Integrated Personal Health Record Use: Association With Parent-Reported Care Experiences

WHAT’S KNOWN ON THIS SUBJECT: Regular use of an integrated personal health record (PHR) may lead to improved outcomes through improved care coordination, communication, and patient empowerment. A limited number of studies have examined integrated PHR use for children.

WHAT THIS STUDY ADDS: Parents of children with chronic disease appear willing to use an integrated PHR to address health care needs for their child. PHRs may lead to improved health care and outcomes by enabling more coordinated care for children with chronic disease.

abstract

OBJECTIVE: To examine integrated personal health record (PHR) use patterns among parents of children with chronic disease and compare ratings of care experiences between integrated PHR users and nonusers.

METHODS: A survey was mailed to 600 randomly selected parents of children with chronic disease ≤5 years old and enrolled at Group Health for ≥1 year. Respondents reported integrated PHR use in the past 12 months, types of services used, or reasons for nonuse. We measured parent ratings of care experiences by using Consumer Assessments of Healthcare Providers and Systems (CAHPS) composite measures: Attention to Growth and Development, Attention to Safety and Health, Getting Care Quickly, Getting Needed Care, Prescription Medications, and Care Coordination. We used multivariate logistic regression to test the association between integrated PHR use and each CAHPS composite measure dichotomized by using the top box score method.

RESULTS: Of 256 respondents (45% eligible response rate), 166 (65%) were integrated PHR users and 90 (35%) were nonusers. The top integrated PHR services used were viewing immunization records, viewing medical records, secured messaging, and scheduling appointments. The top reasons for not using the integrated PHR were “too busy,” “forgot login/password,” and “my child does not have health care needs.” Adjusted logistic regression did not reveal any significant differences between users and nonusers.

CONCLUSIONS: Parents of children with chronic disease appear willing to use an integrated PHR to address health care needs for their child. Integrated PHR use was not associated with higher scores on CAHPS composite measures in this health plan. Pediatrics 2012;130:e183–e190

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KEY WORDS: personal health records, chronic disease, integrated health system

ABBREVIATIONS

CAHPS—Consumer Assessment of Healthcare Providers and Systems
ICD-9—International Classification of Diseases, Ninth Revision
ICE—imputation by chained equations
PHR—personal health record

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Children with chronic disease with access to a medical home, compared with those without one, are less likely to have delayed care, unmet health care needs, and missed school days. Strategies to improve access to a medical home may improve outcomes for these children. Health information technology, including electronic personal health records (PHRs), may be a key component of implementing a successful medical home.

Electronic PHRs can be differentiated by whether the PHR is linked to (ie, “integrated”) or separate from (ie, “stand-alone”) the patient’s electronic medical record. The American Medical Informatics Association recommends the integrated PHR (henceforth referred to as “PHR”) because the PHR data are more relevant to the patient, and data can be restored easily in case of system failure. PHRs enable individuals to view immunizations, laboratory results, after-visit summaries, health plan benefits, and current health conditions, and to manage their medications or send secured messages to their health care providers, as well. Providing parents of children with chronic disease access to these features may improve overall care experiences by increasing a parent’s understanding of their child’s health care needs and providing timely and convenient access to care. PHR use may also improve care coordination for children with chronic disease by facilitating improved communication between parents and all of their child’s health care providers. To date, studies of PHR use for children have been limited to a single PHR developed in cooperation with parents of children with cystic fibrosis, juvenile idiopathic arthritis, and diabetes mellitus.

The objectives of this study were to better understand how parents of children with chronic disease use PHRs and to examine whether users, compared with nonusers, report improved access to and experiences with the health care teams.

**METHODS**

**Study Population**

This cross-sectional study was conducted at Group Health Cooperative, an integrated health care system providing care to 660,000 members in Washington. Group Health’s PHR (MyGroupHealth) was first made available to members in 2000 to improve patient-centered access to care. Members are continuously informed about MyGroupHealth features through multiple channels, including their physician at the point of care, the Group Health magazine, an annual outreach reminder letter, and other communications. Parents access their child’s account as a proxy through their own account. No additional fees are required to access PHR services: secured messaging, medical record viewing (eg, immunizations, test results, after-visit summaries, allergies, medical conditions, health assessments, health plan benefits), medication management, or appointment management. Current estimates indicate that 64% of adult members access MyGroupHealth for themselves, whereas 30% of parents access MyGroupHealth for their child (J. Ralston, MD, MPH, personal communication 2011).

