Patient Portal, Patient-Generated Images, and Medical Decision-Making in a Pediatric Ambulatory Setting

Karolin Ginting[1] Adrienne Stolfi[2] Jordan Wright[2] Abiodun Omoloja[2]

[1] Department of General Surgery, The Jewish Hospital, Cincinnati, Ohio, United States
[2] Department of Pediatrics, Wright State University Boonshoft School of Medicine, Dayton, Ohio, United States

Address for correspondence Abiodun Omoloja, MD, Division of Nephrology, Dayton Children's Hospital, One Children's Plaza, Dayton, OH 45404, United States (e-mail: Omolojaa@childrensdayton.org).

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Abstract

Background Electronic health record (EHR) patient portals are a secure electronic method of communicating with health care providers. In addition to sending secure messages, images, and videos generated by families can be sent to providers securely. With the widespread use of smart phones, there has been an increase in patient-generated images (PGI) sent to providers via patient portals. There are few studies that have evaluated the role of PGI in medical decision-making.

Objectives The study aimed to characterize PGI sent to providers via a patient portal, determine how often PGI-affected medical decision-making, and determine the rate of social PGI sent via patient portal.

Methods A retrospective chart review of PGI uploaded to a children's hospital's ambulatory patient portal from January 2011 to December 2017 was conducted. Data collected included patient demographics, number and type of images sent, person sending images (patient or parent/guardian), and whether an image-affected medical decision-making. Images were classified as medical related (e.g., blood glucose readings and skin rashes), nonmedical or administrative related (e.g., medical clearance or insurance forms), and social (e.g., self-portraits and camp pictures).

Results One hundred forty-three individuals used the portal a total of 358 times, sending 507 images over the study period. Mean (standard deviation) patient age was 9.5 (5.9) years, 50% were females, 89% were White, and 64% had private insurance. About 9% of images were sent directly by patients and the rest by parents/guardians. A total of 387 (76%) images were sent for medical related reasons, 20% for nonmedical, and 4% were deemed social images. Of the 387 medical related images, 314 (81%) affected medical decision-making.

Conclusion PGI-affected medical decision-making in most cases. Additional studies are needed to characterize use of PGI in the pediatric population.

Keywords
- patient-generated images
- patient portal
- electronic health record
- medical decision-making

Background and Significance

Electronic health record (EHR) patient portals are a secure web-based electronic method of communicating with health care providers.[1] Typically, portals are used to view results of investigations, view and pay medical bills, schedule appointments, and message providers. Use of patient portals has been demonstrated to improve patient satisfaction and engagement and improve clinical outcomes for chronic diseases.[2,3]

In addition to message exchange, images and videos generated by families can be sent to providers via portals. In our institution, there were anecdotal concerns that

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providers will be inundated with irrelevant images from families regarding their child's care. However, patient-generated images (PGI) convey accurate information, can augment clinical documentation, and are easy to transmit with the widespread use of smart phones. Indeed, health care providers, especially in the adult population, have leveraged these technologies and EHR functionality to improve care.[4,5]

Despite the widespread use of patient portals, there are no studies that have investigated the role, if any, PGI play in communicating with pediatric and pediatric subspecialty providers in the outpatient setting. This was the motivation to perform our study.

Objectives

The purpose of this study was threefold: (1) characterize PGI sent to providers via patient portals, (2) determine if and how often PGI-affected medical decision-making, and (3) determine the rate of social PGI sent via patient portals.

Methods

A retrospective chart review was conducted of all PGI in our EHR sent to primary and specialty care clinic providers from the beginning of 2011, the year that functionality to send PGI via patient portal was activated at our institution, to the end of 2017. The same commercial EHR was in place for the duration of the period studied. Demographic data collected included patient's age, gender, race, insurance type, and whether the patient or parent (including legal guardians) sent the images. The number of patients/parents sending images, number of images per "portal encounter," and total number of images were determined. For patients/parents that sent multiple images over the study period, all images sent within a 24-hour time period were considered a single portal encounter. Images sent 24 hours or greater after the last image in an encounter were considered new portal encounters. Data collected on the images included days and times images were sent, providers' clinical departments where images were sent, and type of image. All patient portal messages and images are triaged by a pool of clinic staff and then directed to specific providers, all within our EHR. Images were classified as medical related (e.g., blood glucose readings, skin rashes), nonmedical or administrative related (e.g., medical clearance or insurance forms), and social (e.g., self-portraits, camp pictures). For each medically related PGI, we reviewed phone, provider-to-provider EHR and patient portal messages exchanged with providers. Specifically, we reviewed messages that preceded, accompanied, and followed each PGI to determine if the image influenced decision-making. For example, a postcircumcision PGI triggering referral to the emergency department or reassuring a concerned patient about the absence of a postprocedure complication. Other examples included PGI resulting in change to follow-up of a previously scheduled clinic visit, initiating a new ambulatory referral or change in dose of medication. Assessment and categorization were initially and independently made by a single investigator. Random selection of PGIs in each category done by the first investigator were then independently examined by another investigator to confirm initial assessment. Images were classified as unclear if two investigators could not determine if any medical decision was taken after reviewing communication. Also, randomly reviewed images that both investigators could not fit into other categories were placed in this group.

