UC Davis

UC Davis Previously Published Works

Title

Exploring perceptions and use of the electronic health record by parents of children with autism spectrum disorder: A qualitative study

Permalink

Journal

ISSN

Authors

Bush, Ruth A
Stahmer, Aubyn C
Connelly, Cynthia D

Publication Date

DOI

Exploring perceptions and use of the electronic health record by parents of children with autism spectrum disorder: A qualitative study

Ruth A Bush
Rady Children's Hospital—San Diego, USA; University of San Diego, USA

Aubyn C Stahmer
UC Davis MIND Institute, USA

Cynthia D Connelly
Rady Children's Hospital—San Diego, USA; University of San Diego, USA

Abstract

This qualitative project used structured interviews with nine parents to examine perceptions of the electronic health record (EHR) and associated patient portal in the treatment of their child's autism spectrum disorder. Thematic analysis identified six complementary themes including: Familiarity and exposure to the EHR, changing experience of care (streamlining appointments, providing more rapid medical record access, increasing clinician awareness of the complexity of their child's medical treatment, and facilitating prescriptions), portal use, patient/EHR/portal interaction, interoperability, and mother as care coordinator. While aware of the patient portal, only one-third had registered to use it and these parents reported only limited use. In general, perceptions of the electronic health record are positive, but the patient portal has yet to have needed consumer adoption. Further research and functionality are needed to increase portal registration and greater portal integration in patient care.

Keywords

autism spectrum disorder, consumer health information, electronic health record, patient portal, pediatrics

Corresponding author:
Ruth A Bush, Hahn School of Nursing and Health Science, University of San Diego, 5998 Alcalá Park, San Diego, CA 92110, USA.
Email: Rbush@sandiego.edu

Introduction

The electronic health record (EHR) contains individual health-related data and is designed to retain the information in a secure environment while also accessible by clinicians and other related staff.[1] The related patient portal provides a protected online website from which patients can use a secure login to view their health information using an Internet connection, as well as communicate with their health care providers via a secure electronic system, and to schedule appointments.[2] The EHR and patient portals provide potential avenues for patients to become more involved in their health care and could facilitate coordinated multidisciplinary care and shared decision making.[3,4] Currently, little is known about how the increased use of the EHR in the pediatric clinical environment is affecting the treatment of pediatric patients with autism spectrum disorder (ASD).

ASD is characterized by impairments in social interaction and communication along with restricted, repetitive, and stereotyped patterns of behavior,[5] affecting as many as 14.7 per 1000 (1 in 68) children.[6] ASD is a complex health problem with significant co-morbidities including intellectual disability, hyperactivity, and anxiety.[7] The presentation of ASD can vary widely among affected individuals and within an individual over the lifespan.[8,9]

Children with ASD require early and ongoing intensive intervention across multiple treatment areas, including behavioral, educational, rehabilitative (speech, occupational therapy), mental health, and medical treatments. Behavioral treatments comprise the most common interventions for children with ASD.[10] Interventions range from highly structured programs conducted in one-on-one treatment settings to behaviorally based inclusion programs that include typically developing children as models. In addition to behavioral treatment, speech and language therapy, and occupational therapy for their condition, children with ASD are at greater risk for a number of other conditions that are associated with increased health service utilization such as seizure disorders, sleep disorders, and gastrointestinal disorders.[11–14] While some of the therapies are delivered in an educational or behavioral treatment environment, services such as speech and occupational therapy and more recently behavioral services are often delivered in the outpatient hospital or clinical setting and documented in medical records along with physician and specialty medical services.

The prevalence of EHRs is increasing in the United States,[15] and it is estimated that by the end of 2014 most Americans will have computerized health information.[16] Studies have demonstrated the use of EHRs can reduce medical errors, enhance communication between doctors and patients, and promote continuity of care.[16] The EHR can be used to incorporate emergency department, inpatient, outpatient (including satellite clinics), laboratory, and radiology input in a tightly integrated record management system. Computerized physician order entry allows providers to manage and communicate orders and results, which are recorded electronically. The electronic system also captures data resulting from patient registration, appointment scheduling, billing, and other business-related functions, providing a wealth of data.

