient (Brodaty & Arasaratnam, 2012; Gitlin et al., 2003; Zarit & Femia, 2008). Although a number of effective interventions have been tested, they have not been implemented in practice. Dr. Gitlin encouraged the incorporation of implementation science into trial designs. She also recommended consideration of hybrid/pragmatic trial designs for interventions that balance the scales between discovery and translation/implementation. Because the focus of most dementia caregiving research has been during the moderate stages of the disease, research is needed on the early stages as well as the late stages because dementia caregiving can last 20 years.

The breakout sessions and discussion portions of the NNRR concentrated on (a) the practice implications of caregiving science, (b) policy opportunities for caregiving science, and (c) strategies NNRR member organizations and NINR could use to advance care-giving science. The implementation of existing interventions was identified as critical for bringing caregiving science to practice and for improving care-giver health. Educational materials could be developed for home delivery via Skype, WebEx, or other technologies. Caregivers,

patients, families, and the community should be included in the development of interventions. Families need to be apprised of their postdischarge responsibilities and provided with associated resources. Consideration needs to be given to the fact that relatives may not be available to provide care to their family member. Because of this, testing of interventions should include the broader community such as neighbors, friends, and other informal caregivers.

The attendees noted that research can be used to raise awareness of caregiver burdens and contribute to policy changes. Caregiving science shows the impact on caregivers' income, benefits, insurance, retirement, and quality of life. Employer awareness and participation can contribute to the development of policies to support flexible work schedules and employee absences. Additional studies could be conducted on the return on investment for supporting and training caregivers. Because hospital readmissions may affect reimbursement, hospitals can be partners in the development of caregiver readiness plans. Caregiver assessment measures can support quality improvement and the development of a framework to provide family members with reimbursement for caregiving, so that they may keep the care recipient in the home rather than paying for care in institutions.

Participants recommended the application of a variety of methodologies such as pragmatic trials, secondary analysis of existing data sets, testing existing interventions in different settings, and using large data sets to advance caregiving science. The harmonization of measurements (e.g., common data elements and common assessment tools for key constructs) would also enhance research efforts. The impact of unprepared caregivers could be evaluated. An inventory of interventions and what they accomplish could include evidence-based report cards that summarize the research behind each intervention and the variable outcomes for pragmatic application (i.e., which intervention is best for which situation/ caregiver-patient profile). NNRR member organizations could support caregiver research; design conferences on caregiving; and produce journal articles/special issues, blogs, and other communications.

The annual meeting of the NNRR fosters communication, promotes collaboration, disseminates knowledge, and informs research efforts on a national scale. The 2014 NNRR provided leaders of nursing organizations that have a research mission with creative and thoughtful ideas regarding the ways in which their organizations might move the science of caregiving forward. Nurse scientists are at the forefront of interdisciplinary teams that are developing the evidence base for caregiving interventions and translating those interventions into practice and policy.

Acknowledgments

The authors acknowledge the contributions of Drs. Louise Rosenbaum, Arthur Meltzer, Karen Huss, and Lois Tully from the National Institute of Nursing Research in preparation of this manuscript.

References

Beesley VL, Price MA, Webb PM. Loss of lifestyle: Health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Supportive Care in Cancer*. 2011; 19(12):1949–1956. [PubMed: 21125296]

Nurs Outlook. Author manuscript; available in PMC 2015 September 01.

