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An experience with the Patient-Reported Outcomes Measurement Information System: Pros and cons and unanswered questions

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ABSTRACT

The goal of the Patient-Reported Outcomes Measurement Information System (PROMIS) is to create efficient, reliable, and valid assessments of adult and child health. The nursing science literature in which PROMIS measures are used is rapidly expanding. Investigators have been encouraged to consider the integration of PROMIS measures into both descriptive studies and clinical trials. Doing this has created opportunities and challenges for investigators. This article highlights three projects to show the perspectives of nurse scientists who incorporated PROMIS measures into their research. The first project describes advantages of PROMIS to allow for comparisons of a study population with a national sample and to compliment legacy measures. The second project examines issues in the translation of tools for region-specific Hispanic populations. The third project provides a perspective on the use of PROMIS measures to capture cancer-related fatigue and to develop new components of a sexual function scale. As indicated by these three examples, nurse scientists can contribute an important role in moving the PROMIS initiative forward. Results from these types of projects also move symptom science forward within a more interdisciplinary approach to common measures of interest.

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Background

This article provides information shared at the October 2013 Council for the Advancement of Nursing Science Conference Innovative Approaches to Symptom Science: Measurement and Analysis. The authors of this article are investigators who incorporated either one or more Patient-Reported Outcomes Measurement Information System (PROMIS) tools into their National Institutes of Health–funded research projects. Abstracts of these studies are presented in Tables 1 and 2.

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Table 1 – Abstract of a Study in Which PROMIS Pain Measures Were Used in Women with Irritable Bowel Syndrome

A Comparison of PROMIS Pain Measures with Legacy Measures in Women with Irritable Bowel Syndrome (IBS)

Introduction: Patients with IBS are more vigilant to pain-associated stimuli. The purpose of this pilot study was 1) to compare women with IBS to a national data base on the PROMIS pain behavioral and interference measures; 2) to determine the relationship of PROMIS pain behaviors and interferences measures with legacy measures of pain and quality of life (QOL) and pain sensitivity using a test of central pain modulation (CPM).

Methods: Women (n=20) between the ages of 18 and 45 with a medical diagnosis of IBS (Rome III diagnosis) were compared to healthy controls (HC) women recruited from the community. Women completed the PROMIS-Pain Behavior and the PROMIS-Pain Interference short forms (8 items each) as well as a 14-day symptom diary. On the diary GI, psychological distress, and abdominal discomfort symptoms were rated on a 0-4 scale based on severity (none, mild, moderate, severe, very severe). Diary data were collapsed into percent of days with moderate-very severe report of symptoms and life interference. *Pain Behavior* was measured by the Pain Behavior short form which asks about common pain behaviors that can be observed, behaviors associated with pain severity, verbal reports of pain (rated from 1 '*not at all*' to 5 '*very much*'), and one social item. Internal consistency for this study was $r = .89$. *Pain Interference* was measured by the PROMIS-Pain Interference Short Form which asks about the consequences of pain on five relevant aspects including: social, cognitive, emotional, physical and recreational activities over the past 5 days. Internal consistency for this study was $r = .91$. The CPM was tested with a counter-irritation approach in a laboratory between 8 and 10 am on a follicular phase day. The study protocol and findings are described in further detail in (Jarrett et al., 2014).

Results: There were positive associations among PROMIS pain measures and legacy measures of abdominal pain (.416-.430). There were significant inverse relationships with the legacy QOL measure. During the CPM testing, there was a positive relationship between baseline pain sensitivity and PROMIS pain interference measure.

Implications: The PROMIS pain measures allow for characterization of women with IBS in comparison to a national population. In addition, there is good correlation with legacy measures in this population.

PROMIS Advantages

The use of the PROMIS measures by biobehavioral nursing scientists who are focused on understanding the biological underpinnings of symptom reports provides several advantages. A key advantage is the ability to compare symptoms reported by one's sample to a national data base (one of the intended purposes of the PROMIS development). Project 1, "The Pathways to Abdominal Pain," provides an example of this advantage (Table 1).

Project 1 Background

Project 1 was an American Recovery and Reinvestment Act of 2009-funded project with the aim of collecting data in children and adults with irritable bowel syndrome (IBS). IBS is a common functional gastrointestinal (GI) disorder that affects 10% to 17% of the American population. Abdominal discomfort/pain relieved by an alteration in bowel function (e.g., diarrhea, constipation, or mixed) is a key diagnostic criterion (part of the Rome III guidelines) (Drossman et al., 2006). Previous studies by the investigative team used "legacy" measures including a retrospective measure of GI distress and a daily diary to assess 26 symptoms (e.g., gastrointestinal, somatic, and psychological distress) on a scale of "0" (i.e., not present) to "4" (i.e., extreme) (Heitkemper et al., 2011; Cain et al., 2008).

Abdominal Pain/Discomfort Symptom Measures

When the investigators began this project, PROMIS measures were "new" and offered the added advantage of comparing reports of pain in this population with

Table 2 – Abstract of a Study in Which PROMIS Measures Were Used for Latinas with Breast Cancer

Interventions to Improve Quality of Life for Latinas with Breast Cancer

Purpose: To test the effectiveness of two culturally sensitive, expedient psychosocial interventions to improve quality of life (psychological, physical, social and spiritual well-being) for Latinas with breast cancer and their supportive partners.

Design: This study is a randomized clinical trial design with measures obtained at baseline, after the 8-week intervention, and 2- and 4-months post intervention. Latinas and their supportive partners are randomly assigned to either a telephone delivered interpersonal counseling intervention or a health education intervention. All intervention sessions and measurements are conducted by telephone. This study is conducted in the southwestern US and all written materials are provided in either English or Spanish.

Sample: Thus far, the sample includes 72 Latinas, with a mean age of 49 years, 52% were married/partnered with 80% having household incomes of $\leq$ $30K year. Sixty-seven percent of the Latinas had $\leq$ High School education and 32% were unemployed but seeking and 42% were disabled/unable to work. In this sample, 42% had complete mastectomy and only 2% underwent breast reconstruction. Most have public insurance which does not allow for breast reconstruction. Forty percent of the women had stage 3 or 4 breast cancer. The majority (80%) did not participate in any supportive treatment (e.g., support groups). The supportive partners were primarily Latino/a, and have similar incomes, educational and employment histories. Of note, 64% of the supportive partners were female relatives.

Results: (relevant to PROMIS): PROMIS instruments had good reliability ($\alpha \geq .92$), but some Spanish translations were questioned.