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A Shared e-Decision Support Portal for Pediatric Asthma

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Abstract

We describe the user-centered development of an electronic medical record-based portal, “MyAsthma,” designed to facilitate shared decision making (SDM) in pediatric asthma. Interviews and focus groups with 7 parents of children with asthma and 51 clinical team members elicited two overarching requirements: that the portal should support sustained communication and ensure patient safety. Parents and clinicians prioritized features including collecting parent and child concerns and goals; symptom, side effect, and medication adherence tracking with decision support; and accessible educational materials. Iterative usability testing refined the system. MyAsthma provides a model for using technology to foster SDM in ambulatory care settings.

Keywords

Patient Portals; Shared Decision Making; Asthma

BACKGROUND AND SIGNIFICANCE

Shared decision making (SDM) involves participation by both patients and clinicians, sharing of treatment preferences and goals, and joint determination of the treatment plan (Charles et al., 1997). The Institute of Medicine (IOM) (2009) has prioritized research on SDM. However, despite the designation of SDM as a national priority, this process has been difficult to implement in real-world practice settings (Friedberg et al., 2012). One potential approach to overcome barriers to SDM involves facilitating the process through patient portals linked to electronic medical records (EMRs) (IOM, 2009; Centers for Medicare and Medicaid Programs, 2010). Despite this promise, SDM has not historically been prioritized in the design of these portals and research regarding how to design such systems is lacking.

Pediatric asthma, which affects >7 million US children (Bloom et al., 2011), provides an ideal condition to study the design of patient portals that foster SDM. Our objective was to design a portal to facilitate SDM between families of children with asthma and primary care clinicians based upon user-identified criteria and integrated within the electronic medical record.

METHODS

Interviews and Focus Groups with Parents and Clinical Team Members

This project took place in one urban and two suburban practices. Semi-structured individual interviews were conducted with parents of children with asthma and focus groups were conducted with physicians, nurse practitioners, and nurses at primary care practices to generate a list of requirements for the portal. Members of the hospital Legal, Compliance, and Risk Management departments were also interviewed. Study subjects were shown early conceptual prototypes, asked for feedback, and questioned regarding desired features.

Software Development—We used an iterative development process building upon interview and focus group results. The multidisciplinary team met weekly to review interim portal designs. The portal, named “MyAsthma,” was designed to work within the framework of an existing patient portal, MyChart (EpicCare, Verona, WI) and was linked to The Children’s Hospital of Philadelphia (CHOP’s) EMR through a web-based framework, the “Care Assistant,” that appears seamlessly within CHOP’s Epic EMR (Fiks et al, 2012a).

Usability Testing—Once a working prototype was developed, we conducted usability testing with 5 parents and 5 primary care clinicians, a sufficient sample size to identify meaningful problems (Nielson, 1993). Through a scenario-based approach (Britto et al., 2009), we tested components prioritized by parents and clinicians. Subjects followed a think-aloud protocol (Wright & Monk, 1991) while performing tasks in order to communicate their understanding of the user interface. We pre-specified final benchmarks of 100% task completion with 80% of tasks error-free. Open-ended and Likert-scaled responses were collected regarding the utility and usability of specific features and the overall portal system.

RESULTS

Participants

In the requirements gathering phase, we interviewed 7 parents (86% female, 86% African American). Twenty-four pediatricians, 6 nurse practitioners, 17 nurses, 1 each compliance expert, attorney, risk management expert, and pharmacist also participated in interviews or focus groups. Five parents, 4 pediatricians and 1 nurse participated in usability testing.

User Requirements for a Shared Decision Making Portal

In the interviews and focus groups, we identified two overarching themes: the need for the portal to support sustained communication between the clinical team and family and the importance of system design to ensure that errors were avoided. We provide representative

quotations for these themes and summarize portal features prioritized by study subjects in Table 1 and Figure 1.

