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## Envisioning the future in symptom science

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#### ABSTRACT

Symptom assessment and management continues to be a priority issue for nursing science and practice. However, as the complexity of symptom etiology and expression becomes clear, new approaches and technologies are needed to better address biology and context, common data sources need to be built and shared, and addressing the impact of empirical findings on health policy becomes essential. In this article, we provide a forum to reflect on the future direction of symptom science, with the goal of stimulating further dialogue and improving outcomes for patients and families around the world and for years to come.

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A hallmark of nursing practice is symptom assessment and management, with the goal of exposing triggers, reducing severity, and limiting impact. Nurses also teach patients to monitor their own symptoms as a way to self-manage and facilitate the early detection of complications and disease progression. Given the emphasis on symptom assessment and management,

it is not surprising that symptom science and its translation into practice are at the core of nursing. The purpose of this article is to describe and recommend ways our profession can accelerate knowledge development in symptom science and stimulate new frontiers of inquiry and policy. These recommendations include incorporating common tools and measures in

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our research, developing and maintaining a registry of common data elements (CDEs), leveraging the potential of "big data," investigating ways to manage symptoms in context and clusters, considering symptom trajectories, and promoting policy initiatives focused on symptom management to improve health outcomes and patient and family quality of life.

#### **Common Measures**

One key step in accelerating knowledge development in symptom science can be found in the use of the Patient-Reported Outcomes Measurement Information System (PROMIS). The PROMIS system, developed with the support of the National Institutes of Health (NIH), provides clinicians and researchers with access to validated, standardized, and common tools for measuring patient-reported health status, including symptoms of mental, physical, and social well-being (Cella et al., 2010). The overarching goal of PROMIS is to improve patient outcomes by facilitating crossstudy comparisons of symptoms. Although important issues regarding PROMIS exist, including ensuring content validity and the accuracy of translations into different languages and across cultures, the use of PROMIS, or indeed any taxonomy of standardized and validated common measures, has clear potential to advance symptom science (Magasi et al., 2012; Paz, Spritzer, Morales, & Hays, 2013).

The consistent use of common measures across research studies will better position nursing scientists to ask and answer more complex questions in the future. For example, by using common measures across studies, it will be possible to evaluate how one symptom (e.g., pain) might vary in intensity, trajectory, or management across different conditions, such as cancer, multiple sclerosis, or cardiopulmonary disease, as well as across the life span or between men and women. Similar analyses could be undertaken for fatigue or nausea or other symptoms known to cross disease states, exhibit patterns or trajectories, and carry a heavy burden. By comparing and contrasting dimensions of a symptom across common conditions, between populations, and over time, nurses will be able to better tailor interventions to detect and manage that symptom more appropriately, thereby allowing for more personalized health care.

Using a common measure to investigate one symptom across multiple conditions also may help decipher the underlying mechanism of that symptom, leading to the development of strategies to reduce that symptom by blocking that mechanism. For example, consider the benefit of using a common measure to evaluate the symptom of depression across multiple chronic conditions. Standardized and consistent characterization of depressive symptom severity or frequency using a single common measure across studies, when coupled with other overlapping data,

could uncover previously unexpected pathways to depression. For example, if across the country, nursing researchers studying the biological underpinnings of depressive symptoms included both a common measure of depression and a panel of biomarkers in their research, inflammation as a potential common pathway for depressive symptoms might be identified, stimulating clinical research regarding the use of anti-inflammatory interventions to improve depressed mood across conditions. Interventions that target the same underlying mechanism (inflammation) for such a common symptom (depressed mood) may also be effective in other populations as well (e.g., young adults with HIV infection, older adults with heart failure, or patients with Crohn disease across the life span).

Symptoms also might overlap or exist synergistically in patients living with comorbidities. In this case, treating one comorbid condition may not relieve that symptom while treating the common underlying mechanism may provide substantial relief. For example, treating only constipation in a patient with irritable bowel syndrome may not provide total relief of the condition because there are likely other conditions that coexist. Using common symptom measures would allow intervention researchers to identify the overlap in symptoms between diseases and to compare findings across studies.

Lastly, using common symptom measures might also allow researchers and clinicians to better detect and manage symptom clusters. For example, pain, fatigue, and depression often cluster; if common measures were used across conditions where this cluster is expressed, investigators may be better equipped to pinpoint common mechanisms to target. This innovative idea of treating the underlying mechanism of a symptom rather than the symptom itself benefits from the use of common measures including the use of PROMIS panels.

### **CDEs and Data Repositories**

Using common measures is one step toward enhancing symptom science; the next for nursing scientists around the world is to agree to collect multiple CDEs, code them alike, and store them in a designated data repository. These next steps will require significant thought, coordination, and planning.

CDEs can include a spectrum of data, ranging from basic demographic information to sophisticated brain imaging. For example, CDEs collected from patients worldwide who suffer from a chronic disease such as rickets or HIV infection could include demographic data (e.g., gender, race and ethnicity, age, weight, income, and country of origin), medical history data (e.g., comorbidity, medication use, parity, and personal or family risk factors), and biological data (e.g., laboratory values; imaging results; biomarker levels; or "omic" data including genomics, proteomics, and

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