

Adolescent and Caregiver use of a Tethered Personal Health Record System

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Abstract

Supporting adolescent patient engagement in care is an important yet underexplored topic in consumer health informatics. Personal Health Records (PHRs) show potential, but designing PHR systems to accommodate both emerging adults and their parents is challenging. We conducted a mixed-methods study with teenage adolescent patients (ages 13-17) with cancer and blood disorders, and their parents, to investigate their experiences with MyChart, a tethered PHR system. Through analyses of usage logs and independently-conducted surveys and interviews, we found that patients and parents both valued MyChart, but had different views about the role of the PHR for care communication and management, and different attitudes about its impact on the patient's ability to manage care. Specific motivations for using MyChart included patient-parent coordination of care activities, communication around hospital encounters, and support for transitioning to adult care. Finally, some parents had concerns about certain diagnostic test results being made available to their children.

1. Introduction

In a pediatric cancer care setting, both adolescent patients and family members play an important role in the patient's care management. Effective communication among adolescent patients, their parents and clinicians has proven to increase the quality and overall satisfaction of the care.^{1,2} However patients' limited participation in the clinical setting, due in part to their limited health literacy, communication skills and perceived level of confidentiality, could lower the quality of communication.³

Personal Health Records (PHRs) show promising opportunities to alleviate these concerns, yet most currently do not provide different experiences for pediatric patients and their caregivers.⁴ Moreover, we do not fully understand the different information and communication needs of adolescents and their parental caregivers as they relate to the management of personal health records. Research examining how adolescents and their parents use PHRs has largely been limited due to federal and state regulations governing pediatric access to these systems.

In recent efforts to make electronic health records accessible to all patients, some states now offer patient portal enrollment to adolescents ages 12 and up, with proxy access available to their parental caregivers or legal guardians.⁵ Our research is motivated by the opportunity to investigate adolescents' and parental caregivers' experiences and actual use of the patient portal MyChart, a tethered PHR released by the Children's Healthcare of Atlanta (CHOA). Understanding adolescents' and parents' attitudes toward and experiences with the portal—and investigating where they align and where they diverge—can shed light on the electronic information and communication needs of these consumer groups.

We present results of the first study documenting adolescents' and caregivers' actual use and reported experiences with a PHR system, along with the first empirical analysis of adolescent patient versus parental caregiver perspectives stemming from their experience with the system. As such, it is guided by the following research questions: Do adolescent pediatric patients and their parental caregivers use a tethered PHR system when it is available? What features of the PHR do they find valuable? How do patients resolve questions about its content? How does the tethered model of control impact these patients' and parents' perceptions of usefulness and expectations of privacy? Findings from our study contribute knowledge that can help guide the design of health information technology aimed at supporting adolescent patients with cancer and blood disorders and their parental caregivers.

2. Background

Research aimed at supporting patient access to clinical records through electronic patient portals has gained recently momentum.⁶ For adolescents undergoing frequent hospitalizations and complicated therapies, health IT features prominently in illness management and care. Many state regulations mandate that once a pediatric patient turns 13, parent access to their online record be deactivated. For children ages 13-17, the minor patient must authorize proxy

access for the adult. Once the patient turns 18, the now-adult patient must again grant proxy access through an authorization process.⁷ In order to make an informed choice to grant proxy access, the patient must understand what such access entails.

Protection of adolescents' confidentiality in relation to their proxy has been a recent topic of interest in health informatics, with important medical, social and legal implications.⁸ Medical communities are aware of the implications of making electronic medical records accessible to minor patients: special requirements and challenges have been outlined, with emphasis on issues concerning the patient's privacy and their access to sensitive health information.^{8,9} Concerns over lack of perceived confidentiality may deter adolescents from seeking medical care, including consultations with their doctors.^{10,11} Indeed, patients' development of self-care skills and achievement of autonomy is critical for long-term outcomes. The Society for Adolescent Health and Medicine expressed this viewpoint, stating that "confidentiality protection is an essential component of health care for adolescents because it is consistent with the development of maturity and autonomy and without it adolescents will forego care."¹²

