

Caregiver Perspectives on Electronic Portal Use in Integrated Primary Care

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Abstract

Background: Pediatric patient care portals through electronic health records (EHR) provide opportunities to enhance patient care. However, challenges exist for making portals usable and few studies have examined qualitative experiences of caregivers when using Integrated Primary Care (IPC) services for their children.

Objective: To qualitatively examine barriers and facilitators to using electronic patient portals in IBH care.

Methods: Data were collected from seven caregivers of pediatric patients (0-7 years old) during focus groups. Interview data were analyzed qualitatively and coded by an interdisciplinary group. An iterative approach identified overarching themes within the CFIR domains: Outer Setting, Inner Setting, and Characteristics of Individuals.

Results: Overall, caregivers found the portal beneficial. Six themes emerged during the thematic analysis. Outer setting themes included: "lags and barriers to care" and "connections with outside providers." Inner setting themes included: "putting the human in human-centered design" and "virtual access to information." Characteristics of Individual themes included "flexibility" and "personalization."

Conclusions: The current study sheds light on caregiver perceptions of electronic portal use. The patient portal is an effective and well-received tool for patients with developmental delays and families accessing behavioral health information. Future targets for improvement include: personalization, equitable access, and reach beyond single institutions.

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Original Manuscript

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Keywords: Electronic patient portal, Integrated Primary Care, Developmental Behavioral Pediatrics, Pediatric Primary Care, Health equity, Behavioral Health

Introduction

Facilitating between-visit communication between pediatric providers and patient caregivers improves patient outcomes across various pediatric conditions^{1,2}. Effective and accessible mechanisms facilitate provider-patient communication, particularly in delivery of interdisciplinary care³ given the multiple providers involved in coordinating care. Integrated primary care (IPC) links behavioral health providers to medical providers through the embedded delivery of prevention, assessment, and treatment services⁴. IPC services can be co-located appointments, delivered within the context of scheduled medical visit, and/or implemented through communications and supports between visits. Many integrated service delivery models rely on features within the Electronic Health Record (EHR) to improve engagement, increase adherence, and open lines of communication between pediatric providers and caregivers⁵⁻⁷. Modalities of virtual care have become widely utilized across health systems in the wake of COVID-19 and play a particularly important role in the delivery of behavioral health services⁸.

With greater access to technology, the patient care portal embedded within the EHR has been increasingly used as a mode of communication between pediatric providers and caregivers. Embedded EHR portals are typically an “opt-in” electronic space where patients, patients’ caregivers, and pediatric providers can communicate with medical providers and staff regarding scheduling, non-urgent medical concerns, laboratory findings, orders, and referrals. It has been estimated that 60% of healthcare systems implement portals as an element of patient care and communication⁹. Patient adoption rates of portals were estimated to be 15-30% and growing following the COVID-19 pandemic, representing an area of promise for healthcare communication^{9,10}. The American Academy of Pediatrics has highlighted the potential of EHRs to improve patient access to health information, facilitate preventative health, and support disease management¹¹. In the context of IPC, the portal can play an important role in screening, assessment, and in facilitating aspects of care such as communication with multiple providers involved in care,

the provision of links to video visits, and a means of connecting patients to applications for symptom monitoring¹². EHR portals tend to be well received by patients and caregivers, endorsing ease of use¹³ and high ratings of satisfaction^{14,15}.

Despite the utility and ubiquity of patient portals in pediatric care, challenges exist in the uptake and reach of portal technology among underrepresented and marginalized patient populations¹⁶. Such inequities have been documented among economically disadvantaged and racialized groups^{10,17}. For example, African American families and children on Medicaid are less likely to have a portal account set up when available¹⁸. There is limited research on the potential barriers to portal use among marginalized patient groups. Understanding how families navigate health care communication, and their perceived benefit of technology in the delivery of healthcare may help make healthcare technology more accessible and user-friendly. Creating an EHR that works effectively for all medical and mental health providers in integrated practices can be difficult.¹⁹ Patient voices are often left out of the conversation in when institutions make decisions about the adoption and implementation of patient-facing platforms²⁰, which may perpetuate or amplify existing disparities in pediatric behavioral health care²¹. User-experience designs highlight that user voices can be leveraged to more readily align technologies with user needs, desires, and goals.

