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Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review

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**Title:** Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review

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## **Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review**

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### **Abstract**

#### **Background:**

The dynamic healthcare reform initiatives have prompted unprecedented focus on coordination of care. The evolution of technology in the last decade has demanded increased coordination of care and patient involvement. Through *patient portals*, patients are able to view their personal health information and communicate with their providers through a secure web-based interface. However, there is limited research on the use of pediatric patient portals, specifically in the management of pediatric chronic diseases.

#### **Objective:**

To discuss the access, impact, and utilization of patient portals in the management of pediatric chronic diseases.

#### **Methods:**

We conducted a systematic review of the literature about patient portals and electronic health records (EHR) for pediatric patients from January 2009 through October 2014 to identify peer-reviewed publications in bibliographic databases and websites. Reviewers screened each publication for predetermined key themes including use, attitude and experiences, and impact of EHRs and pediatric patient portals. Eighty-five peer-reviewed publications were retrieved, and 19 of them met inclusion criteria (n=19).

#### **Results:**

Themes of improved communication between patient and provider, patient access to healthcare information, and improved management of pediatric chronic disease were found, and barriers to the utilization of patient portals including lack of access to web-based interfaces due to low socioeconomic status and language barriers.

#### **Conclusions:**

The potential for pediatric portals to augment the management of pediatric diseases in the near future is highly promising, though there are some issues in the barriers to utilization that still need to be addressed.

**What this systematic review adds:**

This systematic review:

- Summarizes available evidence identifying the value of patient portals in pediatric patients.
- Demonstrates the potential to leverage patient portals in the management of pediatric chronic disease.

**How to use this systematic review:**

Readers may use this review to:

- Assist in deciding whether patient portals in pediatric settings would be beneficial for the management of chronic disease.
- Enable readers to consider patient portals as a supplement to EHRs in pediatric medicine.

## Section 1. Introduction

Patient portals for pediatric patients show promise in the management of pediatric chronic diseases. The management of pediatric chronic diseases is often dependent on documenting the patient throughout the stages of human development. Patient portals differ from personal health records in that the healthcare organization, not the consumer, is the owner and manager of the health records.<sup>[1]</sup> Patients or parents/guardians are able to access the information provided on a patient portal and share it with others.<sup>[2]</sup> Research suggests that the implementation of electronic health record (EHR) data collection can improve the medication adherence, disease awareness, self-management of disease, a decrease in office visits, an increase in preventative medicine, and an increase in extended office visits, at the patient's request, to seek additional information.<sup>[1]</sup> Approximately 15% of children ages 2-17 are diagnosed with a developmental delay.<sup>[3]</sup> An EHR system that encourages developmental screenings at well check-ups, identifies patients who need additional monitoring for developmental delays, and prompts timely referrals and communication with specialists could improve outcomes.<sup>[2]</sup> When patients can view their EHR through a portal, the management of a pediatric patient's health is accessible to parents and guardians, and ultimately interactive health communication is achieved thus enhancing a patient's health.<sup>[3]</sup> Most patients would prefer to exchange secure messages with their provider.<sup>[4]</sup>

Adoption of patient portals in adult care is becoming more popular, though there is a lag in pediatric patient portal adoption.<sup>[5-6]</sup> There are several barriers on both the patient and provider sides due to the lack of adoption of pediatric patient portals.<sup>[7-8]</sup> Deeper

understanding of pediatric patient portal adoption is needed to be integrated into the routine of pediatric primary care. This article is a systematic literature review of literature related to the adoption of patient portals and the management of pediatric chronic diseases, with an emphasis on the benefits, barriers, and overall impact of pediatric patient portals in the quality of care.

## Section 2. Methods

### Section 2.1. Eligibility Criteria

A research team from Texas State University applied a definition of patient portals consistent with terminology from the Office of National Coordinator of Health Information Technology [9] and performed a systematic search to identify peer-reviewed publications from standard bibliographic databases of medicine, technology, and social science. The Office of the National Coordinator defines a patient portal as:

A secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection. Using a secure username and password, patients can view health information such as: Recent doctor visits, discharge summaries, medications, immunizations, allergies, and lab results. Some patient portals also allow patients to exchange secure e-mail with their health care teams, request prescription refills, schedule non-urgent appointments, check benefits and coverage, update contact information, make payments, download and complete forms, and view educational materials.