Results

A total of 143 individuals sent PGI through the patient portal during 358 portal encounters, with a total of 507 separate images. For 326 (91.1%) of the 358 portal encounters, the parent/guardian sent the images; the patient sent the images for 32 (8.9%) of the encounters. About half of the 143 patients (49.7%) were females, 127 (88.8%) were White, 8 (5.6%) were Black, and 8 (5.6%) were another race. In total, 92 patients (64.3%) had private health insurance, 48 (33.6%) had public health insurance, and 3 (2.1%) were self-pay. The mean (standard deviation [SD]) age of the patients was 9.5 (5.9) years, with a range of 0.2 to 24.0 years. The majority of the patients/parents (61.5%) used the portal for one encounter, 14.7% had two encounters, 9.8% had three encounters, and 14.0% had four or more encounters.

The distribution of portal encounters by year is shown in ►Fig. 1. The highest number of encounters occurred in 2017, with a percent increase of over 250% from 2016, the next highest year. For the 358 portal encounters, 204 (57.0%) occurred on weekdays (Monday–Friday: 8:00 AM–4:59 PM), 107 (29.9%) were on week nights (Monday–Thursday: 5:00 PM–7:59 AM), and 47 (13.1%) were on weekends (Friday 5:00 PM–Monday 7:59 AM). The majority of the portal encounters were with the endocrinology department (57.8%), followed by gastroenterology (22.6%), pulmonary (4.7%), developmental pediatrics (4.5%), nephrology (2.5%), neurology (2.0%), and other departments (5.9%).

The mean (SD) number of images sent per encounter was 1.4 (1.1) and ranged from 1 to 11. For 280 (78.2%) of the encounters, only one image was sent. For the total of 507 images, 387 (76.3%) were medical, 100 (19.7%) were nonmedical/administrative, and 20 (3.9%) were social. For the 387 medical images, 314 (81.1%) affected medical decision-making, 19 (4.9%) did not, and for 54 (14.0%) it was unclear.

For the 314 images affecting medical decision-making, the most frequent were blood glucose reports sent to the endocrinology department (154, 49.0%). Pictures of stool ($n = 23$, 7.3%) and rashes ($n = 22$, 7.0%) were next in frequency. Clinical actions taken for 314 images affecting clinical decision-making are shown in ►Table 1. The most frequent clinical action was a change in diet, resulting primarily from the blood glucose reports sent to the endocrinology department ($n = 114$, 36.3%).

Discussion

Our study is the first to demonstrate that PGI influenced medical decision-making the majority of the time in a pediatric and pediatric subspecialty outpatient clinic setting as evidenced by the need to alter patient diet, instituting new

