



# Providing Adolescents with Access to Online Patient Portals: Interviews with Parent-Adolescent Dyads

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**Objective** To identify perceived benefits, problems, facilitators, and barriers to adolescent online patient portal use.

**Study design** Qualitative, semi-structured interviews with dyads of parents and adolescents with or without chronic illness. The study team purposively sampled for racial and ethnic minorities and fathers. Three team members then performed thematic analysis of the transcripts, with subsequent dyadic analysis of themes represented by related parents and adolescents.

**Results** We performed 102 interviews with 51 dyads of parents and adolescents (26 with chronic illness, 25 without chronic illness). Nearly all participants believed that adolescents should be permitted portal access. We identified 4 themes related to portal benefits: improves adolescent's knowledge of health; supports medical self-management and autonomy; strengthens communication and relationships; and supports parental influence. We identified 4 themes related to portal problems: misunderstanding or confusion; emotional distress; strain on relationships; and irresponsible use of portal. Facilitators of portal use included severity of illness, adolescent's curiosity, and ease of technology use. Barriers included lack of awareness or interest, complexity of information, and access difficulties. Twenty adolescents (39%) did not know they could access the portal, and 23 (45%) lacked interest in portals. Parents and adolescents seldom used the portal as a collaborative tool, and instead were engaging with the portal independently.

**Conclusion** Parents and adolescents perceive several benefits and problems with portal use, but many adolescents lack interest in using portals. Adolescent portals represent an underutilized resource to engage adolescents in their care. (*J Pediatr* 2024;270:114015).

Online patient portals (hereafter referred to as “portals”) are widely available tools that can support communication with patients and caregivers. The 21st Century Cures Act mandates access to electronic health information.<sup>1</sup> Through portals, patients can access medication lists, test results, and clinical notes. For adult patients, portal use has been associated with better medical adherence,<sup>2</sup> perceptions of control over one's health,<sup>2-5</sup> and improved medical understanding.<sup>3,4,6</sup>

Portals provide an opportunity to better engage adolescents in their healthcare, supporting communication and self-management. Most adolescents rely on parents to manage communication and complex logistics of medical care,<sup>7-10</sup> but adolescents also must transition to adulthood and self-management. These transitions rely on ongoing, effective communication between parents, adolescents, and clinicians.<sup>7,11,12</sup> As such, portals could facilitate collaborative communication and care management.

Despite the broad availability of portals, few studies have characterized adolescents' experiences and motivations that influence portal use behaviors. While several studies have evaluated perspectives on privacy and confidentiality related to adolescents' portals,<sup>13,14</sup> little work has focused on how to encourage portal use or make the adolescent portal more useful.<sup>15</sup> This dearth of evidence limits the ability to develop policies and interventions to make the portal a useful tool for adolescents. We aimed to identify the perceived benefits, problems, facilitators, and barriers to adolescent portal use. These findings could inform the development of strategies to further engage adolescents in using their portals.

## Methods

We report these results following Consolidated Criteria for Reporting Qualitative Results.<sup>16</sup> (Appendix 1, online; available at [www.jpeds.com](http://www.jpeds.com))

### Participants and Recruitment

We performed semi-structured interviews with dyads of parents and adolescents who received medical care from St. Louis Children's Hospital or primary pediatricians in the St. Louis area. Parents and adolescents were interviewed separately. We stratified sampling for adolescents with or without chronic illnesses, and we purposively sampled for racial and ethnic minorities and fathers. Purposive sam-

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pling is a nonprobability sampling strategy in which participants are selected based on characteristics that investigators wish to be represented in the study.<sup>17</sup> This strategy helps to ensure that important voices are included. We focused on racial and ethnic minorities because our prior work demonstrated that many communication studies had insufficient recruitment of participants from these communities.<sup>18</sup> We also focused on fathers because many prior studies of communication and psychosocial support have recruited few fathers.<sup>19</sup> We aimed to recruit at least 20 dyads with and 20 dyads without chronic illness, based on prior data showing that 15-20 interviews are likely to reach thematic saturation when participants have relatively homogenous experiences.<sup>20</sup>

