This special issue of Nursing Outlook is focused on symptom science and reflects the results of a conference titled “Innovative Approaches to Symptom Science: Measurement and Analysis” held in Washington, DC, on October 16, 2013. Sponsored by the Council for the Advancement of Nursing Science (CANS), the articles in this special issue highlight state-of-the-art developments in symptom science. We provide a summary here of the articles included in this special issue and describe the contributions of the National Institute of Nursing Research (NINR) to advancing symptom science.

Children, adults, and elders living in the United States often suffer from illness and comorbidities that result in distressing symptoms. These symptoms may profoundly alter or limit activities, with negative impacts on family relationships, work productivity, and quality of life. These symptoms also require additional health care resources and caregiving. A symptom, by its very nature, is a subjective experience that is difficult to measure with current technologies. Without a “gold standard” or common metrics, research findings are difficult to compare across studies and populations.

To realize the goal of a standardized research approach to measurement, many institutes at the National Institutes of Health (NIH), including the NINR, supported the development of the Patient-Reported Outcomes Measurement Information System (PROMIS). The first two articles in this special issue reflect the innovative development and use of PROMIS measures as presented at the CANS conference (Bevans, Ross, & Cella; Badger, Heitkemper, Lee, & Bruner). Symptom domains, such as insomnia, pain, anger, anxiety, depression, nausea, and fatigue, are represented among the various validated and standardized measures in the PROMIS measurement bank (www.nihpromis.org), and the first two articles discuss the history of PROMIS (Bevans, Ross, & Cella) and how some of these symptom measures are currently being applied by nurse scientists (Badger, Heitkemper, Lee, & Bruner).

A symptom, or a cluster of symptoms, may be caused by a disease process or result from the clinical intervention being used to treat the disease or health problem (i.e., iatrogenic). In addition to children and adults living with a disabling chronic illness, there are also many individuals who are undiagnosed or otherwise considered healthy but experience symptoms that are frequent and distressing. These individuals often continue to go to school or work, interact with friends and family, and live productive lives. Therefore, we need to better understand the trajectory of the symptom experience over time and clarify signals indicating when a particular symptom becomes detrimental to the individual, their family, and/or society. The complexity of these trajectories and interactions between the person and the environment require more innovative methods of analyses. Dr. Armstrong describes novel ways to analyze symptom data over time in patients undergoing cancer treatment. Lee, Dziadkowiec, and Meek illustrate the complexity of understanding the symptom experience within complex social environments using examples of fatigue in healthy shift-working adults and fatigue in patients with chronic illness.

The conclusions and recommendations by the authors in this special issue align with NINR’s strategic goals to advance understanding of the mechanisms involved in symptom expression and the development of innovative interventions to relieve or eliminate symptoms. The final article in this special issue by Corwin et al. addresses recommendations for further knowledge development in symptom science and provides corresponding policy recommendations.

The NINR has helped advance the research agenda for symptom science by supporting investigations to improve our understanding of the biology underlying symptoms as well as symptom experiences across illnesses, treatment protocols, settings, and populations. As research in symptom science becomes more complex, interdisciplinary research teams are required to advance the science. Many NINR-supported investigators are currently testing personalized strategies to manage adverse symptoms with interdisciplinary teams. The NINR has helped establish Centers of Excellence in Symptom Science that enable interdisciplinary research through the development of research infrastructure and centralized resources. The centers are intended
to create sustainable, collaborative research programs that use state-of-the-art genomics and bio-behavioral methods. Selected areas of interest for these centers include the genomics of pain, sleep, and cognition.

The complexity of symptom science also requires advanced methodological expertise. The NINR convenes symptoms science methodologies boot camps that bring together researchers to advance symptom science methods. Past boot camps have focused on pain, sleep, and fatigue. "Big Data in Symptoms Research" is the focus of the 2014 boot camp. Another training opportunity for symptoms scientists is the Summer Genetics Institute. The goal of the Summer Genetics Institute is to increase basic science research capability among graduate students and faculty. Additional information is available at the NINR website under training opportunities (www.ninr.nih.gov). Opportunities for training with NINR’s intramural scientists are also available. The focus of NINR’s Division of Intramural Research is to investigate the biology underlying symptoms. Current intramural investigations include the biological mechanisms of fatigue, insomnia, post-traumatic stress, and gastrointestinal symptoms. Understanding biological mechanisms can lead to targeted therapies for symptom management.

The presentations at the 2013 CANS conference, reflected in this special issue of Nursing Outlook, highlight just some of the state-of-the-art developments in symptom science. The NINR continues to advance symptom science through training opportunities and funding to support innovative research methods and analyses. Evidence-based methods to manage distressing symptoms and maximize quality of life are at the forefront of nursing science and clinical practice.

NINR Additional Selected Symptom Science Resources: www.NINR.NIH.gov

Training Opportunities: www.ninr.nih.gov/training/trainingopportunitiesintramural/bootcamp

Symptom Management: http://www.ninr.nih.gov/researchandfunding/symptommanagement

Pain: http://www.ninr.nih.gov/researchandfunding/painspotlight

End-of-Life and Palliative Care Resources: Fact Sheets and Historic Overview: http://www.ninr.nih.gov/researchandfunding/spotlight-on-end-of-life-research

NINR Publication “Palliative Care: The Relief You Need When You're Experiencing the Symptoms of Serious Illness": http://www.ninr.nih.gov/newsandinformation/ninrpublications/palliative-care-brochure
http://www.ninr.nih.gov/newsandinformation/because-of-nursing-research-curtis-eol

NINR Research Highlights: http://www.ninr.nih.gov/researchandfunding/researchhighlights

NINR YouTube Channel: http://www.youtube.com/user/NINRnews

NINR Funding Opportunity Announcements: http://www.ninr.nih.gov/researchandfunding/dea/oep/fundingopportunities

NIH Resources


NIH OppNet: 24 Institutes & Centers and 5 offices participate in the Basic Behavioral and Social Science Opportunity Network to expand the NIH portfolio in basic scientific inquiry that explains the mechanisms and processes that influence individual and group health-related behaviors: http://oppnet.nih.gov/.

NIH Blueprint for Neuroscience Research: a cooperative effort of 15 NIH institutes, centers, and offices that support neuroscience research including the NIH Toolbox, Grand Challenge on Pain, The Human Connectome Project, Blueprint Neurotherapeutics Network for nervous system disorders ranging from vision loss to neurodegenerative disease to depression, and BRAIN Initiative: http://neuroscienceblueprint.nih.gov/.

National Center on Sleep Disorders Research: http://www.nhlbi.nih.gov/about/ncsdr.


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