In theory, a PHR could alleviate some of these concerns by providing different viewing experiences for adolescent patients and adult caregivers. Yet, efforts toward designing for adolescents are still in their early phases.^{13,14} Ongoing efforts to understand adolescents' attitudes toward health IT reveal tensions in information and communication needs of adolescent patients and their parents. For example, a focus group study with adolescents in a pediatric primary care setting found that adolescents had concerns about a lack of confidentiality of their communication, whereas parents were more concerned about "being left out of the loop," or not being informed about significant health issues.¹⁵ Realizing the importance of privacy in adolescents' care, recent efforts are focused on creating personally controlled health records (PCHRs) that promise accessibility at the level of controllable individual features tailored to each patient's needs.^{9,16} Yet, understanding which communications related to adolescent health require confidentiality is a particularly complicated problem, making both individual and hybrid models of control challenging to implement, particularly for complex illnesses that require family involvement.

Adolescents and young adults are known as being highly receptive to Internet search and mobile technology and are often early adopters of computing applications.¹⁷ For example, a recent study of adolescents' actual use of smartphones revealed that, among many other types of applications, they used an average of ten distinct communication applications during two-thirds of the observed three hour period.¹⁸ A survey study exploring adolescents' health information needs has shown that they typically searched the Internet to meet these needs.¹⁹ While adolescents are shown to use the Internet to a great extent, they still consider parents as their primary source for health-related information, reporting a twofold increase in satisfaction with parent-delivered information over Internet-acquired information.¹⁹

Audit log studies on the actual use of patient portals can provide an empirical complement to self-reported attitudes and reveal gaps in uptake. Such analyses report disproportionate enrollment and use of patient portals by certain demographic populations, particularly including white, adult patients who are healthy and without Medicaid.²⁰ While patient portals are now available to many, issues of information complexity and usability can hinder their adoption.^{6,21,22} To our knowledge, these difficulties have only been revealed in studies of adult use of PHRs. One study found socio-demographic disparities in their analyses of portal registrations among pediatric patients: the portal enrollment rate was lower for adolescents (12 years and older) as compared to infants and children (0 to 12) for whom their parents were predominantly involved in the enrollment and activation.⁵ Still, no studies of which we are aware investigate adolescents' and caregivers' ongoing experiences accessing a PHR system.

3. Methods

This work is part of a larger project on health information management practices of adolescents with cancer and blood disorders and their parental caregivers. The full study is an IRB-approved, multi-year and multi-phased project, which began in September 2014 in collaboration with IT staff and clinicians at Children's Healthcare of Atlanta (CHOA). This paper reports results from a longitudinal exploration of patient and parent experiences with and attitudes toward the CHOA MyChart portal.

3.1. Study Site

Patients and parents were recruited in pairs at CHOA, a tertiary pediatric hospital in Georgia. We recruited participants in two Aflac Cancer and Blood Disorders Centers: Scottish Rite (suburban) and Egleston (urban), with each site serving different demographic populations. State regulations mandate that once a pediatric patient turns 13, parent access to their online record be deactivated. For children ages 13-17, the minor patient's parent must consent to

allowing access, while their child must authorize proxy access for the adult. Once the patient turns 18, the now-adult patient must again grant proxy access through an authorization process. Our recruitment targeted a convenience sample of patient-parent pairs in the Aflac clinics, and was conducted both in-person and through flyers and email. We provided informed consent and assent forms to patient-parent pairs who met the eligibility criteria and guided each pair through the documents.

3.2. CHOA MyChart

CHOA released MyChart,¹ a secure, HIPAA-compliant, tethered PHR in mid-summer 2014. Along with secure messaging capabilities to facilitate asynchronous electronic messaging between parents, pediatric patients and CHOA physicians, the tethered PHR (also referred to as a “patient portal”) includes access to laboratory test results, medication lists, patient allergies, prescription refill functions, appointment scheduling, messaging with clinical staff and the ability to store personal data. Once registered, patients and parents are given separate accounts with which they can access MyChart. The portal does not by default provide different viewing experiences of the patient’s information depending on the user, though proxies can be linked to several patients (their children). Physicians can customize whether messages should go directly to them (rather than being triaged first), to whom their message should go (to the proxy only or to both proxy and child), and whether or not an electronic reply to their message is allowed.

3.3. Study Design

To uncover potential attitudinal and experiential differences between adolescent patients and parental caregivers, we conducted a mixed-methods study comprising: 1) portal usage analysis, 2) small-scale survey, and 3) short interviews (see Figure 1). The usage analysis and interviews were conducted to contextualize survey responses.

