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Patient-Centered Validation of a New Palliative Care Patient/Caregiver Questionnaire

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ABSTRACT

TITLE: Patient-Centered Validation of a New Palliative Care Patient/Caregiver Questionnaire (PCQ)

BACKGROUND: This validation study of the PCQ developed for assessing physicians in Palliative Care (PC) practices managing care for chronically or seriously ill patients. Administered through a Practice Improvement Module (PIM)®, it is part of the American Board of Internal Medicine (ABIM) Maintenance of Certification (MOC) program. The case study was a collaboration between ABIM and a social network of patient respondents via PatientsLikeMe through an Open Resource Exchange® (ORE), funded through a grant from the Robert Wood Johnson Foundation. Patients participated in developing and validating of the instrument.

OBJECTIVE: Illustration of patient-centered research for assessing physician skills in providing palliative care

METHODS: 1) Cognitive testing and review of PCQ by patients; **2)** PCQ revised, based on patient suggestions; **3)** then re-administered to a new sample of patients. The PCQ assesses the quality of physician-to-patient communication (10 items) during treatment of chronic medical conditions ,and measures patient-reported outcomes (PROs) using scales for domains of pain, dyspnea, and emotional distress. A subset of the PCQ (4 items) focuses on interactions between the physician and the patient's caregiver, if one is involved. The Global Health Scale (GHS) of the Patient Reported Outcomes Measurement System (PROMIS®) was administered as a validation criterion for the PCQ. PROMIS measures were developed through a NIH-funded initiative to create instruments applicable to the general population, as well as patients with various chronic conditions. The GHS consists of ten Likert-type items that can be combined into four domains: physical health (4 items), mental health (4 items), health status, and ability to engage in social activities. The physical and mental health scores are calibrated through item-response theory into two T-scale measures with means and standard deviations of 50 and 10, respectively. The mean of 50 represents a large, representative sample of the general US population.

RESULTS: Of the 1140 responses, 1016 completed the questionnaire, and 1008 met the age criteria (18–90 years). Of these 1008 patients, 170 indicated a caregiver assisted in their care. The survey covered four primary domains: 1) patient ratings of the quality of physician communication skills when discussing treatment options and addressing patient concerns, 2) level of pain the patient experienced and the response of the physician to it, 3) discomfort associated with dyspnea and the response of the physician to it, and 4) emotional distress associated with the patient's condition and the physician's response to it. The validation correlations between the PC measures and the GHS indicated that patients' overall rating of the care they received was strongly influenced by their perceived mental health (.25, p<.0001) and their ability to carry out usual social activities (.23, p<.0001) and much less by their perceived physical health (.08, p=.16) or overall health status (.14, p<.56). Among caregiver respondents, 19% reported that the patient's physician did not understand what they did to help the patient with health care and daily living needs. About 46% of caregivers reported that the physician never asked the caregiver about their concerns related to the patient's health care needs, and 58% indicated the physician never asked the caregiver about the stress they feel taking care of the patient.

CONCLUSIONS: This case study of the PCQ is an illustration of patient-centered research for assessing physician skills in providing palliative care. The instrument assesses the domains of physician-to-patient communication; patient-reported outcomes of pain, dyspnea, and emotional distress associated with chronic medical conditions; and the relationships between these outcomes and patient's perceptions of the quality of care they receive from their physicians. The measures are not condition specific, and they reflect the interplay between physician and patient encounters and show the effects these encounters have on the quality of life in patients with chronic conditions.

BACKGROUND

The Palliative Care for Primary Care & Subspecialist Physicians PIM focuses on how internists and subspecialists manage the care of patients with progressive chronic conditions or serious, life-limiting illnesses. One element of the module is a newly developed patient/caregiver questionnaire (PCQ).

The PCQ provides feedback on patient-reported measures related to goals of care; advance-care planning; physician communication skills; and patients' self-reported pain, dyspnea, and emotional distress. Patients also provide an overall rating of their physician.

The Global Health Scale (GHS) of the Patient Reported Outcomes Measurement System (PROMIS®) was administered as validation criterion for the PQP.

OBJECTIVES

- list the health domains covered by the Palliative Care questionnaire.
- Compare the validity coefficients of patient reported outcome measures derived from the Palliative Care questionnaire to the criterion measures from the PROMIS Global Health Scale.
- Compare the ratings of healthcare providers from patients with serious chronic conditions to ratings of the same healthcare providers from the patient's caregivers.
- Discuss the strengths and weaknesses of patient-centered research in Palliative Care.
- Evaluate the role of generic, patient reported measures in maintaining certification of physicians in internal medicine.

METHODS

- ❖ PatientsLikeMe social network participated in the initial field test in January 2014
- ❖ The Global Health Scale (short forms) of the PROMIS system were used as criterion validity measures, Spearman correlations were used to assess ordinal correlations with PCQ measures; ☐ <.001 to adjust for multiple testing
- ❖ EFA and CFA methods were used to assess construct domains
- ❖ Sensitivity of PCQ measures were assessed by comparing changes in scales across age, education and health status groups using Wilcoxon and linear rank tests.
- ❖ Physician communication scale with 10 items was developed using a mixed logistic model (RASCH scale)

RESULTS

- ❖ A total of 1008 completed responses to two forms during the initial field test, respondents typically were white (90%), female (74%), between ages 45-64 (69%), with some college education (85%).
- ❖ Most patients reported on (51%) and 14% reported on rheumatologists.
- ❖ Average PCQ scores were one standard deviation below PROMIS norms, PCQ Pain, Dyspnea, and Emotional Distress scales were correlated with PROMIS physical and mental health scales
- ❖ Overall doctor rating and physician communication scale scores were correlated with PROMIS mental health, health status, and QOL.
- ❖ Among patients with caregivers (17%), 19% report that they do not believe that the patient's physician understands the role they play in the patient's care.