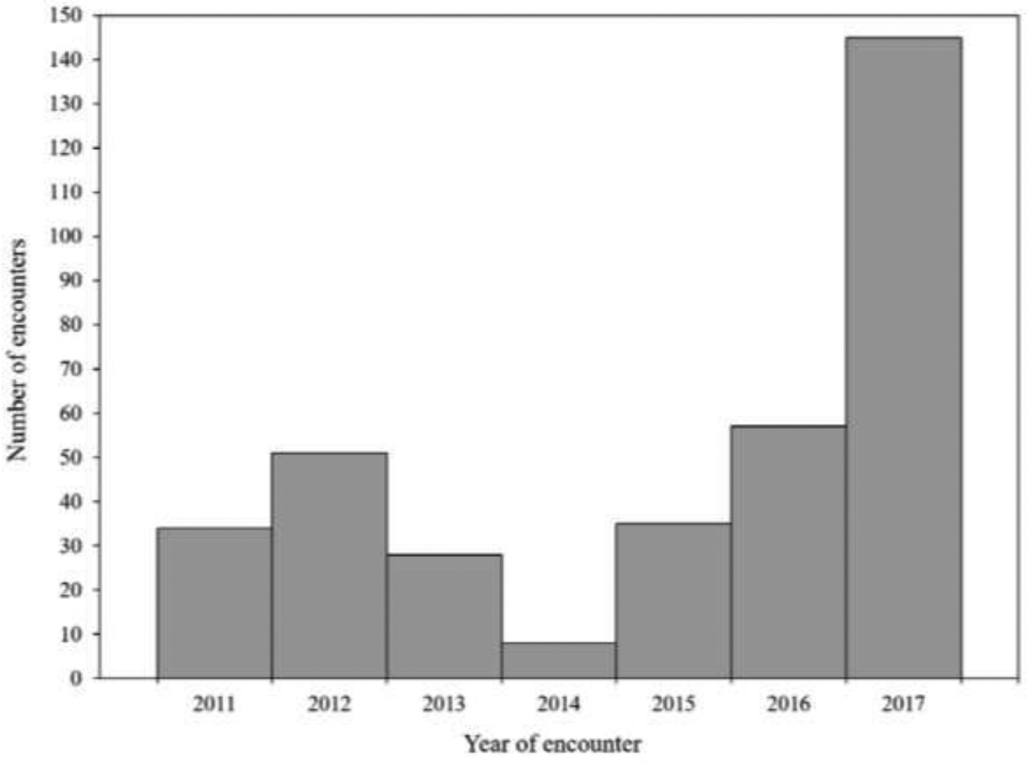

Fig. 1 Distribution of portal encounters by year.

Table 1 Summary of clinical actions taken based on patient-generated images

Clinical action taken	*n* (%)
Change in diet	114 (36.3)
No change/reassurance	73 (23.2)
Follow up	60 (19.1)
Therapeutic intervention	48 (15.3)
Referral	19 (6.1)
Total	314 (100)

therapeutic interventions, and initiating new patient referrals to other services. Equally important and like others found, concerns about the misuse of EHR functionality to send PGI to providers were unfounded.[6,7] Unexpectedly, we found that PGI served as a convenient method to exchange nonmedical/administrative documents with care providers. Our study adds to the growing body of knowledge that imaging applications integrated with EHR can have a significant impact on all aspects of clinical care including documentation and facilitation of communication among patients and their care team.[8,9]

The main advantages of patient portals have traditionally focused on viewing results of investigations, refilling medications, scheduling and canceling appointments, and even bill paying. All these functions have resulted in improved patient engagement[3] and reduction in no show rates, and according to some adult studies, suggest better patient outcomes.[2,10] Our study suggests that a hitherto poorly studied EHR functionality, ability to send PGI, may provide additional clinical and nonclinical benefits to patients. "A picture is worth a thousand words" is a common English adage that explains it is easier to show something in a picture than describe it with words. For patients and families without a medical background, accurate description of an evolving skin rash, postsurgical wound, or bloody fecal matter may be challenging. These were easily captured in images and sent to providers for decision-making. An added advantage, at least in our EHR, was that these images were securely stored and available for future reference, especially for comparative purposes. Studies have highlighted challenges with determining the effect of patient portals on clinical care[11,12]; we speculate that decisions made around medically related PGI could be one of the parameters used to gauge the effect of portals on the domains of health care quality.[13]

Prior to the widespread use of EHRs, exchange of nonmedical information like pre-camp physical examination forms, teacher reports about child behavior, sports authorization forms, etc. were via fax, email, regular mail, and in person delivery. These forms of information exchange had their accompanying challenges such as arrival delays (regular mail), access (fax), and cost (stamp and time off work for in person delivery). In addition, information had to be scanned into the EHR to keep communication records up to date. Ease and convenience of information exchange via PGI was illustrated by our finding that almost half of all images were sent after business hours from 5 PM to 8 AM during the week and all hours of the weekends. Considering the majority of PGI were blood glucose related, it is important to note that this method of communicating was limited to patients who were not on devices that permitted automatic transmission of

readings. For these patients, glucose readings are automatically uploaded to the cloud for easy, efficient, and prompt access to providers, thus reducing potential errors due to legibility, mistranscribing, etc. that can occur with manual methods used in our study. During the period of our study, bidirectional exchange of documents between patients and providers as attachments was not possible. This changed recently with our existing commercial EHR upgrade that enabled the new functionality. We expect this will further boost the use of PGI as a form of communication for patients. Like other pediatric facilities,[14] we noted a rapid rise in PGI shared in 2017, a reflection of the wider acceptance and use of patient portals in general.