Portal Usage Analysis

CHOA IT staff verified patient identification and registration and provided audit log data for patient and proxy usage over the study period. Auditing methods enabled us to examine information access at the level of individual access events (e.g., login events, loading of individual features, composing and sending electronic messages). Only patient log data (i.e., not its contents) were accessible to the research team. MyChart audit data included usage logs collected over a 19-month period ranging from August 2014 to February 2016. We analyzed the data focusing on commonly-used features, when they were accessed, and frequency of access over time.

Table 1. Excerpt of patient survey with selected questions.

Topic	Category	Example Questions
Context of use	Closed-format	<ul style="list-style-type: none"> • “On which device did you access MyChart most?”
Preferred features	Open-format	<ul style="list-style-type: none"> • “What feature was most useful to you? Why?”
Experience viewing content	Likert-style (Agreement)	<ul style="list-style-type: none"> • “Viewing the information in MyChart makes me anxious.” • “Some of the information in MyChart surprised me.”
Communicating about health topics	Closed-format (Yes/No)	<ul style="list-style-type: none"> • “I asked someone in my family a question about information in MyChart.”
Role of PHR	Likert-style (Agreement)	<ul style="list-style-type: none"> • “MyChart would increase my engagement in my healthcare” • “MyChart led me to ask questions that I might not have known to ask before”
Reasons to use PHR	Likert-style (Importance)	<ul style="list-style-type: none"> • “When talking about something with my parents.” • “When speaking with another doctor about my care.”

Survey

Our survey instrument included a mix of open- and closed-format questions and several five-point Likert-style questions with scales designed to capture attitudes and preferences. Table 1 shows major topics covered, with selected questions. The survey took about 30 minutes to complete. Questions were matched for patients and parents, with minor changes to wording to make sure each question adequately addressed the participant type. For example, parents were shown statements such as “*after using MyChart, I feel like I know more about my child's health.*” whereas patients saw, “*after using MyChart, I feel that I know more about my health.*” We used REDCap,²³ a HIPAA-compliant online research tool, to deploy the survey to patients and parents individually, with individual invitations sent after confirming that participants had used MyChart for at least one month.

¹ <http://www.choa.org/mychart>

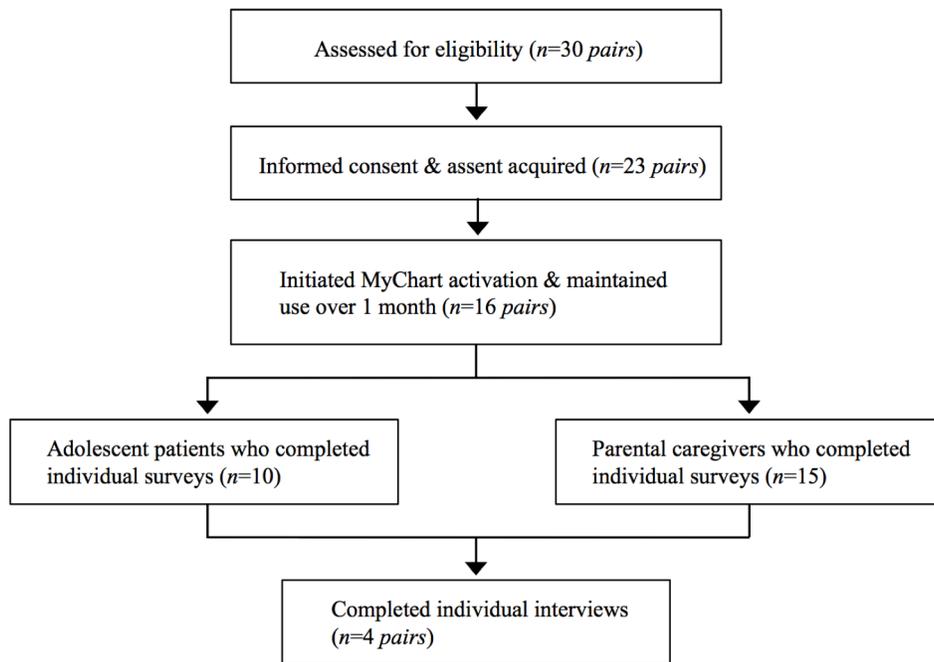


Figure 1. Flowchart of participant enrollment in each study phase.