Usability Testing Results

We next conducted usability testing to ensure that the portal was easy to use and remedy design problems. Greater than 80% of participants were able to complete each scenario, and satisfaction ratings were high (means 8.2-8.4 on a 9-point Likert scale). Suggestions from parents and clinicians were similar; in no case did the usability tests for the two groups generate conflicting recommendations.

Multiple usability issues were identified and resolved through iterative testing. Navigation was originally difficult for both parents and clinicians. In an older version of the portal (Figure 2), parents had difficulty locating components of the portal and identifying navigation menu labels to access the different pages. In particular, videos and handouts were separated in the original design (Figure 2), and parents struggled to identify them as educational content. Combining these pages into one “Education” section and making the navigator more distinct and brightly colored (Figure 1) resulted in successful task completion and high satisfaction scores. Clinicians had difficulty expanding a dynamic online timeline that displayed results of a monthly control survey (Figure 1) from families. In addition, clinicians struggled with assigning educational content using the system because it represented a change from an existing workflow. The system was redesigned in response by placing a link to open the timeline directly below it, and by placing the link to educational content in a familiar position on the screen (Figure 1).

Testing also resulted in improvements in the data presentation format. We presented information on goals, concerns, and asthma survey results to the first usability test participants in several graphical formats including icons and bar graphs (Figure 2); however, participants found these formats confusing. In response, we changed the format to a table which displayed the results of each survey question using text or numeric values, with cells shaded green (good), yellow (of concern), or red (major concern), a format that parents found easy to understand (Figure 1). The change in data presentation resulted in improvements in task completion and high satisfaction ratings from parents and clinicians.

Usability testing also clarified how best to assess parents’ concerns about asthma and its treatment. We initially offered parents a list of options to choose from, and participants selected the entire list. To prioritize concerns, we changed to a Likert-scaled survey (0 (not at all concerned) to 5 (very concerned)) of common concerns identified by parents. Concerns that received a score of 0 were not displayed, and those with scores of 1-5 were presented next to red bars of varying length ranked by the level of concern (Figure 1). Additional concerns could be entered in free text. Participants found this format satisfactory.

DISCUSSION

The MyAsthma portal is a novel application, distinguished by its focus on supporting SDM and integration with the EMR, developed to sustain engagement of families of children with asthma. Key themes from participants included supporting sustained communication

between families at home and the clinical team and including safeguards to prevent the loss of information and errors. Parents and clinicians prioritized similar features: the collection of parent and child concerns and goals; symptom, side effect, and medication adherence tracking with decision support; and accessible educational materials.

The MyAsthma portal extends features of typical portals, such as messaging and appointment scheduling, with a design that closely follows the elements of SDM. Sharing information is a key component of SDM (Charles et al., 1997), and is accomplished through the portal survey function, which conveys information on symptoms, goals, and concerns between parents and the primary care practice. Providing parents access to documents generated in the office also facilitates information sharing. The emphasis on clinicians and parents both tracking concerns and goals is also closely in line with the philosophy of SDM, which depends upon identifying, measuring, and following preferences and goals for care (Charles et al., 1997). This approach may be particularly effective since prior work suggests that parents that more easily reach their children's doctors from home report higher SDM (Fiks, 2010) and this process may reduce health care costs (Fiks, 2012b).

Study subjects were concerned about patient safety and the potential for loss of information through the portal. The IOM report, "To Err is Human: Building a Safer Health System," described latent errors, which include errors in software design, as the greatest threat to safety in a complex system (IOM, 1999). Our study identified strategies to prevent latent errors or system misuse by determining optimal workflows, such as sending asthma control results to a group rather than an individual provider. In addition, the inclusion of decision support directed at both clinicians and families, an extension of common decision support models focused exclusively on the clinician (Fiks, 2011), enabled us to follow another IOM suggestion for safety by prioritizing the inclusion of the patient/family in safety design and the process of care (IOM, 1999).