Parents were eligible if they<sup>1</sup> had a child who was cared for by physicians at participating clinics,<sup>2</sup> spoke English, and<sup>3</sup> had a child aged between 12 and 17 years. Adolescents were eligible if they<sup>1</sup> were cared for by physicians at participating clinics,<sup>2</sup> spoke English, and<sup>3</sup> were 12-17 years old. For chronic illness, we focused on 3 diseases: diabetes mellitus (DM), sickle cell disease, and inflammatory bowel disease. We chose these diseases because they affect patients of various races and ethnicities, affect adolescents across wide age ranges, and create a need for lifelong management and potential health complications.

We recruited adolescents with these chronic illnesses from specialty clinics that cared for patients with sickle cell disease, inflammatory bowel disease, and diabetes mellitus at St. Louis Children's Hospital. We approached 75 dyads by telephone or in clinic, of which 14 declined, 34 initially demonstrated interest but did not answer subsequent phone calls, and 27 were enrolled. We lost contact with 2 dyads from the sickle cell cohort, leading to 25 total dyads with chronic illness. For adolescents without chronic illness, we recruited from 3 general pediatric clinics and an adolescent clinic that shared an electronic health record (EHR) system with St. Louis Children's Hospital. We identified all adolescent patients seen in these clinics during the prior year and contacted eligible dyads by telephone. We approached 178 dyads by telephone, of which 120 declined, 32 demonstrated initial interest but did not answer subsequent phone calls, and 24 were enrolled. All participating specialty and general clinics used the same EHR instance and followed identical policies for adolescent portal access. Adolescents were permitted access to the portal at 12 years of age, and parental access was subsequently discontinued unless adolescents approved their parent's proxy access. We asked the parent most involved in clinical communication to participate. We obtained verbal informed consent from parents and assent from adolescents. The Washington University Institutional Review Board (IRB) approved this study.

### Data Collection

We developed interview guides exploring parents' and adolescents' experiences, motivations, and disincentives for using the portal ([Appendix 2](#), online; available at [www.jpeds.com](http://www.jpeds.com)). The guides were informed by literature review, our prior work,<sup>15,21-23</sup> and a stakeholder advisory board. This

study was guided by the Technology Acceptance Model, which maintains that acceptance of novel technologies is driven by perceptions of usefulness and ease of use.<sup>24</sup> BAS, CB and ME conducted interviews between May and December 2022 via telephone or video-conferencing software. BAS is a pediatric oncologist and communication researcher with training in qualitative research. CB and ME both had master's degrees and past experience with qualitative research. Interviews were audio-recorded and professionally transcribed.

### Data Analysis

BAS and ME developed themes following validated phases of thematic analysis,<sup>25</sup> which included iterative cycles of initial descriptive coding of transcripts, lumping of descriptive codes into groups, and interpretation of coding groups that led to development of themes with definitions. The study team refined definitions of these themes through 6 cycles of independent coding and consensus meetings. They first developed the codebook with parental transcripts, then adapted the codebook based on adolescent transcripts. After reviewing 30 parental and 25 adolescent transcripts, they reached thematic saturation. CB and ME then applied this codebook to all transcripts using Dedoose qualitative software, identifying excerpts that represented the themes and subthemes identified during codebook development. They then reviewed other's application of codes, and resolved disagreements through discussion. Subsequently, BAS and ME reviewed transcripts for each dyad, noting overlaps and contrasts between parent and adolescent.

