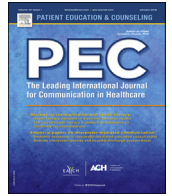




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Parent activation in the pediatric emergency department: Theory vs. reality

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ABSTRACT

Objective: To measure parent activation and test for its associations with sociodemographics, clinical factors, and short-term outcomes.

Methods: By convenience sampling, 246 parents of children treated in an emergency department (ED) of a children's hospital completed the Parent-Patient Activation Measure (P-PAM) and answered socio-demographic questions. Clinical information was abstracted from medical records. Phone calls to parents and primary care physician offices were conducted within one-month post-ED visit for information about short-term outcomes.

Results: We discovered higher than expected activation among our sample (mean = 73), higher activation scores by Spanish language and child chronic illness status, and associations between activation scores and ED visit and discharge instruction comprehension and filling prescriptions (short-term outcomes). However, the theory of parent activation did not adequately fit the data.

Conclusion: Before the P-PAM in pediatric clinical care becomes widespread, further research is necessary to better understand parent activation and its associations with pediatric outcomes.

Practice implications: Although the PAM has shown promise in accurately measuring patient activation across various populations and disease processes, the same is not yet true of the P-PAM. To date, pediatric studies using the P-PAM have called its psychometric properties into question. Further research is needed to understand and measure parent activation.

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1. Introduction

Key to achieving quality health care and improved health outcomes is an engaged and informed patient. Patient engagement is a core component of the patient-centered medical home model [1–4]. In pediatrics, this translates into an engaged patient and family [5]. Measuring adult patient engagement, in the form of patient activation, is a concept with increasing supporting evidence. Historically, different social and behavioral health frameworks (e.g., transtheoretical model, health belief model, theory of reasoned action) have been used to measure different aspects of activation, but capturing the broad range of activation components within a single measure has been a longstanding goal

[6,7]. The Patient Activation Measure (PAM) was designed to address this challenge.

The PAM, a quantitative tool, was first developed in 2004 and has since been validated to assess a person's "knowledge, skill, and confidence for managing their health and health care" [6,7]. Through a 22-item survey, where each declaration statement is linked to one of the four stages of activation, the PAM assesses one's level of activation. Measured on a 100-point scale, an individual's total PAM score can then be translated to a particular activation level: Level 1 (score 0–47.0) suggests the individual may not yet understand that his or her own role is important, Level 2 (score 47.1–55.1) indicates that the individual lacks the confidence and knowledge to take action, Level 3 (score 55.2–72.4) indicates that the individual is beginning to engage in recommended health behaviors, and Level 4 (score 72.5–100) indicates that the individual is proactive about health and engages in many recommended health behaviors [4].

The validity and reliability of the PAM to measure patient engagement and health outcomes have been rigorously studied across different diseases [8–11], and through these studies, the

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theory of activation has been reinforced [12]. Initial results have been consistent with expectations, and revealed patterns of higher activation levels among those with higher incomes, more education, and better self-reported health [9–12]. Furthermore, the literature shows a link between higher activation and ability to manage and coordinate their health care, including less frequent visits to the emergency department, with growing data to suggest improved health outcomes and the potential for lower health care costs [3,9,12–14]. Concepts such as patient activation show promise when it comes to identifying and improving patients' abilities to care for themselves, and the first studies evaluating change in patient activation over time and the ability of specific interventions to improve activation are just now being published [4,14].

In 2005, a shortened 13-question form of the original 22-item PAM was published and validated [7]. A modified version of the 13-item PAM, the Parent-Patient Activation Measure (P-PAM), was developed to determine activation among caregivers of pediatric patients [7,15]. Derived from the patient activation literature, parent activation is theorized as parents' engagement in their child's health [15]. With great emphasis today from professional medical and governmental organizations to encourage consumer-directed care, having a tool such as the P-PAM to measure parent activation and provide tailored assistance for those with low scores to help move them along the continuum of activation has the potential to be extremely beneficial [3,5,16].