This study had several limitations. First, the study involved in-depth testing of the usability of the portal with a small number of parents and clinicians. While the testing provided actionable information that transformed the portal design, our sample size was small. In future work, we will test the use of the portal in multiple ambulatory practices to assess its clinical utility. Additionally, this study was conducted within one health system in one geographic area; as such, the study population may not represent all perspectives. However, we obtained input on the design from diverse stakeholders. The MyAsthma portal is currently restricted to use by families of children aged 6-12 because that is the population in which the control assessment measure was validated. Future work will expand portal use to a larger age group. Children were not involved in the evaluation of the portal because, in many portals and health systems, the parent is the proxy reporter for the child in this age group.

CONCLUSION

This study defined user requirements and tested the design of a portal to foster SDM in chronic illness. The MyAsthma portal provides a model for broadly supporting SDM in

varied ambulatory settings. Future work will test the effectiveness of this tool in promoting SDM in clinical practice

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Abbreviations

SDM	Shared Decision Making
EMR	Electronic Medical Record
IOM	Institute of Medicine
CHOP	The Children's Hospital of Philadelphia

References

- Bloom B, Cohen RA, Freeman G. Summary health statistics for U.S. children: National Health Interview Survey, 2010. *Vital Health Statistics*. 2011; 10(250):1–80.
- Britto MT, Jimison HB, Munafo JK, Wissman J, Rogers ML, Hersh W. Usability testing finds problems for novice users of pediatric portals. *Journal of the American Medical Informatics Association*. 2009; 16(5):660–9. [PubMed: 19567793]
- Centers for Medicare and Medicaid Services. Medicare and Medicaid programs; electronic health record incentive program. Final rule. *Federal Register*. 2010; 75(144):44313–588. Retrieved from <http://www.gpo.gov/fdsys/pkg/FR-2010-07-28/pdf/2010-17207.pdf>. [PubMed: 20677415]
- Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science & Medicine*. 1997; 44(5):681–92. [PubMed: 9032835]
- Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared Decision-Making in Pediatrics: A National Perspective. *Pediatrics*. 2010; 126(2):306–14. [PubMed: 20624804]
- Fiks AG. Designing computerized decision support that works for clinicians and families. *Current Problems in Pediatric and Adolescent Health Care*. 2011; 41(3):60–88. [PubMed: 21315295]
- Fiks AG, Grundmeier RW, Margolis B, Bell LM, Steffes J, Massey J, Wasserman RC. Comparative effectiveness research using the electronic medical record: an emerging area of investigation in pediatric primary care. *Journal of Pediatrics*. 2012a; 160(5):719–24. [PubMed: 22364853]
- Fiks AG, Mayne S, Localio AR, Alessandrini EA, Guevara JP. Shared decision-making and health care expenditures among children with special health care needs. *Pediatrics*. 2012b; 129(1):99–107. [PubMed: 22184653]

- Friedberg MW, Van Busum K, Wexler R, Bowen M, Schneider EC. A demonstration of shared decision making in primary care highlights barriers to adoption and potential remedies. *Health Affairs (Millwood)*. 2013; 32(2):268–75.
- Institute of Medicine. *To Err is Human: Building a Safer Health System*. National Academy Press; Washington, D.C.: 1999. Committee on Quality of Health Care in America.
- Institute of Medicine. Committee on Comparative Effectiveness Research Prioritization. *Initial National Priorities for Comparative Effectiveness Research*. National Academy Press; Washington, D.C.: 2009.
- Nielsen, J. *Usability Engineering*. Morgan Kaufmann; San Francisco, CA: 1993.
- Wright P, Monk AF. The use of think-aloud evaluation methods in design. *ACM SIGCHI Bulletin*. 1991; 23(1):55–7.

Figure 1. The MyAsthma Portal Parent Interface- Homepage

The MyAsthma Portal parent homepage includes parent and child treatment goals, concerns, and a timeline of monthly check-in survey results regarding asthma symptoms, side effects, medication adherence, progress toward goals, and management of concerns. Parent and child educational content, the asthma care plan, and contact information for the clinical team can be reached using the navigator tabs. In order to make the portal accessible to individuals who were color blind, we used text to display the responses to each survey question by month in the timeline. In later versions of the portal, we have included the option of viewing the portal in gray scale. ©2014 The Children's Hospital of Philadelphia. All Rights Reserved.