Providing access to individual health care information, for example, laboratory results and current medications, as well as being able to securely communicate with their health care providers has the potential to improve overall care experience through increased health care understanding and knowledge. In practice, there are acknowledged issues of privacy and security concerns, as well as the potential impact of changing the interaction between the health care professional and the patient when bringing a computer into the relationship.[17] Additionally, the issue of interoperability and sharing of health data across multiple organizations or within different settings of care is a reported frustration and barrier to use of the EHR.[17] Pediatric use of the EHR introduces additional complexities including providing needed access to parents and other designated caregivers, which can result in multiple individuals needing access to a record, as well as tracking

immunizations, growth patterns, and frequent medical encounters. Studies looking specifically in children with cystic fibrosis, diabetes mellitus, and juvenile idiopathic arthritis,[18–20] as well as the use of the EHR for children under the age of 5 with multiple chronic conditions,[21] note generally positive interaction. Parents reported increased understanding of their children's chronic conditions, as well as better communication with their child's health care provider.[18] To date, there has not been a study specifically examining the EHR and its incorporation in pediatric ASD treatment. Further patient and caregiver input is needed in order to design a consumer-friendly interface so that EHR, including the patient portal, becomes a patient care tool and can be used to manage approaches to treatment that recognize individual pediatric patient needs.

The aim of this study was to use qualitative methodology to obtain the perspective of parents whose children have ASD on the utility of the EHR as an instrument in their children's treatment. A secondary objective was to estimate the potential loss of medical encounter information due to EHR interoperability issues.

Methods

Data were collected from parents who had a child less than 19 years old, with a previous diagnosis of ASD recorded in their medical file, and had been a patient at a tertiary academic children's hospital in southern California during 2013 to explore the utility of the EHR as an instrument in their children's treatment. Potential participants were identified using a list of patients at the Autism Discovery Institute (ADI) at the children's hospital who had completed a form indicating that they were interested in participating in autism studies. Some of the first participants referred a parent they knew whose child was seen at ADI whom they thought might want to be interviewed. All study procedures, including protocols for recruiting participants and obtaining informed consent, were reviewed and approved by the appropriate administrative and university Institutional Review Boards for the protection of human subjects prior to study initiation. All parents gave informed consent, including willingness to participate in a telephone interview and to be recorded. The parent sample consisted of 9 mothers of 10 children (1 family with 2 children with ASD) whose children ranged in age from 3 to 18 years. In total, 9 of the 10 children were male. Of the nine mothers, three (33%) were Hispanic/White, four (44%) were non-Hispanic/White, and two (22%) were African American. The mothers ranged in age from 35 to 54 years.

Qualitative methods via a structured telephone interview were used to investigate the use, attitudes, and suggestions from parents with children who have an ASD diagnosis. A telephone interview approach was chosen, based on parent feedback, as the most convenient approach to fitting it in their schedule. The interview was designed by the authors in consultation with experts in areas of autism treatment, the EHR, and qualitative methodology. Initial development of the topic areas included a review of the literature of use of the EHR in pediatric practices and among children with chronic conditions. Previously reported strengths and weaknesses of the EHR and patient portal for children with chronic conditions were reviewed[19,21,22] and provided the foundation for interview questions.

Additionally, the interviews were constructed to determine how complete the medical encounter data were. Parents were asked to review a summary of appointments captured during the study time period by the EHR. Their feedback was designed to identify particular types of encounters/ specialty types that are not captured completely and missed encounters across all divisions. Parents were asked to identify the frequency and scope of services they received outside the hospital system and its integrated delivery providers. The interviews began with broad, introductory questions to create a relaxed atmosphere and to facilitate answering questions without face-to-face contact. A complete list of the EHR interview questions can be found in Table 1. The interview continued

Table 1. Parent interview questions.