Interviews

The study concluded with a phone interview, conducted with adolescent patients and parental caregivers individually, once they completed the survey. Each interview lasted about 15 minutes and focused on confirming participants' responses and eliciting elaboration on open-format responses.

4. Results

A total of 46 participants enrolled in our study including assenting patients ($n=23$) within the ages of 13 to 17 and their consenting parents ($n=23$). All recruited patients had been diagnosed with cancer or blood-related disorders. After collecting consent from all 23 parents and assent from all 23 adolescents, we introduced them to MyChart, explained data auditing plans and survey participation. Patients and parents were given separate accounts for logging in. We recruited additional study participants by sending recruitment ads to patients and parents who were already registered with MyChart. Each individual participant received a \$25 gift card (\$50 per pair) as a gratuity upon completing the study.

Some patient-parent pairs failed to complete MyChart activation. Of the 23 pairs, 12 (52.5%) patients and 15 caregivers (65.2%) responded to the survey. While 12 patients responded to the survey, only ten patients (*mean age*=15.3; *male*=3; *female*=7) and 15 parents (*mean age*=43.3) completed it. Survey responses were excluded if they were incomplete, or if we learned that someone other than the intended participant filled it out. In the following paragraphs, we report on survey results and audit log analyses for only those participants who completed the survey (Table 2 details patient and parent demographics).

We analyzed survey results and portal usage data using descriptive statistics. To explore similarities and differences in Likert-style survey responses between patient and parent groups, we report the difference in mean (*mdiff*) between the two groups, along with standard deviation (*SD*) values, for questions yielding the highest and lowest mean difference between the two groups. Below, we include verbal explanations of which group had higher or lower scores to accompany the *mdiff* value, which is reported as an absolute value.

We analyzed participants' interview data through inductive coding to identify relevant themes in an iterative fashion. We organize our findings under three themes: *perceived value of PHRs*, *keeping track of patient's health*, and *electronic communication and sharing preferences*. For each, we discuss patient and parent viewpoints, drawing attention to mean scores yielding the smallest and largest differences. Below, we refer to adolescent patients and parental caregivers as "patients" and "parents", or T# and P#, respectively.

Table 2. Patient and parent survey participant demographics. A total of 10 patients and 15 parents completed the survey. Patient and parent pairs have matching ID numbers. T=Patient, P=Parent, E=Egleston, SR=Scottish Rite

P ID	P Sex	P Age	P Srvy	T ID	T Sex	T Age	T Srvy	Primary Diagnosis (stage)	Site
P3	M	43	Y	T3	M	14	Y	Osteosarcoma (metastatic)	E
P4	F	48	Y	T4	F	15	N	Osteosarcoma (neoadjuvant chemo)	E
P5	F	37	Y	T5	F	16	Y	Alveolar soft-part sarcoma (metastatic)	E
P6	F	37	Y	T6	F	17	N	Clear cell sarcoma (stage 4 metastatic)	E
P7	F	34	Y	T7	F	15	Y	Osteosarcoma (remission)	E
P8	M	52	Y	T8	M	17	N	Metastatic testicular germ cell (remission)	E
P11	F	38	Y	T11	F	16	Y	Juvenile granulosa cell tumor (remission)	SR
P12	F	36	Y	T12	M	16	Y	Germ cell tumor	E
P13	F	49	Y	T13	F	15	Y	Idiopathic thrombocytopenic purpura	SR
P14	F	47	N	T14	F	13	Y	Sickle cell disease	SR
P15	F	50	Y	T15	F	14	Y	Osteosarcoma (stage 2)	E
P17	F	32	Y	T17	M	17	N	Malignant fibrous histiocyoma (remission)	E
P19	F	52	Y	T19	F	15	N	Von Willebrand disease	SR
P20	F	56	Y	T20	M	15	Y	Liver sarcoma (remission)	SR
P21	M	41	Y	T21	M	14	Y	Sickle cell disease	E
P23	F	41	Y	T23	F	17	Y	Wegener's granulomatosis	E

4.1. Shared Perceived Value of PHRs

Analysis of survey responses with the smallest difference in mean showed that patients and parents both perceived MyChart as valuable. Both saw value in using the portal immediately before and after a visit to the doctor's office. Both saw the most value in using it to navigate the transition from pediatric to adult care. Finally, they agreed strongly about situations when they would *not* use PHRs. Below we elaborate on each of these scenarios.

