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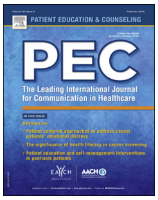

Cross-cultural validation of the parent-patient activation measure in low income Spanish- and English-speaking parents

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ABSTRACT

Objective: (1) To measure healthcare activation among low-income parents by language (English/Spanish); and (2) to assess the psychometrics of the Parent-Patient Activation Measure (P-PAM) in the study population.

Methods: We surveyed parents/guardians of publicly-insured children who were established patients at a pediatrics clinic for $\geq$6 months. Surveys included the Parent-Patient Activation Measure (P-PAM), a 13-item measure adapted from the well-validated Patient Activation Measure (PAM).

Results: Of 316 surveys, 68% were completed in Spanish. Mean activation score in the English-language survey group was 79.1 (SD 16.2); mean score in the Spanish-language group was 70.7 (SD 17.9) ($p < 0.001$). Scale reliability was high (English $\alpha = 0.90$; Spanish $\alpha = 0.93$). The P-PAM had acceptable test-retest reliability, but no previously reported PAM factor structure fit the study data adequately for either language.

Conclusions: Healthcare activation among low-income parents was greater for parents surveyed in English compared with those surveyed in Spanish. The P-PAM has acceptable reliability and validity in English and Spanish, but a different factor structure than the PAM.

Practice implications: Activation as measured by the P-PAM may not have the same associations with or impact on health/healthcare outcomes in pediatrics compared with adults owing to possible measure differences between the P-PAM and PAM.

1. Introduction

Patient engagement is heralded as a key component of health system redesign and achieving the “triple aim” of improved health outcomes, better patient experiences, and lower costs [1,2]. Individual level engagement has frequently been characterized as patient activation. Patient activation is defined as the patient’s willingness to manage their health and healthcare based on understanding one’s role in the care process and having the knowledge, skills, and confidence to do so [3–5]. Adults with greater patient activation have better health outcomes and report better healthcare experiences [3–6]. Interventions have demonstrated efficacy in increasing activation with subsequent improvement in health and healthcare quality for adult patients [3].

There is interest in measuring parent activation as an intermediary outcome for interventions to reduce healthcare disparities in children. To do so, a better understanding of parent activation on behalf of the health and healthcare of children is needed. The Patient Activation Measure (PAM), a well-known measure to characterize patient activation, is validated for use across diverse adult populations [3]. This measure has been adapted for use among caregivers of pediatric patients (Parent-Patient Activation Measure (P-PAM) [7,8]. There has been limited study, however, of parental activation on behalf of their children though the measure is licensed for commercial and research use by the developers. Psychometric assessments of the P-PAM across diverse populations, to our knowledge, have not yet been performed [7]. Thus, it is premature to assume that the P-PAM reflects the same theoretical construct among parents and could be

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used, in its current licensed form, in research and clinical care in the same manner as in adult patients. There is a particular need for information about activation among parents who have difficulty accessing and using the healthcare system, such as those with low-income, limited English proficiency (LEP), and/or limited health literacy [1,9]. Failing to engage these patients and families may worsen healthcare disparities and reduce the potential of patient engagement to contribute to health system improvement for all populations. In this study, our aims were to (1) measure parent activation among English- and Spanish-speaking low-income parents in the pediatric primary care setting and (2) provide an initial assessment of the validity and reliability of the P-PAM in this study population.

2. Methods

We conducted a cross-sectional study at an urban, academic general pediatrics clinic in the US to examine parents' healthcare activation on behalf of their children and assess the psychometrics of the Parent-Patient Activation Measure (P-PAM) in a diverse sample of low-income parents/legal guardians (hereafter referred to as "parents"). The Institutional Review Board at Johns Hopkins Medicine approved the study. All participants provided informed consent after the consent form was orally read to them and understanding ascertained. Respondents received $10 for participation.

The P-PAM was designed to evaluate parents' knowledge, skills and confidence in managing their child's health and healthcare. The P-PAM was adapted from the well-validated PAM by its creators for use in parents and pediatric healthcare. The P-PAM, similar to the PAM, consists of 13 declarative statements. Response options are on a four-point Likert scale ranging from disagree strongly to agree strongly, without a neutral option. Sample items include: "When all is said and done, I am the person who is responsible for taking care of my child's health" and "I am confident I can tell a doctor concerns I have about my child's health, even when he or she does not ask." The P-PAM is licensed by Insignia Health and was used with their permission [8]. The PAM has been validated in Spanish, but different translations have been used. We used a professional translator to generate a draft Spanish language P-PAM. This was then pilot tested and edited by bilingual research team members based on feedback from low-income primarily Spanish-speaking parents.