How familiar are you with the electronic health record (EHR)?
How did you learn about the EHR?
How has the EHR changed your experience of care?
Is most of your child's care being captured in the EHR? Do you receive care in another health system?
How familiar are you with the patient portal? (At this medical center we call it MyChart)
How do you use MyChart?
Is there anything you would do to change MyChart?
How concerned are you about confidentiality and the EHR?
Can you think of any way the EHR and portal could improve you and your child's medical experience?
Is there anything else about the EHR and your child that you think I should know?

with open-ended questions about familiarity and experience with the EHR. The interview then covered capture of appointments, as well as the use of the patient portal. To conclude, the interviewer asked for suggestions from the parents for possible improvements in the EHR and patient portal to enhance their interaction and improve their children's clinical experience. The interview took 50–60 min to administer, depending on the participant's knowledge of the EHR and frequency of medical encounters. All interviews were completed in one telephone call. Parents were thanked for their time, and sent a gift card for their participation.

Data analysis

Each interview was transcribed verbatim and then independently analyzed by two of the investigators (R.A.B. and A.C.S.) to identify themes that emerged from the transcripts. Segments of transcripts ranging from a phrase to several paragraphs were assigned codes based on a priori (i.e. based on questions in the interview guide) or emergent themes. Inter-rater reliability was assessed for a subset of one-third of the participants; there was 100 percent congruence in thematic identification. The same two study team members then met to review their findings. Identified themes showed high concurrence between the investigators. Themes were compared to look for trends. Thematic saturation was reached at nine participants. Parents' reports of benefits and barriers to the use of EHR were captured and quantifiable results in the form of tallies were available for some variables.

Results

Six complementary themes emerged from the parent's responses: familiarity and exposure to the EHR, changing experience of care, MyChart use, patient/EHR/portal interaction, interoperability, and mother as care coordinator.

Thematic issues

Familiarity and exposure to the EHR. The participants' familiarity with the EHR was split. While four of the participants responded that they were very familiar with the EHR, three were not familiar at all. The six respondents who had familiarity with the EHR reported its introduction through multiple venues including seeing it used at a medical appointment,[3] using it to request medical records,[2] have a physician mention it,[1] or working with it as part of her job.[1]

The EHR changing experience of care. The descriptions of changes in care included a more stream-lined approach with fewer complications when making an appointment, easier and faster medical record access, increased sharing of medical information across providers in the children's hospital system with more clinician awareness of the type, complexity, and frequency of treatment sought without the parent having to verbally introduce her child's medical history. Three mothers specifi-cally noted the ease of electronic prescriptions and the ease of arriving at the pharmacy to find a completed prescription that had also met insurance formulary guidelines. Five of the respondents particularly noted improved awareness of their children's care, as long as the care was within the specific hospital system, but that the sharing of information did not occur with either providers outside the system, particularly among behavioral specialists or with insurance companies. Two (22%) felt the introduction of the EHR had not changed care at all. Specifically, one parent responded that most providers were not taking a broad view of her child, which she thought would occur given the provider's ability to immediately access a more complete patient history. The par-ent emphasized she wished the providers would take a broader view of child's condition and the treatment he was receiving. Four of the participants said that they were not concerned about issues of confidentiality, four were non-committal, and one was concerned that records were susceptible to breach.

MyChart use. The participants were less familiar with MyChart, which is the Epic EHR's linked patient portal providing secure messaging, appointment scheduling, result reporting, and health information. Only one respondent was currently signed up and using the portal; two other mothers were registered but reported only limited interaction with the portal. The one user made and tracked appointments in MyChart, reviewed her child's record, and sent messages to the doctor within the portal. Of the six non-users, an additional two were familiar with the idea of a portal, but from their own experience as a patient rather than using it for their children. In fact, both were very enthusi-astic about using it for their own care and used it to check lab results and make appointments but were not interested in MyChart for their children. Parents explained that they did not use the portal because it was difficult to register, requiring a two-step, in-person process to gain access. Once they did have access, they reported losing their password, which also had to be reset using a two-step system. Once on the portal, they found it was not easily viewed on a smart phone and it was not consumer-friendly. Rather, steps such as deleting secure messages were difficult to do and they found the screens to be cluttered and difficult to read.