The current study aims to begin filling in our gaps in understanding marginalized patients' and caregivers' qualitative experiences with patient care portals when used in the context of integrated primary care service delivery and developmental screening. We hypothesized that caregivers and families experience both barriers and facilitators to portal-based care at the systemic, institutional, and individual level. By identifying root causes of barriers and facilitators at each level, this work can inform the development of a multi-level toolkit to facilitate patient access to care and serve as a first step in research to refine EHR experiences for IPCs.

Method

Setting and Overall Study Design

This study was a collaborative effort that included clinician-researchers across multiple service delivery divisions, including Integrated Primary Care (IPC), Developmental Behavioral Pediatrics (DBP), and General Pediatrics (GP). The study occurred in a culturally and ethnically diverse primary care clinic at a Midwest academic medical center. Most families served within the clinic depended on publicly funded insurance and faced many barriers to care (i.e., financial, social, logistical, and cultural). A qualitative research design was employed, utilizing focus groups to explore participants' perceptions and experiences, allowing for in-depth discussions and identification of shared themes and insights. We used the Consolidated criteria for reporting qualitative research (COREQ) guidelines to ensure a rigorous qualitative methodology²². Data were coded, analyzed, and interpreted using the Consolidated Framework for Implementation Research (CFIR)²³ to provide a structured approach for identifying key factors influencing the implementation of the patient portal across both internal and external systems of care. This study was deemed "not regulated" by the institutional review board.

Procedures

CFIR framework

Focus group questions were developed, and qualitative analyses were conducted using the CFIR framework. CFIR is a flexible framework that is adaptable to a variety of study methods. CFIR includes five constructs: Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals, and Process. The study team identified three CFIR domains most relevant to this study: Outer Setting, Inner Setting, and Characteristics of Individuals. As this study was not analyzing the effects of an intervention the other two domains (i.e., Intervention Characteristics and Process domains) were not included in the qualitative analysis.

The focus group questions centered around facilitators and barriers in the Outer Setting, Inner Setting and Characteristics of the Individuals. Questions were open-ended and probed about the

caregivers' experiences and preferences as well as facilitators and barriers to their child receiving care, especially those related to the use of the patient portal. The focus group questions were developed using an iterative process: each interview informed the script for the following focus group to delve deeper into different areas mentioned by the previous group(s).

Recruitment

We completed a retrospective chart review of the EHR from January through March 2023 to identify families with children ages zero to seven who had received IPC or DBP care to inquire about participation in the study. The IPC and DBP clinic were embedded in a racially and ethnically diverse clinic with approximately 66% of children served by Medicaid. This clinic is affiliated with a Midwestern academic medical center. Families were then approached by a phone call with a research assistant and provided study details and next steps for participation if interested. We also shared study information and fliers with pediatric providers, pediatric psychologists, and Developmental Behavioral Pediatric providers for providers to share fliers with families. Our sample therefore included participants from multiple recruitment methods and included a convenience sample of interested families. Families who were interested were provided an option for in-person and virtual groups. Given that this study was IRB-exempt, caregivers verbally assented to the study by phone and were enrolled in the study after caregivers indicated they would like to participate in the study.

Inclusion criteria included families with one or more children receiving behavioral health services (IPC or DBP), age 0-7 years, and who were perceived as having a behavioral or developmental concern needing more care as identified by a pediatric provider. Exclusion criteria included a caregiver who did not speak or understand English sufficiently. A research assistant called caregivers of eligible patients to inquire if they were interested in participating in a focus group. Twenty-eight families were approached by phone about participating in the study. Sixteen families indicated that they would like to attend. A total of fourteen families were scheduled for interviews. Seven families completed interviews, and seven who were scheduled for interviews were not present

for the interviews. It is unclear why these seven families were unable to attend.