Figure 2. Previous Portal Design

This portal design was used in early usability testing.

Table 1

Portal User Requirements and Features: Themes from Interviews and Focus Groups

Theme	Representative Quotations and Comment Summaries
<i>Theme 1: Supporting Sustained Communication</i>	
Expectation That All Information Entered Will Be Reviewed	<p>"If the physician isn't seeing this on a [regular] basis, when [families] come to the doctor's office, they're going to ask the same questions all over again... the doctors need to be onboard with it, because if they're not, the parents are going to be like 'Well, what's the point?'". - Mother</p> <p>"The parents need to know that the clinical team can see this." - Urban clinician</p>
A Simple User Interface with Clear Directions and Recommendations	<p>"[The asthma control survey] needs to be very specific about what it wants from the parents, because some of us are tired.... [It should be] very simple, because... if it's something we're questioning, it's going to make us not want to fill it out." - Mother</p> <p>"You need to tell [parents] to call, and tell them exactly what to do. If you just tell them their symptoms are of concern, they'll go straight to the ER. If you're telling them what to do, that will help." - Mother</p>
<i>Theme 2: Ensuring Patient Safety and Error Avoidance *</i>	<p>"I would hate for a family to use this when a kid is having a flare. So I think that has to be really clear that this is not an acute use tool." - Suburban clinician</p> <p>"[Messages from MyAsthma] can't sit there for a week... in general, you don't want anything that could need immediate attention sent to an individual. You want it sent to a group of individuals." - Urban Clinician</p>
<i>Portal Features Prioritized by Users</i>	
Asthma Educational Materials	<p>Parents and clinicians emphasized providing different types of educational materials, including videos and handouts, to account for different learning styles and literacy levels.</p> <p>Clinicians prioritized a mechanism to recommend specific educational content to families based on their individual needs.</p> <p>Parents requested educational materials targeted toward children to foster child partnership in asthma care.</p>
Access to Asthma Care Plan	<p>Parents and clinicians emphasized the importance of giving families access to documents that were generated in the office, such as the Asthma Control Plan, so they could share them with their child's school or with family members without the inconvenience of going to the office.</p>
Asthma Symptom, Medication Adherence and Side Effect Tracking with Decision Support	<p>Parents and clinicians wanted to track information over time to get a longitudinal view of the child's asthma control, and how it varies seasonally.</p> <p>Parents and clinicians agreed that a mechanism for tracking medication adherence would be helpful.</p> <p>Both groups favored including messages to both the clinical team and families regarding actions needed based on survey results for asthma control and side effects.</p>
Identification of Goals and Concerns [^]	<p>Both parents and clinicians were receptive to sharing information about families' treatment goals and concerns.</p> <p>"... it's a journal that the doctors can actually access and see what your goal is, and maybe you can work together to try and make the plan come together." - Mother</p> <p>"This is valuable. It makes families feel heard. Families might be more willing to type this information in [to the portal] rather than say it to a provider." - Suburban Clinician</p> <p>Parents preferred to have an open-ended question for goals; "It should be a blank box because you may have a treatment goal [that] everyone [else] may not think that's an issue." - Mother</p> <p>Parents also emphasized their preference to report both parent and child goals, since they might differ.[^]</p>

* If a child's clinical status changed during the month, families had the opportunity to update the portal survey to reflect the child's status. In the interest of patient safety, if an issue required immediate medical attention, we encouraged families not to use the portal and to contact their primary care office directly. The system was designed so that the clinical team would review any information entered by the family into the portal.

Goal attainment, which was tracked monthly, was reported for the families' goals overall, rather than separately for parent and child goals. Parents were comfortable with this approach.