## Results

We performed interviews with 51 adolescents and 51 parents, averaging 25 minutes. Adolescents were predominantly White (59%) or Black/African American (41%), non-Hispanic (90%), and female (59%). Parents were similarly predominantly White (55%) or Black/African American (41%), non-Hispanic (92%), and female (98%). Most parents had previously accessed their child's portal ( $n = 33$ , 65%). Fewer adolescents had accessed their portal ( $n = 17$ , 33%) ([Table 1](#)). Every adolescent and nearly all parents ( $n = 49$ , 96%) expressed that adolescents should have access to their portal. The majority of participating parents ( $n = 32$ , 63%) had previously accessed their adolescent's portal. Of the 19 parents who had not access their adolescent's portal, 8 were not aware of the portal, 7 described lack of interest or need for the portal, 3 described losing access when their child became an adolescent, and 1 described limited technology proficiency. Of those who lost access when their child became an adolescent, 2 were not aware that they could request proxy access, and 1 found it too burdensome to activate a proxy account because of logistical challenges. No parents reported that their adolescent had declined to provide them with permission for proxy access.

**Table I. Parent and adolescent dyad demographics**

Characteristics	No chronic illness n = 26	Chronic illness n = 25
	n (%)	n (%)
Parent's mean age in years (SD)	44 (4.8)	46 (6.1)
Parent's gender		
Female	26 (100%)	24 (96%)
Male	–	1 (4%)
Race		
Black or African American	9 (35%)	12 (48%)
Native Hawaiian or Pacific Islander	1 (4%)	–
White	15 (57%)	13 (52%)
Other	1 (4%)	–
Ethnicity		
Hispanic	4 (15%)	–
Non-Hispanic	22 (85%)	25 (100%)
Adolescent's mean age in years (SD)	15 (1.33)	15 (1.26)
Adolescent's gender		
Female	16 (62%)	14 (56%)
Male	8 (31%)	10 (40%)
Non-binary/third gender	2 (7%)	1 (4%)
Race		
Black or African American	9 (35%)	12 (48%)
White	15 (57%)	13 (52%)
Other	2 (7%)	–
Ethnicity		
Hispanic	4 (15%)	1 (4%)
Non-Hispanic	22 (85%)	24 (96%)

## Benefits of Adolescent Portal Access

### Improves Knowledge of Adolescent's Health and Illness.

Parents and adolescents described how the portal could provide adolescents with important health-related knowledge. This knowledge had value in itself, and also provided instrumental value in easing anxiety, informing decisions, and supporting adolescent autonomy. Parents and adolescents also used the portal after visits to clarify when there was confusion, refresh their memory, and access information that was insufficiently explained during the last visit. Adolescents (but not parents) described how the portal can allow adolescents to bypass parental obstruction, such as withholding a difficult diagnosis.

Within some dyads, parents and adolescents disagreed about the value of adolescents seeing results showing worsening health. Several adolescents with diabetes preferred not to see worsening hemoglobin A1c levels, yet their parents thought this could motivate the adolescent to change their behavior. The importance of health-related knowledge seemed more important for adolescents with chronic illness who required frequent clinic visits, medical tests, and treatments (Table II).

**Supports Medical Self-Management and Autonomy.** Parents and adolescents believed the portal could help adolescents to self-advocate and become independent. They described how accessing the portal could encourage or support adolescents in managing logistics (such as finding necessary forms for school) and adhering to treatment plans. These self-management roles differed between adolescents with and

without chronic illness. Adolescents with chronic illness used the portal to schedule appointments around their social activities. Adolescents without chronic illness more often described accessing vaccination records and forms for school.

The portal could also encourage adolescents to make healthier choices. This was especially pertinent for parents of adolescents with chronic illness, who described how reading notes could reinforce the importance of taking medications and following doctors' recommendations. Parents of adolescents without chronic illness described how reviewing clinical notes might encourage teens to exercise or eat healthier if the recommendations came from physicians. However, many participants acknowledged that some adolescents will never use the portal. As such, parents emphasized their important role in the adolescent's healthcare. Although adolescents with chronic illness had more medical needs, they did not seem more likely to desire engagement in their medical care.

### Strengthens Communication and Clinical Relationship.

Parents and adolescents described how the portal could strengthen relationships with clinicians, because reading notes can show that the doctor is listening and cares about them. The additional transparency provided by the portal can support trust by creating open communication with the doctor and encouraging adolescent participation. Adolescents with chronic illness described how the portal helped them to respect their clinicians' efforts in managing their care.