Before the visit: reminding and preparing for patient-provider encounters

Before a clinical encounter, patients ($mean=4.4$; $SD=0.84$) and parents ($mean=4.4$; $SD=0.91$) indicated that reminders were a valuable feature that allowed them to confirm their upcoming schedule, including future tests and doctor appointments, and to coordinate visits among family members. P12 told us, "*I check it when he has an appointment. Sometimes I forget the exact time so I can always go in there. I usually check in a day or two before he has an appointment.*" In the survey, T15 said that having the calendar reminder feature helps her make plans for other activities: "*so I can plan my day and week and not forget times*"

Patients and parents also saw utility in using the portal to prepare for clinical consultations. Both patients ($mean=4.4$; $SD=0.7$) and parents ($mean= 4.53$; $SD=0.64$) indicated that knowing the information in the medical record in advance, such as lab results or imaging scans, could help them when talking to their doctor. In the exit interview, P12 told us that having access to her child's record allowed her to seek better understanding of the lab results and their implications by asking targeted questions to the doctor: "*because sometimes I see numbers on there that I'm not familiar [with]. They haven't really explained about [the numbers] so I would go in and ask them.*"

Having access to previous records in advance was an important feature for those who lived far from the clinic. P13 lamented about the need to travel long distances in order to receive her child's medical record. She remarked, "*living several hours away from T13's doctors, it's sometimes difficult to get info right away or even get in touch with someone who can give us any information. With MyChart, lab results go in, we can view them and decide what we need to discuss with the doctor instead of viewing them while at the appointment and not having much time to look over everything and ask questions.*"

After the visit: fact checking and updates to the record

After a visit from the doctor's office, patients and parents indicated that they would use MyChart to check that electronic information was correct and review updates to the record. For example, P12 said, "*I'm trying to see if there are any updates (her labs, or any notes that were added).*" The ability to see results after each visit helped one teenage patient talk to his doctor. When asked if using MyChart changed the way he talked to the doctor, T12 responded: "*yeah, a little. Like one day I was talking [about] how much it [test results/blood level] would drop for my final week of the chemo and he said it would drop a lot and it [did]—it dropped a lot.*"

Participants especially appreciated the ability to verify information in the record and promptly receive updates. P11 commented about the means to verify lab results, noting *“it saves time. Making sure that everything is accurate. And on top of that I can actually see what the doctor's put in the notes and everything. They tell you but if you want to get thorough, you can actually see what's going on.”* Similarly, T23 responded, *“We can usually find out results faster instead of waiting until my next appointment or waiting for the doctor to call.”* Having prompt updates of lab results also helped ease T7's frustration about delays between visits, *“Yes. It was easier so I didn't have to wait like a month to ask my doctor these questions.”*

Long-term prospects: care transitions

Both patients and parents agreed to a great extent that MyChart could serve to support the transition from pediatric to adult care over the long term, as well as better support communication with doctors in the short term. Interview data with patients revealed why this might be the case.

Both P7 and T7 commented on an upcoming transition to a different provider. In this case, they both saw MyChart as an important tool to archive information about the patient's illness to retrieve later. For example, T7 remarked, *“I think maybe a little bit more about my cancer history and just overall surgeries or just what happened. I think it's just good for me to know. So in the future, (when) I end up going to a different doctor or anything, I kind of know what was done to me.”*

Both patients and parents responded that it would be important to refer to the information in MyChart during transitions to adult care (*mean=4.6; mdiff=0*), as well as to remain in touch with their current doctor once transitioning out of pediatric care (parent *mean=4.33*; patient *mean=4.4; mdiff=0.07*), and when speaking with another doctor about their care (parent *mean=4.47*; patient *mean=4.4; mdiff=0.07*).

P7 especially considered the need for access to her daughter's histories, imagining a future scenario when her child would be entering college: *“I can speak to her what the historic information is and kind of compare to whatever is told to me currently in regards to [T7]. I mean she's there ready to go off to school and if there is a need to see a doctor who doesn't have her history it would be readily available for them or even for her.”*

Unhelpful use cases of MyChart

Not all aspects of MyChart appeared useful to adolescent patients and parents. For example, while both patients (*mean=4.4; SD=1.07*) and parents (*mean=4.6; SD=0.6*) appreciated the ability to see doctor's instructions or notes in the patient's record, they were hesitant about adding new information or their own notes to the record (patient *mean=3.5*; parent *mean=3.4; SD (both)=1.35*).