### Section 2.3. Information Sources

Figure 1 displays the selection process for articles from bibliographic databases and describes the inclusion criteria. Eighty-five

peer-reviewed publications were retrieved, and 19 of them met inclusion criteria used in the systematic literature review.

Selection process for publication included in the systematic review. Inclusion criteria included: (1) the content was regarding patient portals, pediatric patient portals, or pediatric electronic health record; (2) was published between January 2009 and October 2014; (3) the publication was available in English.

### Section 2.3.3. Data Extraction and Analysis

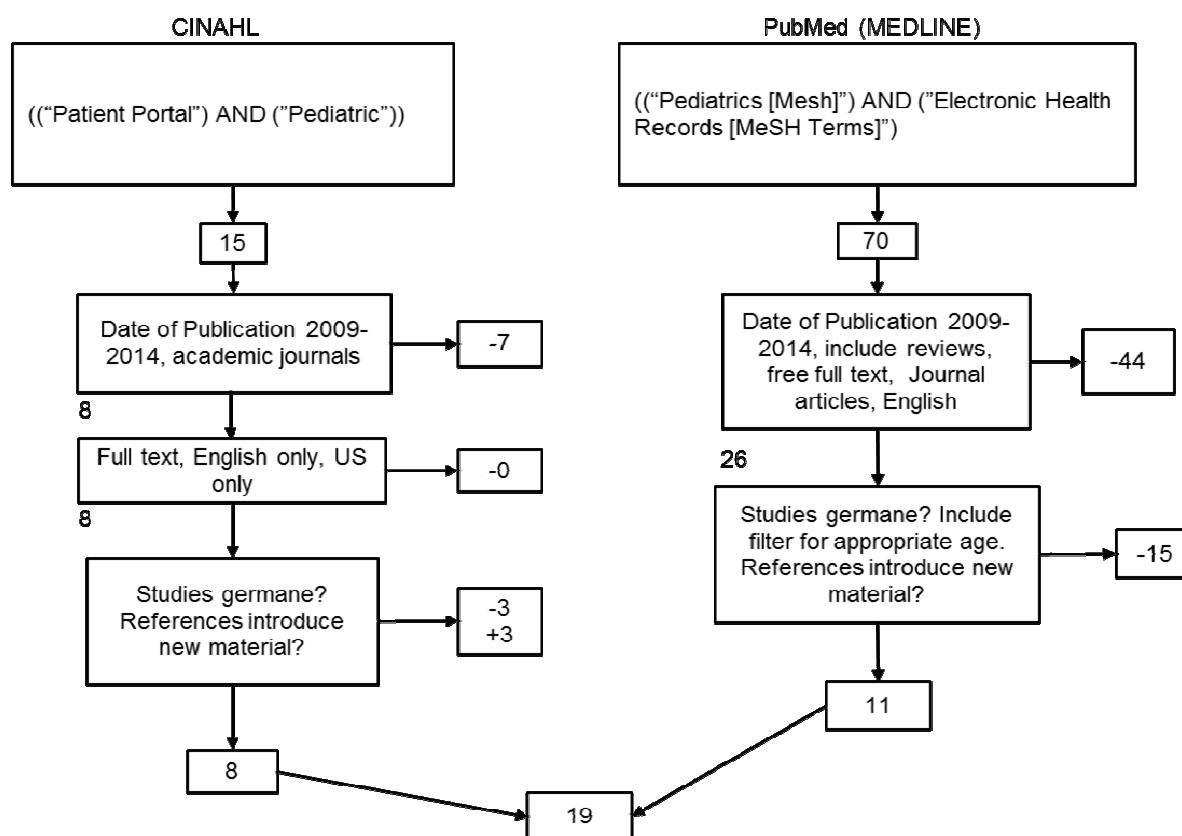
We systematically identified themes from the publications reviewed and recorded them on a spreadsheet. The themes included: a call for adoption of portals, attitudes towards

patient portals, impact of patient portals on the healthcare organization, and the utilization of patient portals. We used the help of an affinity diagram to group the themes, and together analyzed the application to pediatrics and the management of pediatric chronic diseases.

### Section 3. Results

The search resulted in eighty-five papers between the CINAHL and PubMed databases. We removed sixty-eight papers as they did not meet our criteria. A total of 19 full-text papers were obtained for analysis and met all the inclusion criteria for review. Reasons for exclusions are depicted in Figure 1.