Parents were potentially eligible if they had a child with at least 1 outpatient claim, who was <5 years old, had at least 1 chronic disease, and was continuously enrolled for at least 1 year through December 31, 2009 (Fig 1). We focused on children with chronic disease, because adults with chronic disease are more likely to use the PHR. We focused on children ≤5 years old, because we assumed that parents of young children would have a greater need for a PHR secondary to increased visit frequency with their child’s health care providers during the first 5 years of life. We used claims and administrative data to identify potential subjects and a validated list of International Classification of Diseases, Ninth Revision (ICD-9) codes to define chronic disease states for children. Children were included in the eligible sample if they had 1 or more outpatient claims with a listed ICD-9 chronic disease code. To reduce potential misclassification, children were classified as having asthma if they had 2 or more claims for asthma (ICD-9 493.00–

**FIGURE 1**

Patient eligibility. Passive refusers did not call to opt out of the study or return a blank survey. Active refusers called to opt out of study or returned a blank survey. Ineligible patients were excluded from response rate calculation. They were ineligible because they were members of the Group Health Research Institute.

![Diagram](https://example.com/diagram.png)
493.99). From this eligible population, we randomly selected 600 households for the survey. If a household had >1 eligible child, we randomly selected 1 of the children for the study. We based our sample size on the estimated proportion of MyGroupHealth use by parents (30%), the expected response rate (50%), and our a priori determination of what might indicate a clinically significant difference between users and nonusers for each of our a priori outcomes (15 points on a 0–100 scale).

Survey Design and Methodology
We designed a questionnaire based on the recommended survey guidelines of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. Group Health Research Institute’s Survey Research Program was responsible for all mailings, survey collection, and data entry. A study identification was assigned to a child, and this same study identification was placed on his/her corresponding survey, which enabled us to link survey responses by a parent to the child’s administrative data as well as determine which children required a nonresponder mailing. Survey packets were addressed to the “parent or guardian primarily responsible for the health care of” the child and sent to the child’s home address along with a 2-dollar bill. We sent 2 additional survey packets to nonresponders. There was no telephone outreach to nonresponders.

PHR Use Patterns
The PHR use pattern questions were informed by previous surveys developed and used at Group Health. A PHR “user” was defined as any respondent who answered “Yes” to the following question, “In the last 12 months, have you used one of MyGroupHealth services for your child?” whereas a “nonuser” was defined as a respondent who answered “No.” Both users and nonusers were asked if any health care provider encouraged PHR use for their child, if the respondent used the PHR for his/herself, and if the respondent had ever signed up their child for the PHR regardless of use in the past 12 months. To further evaluate use patterns, we asked users about frequency of use (1, 2–5, 6–9, ≥10 times in the past 12 months) and the number of times (0, 1–2, ≥3 times) each specific PHR service (eg, viewing immunization record) was used for the child during the past 12 months. To evaluate barriers to using the PHR, we asked nonusers to select 1 or more reasons from a predefined list (eg, too busy), including an option to write in other reason(s).

Primary Care Experiences
We measured access to and experiences with the health care services provided to these children by using CAHPS composite measures for members enrolled in commercial plans. We used CAHPS composite measures from the Health Plan version 4.0 (“Getting Needed Care,” “Getting Care Quickly,” “Parents’ Experiences with Prescription Medicines,” and “Parents’ Experiences with Coordination of their Child’s Care”) and Clinician and Group version 2.0 (B) (“Doctor’s Attention to Your Child’s Growth and Development,” and “Doctor’s Advice on Keeping Your Child Safe and Healthy”). These CAHPS measures address domains most applicable to children with chronic disease because these children have increased needs, are often on medications, are cared for by multiple health care providers, and may have gaps in preventive care because of the focus on chronic disease management during visits. We dichotomized each of the 6 composite measures by using the CAHPS composite “top box score” method at the respondent level. With the use of this method, the top box score equaled “1” if the respondent answered all questions within a composite measure in the highest category (eg, “Always” or “Yes”) and “0” otherwise. If no question (s) within a particular composite measure were relevant to the respondent (ie, a parent did not need to refill medications in the past 12 months), a score was not calculated for that composite measure.

Covariates
We used CAHPS standard case-mix adjustment questions to collect child characteristics (overall health status, age, gender, race/ethnicity) and respondent characteristics (gender, highest level of education) from our survey. Child’s insurance type (Medicaid or commercial) and enrollment duration at Group Health were based on administrative data.

