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Leveraging Electronic Tablets and a Readily Available Data Capture Platform to Assess Chronic Pain in Children: The PROBE system

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Abstract

The Patient Risks Outcomes and Barriers Evaluation (PROBE) system is developed using a readily available data capture platform (REDCap) and iPads. PROBE performs complete and consistent assessment of pain at every patient visit in pediatric rheumatology practices of our very large healthcare system. Using evidence based clinical guidelines, it combines the following essential elements for care: 1) screening for behavioral risks for chronic pain such as anxiety, sleep deprivation, or painful conditions affecting a caregiver living in child's home, 2) capturing disease activity related measures and enabling 3) clinical decision support. In this demonstration project we describe PROBE and evaluate it for usability in practice. Using PROBE, we observed significant differences for behavioral risk factors in children with juvenile idiopathic arthritis in those who report chronic pain vs. not.

Keywords:
Electronic Tablets; iPad; REDCap; PROBE; CDSS; JIA; Pain; Children

Introduction

Pain is the most distressing aspect of disease in children and can play a predominant role in their everyday lives. Despite pain's impact on both children and their families, the medical community has only recently begun to focus its resources on the investigation and treatment of pain. The field of pediatric rheumatology is not alone in this delay. In June 2011, the Institute of Medicine (IOM) released a landmark report, Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research. This report addresses the US healthcare system for its deficiencies in the assessment and management for pain in the United States[1]. The report calls for progress in the collection and reporting of data on pain. It also emphasizes the need to provide complete and consistent assessment of pain as well as the necessity for expanding opportunities in pain research. Children and families who live with juvenile idiopathic arthritis (JIA) can ardently verify the findings of this IOM report.

Children with JIA who experience pain regularly perceive themselves to be more disabled and are more likely to restrict their activity[2-5]. Their pain related to disease commonly persists into adulthood and can significantly impact their productivity and quality of life[6-8]. However, the relationship between disease activity and pain in children and adolescents with rheumatic disease is known to be inconsistent [3,9] but certain behavioral risk factors have shown to influence the pain experience in children with JIA[10-12]. These include sleep deprivation, anxiety, or painful conditions affecting a caregiver in the child's home. Because early identification of risks may help in improving long term patient outcomes, numerous studies have shown that healthcare providers need to implement complete and consistent assessment of pain in their everyday practice[13-18]. Besides, many evidence based guidelines exist for screening and assessing pediatric chronic pain. However, it remains a formidable challenge for most practices to implement these guidelines in routine care [12,19,20] let alone initiate any intervention following screening. Difficulty in implementing guideline components within the workflow and constraints of the clinical workflow are often cited as potential hurdles. In our previous work in general pediatric practices, we have shown that computerized clinical decision support systems (CDSS) can automate screening in waiting rooms [21,22] and alert the providers based on screening. CDSS can be effective tools for case finding [23] and for improving physicians' use of and adherence to care guidelines[23-27]. More recently, we have also shown that electronic tablets are desirable mediums for implementing screening in the waiting rooms, and using these devices, CDSS can gather more complete patient data for making care decisions[28].

Therefore, to address complete and consistent assessments of pain in children and adolescents with JIA at every visit, we have developed an electronic data capture and clinical decision tool - *Patient Risks, Outcomes and Barriers Evaluation (PROBE)*. PROBE is currently being used in three pediatric rheumatology practices of our large health care system. It screens patient families for pain and associated behavioral risk factors in the waiting room using an electronic device (iPad) that communicates with the PROBE back end server in real-time. The objective of this pilot study is to demonstrate - 1) the feasibility of using a readily available data capture platform and electronic tablets for complete and consistent assessment of pain during routine care in pediatric rheumatology practices; 2) that differences are observed on screening in patient reports of chronic pain; and 3) that PROBE can evolve into a viable Health IT platform for pediatric pain management and patient engagement.

Materials and Methods

The PROBE System

The PROBE system consists of three data capture forms, a central server and electronic tablets such as iPads. Access to the data forms is provided using secure wireless network via a

web browser interface. The data forms capture information from patients or caregivers in the waiting room and clinical data from the clinical team in the exam or the work room. The three PROBE forms are - the Patient Screening Questionnaire (PSQ), the Patient Nursing Form (PNF) and the Provider Work form (PWF). Below we describe a workflow using PROBE. Please refer to Figure 1 for details of the workflow.