The literature studying parent activation and using the P-PAM is limited, however, with no published studies of parent activation in the pediatric emergency department setting, a place that could possibly have lower than average parent activation scores given the frequency of low acuity, ambulatory-sensitive ED visits [8,17–20]. With this in mind, this study aimed to measure parent activation through administration of the P-PAM to Spanish- and English-speaking parents in the pediatric ED, and to evaluate whether scores on the P-PAM were associated with specific parent and family demographic characteristics or their child's clinical characteristics, and short-term health outcomes. Further, with little data confirming that the psychometrics of the P-PAM are consistent with the theory of parent activation, we sought to evaluate the psychometrics of the P-PAM among our study population.

2. Methods

2.1. Study setting and design

We conducted a prospective cohort study of parents of children being treated in the ED at a children's hospital. The institution is an urban, tertiary care pediatric medical center, with an annual ED census of approximately 80,000. Using convenience sampling over the course of 14 months (July 2015 to September 2016), parents were approached for study participation. Study eligibility included parents who were aged 18 years or older, and spoke English or Spanish (the languages spoken by the majority of families at the study site). Study exclusion criteria included: the caregiver was not the parent, the child was over 18 years old, or the child was triaged as critically ill. The study was approved by the Institutional Review Board at our institution.

2.2. Data collection

At the time of the ED visit, parents were administered a brief survey created specifically for this study. The survey contained 3 sections. The first section asked about parent demographics such as parent age, nationality, language spoken at home, highest level of education achieved, and how they would rate their own health.

The second section asked questions about their child, such as gender, age, insurance coverage, chronic medical problems, knowledge of primary care physician's name and phone number, and frequency of interactions with the health care system outside of routine well visits for this child and any other children in the family. The third and final section asked about this particular ED visit, such as arrival day of the week and time of day, triage level, chief complaint, disposition, and discharge diagnosis. Data for the third section were abstracted from the child's electronic medical record.

The parents then completed the P-PAM, a 13-item short form, developed and modified by its authors and used with their permission. According to the creators of the PAM, there are four activation factors: beliefs, confidence, action, and perseverance. "Beliefs" refers to the parent's beliefs about being actively involved in the child's health (items 1–2). "Confidence" refers to the parent's possession of confidence and knowledge in managing the child's health (items 3–8). "Action" refers to the parent's preparedness to take action related to the child's health (items 9–11). "Perseverance" refers to the parent's willingness to persevere through challenges related to the child's health (items 12–13). Example statements from the P-PAM include: "Taking an active role in my child's health care is the most important thing that affects his/her health," and "I understand my child's health problems and what causes them."

Each P-PAM item was answered on a 4-point Likert scale (anchors: disagree strongly, disagree, agree, agree strongly) with an option to answer not applicable. A continuous activation score was then calculated, ranging from 0 (no activation) to 100 (highest activation). Within one month of the ED visit, study-enrolled parents were contacted by phone and asked about their understanding of the ED visit and discharge instructions, their comfort in caring for their child's illness at home after this visit and in the future, information about post-discharge follow-up with their primary care physician, and adherence to care recommendations and any medications prescribed. Furthermore, the child's primary care physician's office was contacted within one month of the ED visit and asked to confirm whether the child did indeed have a follow-up visit, and whether the content of that visit included discussion of the recent ED visit.

Trained research assistants performed all survey administration and follow-up phone calls. A certified hospital translator translated both the survey and the P-PAM from English into Spanish. Bilingual research assistants administered surveys and performed the follow-up phone calls for all Spanish-speakers enrolled in the study. Data entry was performed by two of the trained research assistants. Data were entered into Research Electronic Data Capture (REDCap) [21]. REDCap is a secure, web-based application designed to support data capture for research studies (<http://project-redcap.org>). Ten percent of the data was randomly audited by the principal investigator to confirm accuracy of the data entry.

2.3. Data analyses

First, data analyses began with descriptive statistics (means, standard deviations, ranges, frequencies, and percentages) to examine parent and child demographic and clinical characteristics. Second, P-PAM total score was computed by summing all items, and as previously described, each P-PAM factor was calculated as the mean of respective items. Differences in total and factor scores by survey language and by child chronic illness status were examined using independent samples *t*-tests. Third, associations with P-PAM total and factor scores were tested using point-biserial correlations (for binary data, such as primary care physician follow-up after ED visit), Spearman's correlations (for ordinal data, such as parent personal health status), or Pearson's correlations

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