- Braun M, Mikulincer M, Rydall A, Walsh A, Rodin G. Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology*. 2007; 25(30):4829–4834. [PubMed: 17947732]
- Brodaty H, Arasaratnam C. Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *American Journal of Psychiatry*. 2012; 169(9):946–953. [PubMed: 22952073]
- Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database of Systematic Reviews*. 2011; (6):CD007617. [PubMed: 21678368]
- Eisenberger NI, Inagaki TK, Mashal NM, Irwin MR. Inflammation and social experience: An inflammatory challenge induces feelings of social disconnection in addition to depressed mood. *Brain, Behavior, and Immunity*. 2010; 24(4):558–563.
- Eisenberger NI, Inagaki TK, Rameson LT, Mashal NM, Irwin MR. An fMRI study of cytokine-induced depressed mood and social pain: The role of sex differences. *Neuroimage*. 2009; 47(3): 881–890. [PubMed: 19376240]
- Frasure-Smith N, Lesperance F, Irwin MR, Sauve C, Lesperance J, Theroux P. Depression, C-reactive protein and two-year major adverse cardiac events in men after acute coronary syndromes. *Biological Psychiatry*. 2007; 62(4):302–308. [PubMed: 17210140]
- Gimeno D, Kivimaki M, Brunner EJ, Elovainio M, De Vogli R, Steptoe A, Ferrie JE. Associations of C-reactive protein and interleukin-6 with cognitive symptoms of depression: 12-year follow-up of the Whitehall II study. *Psychological Medicine*. 2009; 39(3):413–423. [PubMed: 18533059]
- Gitlin LN, Belle SH, Burgio LD, Czaja SJ, Mahoney D, Gallagher-Thompson D, Ory MG. Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging*. 2003; 18(3):361–374. [PubMed: 14518800]
- Hartmann M, Bazner E, Wild B, Eisler I, Herzog W. Effects of interventions involving the family in the treatment of adult patients with chronic physical diseases: A meta-analysis. *Psychotherapy and Psychosomatics*. 2010; 79(3):136–148. [PubMed: 20185970]
- Knafel KA, Deatrick JA, Knafel GJ, Gallo AM, Grey M, Dixon J. Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing*. 2013; 28(6):523–535. [PubMed: 23602651]
- Ko YJ, Kwon YM, Kim KH, Choi HC, Chun SH, Yoon HJ, Park M. High-sensitivity C-reactive protein levels and cancer mortality. *Cancer Epidemiology, Biomarkers & Prevention*. 2012; 21(11):2076–2086.
- Martire LM, Schulz R, Helgeson VS, Small BJ, Saghafe EM. Review and meta-analysis of couple-oriented interventions for chronic illness. *Annals of Behavioral Medicine*. 2010; 40(3):325–342. [PubMed: 20697859]
- McCurry SM, Logsdon RG, Teri L, Vitiello MV. Sleep disturbances in caregivers of persons with dementia: Contributing factors and treatment implications. *Sleep Medicine Reviews*. 2007; 11(2): 143–153. [PubMed: 17287134]
- Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*. 2010; 60(5):317–339. [PubMed: 20709946]
- Northouse LL, Mood DW, Schafenacker A, Kalemkerian G, Zalupski M, LoRusso P, Kershaw T. Randomized clinical trial of a brief and extensive dyadic intervention for advanced cancer patients and their family caregivers. *Psychooncology*. 2013; 22(3):555–563. [PubMed: 22290823]
- Northouse LL, Walker J, Schafenacker A, Mood D, Mellon S, Galvin E, Freeman-Gibb L. A family-based program of care for women with recurrent breast cancer and their family members. *Oncology Nursing Forum*. 2002; 29(10):1411–1419. [PubMed: 12432412]
- Raison CL, Rutherford RE, Woolwine BJ, Shuo C, Schettler P, Drake DF, Miller AH. A randomized controlled trial of the tumor necrosis factor antagonist infliximab for treatment-resistant depression: The role of baseline inflammatory biomarkers. *JAMA Psychiatry*. 2013; 70(1):31–41. [PubMed: 22945416]
- Ridker PM, Hennekens CH, Buring JE, Rifai N. C-reactive protein and other markers of inflammation in the prediction of cardiovascular disease in women. *New England Journal of Medicine*. 2000; 342(12):836–843. [PubMed: 10733371]

- Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*. 1999; 282(23):2215–2219. [PubMed: 10605972]
- Slavich GM, Irwin MR. From stress to inflammation and major depressive disorder: A social signal transduction theory of depression. *Psychological Bulletin*. 2014; 140(3):774–815. [PubMed: 24417575]
- Zarit S, Femia E. Behavioral and psychosocial interventions for family caregivers. *American Journal of Nursing*. 2008; 108(9 Suppl):47–53. quiz 53. [PubMed: 18797226]
- Zulman DM, Schafenacker A, Barr KL, Moore IT, Fisher J, McCurdy K, Northouse L. Adapting an in-person patient-caregiver communication intervention to a tailored web-based format. *Psychooncology*. 2012; 21(3):336–341. [PubMed: 21830255]