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The National Institutes of Health/National Institutes of Nursing Research Intramural Research Program and the Development of the NIH Symptom Science Model

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Abstract

The National Institute of Nursing Research (NINR) Intramural Research Program conducts basic and biobehavioral symptom science research, and provides training opportunities to the next generation of scientists. Recently, NINR developed the Symptom Science Model to guide research. The model begins by identifying a complex symptom, which is then characterized into a phenotype with biological and clinical data, followed by the application of genomic and other discovery methodologies to illuminate targets for therapeutic and clinical interventions. Using the Symptom Science Model, the intramural program organizes and implements biobehavioral, symptom management, and tissue injury research. The model is also used as a framework for training and career development opportunities including oncampus trainings, and research fellowship. The scientific goal of the intramural program is to enhance patient outcomes including health-related quality of life. Achieving this goal requires a long-term vision, continued resource investments, and a commitment to mentoring our next generation of scientists.

Introduction

With training and expertise in both clinical and research enterprises, nurse scientists occupy a unique and fundamental position in health research. At the National Institutes of Health (NIH), an intramural research program (IRP) was established within the National Institute of Nursing Research (NINR) to conduct basic and biobehavioral symptom science research, in an environment that provides training for the next generation of nurse scientists in symptom science. The NINR-IRP undertakes leading-edge research to determine the underlying behavioral and molecular mechanisms of symptoms associated with a variety of disorders. The overall goal of the program is the development of novel clinical interventions to alleviate these symptoms. Recently, NINR scientists developed a new model, the National

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Institutes of Health Symptom Science Model (NIH-SSM), to provide direction and focus to the research conducted within the NINR-IRP, and, with potential to inform scientific communities within the NIH and in the extramural research enterprise. The purpose of this article is to provide an overall scientific framework using the NIH Symptom Science Model, briefly describe how the research and training programs within the NINR-IRP use the model, and, to suggest ways that research investigators can use the model to move symptom science research forward.

The NIH Symptom Science Model

In the NINR-IRP, scientists conduct symptom science research through a disease agnostic lens. They have expertise in quantifying subjective symptom experiences and measuring the biologic, physiologic, and 'omic' underpinnings of the symptoms and sequelae common to health conditions and their treatments. This expertise is critical to continued scientific progress and innovation, as novel discoveries require the integration of behavioral and biologic data and development of models to predict, treat, and manage the symptoms of diseases and treatments. One such model, the NIH Symptom Science Model (Figure 1), was developed to guide research in symptom science, initially within the NINR-IRP, but with broader application to symptom science across the NIH and extramural research communities. The model describes an investigative sequence for symptom science, beginning with a complex symptom, sequelae, or cluster of symptoms, which can then be characterized into a phenotype with biological and clinical data, followed by the application of genomic and other discovery methodologies to illuminate targets for therapeutic and clinical interventions.

For example, a kidney transplant recipient may present with extreme weight gain following transplantation. Knowing that weight gain can lead to such adverse outcomes as diabetes, hypertension, cardiovascular disease or further deterioration of renal function, health care providers may be interested in developing and tailoring interventions to predict, prevent, and/or treat weight gain in this patient population. To phenotype post-transplant weight gain, researchers can gather clinical and biomarker data such as longitudinal measures of weight, related metabolic markers, and standardized reports on behavioral and mental health conditions such as depression, which have been previously linked to weight gain. The emerging phenotype(s) would then be examined through conducting biologic, physiologic, 'omic' analyses to refine discovery of biomarkers, pathways, and conditions that predict or protect against post-transplant weight gain. Finally, the 'omic' data in combination with clinical and behavioral information, ultimately lead to informed clinical applications and precision medicine for symptom reduction, improvement, and prevention. In the NINR-IRP, this model is currently being used to guide research as well as to provide a framework for science training programs.

Science and Organization of the NINR-IRP

The multitude of symptoms associated with a single illness; or, in many cases, occurring with co-morbid illnesses or conditions, often compromise or govern the lived experience of individuals suffering from these conditions. Nursing science, with its foundational link to the lived experiences of individuals, provides a unique scientific perspective into both the

clinical and biologic features of symptoms and sequelae. This expertise is critical to continued scientific progress towards innovation in symptom science. In recent years, scientists in the NINR-IRP have been successfully employing what would become the essential components of the NIH Symptom Science Model, guiding productive research in the area of symptom science, using complex phenotypes and illustrating how to employ ‘omic’ methods to predict at risk groups, monitor treatment, and guide interventions.¹ In the NINR intramural research program, scientists are actively engaged in conducting symptom research, with expertise in quantification of both the experiences and expressions of symptoms and sequelae common to a broad variety of conditions and treatments. Specifically, NINR-IRP scientists are dedicated to conducting research on the molecular and behavioral mechanisms underlying symptoms, recognizing that environmental influences, such as behavior, lifestyle, and diet can impact individual outcomes.

The NINR-IRP is organized into three program areas focusing on biobehavioral research, symptom management research, and tissue injury research. Each research program organizes and implements its research using the NIH Symptom Science Model. The support provided by the NINR-IRP structure, the leading-edge resources of the NIH, and the clinical-science expertise of the NINR-IRP scientists provide an ideal combination to examine the impact of individual genetic variability inherent in symptoms associated with conditions such as cancer related fatigue, digestive disorders, post-traumatic stress and traumatic brain injury. The ultimate scientific goal of the NINR-IRP is to enhance patient outcomes including health-related quality of life. Achieving this goal requires a long-term vision, continued resource investments, and a commitment to mentoring our next generation of scientists.