As P7 explained: *“my notes are my part of own notes, but I feel like MyChart...there should just be professional notes—nurses and doctors. There shouldn't be any intertwining, as far as my opinions or my interpretation of that [...] I take those notes for me personally in my journal, my book—not solely relying on MyChart.”*

For some, MyChart was only useful during stages of diagnosis when patients and their parents were having several encounters with the hospital. Once entering recovery stages and remission, patients saw less value in using MyChart as they did before. T12 expressed this point, *“if something comes up, I would use MyChart. But for now, since I'm in the recovering stage, I don't plan to. Like when I got off chemo, I used it one more time and stopped (using MyChart).”*

4.2. Keeping Track of Patient's Health

Analysis of survey responses with the greatest difference in mean showed that patients and parents had somewhat different views about the impact of the PHR on the patient's ability to manage care. We learned that both used MyChart to make sense of the patient's illness and treatment process, but they still sought information from external resources to resolve unclear information. Furthermore, adolescents relied on parents to provide explanations of information that was unclear to them. Below, we elaborate on these findings and provide analysis of portal usage activity and most commonly accessed features.

Perceived ease of use of MyChart for managing care

Overall, parents reported having experienced more difficulty than patients when using MyChart to keep track of their child's health. When asked whether keeping track of the patient's health was difficult, parents showed mixed sentiment (*mean=3.53; SD=1.51; mdiff=1.13*). On the other hand, patients were more likely to respond that they

experienced less difficulty in keeping track of their own health ($mean=2.4$; $SD=1.51$; $mdiff=1.13$). Parents were also more likely to report their desire that MyChart be designed differently ($mean=2.8$; $SD=1.37$; $mdiff=0.9$).

When compared to parents, adolescents reported a slightly more positive attitude toward the impact of MyChart on their ability to manage their care. After using MyChart, they reported having known more about their health ($mean=4.1$; $mdiff=0.7$) in general and the care their doctor provides ($mean=3.9$; $mdiff=0.5$). They also reported that the information in MyChart led them to ask questions that they might not have known to ask before ($mean=4.2$; $mdiff=0.6$), and had slightly higher expectations that MyChart would lead them to take actions to improve their health ($mean=3.8$; $mdiff=0.4$).

Perceived ability to make sense of illness and treatment

Having access to digital records allowed participants to engage with and understand their health differently. In the interview, P12 reflected on her experiences both prior to and after using MyChart to make sense of her child's health: *"they would just give us a paper with the numbers, and the following two weeks we had to go back and they would give us another paper so...I had nothing to compare [the current results] to anything before and I didn't know where we were actually standing..."* Since having access to her child's medical record, P12 shared one of her exciting moments about how MyChart helped her and T12 make sense of the patient's improved health: *"When they told us that he was free of cancer, we saw the levels...we saw how [drastic]...that the numbers changed [...] I showed him where it started, during the chemo cycles and when it ended."*

For many, the portal was not the only source of information. Patients and parents also reported that they sought information on the Internet to help make sense of the medical record and seek additional information not readily available in MyChart. Nine out of 10 patients (90%) and 13 out of 15 parents (86.7%) had searched the Internet in the past to clarify information the medical record that was unclear to them. Reasons for searching typically included understanding medical terminology, interpreting lab results and radiology reports, and effects of medication on chemotherapy. While the Internet served general information needs for many patients and parents, it also seemed limited to some. For instance, P23 responded in our survey, *"When reading a copy of the path report, it's very difficult to just Google a word or term and find its meaning in relation to my daughter's situation. Finding the words isn't difficult. Translating what it all means seems almost pointless."* In this case, both P23 and T23 reported using private support groups or blogs to seek more information relevant to the patient's condition. T23 said that she would look at, *"blogs that have other people with the same disease as me."* We saw these preferences reflected in patients and parents' attitudes about searching the Internet; While most had searched for information in the past, only four out of 10 patients (40%) and eight out of 15 parents (53.3%) reported that they would search the web in the future to understand information in their medical record.