Focus Groups

An in-person focus group and two virtual focus groups were led by a parent advocate and community partner trained in reflective practices while one virtual focus group was led by the research assistant. The parent advocate told the participants that their passion for helping on this project came from their own children with disabilities and their desire to help other families get the medical care they needed for their own children. The in-person focus group occurred at a local library while the virtual focus groups were conducted from wherever the caregiver desired. The parent advocate and research assistant were given interview guides with sample questions and prompts which were created by the authorship team. Two children were also present at the in-person group along with two researchers. The Zoom focus groups occurred in the home environment, so there may have been other individuals in the home listening who were not directly involved in the focus group. Participants engaged in a single focus group.

All focus groups were recorded and transcribed. The virtual focus groups were video recorded while the in-person focus group only recorded audio. Field notes were made both during and after the focus groups. Transcripts were not returned to participants for comment and/or correction. Interested caregivers were placed into focus groups according to availability and modality preference (in person vs virtually). One focus group was held in person and three occurred virtually. A Zoom link was sent to the primary email of caregivers participating in the virtual group. After low attendance with the first virtual focus group, caregivers in the subsequent groups received a reminder email one week before, a reminder call within 48 hours of the focus group, and a call 10 minutes after the focus group began if they were not on the Zoom link to double-check if technology was working. In some cases, the Zoom link needed to be re-sent. Each caregiver was compensated with a \$60 gift card for their time. After families were identified for inclusion in the study, a chart review was conducted to determine the child's race/ethnicity, age, gender, and insurance provider.

Qualitative Analysis

Focus Group Coding Scheme

The CFIR framework was used to categorize responses relevant to implementation in combination with grounded theory methods to allow novel themes to emerge. After each focus group, the research team met as a group and independently read the transcripts to discuss major themes that emerged from each relevant CFIR domain. A coding tree was developed within the CFIR domains with two themes per CFIR domain. The research team consisted of 3 medical physicians (MD), 2 licensed psychologists (PhD), and one research assistant. Two of the physicians were developmental behavioral pediatricians and one was a primary care pediatrician. The two PhD psychologists were integrated behavioral health psychologists. The research assistant was a PhD candidate in clinical psychology. All members of the research team identified as women, from a diverse range of backgrounds (Middle Eastern, Black, White, and Asian), worked at an academic medical center, and with experience working on qualitative research within integrated primary care. The participants knew that the researchers consisted of physicians and psychologists within an academic medical center. The focus groups were read by all six researchers to create themes and identify exemplary quotes. Two researchers (one MD and PhD) returned to the transcripts to code for themes iteratively. Following each focus group discussion, we discussed conceptual depth of themes and agreed by collaborative consensus that following four focus group interviews that adequate conceptual depth and data saturation were achieved. Data was managed in Microsoft Excel. The Outer Setting domain involves how well the institution is connecting and communicating with outside referrals and agencies. For this study, many barriers were identified in the Outer Setting including structural barriers to accessing the portal and portal resources. The Inner Setting domain details how well the institution connects and communicates within the organization. Many strengths were identified in the Inner Setting including benefits and opportunities for portal use. The Personal Attributes domain included aspects of caregivers' own preferences or personality that aided or

hindered their portal use and their preferences for communicating with providers through the portal. Many structural barriers existed for caregivers' participation in this study, contributing to a small sample size. However, in the traditions of qualitative research, high information power was achieved through the narrow aim, dense specificity, use of an applied theory, strong dialogue, and case analysis²⁴.

Results

One in-person and three virtual 90-minute groups were hosted consisting of seven parents of children 2 to 7 years of age. Over the course of the four focus groups, seven caregivers attended. All seven caregivers were female. The races of the children receiving behavioral health services included White (n=3), Black (n=3), and Other (n=1). Participants provided feedback to the research team about clinic changes they would like to see.