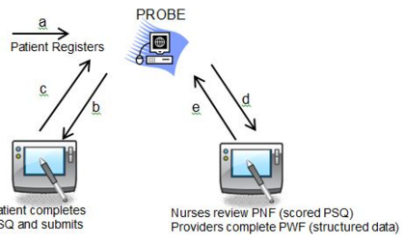

Figure 1 - PROBE Workflow

Workflow: At each patient registration visit (step a) patients or their caregivers are instructed to answer questions on PSQ using an electronic tablet device in the waiting room. Answers to each page of questions are securely recorded in the PROBE central server in real time (b), and no data is ever recorded on the electronic device (c). When responses to screening questions are submitted (d) the nursing form (PNF) is automatically populated with patient answers and scores (e). Inside the exam room, either the provider or the nursing staff completes the PWF (f).

Pain and Behavioral Risk Screeners: Children, adolescents and young adults, ages 3 to 23 years are screened. The following validated screening instruments are implemented using PSQ: *1) Mood disorder screening:* Childhood Depression Index and Screen for Child Anxiety Related Emotional Disorders (SCARED)[29]; *2) Sleep assessment:* Bedtime problems, Excessive daytime sleepiness, Awakening during the night, Regularity and duration of sleep and Snoring (BEARS)[30]; *3) Parental Pain History Questionnaire* (PPHQ)[31]: which is directed towards the caregiver; and *4) Pain Coping Questionnaire:* consisting of *Pain coping efficacy* and *Brief pain inventory scales*[32]. The latter measures weekly pain level on a 0-10 VAS scale, with 0 being the lowest and 10 the highest pain level. Please see Figure 2 below. The *Chronic pain (CP)* report is screened as pain greater than 3 days per week for more than 3 months.

Implementation: PROBE is developed using a readily available electronic data capture platform, the Research Electronic Data Capture (REDCap)[33] platform in collaboration with the Department of Quantitative Health Sciences (QHS) at Lerner Research Institute, Cleveland Clinic. REDCap is a secure data capture tool for research purposes and is supported in our environment. For the PROBE implementation, a REDCap project was created and an anonymous surveys consisting of validated screening questionnaires (*SCARED, BEARS, Brief Pain Inventory Scale, Parental Pain History and Pain Coping and Efficacy* as described above) were implemented for PSQ. The patients do not need login credentials but the front-desk staff enters patients' identifying information into PSQ before handing out the electronic tablet device. At each visit, the front desk staff confirms that the patient is an established JIA patient (from registration) and records the patient's medical record number, age and gender (of the child) and selects the provider and visit type (i.e. for infusion or provider) from a menu item in PSQ. No patient information for race/ethnicity or insurance category is currently recorded in PSQ. Additionally, if the child is between 3 and 12 years of age, the front desk asks the parent or the caregiver to complete the PSQ. Adolescents and young adults (12 – 23 years) complete their own PSQ. The screeners implemented in PSQ have both a parent and a child version, and based on the age entered by the front-desk staff, the appropriate one is automatically presented in PSQ. We use the branching logic capabilities of the REDCap software to implement age-based questions. Using REDCap database functionality, PROBE also automatically assigns a unique system identifier for all three data capture forms and together they constitute a record for the patient's visit. PROBE was initially implemented for a pilot test in one pediatric rheumatology clinic at our main hospital in March 2014. We currently have three practice sites, including two community sites using PROBE. Each site has at least two electronic tablet devices for patient use and they all communicate with the PROBE central server in real-time.

Clinical decision aid tool: PROBE implements clinical decision support via scoring screening questionnaires. When the PSQ form (Figure 2) is submitted by the patient, numeric scores (e.g. anxiety screening) are computed in real-time by the system and displayed to the clinical staff on the nursing form (PNF). Please see Figure 3 for PNF. The providers can access patients' PNF to view scores or any screening information via a secure login to the REDCap website either using an exam room computer or an electronic tablet device. At the conclusion of a visit, providers or their staff document current labs, medications, and disease activity scores. Please see Figure 4 for PWF documentation. More structured data item additions are planned for PWF in the near future. These include orders (labs, medications, imaging) and results from other investigations (e.g. eye exam) to support clinical decision-making. The following types of documentation notes are also planned as additions in the near future for PWF - psycho-social, and sleep evaluation, nutrition, physiotherapy and occupational therapy referrals**.**

At each visit, data from all the three forms are available to the providers and their nursing staff for any further action. However, currently no reminders or prompts to providers or their clinical staff are provided using PROBE. These are planned as future additions as well. Although information for orders, labs and referrals may exist in our electronic medical record (Epic Systems), they may mostly exist as free-text notes, so PROBE offers the capture of structured data items and the ability to use these data for follow up visits using a computer-based clinical decision support system that is also planned for development in the near future.