Mode of access

When accessing MyChart, adolescent patients reported a greater preference for using smartphones or tablet devices over other modes of access including laptop and desktop PC ($mean=4.2$; $SD=1.03$; $mdiff=0.8$). This finding is consistent with other studies that report adolescents' inclination to use their smartphone for Internet use.¹⁸

**Table 3. Summary of portal activity data analysis (n=16).
Mo=Number of months, Q=Quartile**

	Min	1st Q	Mean	Median	3rd Q	Max
Mos. since signup	9	13.3	14.4	14.5	17	19
Mos. active (from signup to last recorded activity)	1	4.8	8.9	9.5	12	19
Mos. MyChart data was accessed since signup	1	3.3	5.9	5	6.8	19
Activity over observed period (%)	5.9	22.5	41.2	42.0	46.1	100
Activity over active period (%)	23.1	51.8	73.7	73.2	100	100
Average access attempts per mo. since signup	1.2	8.4	22.4	13.4	20.9	131.8
Average access attempts per mo. over active period	9	16.2	31.6	20.7	33.6	131.8

Table 4. Frequently accessed MyChart features (n=16)

MyChart Features	# Accesses; n=3732 (%)	# of patients accessed (%)
Lab results	985 (26.4)	13 (81.25)
Messaging	763 (20.4)	12 (75)
Lab Test Order	723 (19.4)	14 (87.5)
Appointment Review	425 (11.4)	12 (75)
Problem List	186 (5.0)	13 (81.25)
Immunizations	168 (4.5)	12 (75)
Allergies	162 (4.3)	12 (75)
Health Maintenance	161 (4.3)	12 (75)
Medication	159 (4.3)	12 (75)

Features accessed

Our analysis of audit logs shows that patients most frequently accessed MyChart features in the following order: Lab Results (25.6%), Messaging (20.4), Lab Tests (20.3) and Appointment Review (11.9%). Frequent use of these features support findings of our survey regarding how patients and parents utilized MyChart for clinical encounters.

Most patients we audited regularly accessed MyChart over the 19-month observation period. Table 3 and Table 4 summarize analyzed usage. Participant activation occurred on a rolling basis over the 19-month period and averaged 8.9 months between the time of activation and the last-recorded activity (mid-Feb 2016). Most had periods of inactivity lasting one month or more. Participants logged into MyChart at least once a month (making it an “active month”) for an average of 5.9 months. Only three patient participants stopped using MyChart after one to two months of use. While patients were actively using MyChart, the period of active use and number of access attempts varied greatly across patients, as exhibited by wide gap between median and maximum access attempts. For example, T23, the most active user in our studied sample, accessed MyChart every month for the entire observed period and her average monthly access attempts equaled 131.8.

4.3. Communication and Sharing Preferences

Analysis of closed-format and Likert-style survey responses revealed insights about how patients and parents prefer to communicate with each other, with clinicians, and other people about their health regarding MyChart. The responses revealed slightly different attitudes and preferences between patients and parents when communicating with clinicians.

Adolescent patients communicated less frequently with clinicians through MyChart than their parents: only one out of 10 patients (10%) reported using MyChart to communicate with clinicians, whereas five out of 15 parents (33.3%) did. Patients’ reluctance to communicate directly with clinicians aligned with their preferences for communicating about their health in general: only two out of 10 patients (20%) reported they talked to their clinical caregivers about their health the most—the remaining eight talked to their parents the most and preferred to take questions about their health to parents over doctors. Seven out of 15 parents (46.7%) reported that they talked to a doctor or nurse about their child’s health more than they do the child. These findings suggest that parents act as intermediaries between clinicians and their children, even when electronic records are accessible to all.

Preferences for communicating about patient’s health

Adolescent patients and parents also had different viewpoints about their intention to communicate the patient’s health status to others, as well as different desires to learn about others like them. When asked if they would like to be able to share their health information with someone else, patients ($mean=4$; $SD=0.94$) agreed slightly more than parents ($mean=3.6$; $SD=1.18$). They also reported slightly more interest than parents in seeing information about other people who have similar health conditions ($mean=3.9$; $SD=0.99$; $mdiff=0.37$).