Respondent Demographics N = 1,008	
Sex, female: % (N) - missing=4	**74% (740)**
Age in years: % (N) - missing=2	
18-24	**1% (7)**
25-34	**4% (44)**
35-44	**11% (114)**
45-54	**30% (299)**
55-64	**39% (388)**
65-74	**13% (132)**
≥ 75	**2% (22)**
Race: % (N) –missing=10	
White	**90% (905)**
Black or African American	**4% (38)**
Multiple races	**3% (31)**
Asian	**1% (11)**
American Indian, Alaska Native, Native Hawaiian, or Other Pacific Islander	**1% (7)**
Other	**1% (6)**
Highest education level attained: % (N) – missing=7	
8th grade or less	**<1% (1)**
Some high school, but did not graduate	**1% (12)**
High school graduate or GED	**13% (134)**
Some college or 2-year degree	**44% (446)**
4-year college graduate	**18% (182)**
More than 4-year college degree	**22% (226)**
Hispanic or Latino origin: % (N) - missing=8	**2% (22)**
US Residence % (N)	**90% (903)**

RESULTS

You may see several different doctors for your condition(s). He or she should be someone who provides a large portion of your medical care and someone you have seen at least twice in the past 12 months. What is the specialty of this doctor?

Specialty % (N)
Internal medicine (primary care) 51% (518)
Rheumatology (arthritis, lupus) 14% (144)
Oncology (cancer) 4% (37)
Pulmonary medicine (lungs) 3% (35)
Gastroenterology (stomach, liver, pancreas) 3% (28)
Nephrology (kidneys) 3% (28)
Cardiology (heart) 2% (17)
Infectious disease 2% (16)
All Others 17% (181)

NIH PROMIS® Measures & Global Health Scales	Palliative Care Questionnaire PIM® Measures				
	Pain frequency: Never (1) to Always (4)	Dyspnea frequency Never (1) to Always (4)	Emotional distress frequency: Never (1) to Always (4)	Overall rating of doctor: Worst (0) to Best (10)	Doctor-patient Communication (10 items) Scaled: Mean=0, SD=1
	r (n) Ha: |ρ| > .1				
Physical health: T score[1] Mean = 39, SD = 5	-.50** (428)	-.33** (428)	-.33** (431)	.05 (911)	.08 (914)
Mental health: T score[1] Mean = 40, SD = 6	-.47** (474)	-.26* (477)	-.42** (479)	.23** (977)	.25** (1000)
Health status: In general health is: Excellent (5) to Poor (1)	-.51** (475)	-.40** (477)	-.41** (480)	.12 (1002)	.14 (1005)
Engage in usual social activities and roles: Excellent (5) to Poor (1)	-.50** (474)	-.27** (477)	-.44** (479)	.19* (999)	.23** (1002)
Quality of life[2]: In general QOL is: Excellent (5) to Poor (1)	-.54** (477)	-.35** (479)	-.48** (482)	.23** (1005)	.23** (1008)
Pain[3], past 7 days: No pain (0) to Worst pain imaginable (10)	.75** (477)	.28** (479)	.37** (482)	-.10 (1005)	-.13 (1008)
Fatigue[3], past 7 days: None (1) to Very severe (5)	.51** (477)	.30** (479)	.46** (482)	-.15 (1004)	-.20* (1007)

[1] Representative sample of the general US population (2000 US Census) has a T score mean = 50 and a SD = 10

[2] Quality of Life included in Mental health scale

[3] Pain and Fatigue are included in the Physcial health scale

*** p<.0001 * p<.001*

RESULTS

Caregiver Questions and Responses

Does a family member, friend, or other caregiver help you with all or most of your healthcare needs?	Yes % (N)		No % (N)	Not reported* % (N)
	17% (170)		83% (832)	1% (6)
From 170 respondents who reported "Yes" above.	**Yes, definitely % (N)**	**Yes, somewhat % (N)**	**No % (N)**	**Not reported* % (N)**
In the past 12 months, did you feel that this doctor understood what you do to help with the patients medical care?	50% (85)	25% (42)	19% (33)	6% (10)
In the past 12 months, did you feel that this doctor understood what you do to help with the patient's personal care (e.g., bathing, grooming, feeding)?	47% (80)	22% (38)	19% 33	11% (19)
In the past 12 months, has this doctor (or someone on the healthcare team) asked you about your concerns related to caring for the patient?	27% (46)	18% (31)	46% (79)	8% (14)
In the past 12 months, has this doctor (or someone on the healthcare team) asked you about the stress or burden you may feel from caring for the patient?	22% (38)	10% (17)	58% (99)	9% (16)

** Not reported includes: refusals or skips*

CONCLUSIONS

- PCQ questionnaire is an example of patient-centered research through a social network for assessing physician skills in providing palliative care.
- PCQ domains: physician-to-patient communication; PRO outcomes: pain, dyspnea, and emotional distress associated with chronic medical conditions; and the relationships between these outcomes and patient's perceptions of the quality of care they receive from their physicians.
- PCQ measures are not condition specific, and they represent the interplay between physician and patient encounters, as well as the effects these encounters have on the quality of life in patients with chronic conditions.

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