P-PAM responses were converted to activation scores ranging from 0 to 100 using the same methodology as for the PAM [5]. Higher scores represent higher activation. The activation score corresponds to one of four activation levels generated using a proprietary algorithm from the licensor. At Level One, parents may not understand how or why they can play an active role in their child's health; at Level Two, parents lack some needed knowledge and confidence to take actions; at Level Three, parents are beginning to take action to improve their child's health, and at Level Four, parents are taking action and have proactive behaviors that reflect their knowledge, skills and confidence to effectively manage their child's health [4–10].

From September 2014 through March 2015, a convenience sample of participants was recruited from an urban, academic pediatric primary care clinic. The majority of the clinic's patients have public insurance and are Latino children with LEP immigrant parents. The clinic, however, serves a racially and ethnically diverse patient population of immigrant and non-immigrant families. Providers at the clinic include board-certified pediatricians, resident physicians, and a pediatric nurse practitioner. The clinic averages ~11,000 visits annually. Nearly all providers at the clinic communicate directly in Spanish with patients and parents for whom this is their preferred healthcare language. All providers who communicate directly in Spanish have had their language proficiency assessed according to health system policy.

This study included parents of children aged 6 months to 5 years. Additional inclusion criteria were: minimum respondent age of 18 years, preferred healthcare language of English or Spanish, and a child in the target age range with public health insurance who had been a clinic patient for at least 6 months.

Trained research assistants proficient in both English and Spanish screened parents for inclusion during regular clinic hours. They then administered the survey in the parents' preferred healthcare language during any available time gap while the parent was waiting in clinic. The default mode of survey administration was oral administration because of known limited literacy among many parents. Parents, however, could request to complete the survey themselves; 21% of respondents elected this option. Survey responses were captured simultaneous with survey administration via recording of responses onto a touchscreen tablet computer using REDCap (Research Electronic Database Capture) software [11–13]. A small minority of surveys were completed using the paper survey form, either due to participant preference or tablet malfunction. Paper survey responses were subsequently double-entered into REDCap.

Parents were asked to consider only one of their children in the specified age range when responding to questions. For parents with more than one eligible child, the child with an appointment on that day was the index child. If this method failed to identify a single child, RAs selected one child at random.

Surveys consisted of four parts: (1) Information about the parent and family, (2) Information about the index child and their health status, (3) the P-PAM, and (4) a validated measure of health literacy.

Parent information included parent age, gender, race/ethnicity, educational attainment and health status. Family information included number of children in the household, family income, language(s) spoken at home, US nativity and English language proficiency. English proficiency was assessed using the US Census Bureau question, "How well do you speak English? [13]. Foreign-born parents completed questions on country of origin and years of residence in the US. Child information included age, gender, US nativity, and health status. The child's health conditions were identified via electronic medical record review of the problem list and visit diagnoses in the past 12 months (since birth for children <12 months). Few children met criteria for a complex chronic condition (CCC) so we elected to specify children with health conditions inclusive of less severe diagnoses [14]. We defined children with a health condition if any of the following were documented in the problem list: asthma/chronic cough/wheezing, prematurity with gestational age <35 weeks, developmental disorder or delay (autism or similar), or if they met ICD-9 criteria for CCC designation [14].

We measured health literacy using the Newest Vital Sign (NVS), a validated and widely used measure of health literacy available in both English and Spanish [15]. The NVS requires participants to examine a nutrition label and respond to six questions based on the label content. Research assistants administered the health literacy assessment in a nonjudgmental manner and encouraged participants to try their best on each item. Scores on the NVS correspond to three categories of health literacy based on the number of correct answers: Limited (0–1), Marginal (2–3), and Adequate (4–6). As the NVS requires reading the nutrition label even during oral administration, participants who indicated they could not read the label or preferred not to complete the NVS were assigned a score of 0.

All statistical analyses were conducted using STATA/SE Version 13 (StataCorp LP, College Station, TX). Analyses were stratified by preferred healthcare language (English or Spanish) to assess P-PAM

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