Suggestions for improved patient/EHR/portal interaction. There was no shortage of parental sugges-tions for improvements, especially to MyChart, that would increase their use of the tool. The first was to have a smart phone application for MyChart. Many of the mothers expressed frustration that at this point, they had to log into the portal using a computer rather than by smart phone. Having smart phone access would allow them access to manage the calendar or send a message to a car-egiver when they might have a few minutes at school pickup or during a sports practice. They also noted they would like the option to have a real-time conversation with their child's multiple provid-ers—similar to something like Skype or Facetime—within the secure portal to discuss interdisci-plinary treatment. Other additional improvements would be more rapid access to lab results (three respondents), a family calendar, and a single push button to request medical records. Current limi-tations barring or reducing portal use include many emails on one issue which the users find hard to delete, the fact that it is hard to log in, and the lack of a robust patient education center, links to appropriate medical literature, or vetted websites. The number of weekly contacts with the medical system makes it difficult for the parents to use the portal. Five of the parents reported an average of more than three medical appointments a week. The mother with two children with ASD said a

typical week can involve 15 appointments among her children, who have an additional chronic condition. Thus, the number and variety of type of medical appointments challenge the scheduling system.

Interoperability. Five of the participants drew upon their child's treatment in another medical system to illustrate adaptations that might be made in the current system's logistics, as well as to point out limitations within the Epic EHR. Those parents who also subscribe to a behavioral electronic data collection system such as Autism Tracker Pro and ABC Data Pro (which are not necessarily required to meet Health Insurance Portability and Accountability Act (HIPPA) requirements as those associated with an EHR) reported getting more provider emails, finding the interface to be more easily accessible, receiving frequent emailed progress notes (four respondents), and welcomed the ability to share information with providers across multiple clinical systems. They particularly liked being able to share information more easily with their children's schools, as well as with other behavioral providers. When the participants were asked to match their children's medical appointments versus what was captured in the hospital EHR, it became apparent that because of logistics, insurance restrictions, and personal choice, 9 of 10 were receiving treatment outside the hospital system. Thus, the information currently captured in the hospital and integrated delivery system EHR results in a partial data capture of the true type and volume of medical utilization associated with pediatric patients with ASD.

Mother as care coordinator. An unanticipated theme was that of the mother functioning in the role of care coordinator and what that means for the EHR and related patient portal. Many of the respondents[6] described years of laboriously requesting paper copies of medical records for other care providers, schools, insurance, and even entry into developmental programs sponsored by social agencies. Most referred to the hard-copy binder that they carried (and sometimes still carry) to their children's appointments and would welcome a comprehensive, secure alternative to this approach. In order to replace hard copies, the parents would need "on-demand" evidence of appointments attended for school absences, as well as for insurance requirements. They would need a document and record management that would allow the capture of information (including reports and treatment notes) from all of the members of their child's care team. One mother described the idea of an electronic version of notebook divider tabs on which she would click to get the needed information according to provider. The number of participants whose responses matched each theme is captured in Figure 1.