## Study Selection



**Figure 1. The study-selection process**

**Table 1. Study themes and potential applicability to the review**

**Medical Research Archives**

**Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review**

**Volume 2**

**Issue 1**

<b>Author(s)</b>	<b>Use</b>	<b>Attitude &amp; Experience</b>	<b>Impact</b>
Jensen et al. [5]	The medical community needs to use the EHR and patient portal to conduct and track quality measures for screening for developmental abnormalities.	A disparity exists among the capability offered by existing EHR solutions; some users were able to track referrals to some non-medical services but could not communicate with medical specialists.	Portals could facilitate monitoring of developmental conditions and assist in the coordination of care in response to abnormal screening results.
Byczkowski et al. [6]	Parents of patients with chronic disease should use portals to help monitor and manage conditions.	Race and income disparities were observed – a digital divide with portal use. African Americans and Medicaid recipients were less likely to use the portal.	Portals could augment disease management for parents of children with chronic diseases.
Nordqvist et al. [7]	Portals should be leveraged to provide young type 1 diabetes patients with interactive pedagogic devices, social networking tools, and locally produced self-care and treatment information.	Most interviewees were satisfied with the capabilities and usability of the portal, and those who used it felt a sense of community with other users.	Portals could increase autonomy, self-management of chronic disease, communication, and patient empowerment. The portal provides timely access to information when staff is not available.
Nordfeldt et al. [8]	Patients' and parents' attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes; use of social networking tools such as message boards and blogs; locally produced self-care and treatment information; and interactive pedagogic devices. Lack of access to the Internet could be a barrier to use.	Patients/ families experiences were mixed. Portals served as a verifiable source of information on diabetes, which is a Web 1.0 tool. The portal also served as a viable communication tool, not only between patient and provider, but also among patients through chat functions.	Portal could serve as integration tools to gradually insert the management of type 1 diabetes into the lives of both patients and their families. Portals could also serve to shift responsibility of the management of type 1 diabetes from the practitioners to the patients.

**Medical Research Archives**

**Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review**

Volume 2

Issue 1

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Osborn et al. [10]	The transition to EHR from paper is an important goal, but barriers to adoption impede its progress.	Patients reported interest in the enhanced communication capabilities and access to lab results.	Innovative use of patient web portals yields insights on health behaviors, patient distress, and patient willingness to pay for access.
Fontaine et al. [11]**	Lack of data standards will inhibit the potential for portals. Other barriers are cost, privacy and concerns about liability.	Approximately 70% of hospitals report the implementation of a portal, and hospital executives perceive a competitive advantage in the offer and continual development of portals.	The EHR offers significant decrease in cost of care and increases in efficiencies and quality of care in an ambulatory setting.
Emont [12]**	Portals should provide beneficial services for patients and providers. Barriers include resistance to change, staff retraining needs, lack of internal expertise, fear of product failure, and lack of evidence on ROI.	Patients pay more attention and become more engaged in their health and medical care when they have easy access to their health information online.	Patient portals have a high potential to improve quality and access to care through communications channels and secure web interface with the patient record. Portals offer secure messaging, appointment scheduling, bill paying, and prescription refills.
Fiks et al. [13]*	The EHR can be used for the management of diabetes.	Providers accessed the EHR 27% (2.30 min) of the time spent in the exam room (9.06 min).	The EHR can be used during an exam in a pediatric encounter without impact on appointment time or communication with the patient.
Pinsker et al. [14]	The use of patient portals should increase quality of care of pediatric diabetes.	Users perceived better communication between patient and provider, but this increase was not statistically significant. Portal users reported greater patient satisfaction with interventions and felt that portal use would lead to an improvement of their diabetes care.	Portals provide continuing education and enable better decision making in the care of diabetes. Mean HbA1c of portal users decreased from a baseline of 10.5% to 9.1%, but this change was not statistically significant.