Statistical Analysis
We conducted bivariate analyses to analyze relationships between PHR use and child/respondent characteristics as well as each of the dichotomized CAHPS composite measures by using a $\chi^2$ test of independence for categorical variables and the Student $t$ test for continuous variables. We used multiple logistic regression to evaluate the association between PHR use (user versus nonuser) and our dichotomized CAHPS top box scores: “Getting Needed Care,” “Getting Care Quickly,” “Prescription Medicines,” “Coordination of Care,” “Growth and Development,” and “Safety and Health.” We adjusted for key demographic covariates (respondent’s age and education, child’s overall health status) as well as child’s race/ethnicity and type of insurance (commercial versus Medicaid). We used multiple imputation by chained equations (ICE) to mitigate the impact of missing values in some of the covariates. ICE uses observed data and sequential regression modeling to generate plausible values.
for missing data. We chose ICE over the joint distribution method because the covariates with missing values are of mixed types (binary, categorical, and continuous) making it challenging to specify a joint distribution for them. Twenty surveys required imputation for missing covariates (11 users, 9 nonusers). To evaluate potential response bias, we evaluated differences in aggregate child characteristics between survey respondents and those who chose not to return a completed survey (ie, “passive refusers”). As a sensitivity analysis, we conducted an unadjusted bivariate analysis to evaluate the frequency of PHR use (0, 1, 2–5, 6–9, ≥10 times) in relation to our dichotomized outcome (data not shown; no statistically significant relationships identified). We originally planned to linearly transform each composite measure to a score from 0 to 100 similar to a previous study.20 However, because of the nonnormality of all but 1 of our linearly transformed outcomes (median score of 100), we chose instead to use the CAHPS top box score method with logistic regression.

We analyzed the data with STATA10 and set the statistical significance by using 2-tailed tests at the P < .05 level. This study was approved by institutional review boards at Group Health and Seattle Children’s Research Institute.

**RESULTS**

Of the 7666 eligible children, 1154 (15%) children had at least 1 chronic disease (Fig 1). Of the 600 mailed surveys, we received 256 completed surveys, which resulted in a 43% eligible response rate (7 active refusers, 36 missing addresses, 3 ineligible). Child characteristics of nonresponders were similar to those of responders, with the exception that children of nonresponders were more likely female (57% vs 43%, P < .001) and on Medicaid (21% vs 11%, P < .001).

Sixty-five percent of respondents (n = 166) reported use of the PHR in the past 12 months for their child. Users (versus nonusers) were more likely to have commercial insurance for their child (97% vs 73%, P < .001) and have at least a 4-year college degree (74% vs 50%, P < .001; Table 1). Our population’s top chronic diseases were asthma (24%), congenital musculoskeletal abnormalities (20%), congenital heart disease (18%), inborn errors of metabolism (9%), cystic fibrosis (7%), and hereditary and acquired hemolytic anemias (5%).

The most highly used PHR services were viewing the child’s immunizations, viewing the medical record (nonimmunizations), and secured messaging (Table 2). Nearly 32% of respondents used the PHR 6 times or more in the past 12 months; 90% of respondents used the PHR at least twice. Among nonusers, the top reasons for not using the PHR were “too busy,” “forgot login name and/or password,” and “child does not have health care needs” (Table 3). Only a small number did not have internet access (n = 6) or a computer (n = 4). Approximately 25% (n = 22) of nonusers reported signing up for PHR access for their child at some point since becoming a health plan member. Nearly 50% (n = 43) of nonusers indicated use of the PHR for themselves (vs 97% among users).

The proportion of users versus nonusers who answered all questions within a composite measure in the highest category were as follows: “Getting Needed Care” (48% vs 56%, P > .20), “Getting Care Quickly” (52% vs 52%, P > .20), “Experiences with Prescription Medications” (68% vs 65%, P > .20), “Care Coordination” (62% vs 70%, P > .20).
“Attention to Safety and Health” (48% vs 45%, P > .20), and “Attention to Growth and Development” (61% vs 53%, P > .20). After adjusting for child characteristics (overall health status, type of insurance, and race/ethnicity) and respondent characteristics (age and education) by using multivariate logistic regression, we did not find differences between users and nonusers on the dichotomized CAHPS top box scores (Table 4).

**DISCUSSION**

In this study, parents were willing to use a PHR as an adjunct method to address their child’s health care needs through viewing their child’s immunizations, viewing their child’s medical record other than immunizations (eg, after-visit summaries), and sending secured messages. However, PHR use was not associated with higher CAHPS composite scores. This study is one of the first to examine how PHR use might improve care for this vulnerable population of children.