Discussion

This article provides one of the first examinations of use of and attitude toward the EHR and patient portal from the perspective of parents of children with ASD. These interviews provide insight into the parental caregivers' perceptions of the experience and modifications to clinical care that have resulted from inclusion of the EHR in clinical practice. In general, parents were enthusiastic about the introduction of the EHR and felt it has made medical record access easier, facilitated prescriptions, was streamlining appointments—especially providing patient history, and sharing medical conditions and treatment information among providers. While generally positive about the EHR, the parents indicate several adjustments need to be made before they would be able to abandon their hard-copy binders as their primary instrument for managing their children's care. As other studies have noted, one of the major issues remains that of interoperability. Not being able to share treatment approaches and outcomes with the multitude of providers that are part of their children's care team is a significant limitation. When compared to the
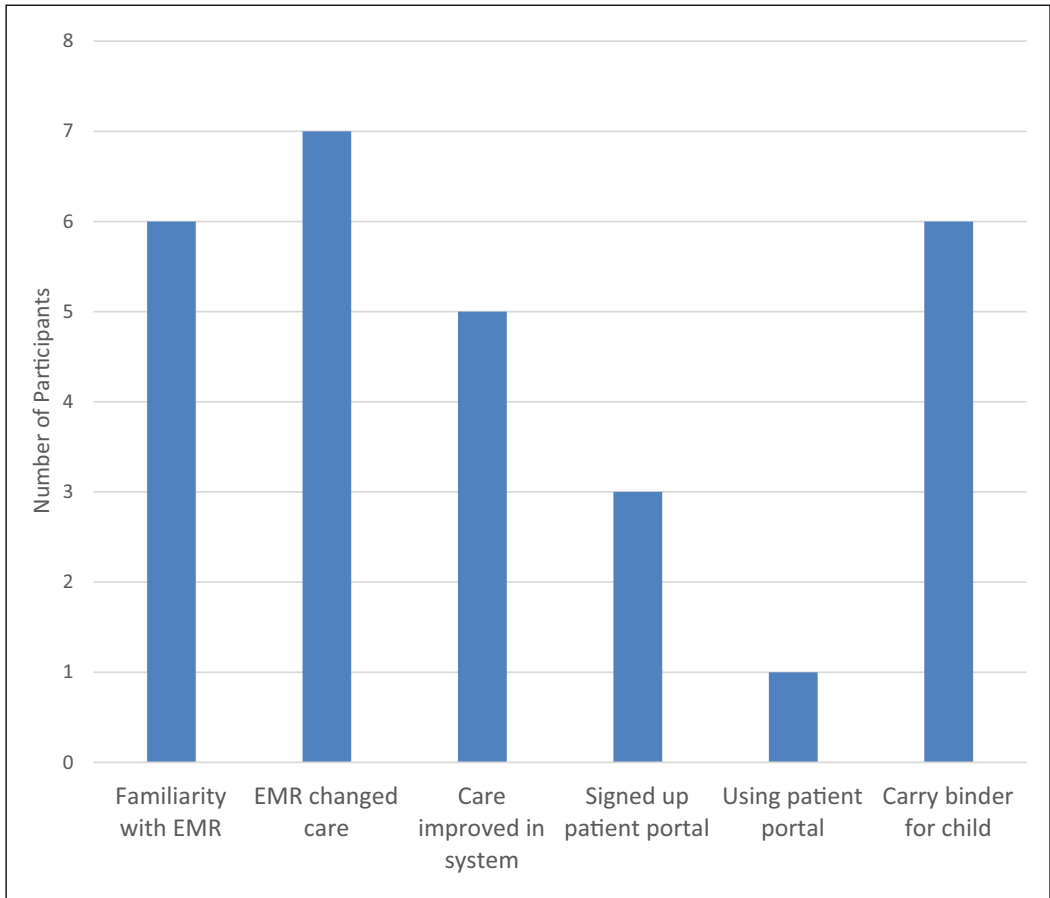
Figure 1. Number of parents of children with ASD endorsing themes about the electronic health record.

interoperability of behavioral trackers and portals such as Autism Tracker Pro and ABC Data Pro, the EHR, particularly the patient portal, is seen as less flexible and less useful in serving as an easily accessed repository for information and an instrument for sharing treatment information.

The minimal use of the patient portal and the reported obstacles to use are important findings of this study. The rate of patient portal adoption, with 33 percent of participants registered to use MyChart, is similar or somewhat lower than the rates reported elsewhere.[21,23] The higher rates of adoption seen in studies by Byczkowski et al., Ketterer et al., and Tom et al. may reflect that the portals they studied were developed in-house specifically for pediatric patients rather than using an off-the-shelf application for an EHR designed primarily for adult use. However, the use of a structured interview in our case indicated even registered participants are unlikely to use the portal which illustrates that registration is not utilization. These data suggest the patient portal may need additional modifications for ease of use in the pediatric environment, especially in cases of chronic conditions that require multidisciplinary care. Interestingly, although some parents did not report thinking of, let alone using, the patient portal for their children, they do use the tool for their own care. Thus, two groups emerged. There were parents who were willing to use the portal, but did not find it enhanced or streamlined the care for their child and the majority who do not use a portal