**Medical Research Archives**

**Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review**

Volume 2

Issue 1

Author(s)	Use	Attitude & Experience	Impact
Savinon et al. [15]*		Users reported an increase in the frequency of recording BMI, completing BMI growth charts, and scoring questionnaires between written and EHRs.	Portals offer greater potential for obesity screening; effects are particularly enhanced when EHRs are customized with EB practice guidelines.
Casciato et al. [16]*	The EHR should be better leveraged to more accurately reflect how care is delivered.		Reporting capabilities of the EHR can be greatly improved when less-strict definitions of quality are used. National quality measure definitions, slightly modified and applied to data queries in an EHR, yield greater data granularity and greater applicability of results.
Hacker et al. [17]*		EHR implementation is tremendously disruptive to the process of care.	
Urowitz et al. [18]	Portals could be used by both patients and providers for the management of type 1 diabetes. Barriers to adoption are user-friendliness, speed of secure messaging, and availability of technical support.	Portal increased patient awareness of their disease (noted by both patient and provider). Behavior changed in small ways to better manage diabetes.	Portals should serve to improve patient education, patient engagement, communication with providers, and disease management by the patient.
Adhikari et al. [19]	The use of electronic resources can be beneficial in managing pediatric obesity.	The EHR users perceived themselves more highly skilled in lifestyle counseling.	Electronic resources can greatly improve the management of childhood obesity.
Leu et al. [20]*	Barriers to adoption of health information technology are cost, perceived value, and efficiency.	Users of EHRs in pediatric settings are greatly concerned that existing EHR solutions provide the functionality necessary to care for pediatric patients.	

**Medical Research Archives**

**Patient Portals and the Management of Pediatric Chronic Diseases – A Systematic Literature Review**

**Volume 2**

**Issue 1**

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Hanberger, et al. [21]	Use of the patient portal should be leveraged to manage chronic disease, specifically diabetes.	Mothers were more likely than fathers to use the portal. Patients who had family members visit the portal more than 5 times demonstrated shorter diabetes duration, were younger, had lower HbA1c after 1 year, and were more often female.	Patient portals offer efficiencies and access to critical information when medical staff are unavailable for contact.
Ketterer et al. [22]	The patient portal should be used to improve the management of pediatric chronic disease.	African-Americans and lower incomes were less likely to use the patient portal.	The portal has the potential to improve pediatric chronic disease.
Or et al. [23]	Consumer health information technologies (CHITs) can improve outcomes in the patient self-management of diabetes.	Consumer health information technologies (CHITs) changed patient behaviors and frequency of self-monitoring.	The potential for consumer health information technologies (CHITs) to positively impact medical outcomes is high. The results from 67 RCTs demonstrate improvement in 64% (16/25) of measured outcomes related to diabetes.
Sherek & Gray [24]	Patient portals should be leveraged in the care of pediatric medicine.	Issues to consider when creating a portal are the proper role of the HIM professional and the establishment of a protocol for a minor's access to the portal.	The portal impacts state laws and minors' rights.

\*Article did not mention portal

\*\*Systematic literature review

### Section 3.1. Results of Individual Studies

As the authors reviewed each article, three themes regularly surfaced: *Use, attitudes and experience*, and *impact*. Not all articles addressed all three themes, but 75% did. Table 1 illustrates the affinity diagram that the authors used to group their comments into the themes. The “use” theme is used to describe articles pertaining to the adoption, use, need for, study limitations, and barriers pertaining to pediatric patient portals. The “attitudes and experiences” theme describes the perceptions of portals before, during, or after use by patients, family, and providers. The “impact” theme lists the various services portals offer, the benefits of the services, impact on coordination of care, and the impact on patient outcomes. An underlying message from the literature review is that there is inadequate data to associate patient outcomes with use of the patient portals in the pediatric patient population, but there is general consensus that it has the potential to do so.

### Section 3.2. Risk of Bias within Studies

The literature reviewed did have opportunities for bias. Selection bias is inherent to most of the studies because patient portals have limited exposure to the general population, therefore those most predisposed to technology will be the ones most likely to volunteer for use of the portal. It is unlikely that the results from this sample are representative of the population. Some studies were conducted in few or even one practice setting, thus not collecting a large or diverse enough sample size. Small sample sizes are also prone to random error. The random error will decrease with larger sample sizes. Because

our research team consisted of four people, there is a chance for inter-rater reliability. To reduce the chance for inter-rater reliability, the team was trained by CSK on what to look for and how to record the observations. A Kappa was calculated for selection of articles ( $K = 0.977$ ), which is a strong level of consistency. To further control for inter-rater reliability, the research team met weekly to share observations from articles. Inconsistencies were discussed. The final selection was left up to CSK.

Lastly, there is not enough research on the relatively new technology of patient portals and little is known about their impact on care and outcomes. To control against this bias, this review included other systematic reviews. Results of this review are consistent with other reviews; the unique aspect of this review is the affinity diagram that categorized author comments into themes.