Concerns about viewing information in MyChart

The adolescent patients we surveyed indicated having no concerns about what their parents would see in MyChart. When asked if there was information in MyChart that patients would not like their parents to see, *all* patients reported that they were *not* concerned. When probed to describe any concerns, most patients reported having none. T23 remarked, “*there’s nothing in MyChart that I wouldn’t share with my mom.*” The same was true for *all* parents when they were asked if there was information in MyChart that they would *not* like their child to see. When further probed, some parents, however, some did have concerns. For instance, P13 noted her concern for the possibility that her child might misinterpret results of the diagnostic test, being concerned about “*medical details she might misunderstand or misinterpret that might get her concerned, anxious or upset.*”

Two parents noted that information containing a negative test result would be concerning if it were accessible to the patient only. For example, P15 wanted to see the negative result firsthand in an effort to allay the impact it may have on her daughter: “*anything that would appear to be negative, I would like to see it first so that I’m prepared for any questions my daughter may have. Soften the blow, so to speak.*” In an interview, P7 expressed similar sentiment that she would prefer having the information relayed to her first or when T7 is also present. She also preferred that the information be delivered in a different setting than MyChart. “*I would prefer for her to not know firsthand through MyChart, if there was a negative result. I would want her to know eventually. I wouldn’t hide that from her. But the way that I would deliver it to her... I would probably want to have that information in a different setting than her actually seeing that on MyChart.... My personal preference would be that the information is relayed to me first or to both of us together, but never to [T7] by herself.*”

These concerns were upheld by other survey responses. When asked whether viewing the information in MyChart would make the patient anxious, patients ($mean=3.2$; $SD=1.14$) tended to agree with the statement slightly more than their parents ($mean=2.73$; $SD=1.16$).

5. Discussion and Conclusion

Parents and patients reported the importance of using the PHR shortly before and shortly after their clinical encounters. Survey results revealed that parents made more use of MyChart messaging features. Still, patients expressed more confidence in managing their health when using MyChart. They sought information in MyChart, and more broadly, the Internet, to clarify information in their records. Yet, consistent with previous findings,¹⁹ most of the patients in our study regarded their parents as their primary information source for health-related information and preferred to take questions about their health to their parents over their doctors. As part of their gradual transition to adulthood, teenage adolescents reconcile who is an authority on their health. Maintaining adolescent patients' confidentiality while also meeting caregivers' needs poses challenge for designers of health IT systems. In Hong et al.'s study of the ways in which adolescents with cancer and blood disorders participate in their care, the authors found that adolescent patients faced challenges representing their interests in communications with their physicians and relied on their parents heavily to manage their personal health.³

Innovations in health IT are predicted to play a critical role in decision-making about treatment choices, care continuity, and improved measurement of outcomes of clinical trials. To make PHR systems valuable to adolescent patients and their parents, system design efforts must take into account the need to reconcile differing assessments of illness-related measures, and different communication preferences of adolescents and parents. We believe that many opportunities exist for health IT systems to provide age-appropriate mechanisms for reviewing clinical health data, and reporting on health status, health care experiences, and quality of life.

In particular, our findings point to the importance of further research focused on role of PHRs in supporting parental caregivers in communicating with their children, and in facilitating coordination and communication with clinical caregivers. Studies addressing teenage adolescents' communication needs and preferences for health-related information will be critical to aiding what is currently a challenging transition from pediatric to adult patient care,³ particularly in light of the challenges inherent in providing adolescent and family access to PHRs. These challenges include the need to formulate unique consent and privacy laws that align with state and institutional policies, provide content at appropriate health literacy levels, and maintain accountability in the disclosure of health information while meeting expectations of privacy.⁷

Limitations

By studying experiences with a tethered PHR, our study did not focus on the intricacies of enabling access control by patients or parents. To activate their accounts, patients and parents in our study agreed to the release of shared information in MyChart. The experiences, attitudes, and preferences we distilled should be viewed with the understanding that access control lay in the hands of the institution (i.e., limiting the sharing of individual data types or adjusting access control was not possible). We included a relatively small number of participants and focused only on the experiences of patients with cancer and blood disorders and their parental caregivers. We did not find conditions under which adolescents with cancer and blood disorders preferred to limit information, but prior work suggests that situations related to reproductive health, sexually transmitted diseases, substance abuse, domestic violence, and psychiatric concerns will demand fine-grained privacy protections in order to make PHRs useful.^{3,7} Assessing attitudes toward the use of PHRs and preferred avenues for communicating (and limiting or sharing) electronic data for these situations is an important avenue for future work.

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