Analyses: As part of this study, we report descriptive statistics, i.e. number of visits since deployment and patient visit characteristics. We also condcuted bi-variate analyses for an outcome of the self-report of chronic pain with a self-report of anxiety symptoms, sleep impairment issues and parental history of pain as explanatory variables. For purposes of the statistical analyses, we dichotomized (yes or no) the explanatory variables according to the screener scoring thresholds (e.g. anxiety) and questions that were answered in affirmative (e.g. sleep and parental history).

Statistical analyses were performed using Stata Software version 12 (StataCorp, College Station, TX). The study was approved by the Cleveland Clinic Institutional Review Board.

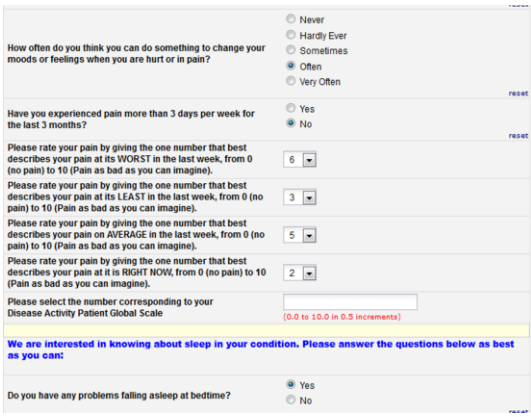

Figure 2 - Patient Screening Questionnaire (PSQ)

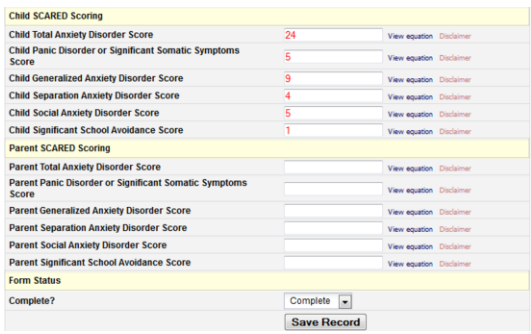

Figure 3 - Patient Nursing Form (PNF)

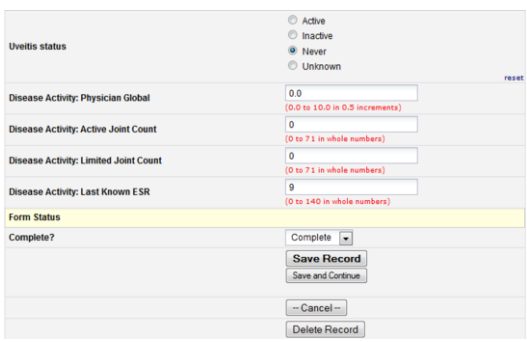

Figure 4 - Provider Work Form (PWF)

Results

Initial results: Over a three-month initial period, PROBE recorded 21 patient visits in the main hospital, our first pilot site. From these visits, we found that patients reporting chronic pain are more likely to report higher average pain scores (>=5) in the last week. They show symptoms of anxiety on as many as 17 of the 41 items screened using three point SCARED scale and are more likely to report sleep issues, e.g. problems falling asleep at bedtime, or feeling sleepy a lot during the day, in school or while driving when compared to those who do not report chronic pain. The patients reporting chronic pain are young adolescents (> 12 years) and more likely to be females with a parental history of pain.

Descriptive Results: As we observed these differences in one practice during routine care, we extended the use of PROBE to the other two practices at our community sites. Subsequent results presented here are from all three practice sites. At the time of this writing, there are 192 patient visits recorded in PROBE. Please see Table 1 below for patient visit characteristics. Please note that in Table 1 there may be missing data for explanatory variables (e.g. sleep) as the patient or the caregiver need not answer all questions at every visit. Similarly, as the system was being deployed and the front-desk staff was getting acquainted with the procedures for recording patient identifying information, there may be some missing values for socio-demographic variables (age, sex). A majority of visits are for female patients (77%) and over 12 years of age (~70%). Patients reported chronic pain in almost half of all visits (49%).