While the focus of our study was in pediatrics, we believe our findings can be generalized to adults. This feature can provide an alternative way to convey not only descriptive clinical findings, but also data points such as blood pressure and glucose reading for adult patients with limited access to wi-fi enabled devices. Leveraging a PGI can enhance communication and potentially impact decision-making and improve management of chronic care.

Although our findings may suggest the presence of a racial digital divide, this was not found to be accurate when compared with the racial makeup of our entire population. Based on our findings, we do not see the need to embed guidelines in the portal discouraging sending "social" images. Although all images sent via our portal are secure, we are taking steps to provide guidelines to ensure privacy and confidentiality of all images sent, especially those that might contain sensitive body parts such as a diaper rash image with exposed genitals. Guidelines include deleting images from a device after sending, avoiding inclusion of recognizable features (birth marks, tattoos, face, etc.) in the image, and avoiding identifiable settings or location s(dining room, trophies in the background, etc.) in the image. For sensitive areas, speak with provider first before sending images, only include the smallest possible sensitive area of the body in the image by placing an item of clothing or diaper on the surrounding area, and only send via the portal.

Our study has several limitations. First it is from a single free-standing children's hospital primary and specialty care clinic practice which limits the generalizability of the findings to other types of ambulatory care such as urgent or acute care facilities. Second, it was focused solely on PGI; we did not evaluate or correlate PGI with number of active patient portal accounts, viewing of test results or other patient portal functionality. Third, there was a degree of subjectivity in deciding if images-affected medical decision-making. Finally, our characterization was limited to patients and not their proxies who sent the majority of PGI.

Conclusion

To our knowledge, this is the first study that evaluated if PGI sent by families to pediatricians in a specific ambulatory setting played a role in provider medical decision-making. We have demonstrated that PGI influenced clinical decisions and should be encouraged as a tool to enhance better and more accurate communication between patients and caregivers. PGI help achieve some of the six dimensions of care. Additional studies are needed to better understand use of PGI in delivery of health care and information exchange.

Clinical Relevance Statement

Accurate communication between care providers and patients is critical to deliver quality care. While use of patient portals have improved this ability, role of PGI in the pediatric ambulatory setting has not been investigated. Our study, the first of its kind in pediatric outpatient setting, suggests that PGI sent to clinicians influenced clinical decisions and may have increased the efficacy and accuracy of communication, in keeping with the adage that "a picture is worth a thousand words." Additional studies are needed on this topic.

Multiple Choice Questions

1. Nonmedical or administrative related images included:

a. Self portraits
b. Medical clearance forms
c. Blood glucose readings or logs
d. Camp pictures

Correct Answer: The correct answer is option b. There were a variety of images sent during the study period that could be cataloged as medical related, nonmedical related, or social. The medical related were to report symptoms such as rashes or providing information such as blood sugar logs to providers. Nonmedical uses of PGI included medical clearance forms and insurance forms. While not directly impacting the medical care, these were important information for providers and the use of the EHR allowed for many to be sent in the evenings and weekends. This decreases a burden on patients and families of having to mail, fax, or hand deliver these types of documents during work hours. Finally, there were a small number of items that were not relevant to patient care such as self-portraits or camp pictures. These social photos were not found to be questionable in nature or a misuse of the EHR in the study.

2 The ways that medical decision-making was influenced by PGI included:

a. Changes in diet
b. Referrals
c. Reassurance
d. All the above

Correct Answer: The correct answer is option d. The ability for patients and families to accurately describe symptoms in between visits has been difficult for those without a medical background. The ability to capture and send images when a symptom occurs no matter the time of day was useful in the study to medical decision-making. Reporting of visual symptoms such as rashes, stool consistency, or bloody stools are some examples of the symptoms that were reported in the study. This information then influenced the medical

decision-making. The most common change was dietary changes in relation to blood glucose logs by endocrinology during the study. Other changes included referrals, reassurance, or therapy changes based on the images.

Note

Results of this study were presented in part as a podium presentation at the 2018 Pediatric Academy Association annual meeting in Toronto, Canada. The first author, K.G., was a final year medical student at the time the study was conducted and presented at the PAS.

Protection of Human and Animal Subjects

The study was performed in compliance with the World Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects and was conducted after approval from the institutional review board of the study site. This study was conducted after approval from the Dayton Children's Hospital Institutional Review Board.

Funding

None.

Conflict of Interest

None declared.

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