Regular use of a PHR may potentially lead to decreased health care utilization and/or improved disease control through improved care coordination, communication, access to care, and patient empowerment.21–25 The results of studies evaluating health care utilization in adults have been mixed and have revealed increased emergency department visits among users,24 but inconsistent results for telephone calls,24–26 office visits,11,25–28 and hospitalizations.24,28 Results have been more consistent for the association of PHR use and chronic disease control. Use of secured messaging by adults managing their own chronic disease has been associated with improved glycemic control among patients with diabetes, improved blood pressure control among patients with hypertension, and decreased depressive symptoms and improved medication adherence among patients with depression.21–23,29 Few studies have evaluated PHR use for children. The studies evaluating PHR use for children with cystic fibrosis, diabetes, or arthritis identified convenience and empowerment as one of the key benefits of a PHR.6–8 This finding suggests that PHR use may lead to more positive care experiences for parents of children with chronic disease, although no studies have examined PHR use with respect to patient-reported care experiences. Our assessment of care experiences with the use of the CAHPS composite measures did not support this hypothesized association. This may be explained by ongoing initiatives to improve access to services and patient-centered care (eg, the “medical home experiment”50) within this integrated health care delivery system. We also observed a “ceiling effect” for 5 of the 6 CAHPS composite measures assessed that may have minimized our ability to detect a difference between PHR users and nonusers.

Among parents not currently using the PHR for their child, being too busy to incorporate PHR use into their regular health care routines for their child was the most frequently mentioned barrier. With an increasing use of smartphones, 1 solution to help these families is the creation of a mobile platform for the PHR. We also found that 16% of parents did not use the PHR because their child did not have health care needs. One explanation is that their child may have stable disease and required minimal active care management. Alternatively, the PHR may not offer services parents actually need or would find valuable, such as downloadable signed medical forms or letters. Although one of the top barriers to use cited in previous studies was privacy and security concerns,31–33 only 1 parent in our study felt uncomfortable sharing information over the Internet. Consumers may feel more comfortable with a PHR offered through their health plan than from third-party companies.35 Finally, simplifying access issues, such as retrieving forgotten login information, may also increase

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**TABLE 2** PHR Services Used in the Past 12 mo for the Childa

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage of PHR Users Accessing Each Serviceb</th>
</tr>
</thead>
<tbody>
<tr>
<td>View immunizations</td>
<td>≥1 Times</td>
</tr>
<tr>
<td>View medical record (nonimmunizations)</td>
<td>≥3 Times</td>
</tr>
<tr>
<td>Secured messaging</td>
<td></td>
</tr>
<tr>
<td>Schedule appointment</td>
<td></td>
</tr>
<tr>
<td>View laboratory results/radiographs</td>
<td></td>
</tr>
<tr>
<td>Refill/view medications</td>
<td></td>
</tr>
<tr>
<td>View health coverage and benefits</td>
<td></td>
</tr>
<tr>
<td>Choose a doctor</td>
<td></td>
</tr>
</tbody>
</table>

Values are given as percentages.

a A PHR user can check >1 service.

b A respondent can indicate not using a particular PHR service (frequency not shown).

**TABLE 3** Reasons for Not Using the PHR in the Past 12 mo for the Childa

<table>
<thead>
<tr>
<th>Reason</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too busy</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>Forgot login name and/or password</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>Child does not have health care needs</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Too difficult to get online access for MyGroupHealth</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>I don’t know about it</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Prefer other routes of care (eg, face to face)b</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>I don’t have access to the Internet</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>No high-speed Internet</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>I don’t have a computer</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Too difficult to use</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>No response from systemb</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Not comfortable sharing medical information on the Internet</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not sure how to use the Internetb</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>It is a waste of time</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

a A PHR nonuser can indicate >1 reason.
b These reasons were based entirely on write-in responses.
PHR use. Consistent with studies focusing on adults with chronic disease, PHR use by parents of children with chronic disease was high.10 We also found similarities in the most frequently used PHR services and user demographics (high education, commercial insurance) in comparison with studies of adults using a PHR for themselves or for their child.22,31,34,35

This study has several limitations. We evaluated only a single health system’s PHR. However, the services offered are similar to other large health systems with a PHR.36–38 The cross-sectional nature of this study did not allow us to examine our outcomes of interest both before and after parents started using the PHR. A prospective study that examines outcomes over time is needed to better understand whether an association between PHR use and improved care experiences exists. Because only 43% of eligible parents completed the survey, our findings may be subject to response bias with an artificially high proportion of parents being PHR users in comparison with the source population. Future studies should attempt to understand PHR use among a larger Medicaid population, because these children are more vulnerable and their parents may have different use patterns and needs.31 The frequency of use and services used for the PHR were based on self-report and thus were subject to possible recall bias. Despite these limitations, we found that most parents of young children with chronic disease were willing to use a PHR to help address health care needs for their child. Our rate of PHR use was higher than other health plans with Medicaid population, because these patients outside of integrated health care delivery systems may eventually have access to a PHR as medical practices are encouraged to adopt electronic medical records. Because PHRs have been identified as the only health information technology solution covering all aspects of a patient-centered medical home,4 policy makers may want to facilitate PHR adoption at the time of electronic medical record implementation.

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