Table 1 – Patient Visit Characteristics

Sex (n=191)	
Female	148 (77.5%)
Age(n=183)	
3 to 7 years	17 (9.3%)
8 to 11 years	39 (21.3%)
12 to 18 years	107 (58.5)
18 to 23 years	18 (9.6%)
Chronic Pain Report (n=181)	
No	92 (50.8%)
Yes	89 (49.2%)
Anxiety Report (n=192) §	
No	161 (83.9%)
Yes (score >= 25 and < 30)	11 (5.7%)
Yes (score >= 30)	20 (1%)
Sleep Issues Report (n=171)¥	
No	59 (34.5%)
Yes	112 (65.5%)
Parental History of Pain Report (n=154)£	
No	25 (16.2%)
Yes	129 (83.8%)

scoring or interpretation according to § SCARED; ¥ BEARS; £ PPHQ

Bi-variate Analyses: Using the chi-square test, the report of one or more sleep impairment issues was significantly associated with the report of chronic pain ($X^2 = 15.7$, p-value < 0.0001). The total score on anxiety symptoms were not significantly associated with the report of chronic pain, as was the parental history of pain report from this pilot study data.

However, we observed differences based on specific anxiety symptoms reported on the SCARED screening tool. In the bivariate analysis, the presence of panic disorder or significant somatic symptoms (score of 7 or more), separation anxiety (score of 5 or more), and significant school avoidance (score of 3 or more) on specific questions are significantly associated with the patient report of chronic pain (X2 = 4.24, p-value = 0.039) and (X2 = 7.11, p-value = 0.008) respectively.

Similarly, we observed differences in responses to pain coping questions for patients reporting chronic pain versus no chronic pain. In general, those reporting chronic pain reported higher pain score levels (4 to 5 on a 10 point VAS) as opposed to 2 to 3 on a 10 point VAS and lower coping levels (e.g. "When hurt or in pain for a few hours or a few days how often do you think you can do something to change it?" The responses were never, or hardly ever for patients reporting chronic pain versus often or very often for those reporting no chronic pain).

Discussion

We have demonstrated that by using a readily available data capture platform and by leveraging electronic tablets such as iPads as an interface, we can create a tool for complete and consistent assessment of pain at every visit in children and adolescents. Furthermore, our analyses show that there are differences in behavioral risks for patients who report chronic pain versus those who do not and we have demostrated this in a real-world clinical setting.

In this pilot work, we have also shown that the PROBE system can effectively screen patients or their caregivers in pediatric rheumatology waiting rooms. Our results show that impaired sleep is a strong predictor for a chronic pain report in children and adolescents with JIA. However, as we write this, we are collecting more data to develop and evaluate a comprehensive prediction model for chronic pain in this population. Simultaneosuly, we are working on developing PROBE into an automated computer-based clinical decision support system. We hope to evaluate it in near future for patient and system based interventions for pain management in clinical studies.

Because the use of PROBE in routine care can help identify patients' risk factors, i.e. chronic pain vs. no chronic pain group patients, we hypothesize that it can be used to support patient engagement activities, for example to ask more detailed questions about a patient's painful condition, their coping style and/or to provide educational content. Potentially, these activities can promote patient-clinician interaction and lead to informed clinical decisions such as a referral for sleep medicine, psycho-social evaluation or cognitive behavioral therapy (for example for pain coping). Therefore, PROBE based clinical decision support can be used to manage patients who are at higher risk of chronic pain prospectively, however all this needs to be studied in well-designed clinical trials.

As with all such work, there are limitations to ours too. First, the PROBE system is limited by use of REDCap and its built-in programming functionality (e.g. unable to query data on a survey form in real-time). In that respect, the current system is a prototype or demonstration project. Secondly, because of the above limitations, we have not built automated clinical decision support (e.g. prompts and reminders) functionality into the current system. Therefore, our future work would involve migrating PROBE to a more robust data capture and query platform so that we can build robust patient engagement tools, and provide clinical decision support. Lastly, our bi-variate analyses of pilot data may suffer from sample and confounding bias. Regardless, our demonstration project highlights the importance of using eHealth enabled tools in pediatric specialty care practices.

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