Caregiver access and comfort with their child's patient portal was revealed as the most influential variable to their behavioral healthcare experience. Caregivers who could access their child's EHR portal shared that they liked the ability to schedule, see appointments, receive appointment reminders, and communicate with providers. Conversely, parents who identified portal access as a barrier reported difficulties utilizing technology, limited access due to child's age, and/or caregiver status. Overall, six themes were identified which we categorized in the CFIR framework into Outer Setting, Inner Setting, and Characteristics of Individuals (Table 2).

Outer setting themes

In the Outer Setting, themes identified included: "lags and barriers to care," and "connections with outside providers." Lags and barriers to care emerged as a concept that referred to systemic factors shaping caregiver access to care. Caregivers generally viewed the portal favorably to reduce the lags and barriers to care such as allowing easy scheduling and rescheduling of appointments, but some families were not provided equitable access. Some of the lags and barriers to care were mentioned 11 times during the focus groups and included long waits for the call center, no portal

access for foster parents, and delays in care when parents need to reschedule appointments. The lags and barriers to care were perceived as critical. For example, a caregiver stated, “...with early intervention, every day lost is a day that you can’t get back.” As represented by the theme “connections with outside providers”, caregivers reported a strong desire for care coordination between providers using the portal and included difficulties and lengthy intake processes with outside referrals as major barriers to care. One caregiver wished there was a “universal” portal system, “Can we streamline this process and make life simple for everybody?” Connections with outside providers were mentioned six times during the focus groups.

Inner setting themes

In the Inter Setting, themes identified included “putting the human in human-centered design” and “virtual access to information.” Putting the human in human-centered design theme refers to the various ways that caregivers can use the portal as a tool for medical information, accessing providers, and coordinating their child’s care. This theme included statements about how the portal is an effective tool and ways in which it could be more tailored to meet families’ needs. One caregiver even noted, “I do [use the portal], as much as possible. That’s why I don’t want to go see a doctor anywhere else because it makes my life easy.” The theme of putting human in human-centered design was identified eight times throughout the focus groups. Virtual access to information refers to the overarching ways that families seek online medical decisions and was identified 12 times during the groups and included how caregivers access information about their child’s health care including videos and social media. Without information provided through visits or the portal, parents stated they would refer to social media.

Characteristics of Individuals

Themes identified in Characteristics of Individuals included “flexibility” and “personalization.” Flexibility was conceptualized as the desire to have a responsive medical system that suits each unique family system and was mentioned six times during the focus groups. Some

parents prefer that visits are in-person while others prefer virtually. One caregiver mentioned that it was very challenging to bring her child to an in-person visit while another caregiver mentioned that it was difficult to get her child to sit still for a virtual visit. Personalization was conceptualized as the caregiver's need for tailored and individualized care for their child and was mentioned ten times during the focus groups. One caregiver noted, *"Well, I know what's best 'cause I'm the parent. I'm the one dealing with it. But I want them to feel heard and I wanna feel heard. I wanna come to a good compromise."* Whatever method of communication (in person, virtual, phone, portal message), parents want personalized care that fits their child and family. Caregivers are seeking flexibility and personalization in their care and the portal can either help facilitate these goals or hinder them depending on how it is designed and utilized.

Discussion

To our knowledge, this is the first study of its kind to use the CFIR framework to better understand caregiver reported facilitators and barriers surrounding access and utilizing patient care portals in the context of pediatric IPC. The purpose of this investigation was to gather information toward the development of a streamlined behavioral health toolkit that would guide institution policies and procedures surrounding the use of patient-facing EHR tools to improve patient care. The current study is the first study to our knowledge to examine caregiver perspectives in use of the patient EHR portal for pediatric IPC, finding that caregivers believe it is a useful tool but there continue to be access issues to the portal.

Overall, the caregivers included in the study viewed the patient care portal as a positive space to participate in care for their children, in particular helping to meet needs within the context of the health system (inner setting). Structural barriers and inequities in caregiver access to electronic behavioral health records were also reported across participants, particularly surrounding care coordination and the need for more tailored and individualized care.