under any circumstance. While the word training was never used, the parents did describe the portal as being difficult to use and having limited capabilities. Of note, is that one user who reported using the portal frequently and for several different types of tasks also worked for the hospital system. As part of her employment, she had received extensive EHR training and through the nature of her daily tasks understood how the portal connected to various segments of medical care. Other parents described the use of the portal as "taking too much time." It either took too much time to register, to obtain a new password, or to try to scroll through messages. The services it offered in return such as scheduling for appointments were seen as easier by making a telephone call. The screen was too complicated to see on a smart phone. Thus, the patient portal is not regarded as being consumer-friendly. Unlike many online shopping applications or airline portals where the customer would rather interact by computer, or increasingly tablet and smart phone, rather than speaking to a human, the patient portal is still regarded as making the interaction more complicated rather than simpler.

This study has several important limitations. Because of the small sample size, caution should be used before generalizing the findings to other groups. In addition, the study sample was restricted to individuals who had already self-identified as being interested in participating in research, indicating their enthusiasm for potential solutions. While it may be a limitation that only mothers participated rather than the full complement of potential caregivers, it is established that mothers are usually the coordinators of children's health, especially of chronically ill children.[24,25] The study also illustrated that not all patients with ASD who live in San Diego County receive their treatment either solely or primarily from the tertiary academic pediatric health system, and the medical utilization would be underreported if the EHR from this institution was the only source of information. Despite these limitations, this qualitative research has been useful for generating hypotheses, but analysis of the impact of the EHR and patient portal on enhancement of care and patient-centered outcomes will need to be tested using comparative effectiveness research with measurement of the use of the portal and health outcomes.

Conclusion

This study found participating parents have mainly positive feelings about the EHR but have yet to use the patient portal consistently or to think it might make their clinical experience or care coordination easier. Overcoming logistical issues currently dampening the potential of a portal to increase access to care and improve health care outcomes for children with chronic conditions, such as ASD, will be an important direction for future research.

References

1. Electronic Medical Record Systems, http://healthit.ahrq.gov/key-topics/electronic-medical-record-systems#one (accessed 2 August 2014).

2. What is a patient portal? http://www.healthit.gov/providers-professionals/faqs/what-patient-portal (accessed 2 August 2014).

3. Fiks AG, Mayne S, Karavite DJ, et al. A shared e-decision support portal for pediatric asthma. *J Ambul Care Manage* 2014; 37(2): 120–126, http://www.ncbi.nlm.nih.gov/pubmed/24594560 (accessed 2 August 2014).

4. Ammenwerth E, Schnell-Inderst P and Hoerbst A. The impact of electronic patient portals on patient care: a systematic review of controlled trials. *J Med Internet Res* 2012; 14(6): e162, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3510722&tool=pmcentrez&rendertype=abstract (accessed 28 July 2014).

5. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 4th ed. Washington, DC: American Psychiatric Association, 2000.

6. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveill Summ* 2014; 63(2): 1–21, http://www.ncbi.nlm.nih.gov/pubmed/24670961 (accessed 2 August 2014).

7. McPheeters ML, Warren Z, Sathe N, et al. A systematic review of medical treatments for children with autism spectrum disorders. *Pediatrics* 2011; 127(5): e1312–e1321, http://www.ncbi.nlm.nih.gov/pubmed/21464191 (accessed 2 November 2012).

8. Volkmar FR and Pauls D. Autism. *Lancet* 2003; 362(9390): 1133–1141, http://www.ncbi.nlm.nih.gov/pubmed/14550703 (accessed 9 October 2012).

9. Wing L. The autistic spectrum. *Lancet* 1997; 350(9093): 1761–1766, http://www.ncbi.nlm.nih.gov/pubmed/9413479 (accessed 19 October 2012).