**Supports Parental Influence.** Parents described how using the portal provided them with an opportunity to teach their adolescents about their health or illness. Additionally, parents described how the portal could reinforce their advice or guidance to their children, because adolescents are more likely to follow the doctor's guidance. No adolescents described these benefits.

## Problems with Adolescent Portal Access

**Misunderstanding or Confusion.** Parents and adolescents expressed that portal contents are complicated and confusing, which could lead to misunderstanding or misinterpretation. Laboratory values often have warning flags, and imaging results are full of complex medical terms. This misunderstanding made the portal less useful and disincentivized portal use. Furthermore, misunderstandings could create distress, frustration, or mismanagement of medical care. Misunderstandings were more pronounced for adolescents with chronic illness, who had more complex medical information in their portals (Table III).

**Emotional Distress.** Parents and adolescents described how misunderstandings or misinterpretations could lead to incorrect assumptions and worry. This unnecessary worry could create significant challenges for adolescents who struggle with anxiety or depression. The content of the portal could also create distress and worry, such as learning about a

**Table II. Benefits of adolescent portal access**

Improves knowledge of adolescent's health and illness	<p>"I always tell my kids' information is ours. The more they know about what is going on with them the better. Obviously, again, this is information they hear when they go to the doctor. Who knows if they're really paying attention, so it's nice to have that home for that information where they can read." [Parent 23 – No chronic illness]</p> <p>"I like to have all the information about what's happening with me and my body, and that is an easy way to access it... It made me more aware of the type of things that were happening with myself and how my physicians were thinking about how to help me." [Adolescent 41 – No chronic illness]</p> <p>"Shortly after a visit or something, I forget something, I can just look back and see. There's something maybe more important about our last visit that I can bring up with my doctor before I go in, an important note or important just sentence they said that I didn't really get on." [Adolescent 6 – IBD]</p>
Supports medical self-management and autonomy	<p>"It helps to give a teenager a feeling of control over his or her own life and how to handle different medical conditions, what to do if something happens, or if something's going on, the reason why it's going on and how to handle it." [Parent 10 – DM]</p> <p>"I'm getting older and it's time to start taking responsibility for medications and stuff. I'm going to go to college soon. I need a way to keep track of everything." [Adolescent 7 – DM]</p> <p>"I think that they should be able to access their records, but at the same time, I don't know how many teenagers are gonna be sitting down every day to check, 'Oh, what did I get from my MyChart account?'" [Adolescent 31 – No Chronic Illness]</p>
Strengthens communication and clinical relationship	<p>"Knowing that their doctor is listening to them, knowing that the doctor hears them and is trying to come up with the best things as far as helping them." [Parent 51 – SS]</p> <p>"If anything, it made me look at them like just better doctors that are there to look out for me, and keep me healthy and safe. I mean it's good to see the—sometimes the dedication they have." [Adolescent 6 – IBD]</p>
Supports parental influence	<p>"If she was having trouble with keeping her blood sugars regular and we were having a conversation and I wanted to have that pulled up so we could say, 'Hey, look. Look at these notes again. Remember, he talked about how important this is.' If I wanted to reiterate with the responsibility of that, I can see that might be a good reason for her to read it." [Parent 4 – DM]</p> <p>"If it was something that I'd been saying. You need to exercise more, or you need to eat more vegetables, or something like that, and I kept getting the shrugged shoulders and everything else. Then, if a doctor put the same thing in doctor's notes, I would want them to see it. Then it's like, 'Look. I'm not the only one saying it.'" [Parent 11 – DM]</p>

DM, Diabetes mellitus; IBD, Inflammatory bowel disease; SS, Sickle cell.

difficult diagnosis or poor prognosis. Some adolescents preferred to get this information from their parents. Several adolescents with diabetes also described distress when their

hemoglobin A1c levels were worsening, because they felt guilt or frustration about poorly managing their blood glucose levels. Some parents and adolescents also described how the