Using the family voice in our study design allowed for the identification of human-centered

design principles to inform potential improvements in the patient/caregiver experience. Caregiver reported positive interactions with the portal fell primarily within the inner setting of the CFIR framework, which suggests that at the individual patient level, the portal aids in effective communication between caregivers and providers. Specifically, the patient care portal was helpful in aiding caregivers scheduling of appointments and their access to clinical care services, such as video visits. Families also reported accessing health information on social media and through other open online sources, suggesting that future portal integration of healthcare information in trusted resources may be an area families may find beneficial. Ultimately, families perceived the patient portal as an effective bridge to healthcare access. Yet families often ranged in their preference for virtual versus in-person care and communication for behavioral health needs.

A structural barrier commonly reported by participants was the common problem of lengthy wait times to be able to schedule or reschedule behavioral health services when having to go through call centers. The patient portal however was perceived as something that helped increase access to care and reduce wait times. Prior work using time-use diaries has found that low-income families were more likely to spend an additional 12 minutes per day waiting for services compared with higher-income counterparts²⁴. One potential mechanism might include a dearth of providers accepting Medicaid²⁵, which limits caregiver access to medical care overall. In this study, families indicated the patient portal was one way to bypass long waits in the call center and that the patient portal was the more ideal way to re-schedule care. Patient portals may be an important way to accommodate time-restraints of low-income families, whose employment may not have substantial flexibility to address scheduling and make phone calls during regular clinic hours.

Another area of potential future innovation that should be considered is developing capabilities to allow for communication across providers and institutions. Families noted that systems-based communication between Early Intervention or Community Mental Health were lacking, but a portal system that was universal and not institution specific could facilitate warm

handoffs and referral monitoring between disparate systems. For example, the patient portal could display referral status across systems to create continuity and personalization of care that families valued and desired.

Finally, an important barrier identified by caregivers was the lack of universal accessibility of the patient portal to foster parents. The number of children in protective custody has increased from about 397,000 in 2012 to 442,000 in 2017²⁶. Children in foster care experience increased health problems compared to the general population and may require more extensive communication with their pediatric providers²⁷. For this population, there may be multiple encounters with the healthcare system in many settings and caregivers, leading to fragmented care²⁸ and complicating the communication of critical health information²⁹. There is promise in leveraging the patient portal to create more streamlined system to detangle health care delivery among children experiencing foster care. Recognizing this gap in service delivery, Texas, Cincinnati, Ohio, and Allegheny County in Pennsylvania have passed laws or created data systems that improve health care communication for children in foster care. Lessons learned from these regional efforts could be used to inform how health systems can incorporate more inclusive policies to allow foster parents to have portal access to access services and features that can facilitate patient care, while maintaining protection and privacy of patients in state custody.

Our study had several limitations. As a single-center study, our work may not be generalizable to other populations using different EHR portal systems or in other states with different regulations around foster care or privacy rules. In addition, data were qualitative and included a small number of participants. Patient perspectives may not reflect the views of other populations. Strengths of this study include the specificity of behavioral health information and inclusion of a low-income and racialized populations, who experience greater barriers to healthcare and access. Future research should explore caregiver education around feature and functions of the patient portal as well as how policy changes can help caregivers better access behavioral health information,

provide a more positive experience around scheduling appointments, and be more inclusive.

Conclusion

Using in-depth qualitative methods, we found that the patient portal is an effective and well-received tool for patients accessing behavioral health information. Despite positive perceptions, improvements in how these tools can be personalized and can reach beyond single institutions were identified as potential areas of improvement. It was also evident that disparities remain in health-IT access that requires systemic work to ensure all populations have access to high-quality care, streamlined communication, and behavioral health information.

Table 1. EMR Demographic Information

Variable (n=7)	n (%)
Patient Age	
2 years	1 (14%)
3 years	1 (14%)
4 years	1 (14%)
5 years	2 (29%)
6 years	0 (0%)
7 years	2 (29%)
Child Gender	
Male	3 (43%)
Female	4 (57%)
Child Race	
Black	3 (43%)
White	3 (43%)
Other	1 (14%)
Insurance	
Public	1 (14%)
Private	6 (86%)

Table 2. Theme and construct with exemplar study quotes.

