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The Levine Experience in Piloting Electronic Patient Engagement Tools in a Pediatric Specialty Clinic Setting

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ABSTRACT

Through Improve Care Now, a quality improvement and research collaborative for pediatric patients with inflammatory bowel disease, our clinic piloted the feasibility and acceptability of patient-facing electronic technology to enhance engagement. This article qualitatively describes our experience piloting the technology. Participants included 36 families. Tools included a Web-based report pushed to families before office visits explaining current and past results on key health metrics and a mobile app for tracking symptoms and concerns and previsit planning between scheduled office visits. Building technology into clinical care required more support than anticipated. The tools improved collaboration and were well received.

Keywords: electronic tools, inflammatory bowel disease, Improve Care Now, patient engagement, self-management support

BACKGROUND

Patient engagement is an essential strategy to achieve the "triple aim" of improved health outcomes, better patient care, and lower costs.[1] It has been defined as "actions individuals must take to obtain the greatest benefit from the health care services available to them."[2] Engagement focuses on the behaviors that patient and families do in support of their health and health care as opposed to behaviors coming from the health care system.[2] Growing evidence supports that patients who are more actively engaged in the health care process have better outcomes.[3,4] Finding strategies to optimize patient engagement in care is essential to improving health care outcomes. This is particularly true in patients with chronic illness who account for a large portion of health care costs, require ongoing care, and have a vital role in their own disease management. This article describes our clinical experience pilot testing electronic patient-facing technology designed to increase engagement in patients with pediatric inflammatory bowel disease (IBD).

IBD is a chronic medical condition that can be difficult to diagnose and treat and is characterized by a relapsing and remitting course, causing significant burden to the patient and family. Improve Care Now (ICN) is a growing network of over 62 hospitals that strive to improve and transform care provided to children with IBD. ICN promotes improved remission rates and outcomes in care by a process that collects data in a large dynamic registry and offers real-time analysis of the data for review by individual sites for improved outcomes. This network strives for care providers, researchers, patients, and families to work together using scientific data to drive improvements for kids with Crohn disease and ulcerative colitis.[5] The collaborative network also encourages sharing a variety of resources among the centers including a variety of tools to help plan for visits to make them productive and efficient.

Another unique focus of ICN is the network's emphasis on the importance of self-management support (SMS). In ICN, SMS is seen as a tool to activate patients and families to be stakeholders in their care as opposed to passive participants and, thus, a strategy to improve outcomes. SMS encompasses increasing knowledge, developing unique skills, building confidence, and becoming more motivated to effectively manage one's own health or, in this case, the health of the child.

ICN partnered with the Enhanced Registeries[1] and the Collaborative Chronic Care Network[2] projects to develop and pilot test electronic tools designed to increase engagement in care. As an ICN site, we participated in a network-based, randomized pilot trial assessing the feasibility and acceptability of the technology. The objective of this article is to qualitatively describe our clinic's experience implementing 2 different types of digital engagement tools into clinical care.

METHODS

Our pediatric gastroenterology clinic was 1 of 6 sites within the ICN network to participate in evaluating the feasibility and acceptability of 2 electronic patient-facing engagement tools. It is a large, multidisciplinary, pediatric subspecialty clinic based in an urban, tertiary care teaching hospital. Institutional review board approval was obtained for our individual site as well as for the overall coordinating center.

Sample

Families were eligible to participate if they met the following criteria: (1) patient between 5 and 17 years who had been diagnosed with IBD for greater than 6 months, (2) anticipated clinic visit frequency occurring at least every 4 months, (3) English speaking, and (4) regular access to a smart phone (android or iPhone [Apple, Cupertino, CA]) or tablet (ie, iPad [Apple] or Kindle Fire [Quanta Computer, Amazon.com]).

Study Design

Eligible families were identified by reviewing our master list and prescreening those who were eligible. Every attempt was made to approach families at the time of an appointment, scheduled infusion, routine procedure, or during hospitalization. Interested families then met with the study coordinator, and written, informed consent was obtained from the primary caregiver. Once consented, parents completed a brief demographic survey and an assessment of health care literacy (Rapid Estimate of Adult Literacy in Medicine-Short Form).[6] Both the provider who saw the patient as well as the nurse who discharged the family completed a brief survey regarding their perceptions of participant's engagement during the visit.

We enrolled participants by entering basic identifying information into a study registration page via a Web-based platform. Once this enrollment was complete, the participant received a welcome e-mail and Web link to complete a brief online survey assessing their engagement in their child's clinic visit. After completion of the survey, participants were randomized via the Web-based platform to 1 of 3 conditions: usual care, patient status tracker (PST), or inter-visit planner (VP). The participant received a second e-mail with their assigned study group and detailed next steps, which varied based on group assignment. At each follow-up clinic visit, parents and providers completed the engagement survey. Parents also answered qualitative questions about their experiences using the electronic tool. Each participant remained in the study until the end of the data collection period.

Usual care. Parents did not receive an electronic engagement tool. They did participate in baseline and follow-up assessments at each scheduled clinic visit.

Electronic Engagement Tools

Helping patients attain the benefits of advances in health care is contingent on them becoming active in their own care.[1] The engagement tools were designed to optimize clinical interactions and shared decision making. The tools provided patients and parents with the right information at the right time and helped them understand the information and how to use it with their health care team.

Patient status tracker. Parents in this group received a personalized report of their child's key laboratory results before their clinic visit. The report was delivered via e-mail with a Web link 1 week before a scheduled visit. The PST[7] was designed to translate relevant laboratory results and health metrics into easy-to-understand visualizations and layperson-friendly language. It provided an easy-to-read description of each laboratory test reported, most recent data as well as data reported over the past 1 year, and personalized questions based on these results. The metrics contained in the tool included key laboratory values from the ICN registry (C-reactive protein,