### Section 3.3. Synthesis of Results

Patient portals are a unique resource for patients in that they shift the power to the consumer and enable them to better manage chronic diseases. Though the topic lacks depth of research, our systematic literature review provided strong evidence that this resource can benefit patients especially when managing chronic conditions. Though evidence established a need for patient portals, there are barriers to adoption of this resource. Regardless of the barriers, there are many benefits presented in the research.

Eighteen of 19 articles reviewed (90%) illustrated a call to adopt consumer health information technologies. Reasons for this

call for adoption ranged from the screening of behavioral abnormalities [5] diabetes control [7,8,13,14,18,21-24], pediatric obesity [15,19], access of lab results [10], increased secure communication with provider [12], and measurement of quality [16]. Barriers to adoption were lack of internet access [8], cost [11,20], privacy and liability [11], resistance to change [12], lack of expertise [12,18], user friendliness and speed of secure messaging [18], perceived value and lack of efficiency [20].

The need for patient portals was evident for pediatric patients. In congruence with pediatric quality measures, only 61% of children had the recommended provider “well-child visits” by age 2 compared with 52% by age 15 months [16]. This gap in provider visits by pediatric patients demonstrates the need for a secondary resource to increase interaction between providers and patients.

According to a study by Jensen et al, patient portals can be used to limit barriers associated with developing quality measures, specifically by eliminating concerns of data reliability and tracking the coordination of care [5]. Patients and providers can utilize an electronic questionnaire, a common tool of patient portals, which can reduce the amount of missing data in a patient’s electronic medical record [5]. Benefits to patient behavior and knowledge are also a result of patient portals.

According to Calvin, patient portals could lead to more self-monitoring, higher

frequency of attending health checks, increased patient exercise, improved diet, improved medication adjustment, and improved diabetes and disease management knowledge [23].

According to a study in 2008, 90% of patients wanted to communicate with their care provider via email yet very few care providers were interested in offering this service due to concerns of the increased work load, lack of reimbursement, and insufficient security [4]. Common patient portal services, such as a secure electronic messaging system, can answer the patient demand for communication while relieving concerns of security measures. However, provider incentives must be considered to increase provider participation [15].

Patient portals can also be used to improve patient outcomes. In efforts to reduce childhood obesity, clinicians were asked to accurately document and track pediatric patients’ BMI, as well as educate obese patients to improve outcomes. However, many physicians are unable to fulfill these demands partly due to time concerns [19]. A patient portal could be used for families to continuously document the pediatric patient’s BMI so that a physician could quickly review the patient’s progress during the patient visit and make an accurate diagnosis, as well as offer a means of providing continuous patient education.

Patient portals are needed as a resource to increase patient and provider interaction, increase data reliability in the patient’s EHR, assist in the coordination of care, increase patient self-management of their health, offer additional resources to the

patient to manage their health, and to improve patient outcomes. Though the need for patient portals has been established by the literature, there are still barriers to the adoption, implementation, and use of patient portals in the health care industry.

Barriers to adoption, implementation, and use of a patient portals limit provider incentives and their ability to offer and utilize a patient portal system. Barriers to adoption may be related to the size of the provider's practice. When reviewing the adoption rates of EHRs, an electronic resource similar to a patient portal, adoption rates were higher in larger practices [24], which may be attributed to the practice's access to capital and funds. With less access to capital for IT expansion, smaller pediatric practices do not have the ability to adopt a patient portal system. Even if a practice has the ability, financially speaking, to adopt a patient portal, implementation can still be difficult. When implementing a patient portal for minors, for example, many factors must be considered. Health organizations must clearly define the medical professional's role with the patient portal, establish whom they will grant patient portal access to, and adhere to state and federal laws concerning minors' rights [22]. All of these factors may be too much for a practice to consider when implementing a patient portal, especially if the practice is smaller in size and has fewer individuals to assist with implementation. Practice size is not the only impact on the ability to adopt and implement a patient portal, as some data provides evidence that patient portal use by the patient is infrequent which would not support adoption.

Adoption and implementation of a patient portal are timely and expensive and in order for a health organization to buy into this technology, there must be a clear return on investment. Some evidence suggests that patients would not utilize patient portals and that the technology is not worth the investment and time. An analysis of patient portal enrollment at an academic children's hospital reviewed data for 84,015 children to measure enrollment over a four-year period. The results were that one if four patients and families actually activated the patient portal account, however evidence did suggest that guardians of patients with more complex conditions were more likely to activate their account [5]. This evidence supports the claim that patient portals would be utilized to manage chronic conditions.