Construct	Description	Exemplar Quotes
Outer setting: Lags and barriers to care	This theme emerged as a concept that referred to systemic factors shaping caregivers access to care.	"...if you have to call for an appointment, a lot of times with the call center you have to wait or they transfer me to the wrong people and then I spend easily an hour on the phone trying to figure out what his appointment is or following up on a referral that didn't get placed." No portal access for foster parents: "And because they're not fully adopted, they are not allowing me to use the portal. And not being able to use the portal is unfair from my standards..." Rescheduling leads to delays in services: "It could be long, long wait times to get another appointment back. It could be six weeks, it could be eight weeks.... And especially with early intervention, because with early intervention, every day lost is a day you can't get back."
Outer setting: Connections with Outside Providers	This theme referred to caregivers' desire for care coordination between providers using the EHR patient portal.	"I'm a fan. In fact, I think that there should be like a universal one [portal system], because it shouldn't be... That's the one hassle I've had. And I get like why these privacy laws are there and whatnot....Can we streamline this please and make life simple for everybody?"
Inner Setting: Putting the Human in Human-Centered Design	This theme refers to the various ways that the portal can be used as a tool for medical information, accessing providers, and coordinating their child's care.	"I do [use the portal], as much as possible. That's why I don't want to go see a doctor anywhere else because it makes my life easy." Difficulties with setting up the portal: "What I don't like about it is I just had my son and nobody has showed me how to sign up for the portal. I mean, they gave me a piece of paper, but I'm like, I'm a more show me type person, so show me how to access this patient portal."
Inner setting: Virtual Access to Information	This theme refers to the overarching ways that families seek online information to make medical decisions.	"It wasn't until I seen the video about a kid with ADHD that I really realized I wept, I cried and cried when I understood how my baby was seeing the world." "Oh, my gosh, I learned so much from like Facebook groups, but then you also have to take that with a grain of salt because you got a lot of different opinions, whatnot. But I probably learned more there than anyone else or anywhere else. That at least got me googling other things."
Characteristic s of Individuals: Flexibility	This theme emerged from caregivers desire to have a responsive medical system that suits each unique family system.	"I like in-person just 'cause I mean, I feel like if it's relating to my kid, she probably needs to be present and she's not going to be present for a virtual meeting. [chuckle] That's not going to happen." "And she called me at home before the holiday and said, 'I just wanna make sure, is there anything else? Did you think about what I said? Is there anything more for you? How he is...' And my heart just melted. I said she didn't have her nurse or you know, some other person. She called me. I felt like so great."
Characteristic s of Individuals: Personalization	This theme emerged from caregivers need for tailored and individualized care.	" Well, I know what's best 'cause I'm the parent. I'm the one dealing with it. But I want them to feel heard and I wanna feel heard. I wanna come to a good compromise."

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Authors Contributions:

ETK- Data curation, formal analysis, investigation, project administration, software, validation, visualization, writing original draft, writing- review & editing

TGM- Conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, supervision, visualization, writing- original draft, writing- review & editing

TBB- Conceptualization, formal analysis, investigation, methodology, supervision, visualization, writing- original draft, writing- review & editing

BML- Resources, writing- original draft, writing- review & editing

SDH- Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, validation, visualization, writing- original draft, writing- review & editing

Abbreviations: EHR (electronic health record), IPC (Integrated Primary Care), Developmental Behavioral Pediatrics (DBP), General Pediatrics (GP), CFIR (Consolidation Framework for Implementation Research)

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Supplementary Files

CONSORT (or other) checklists

Consolidated criteria for reporting qualitative research (COREQ) Checklist.
URL: <http://asset.jmir.pub/assets/8c43c79ff423bf6ff74228c08a149eca.pdf>