NINR Intramural Training

The NINR-IRP provides scientific leadership and intensive research training to enhance the biologic, physiologic, and ‘omics’ research enterprise and success of the nurse scientist workforce of the future. NINR provides intramural research training for nurse scientists at all stages of their careers to strengthen the scientific foundation and basis for clinical practice. NINR-IRP offers training and career development opportunities through NIH on-campus trainings, research fellowship, and career development awards. The NINR-IRP offers a place for a diversity of nurse scientists to develop, and continue building cutting-edge research skills, refining their application within the NIH Symptom Science Model.

The on-campus training programs include the NINR Symptom Methodologies Boot Camps, the Summer Genetics Institute, the Graduate Partnerships Program, and research fellowships at a variety of pre- and post-graduate levels. In its four-year history, the Boot Camps have provided over 250 graduate students, faculty, and clinicians from 50 institutions around the nation with a foundation in research methodologies focusing on symptoms such as pain, fatigue and sleep. In 2014, the focus was on Big Data in Symptoms Research. The methodologies include measurement, treatment, genetics, and laboratory experiences. Another research training opportunity on the NIH Bethesda campus is the annual Summer

¹Council for Advancing Nursing Science in the Fall of 2014, “Combining Complex Phenotypes with Genomics/Proteomics to Predict and Improve Patient Symptoms” and Note: This paper and the next paper (Henderson, Gill, Saligan, Hawes, Cashion) are a result of the original presentation.

Genetics Institute (SGI), a month-long intensive program of laboratory and classroom instruction aimed at building molecular genetics expertise for use in biobehavioral research and clinical practice. More than 300 alumni from the fifteen SGI programs are now advancing genetics and genomics research, integrating new knowledge into nursing school and other curricula, and helping shape the policies and clinical practices of the emerging field of personalized medicine.

NINR-IRP offers research fellows, across the continuum of academic training, with opportunities to develop and refine their symptom science research skills within the framework of the NIH Symptom Science Model. The NINR Graduate Partnerships Program provides an exceptional opportunity for students who are enrolled in any PhD program in nursing across the nation to complete dissertation research here at the NIH campus (Engler, Austin, & Grady, 2014). The goal of this two to three-year doctoral fellowship program is, in partnership with their university, train promising doctoral students in the foundational basic and clinical symptom science research skills that are needed by the next generation of nurse scientists to ultimately conduct research using the NIH Symptom Science Model. For those who have completed their doctoral degrees, NINR-IRP offers a place to continue building cuttingedge research skills, under the mentorship of an NINR investigator, and refining their application within the NIH Symptom Science Model. For individuals who are in between their undergraduate and graduate degrees and have had their bachelor's degree for less than two years, NINR provides the opportunity to conduct research in a real-world setting with an outstanding investigator serving as mentor. In addition to the Post-baccalaureate Institutional Research Training Award, NINR also supports the Technical Institutional Research Training Award, for those individuals who hold a master's degree and are interested in learning the most advanced techniques for basic and/or applied biomedical research. NINR also supports the Minority Faculty-Student Partnership Traineeship in Biotechnology Program, which was developed to address the underrepresentation of minorities in research science, biotechnology, and medical careers. It provides training in the latest principles and techniques in biotechnology for faculty and students from Historically Black Colleges and Universities, Hispanic Serving Institutions, and Indian Tribal Colleges or Universities.

The benefits of learning and experiencing the science conducted within the NINR-IRP extend beyond the scientists and fellows, as many of these training program graduates subsequently return to the extramural community as university faculty in nursing programs across the country. These scientists are increasing the research intensity and capacity of schools of nursing, serving as role models to future nurse scientists and as educators and mentors in laboratory and clinical research arenas. Further, these NINR-IRP 'alumni' serve as ambassadors of symptom science and NIH Symptom Science Model, to scientific programs in nursing and allied enterprises across the nation.

In summary, the NINR Intramural Research Program supports leading-edge research to understand the underlying mechanisms of symptoms associated with a variety of disorders, and to develop clinical interventions to alleviate these symptoms. To guide the NINR-IRP, the NIH Symptom Science Model was developed, providing a framework to incorporate phenotypic and well as 'omic' data when designing interventions to treat and manage

illnesses. Over the next decade, the NINR-IRP is poised to expand and sustain a unique and vibrant program of innovative symptom science research and training that will provide leadership to the scientific community. The focus will be to develop and evaluate novel interventions to manage symptoms and thereby reduce the burden of symptoms and mitigate their impact on health and well-being. The overall goal is to develop a scientific workforce that is innovative, diverse, and able to lead the future of nursing science to improve health outcomes through advances in symptom science.

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Highlights

- The NINR-Intramural Research Program has a robust research and training program in symptom science.
- The NIH Symptom Science Model was recently developed to guide research and training programs.
- The goal of the intramural program is to enhance patient outcomes including health-related quality of life.
- Achieving this goal requires a long-term vision, continued resource investments, and a commitment to mentoring our next generation of scientists.

Figure 1.

NIH Symptom Science Model

The National Institutes of Health Symptom Science Model was developed to guide research. It begins with the presentation of a symptom, the symptom undergoes phenotypic characterization, then biomarkers are identified and this ultimately leads to clinical applications resulting in symptom reduction and improvement.