10. Volkmar FR, Lord C, Bailey A, et al. Autism and pervasive developmental disorders. *J Child Psychol Psychiatry* 2004; 45(1): 135–170, http://www.ncbi.nlm.nih.gov/pubmed/14959806 (accessed 19 October 2012).

11. Bauman ML. Medical comorbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics* 2010; 7(3): 320–327, http://www.ncbi.nlm.nih.gov/pubmed/20643385 (accessed 19 November 2012).

12. Buie T, Campbell DB, Fuchs GJ, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics* 2010; 125(Suppl. 1): S1–S18, http://www.ncbi.nlm.nih.gov/pubmed/20048083 (accessed 29 October 2012).

13. Coury D. Medical treatment of autism spectrum disorders. *Curr Opin Neurol* 2010; 23(2): 131–136, http://www.ncbi.nlm.nih.gov/pubmed/20087181 (accessed 13 November 2012).

14. Coury D, Jones NE, Klatka K, et al. Healthcare for children with autism: the Autism Treatment Network. *Curr Opin Pediatr* 2009; 21(6): 828–832, http://www.ncbi.nlm.nih.gov/pubmed/19745738 (accessed 19 November 2012).

15. Busby LT, Sheth S, Garey J, et al. Creating a process to standardize regimen order sets within an electronic health record. *J Oncol Pract* 2011; 7(4): e8–e14, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3140457&tool=pmcentrez&rendertype=abstract (accessed 29 November 2012).

16. Harshberger CA, Harper AJ, Carro GW, et al. Outcomes of computerized physician order entry in an electronic health record after implementation in an outpatient oncology setting. *J Oncol Pract* 2011; 7(4): 233–237, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3140445&tool=pmcentrez&rendertype=abstract (accessed 29 November 2012).

17. McGinn CA, Grenier S, Duplantie J, et al. Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. *BMC Med* 2011; 9: 46, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3103434&tool=pmcentrez&rendertype=abstract (accessed 21 October 2014).

18. Byczkowski TL, Munafo JK and Britto MT. Family perceptions of the usability and value of chronic disease web-based patient portals. *Health Informatics J* 2014; 20(2): 151–162, http://www.ncbi.nlm.nih.gov/pubmed/24056751 (accessed 2 August 2014).

19. Britto MT, Hesse EA, Kamdar OJ, et al. Parents' perceptions of a patient portal for managing their child's chronic illness. *J Pediatr* 2013; 163(1): 280–281.e1–e2, http://www.ncbi.nlm.nih.gov/pubmed/23541773 (accessed 2 August 2014).

20. Britto MT, Jimison HB, Munafo JK, et al. Usability testing finds problems for novice users of pediatric portals. *J Am Med Inform Assoc* 2009; 16(5): 660–669, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2744717&tool=pmcentrez&rendertype=abstract (accessed 2 August 2014).

21. Tom JO, Mangione-Smith R, Solomon C, et al. Integrated personal health record use: association with parent-reported care experiences. *Pediatrics* 2012; 130(1): e183–e190, http://www.ncbi.nlm.nih.gov/pubmed/22689872 (accessed 2 August 2014).

22. Bergman DA, Brown NL and Wilson S. Teen use of a patient portal: a qualitative study of parent and teen attitudes. *Perspect Health Inf Manag* 2008; 5: 13, http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2556441&tool=pmcentrez&rendertype=abstract (accessed 2 August 2014).

23. Ketterer T, West DW, Sanders VP, et al. Correlates of patient portal enrollment and activation in primary care pediatrics. *Acad Pediatr* 2013; 13(3): 264–271, http://www.ncbi.nlm.nih.gov/pubmed/23680344 (accessed 2 August 2014).

24. Patterson JM, Leonard BJ and Titus JC. Home care for medically fragile children: impact on family health and well-being. *J Dev Behav Pediatr* 1992; 13(4): 248–255.

25. Stewart MJ, Ritchie JA, McGrath P, et al. Mothers of children with chronic conditions: supportive and stressful interactions with partners and professionals regarding caregiver burdens. *Can J Nurs Res* 1993; 26(4): 61–82.