Another barrier to patient portal implementation and adoption is within the system's design. Many providers are concerned that the patient portal will not meet the organization and patient needs. According to research current EHR systems do not meet the needs to care for pediatric patients [20]. When developing a patient portal to treat pediatrics, organizations must ensure that the system contains pediatric-supportive features otherwise there may be a lag in implementation that mirrors the current lag in implantation for EHRs to treat pediatrics.

Providers are not the only barriers to adoption. Patients play a pivotal role as their enrollment, or demand for the patient portal, drives implementation. One study that concluded that patient portals are not utilized, which was evident in the data in that only 15.9% of the study population

continued use of the portal after three months, suggested that there was not a need for portals since test results and education were given during the patient's visit with the provider [6]. However, this study included adults and was not focused on managing chronic conditions.

Though there are multiple limitations to patient portal implementation, the benefits of these systems outweigh the barriers. Patient portals also have positive impacts when targeting diabetes patients in that the portal enhance patient-provider communication increase overall satisfaction with care expand access to health information and improve disease management and patient outcomes in diabetes [10]. In order to fully take advantage of the benefits of patient portals, healthcare organizations must overcome the barriers to adoption and implementation.

#### **Section 4. Discussion**

There is increasing access to web-based interfaces; even to low socioeconomic status families and the literature cannot keep up with the accessibility to these devices. The management of pediatric chronic diseases is often dependent on documenting the patient throughout the most crucial of developmental stages. Pediatric patient portals are improving the communication barriers between patient and provider and allow for better management of pediatric chronic diseases. Although direct evidence linking patient portals to outcomes has not been established, patient portals provide the opportunity for improved patient care, especially when they are integrated with EHR system.

There are many barriers to address when implementing an effective patient portal. Financial barriers are one of the hardest to overcome and coincidentally the most prominent. The size of the provider's practice may also limit what the practice can achieve or implement and therefore is another barrier to patient portal integration as well. Minimal patient portal use by the patient is due to design and navigation issues, as well as a lack in education. Evidence of negative feedback from the patients is attributed to the lack of ease in using the portal and difficulties navigating it. By designing a more user-friendly portal, patients would be more likely to use the patient portal. Also, patients need to be educated on the benefits and use of patient portals. A common theme of "lack in awareness of patient portals" was observed in the literature. While patient attitudes toward portals were generally positive, providers had different opinions toward the portals; fears of reimbursement, disruption of productivity, and loss of patient control must be addressed in order to create more buy-in to patient portals on behalf of the providers. Providers play an imperative role in the success of patient portals.

The healthcare setting is continuously moving towards an environment of empowering the patient in the coordination of their care. The patient portal is an important asset assisting in this transition. Although a direct tie between portal use and improved clinical outcomes has not been established, this literature review documents observations that patient portals appear to be a beneficial resource assisting in the coordination of care. Evidence suggests that

patient portals increase communication between patients and providers, which can be lacking in traditional healthcare settings. Patient portals also provide patients with a resource that empowers them to better manage their care, which overtime can result in better outcomes.

#### **Section 4.1. Limitations**

We recognize some limitations in this study. While much research has been conducted on the benefits and barriers to patient portals in adult medicine, the intricacies and complexities of pediatric chronic disease management and the slow adoption of patient portals in the outpatient setting has made it difficult to conduct extensive research on this topic. Further, the term “patient portal” is not yet a MeSH term, thus we could not effectively capture this term in our search. The rapid development of technology has also made it impossible to keep up with the literature on the access of web-based interfaces in low socioeconomic status demographics, as technology is increasingly more available in many domains.

#### **Section 5. Conclusions**

The studies included in this review suggest that there are certainly barriers to the utilization of patient portals in pediatric

patients at its maximum potential. However, the data also suggests that the value of patient portals in pediatric patients with chronic diseases, especially in conjunction with electronic health records, improves the quality of care and coordination of care significantly. Patient portals enable patient engagement, the self-management of chronic conditions, and increased secure communication between patients and their providers. Time will tell whether these capabilities will lead to significantly better outcomes. Future research could address increased access to web-based interfaces to all demographics. With increased access to these interfaces and heightened emphasis on direct patient involvement, patient portals will play a significant role in both adult and pediatric health care.

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