**Table III. Problems with adolescent portal access**

Misunderstanding or confusion	<p>"Well, I guess, like anything, it would just be taking something out of context, maybe; them not understanding something." [Parent 52 – No Chronic Illness]</p> <p>"Just like the medical terms. I don't really understand everything, but [laughter] there's just a lot of stuff to read." [Adolescent 4 – DM]</p> <p>"Seeing a chart of facts and other people's perspective can be confusing, and just not super fun to look at." [Adolescent 15 – No Chronic Illness]</p>
Emotional distress	<p>"I think that they could be scared and misunderstand... They may think that something is more dire than it really is." [Parent 12 – IBD]</p> <p>"I know a lot of teenagers recently struggle with anxiety. If they see something that they might not be familiar with, they might panic and think that something is terribly wrong with them." [Adolescent 41 – No Chronic Illness]</p> <p>"I think, if you have somebody who's in a delicate mental stage, I don't think reading some pretty blunt, straight-forward notes would necessarily be wise. But now, I'm older than—in my generation I've seen doctors can be cruel a times in their notes." [Parent 20 – No Chronic Illness]</p> <p>"[Seeing your weight] could be kind of triggering... I definitely think that's the big one just because, especially to girls. Anorexia is really relevant... I know a good amount of girls that have struggled from that mental health disorder, and I definitely think that would be a downside, or I honestly think that would be probably one of the biggest downsides." [Adolescent 29 – No Chronic Illness]</p>
Strain on relationships	<p>"If a doctor was saying something specifically to parent about a future condition that occurring and not giving that information to the child or the doctor telling the parents and then the parents not telling the child. I think that would be a downside if they're keeping something that needs to be kept. I don't know." [Adolescent 29 – No Chronic Illness]</p> <p>"If for some reason there's a discussion that possibly I had to have with the provider about some concerns we had that I did not think that my teenager or adolescent necessarily would understand or it's something that hasn't been fully addressed yet, I wouldn't want them to read it and think the doctor—really just that it's not—create an environment in which the doctor is only listening to mom or dad." [Parent 36 – No Chronic Illness]</p> <p>"The way that some providers speak in their notes, it's a little odd... I felt like they were a little judge'y... It just made me—I was a little taken back by it." [Adolescent 10 – DM]</p>
Use of portal irresponsibly	<p>"Well, they might post it online, share it with their friends at school, and that's the only downsides I see." [Adolescent 16 – SS]</p> <p>"I can't imagine what a teenager could do—maybe put their information on social media and then have regret. Sometimes kids do dumb things, and then they have to live through it." [Parent 1 – DM]</p> <p>"I feel like sometimes teenagers can be immature or joke about things when it's not funny. They can maybe abuse their independence and their power by maybe making prank calls or joking or saying that they have something when they don't." [Adolescent 27 – No Chronic Illness]</p>

DM, Diabetes mellitus; IBD, Inflammatory bowel disease; SS, Sickle cell.



tone of notes could make clinicians seem harsh or judgmental. Several parents and adolescents described specific concerns about adolescents (especially female adolescents) fixating on their weight through the portal. This concern about weight was especially worrisome for girls with eating disorders.

**Strain on Relationships.** Parents and adolescents described how adolescents might lose trust in their doctor if they find information on the portal that was not previously disclosed. Parents also worried about a strain in the parent-child relationships if the adolescent found information that the parents attempted to withhold. Many adolescents described how doctors' notes might seem insensitive or judgmental. These negative comments could relate to adherence to medication, management of one's illness, or other behaviors that might affect health.

**Irresponsible Use of the Portal.** Parents and adolescents worried about adolescents oversharing their medical information from the portal. This oversharing could occur in person, via social media, by printing results, or sharing log-in credentials with friends. Parents and adolescents were concerned especially for less mature adolescents.

### Facilitators of Adolescent Portal Use

**Severity of Illness.** Many adolescents without chronic illness would have been more interested in their portal if they had

health complications. Adolescents with chronic illness described how they would have less interest if they did not have health problems. However, some adolescents described how their interest would again be limited if they were seriously ill, or if their chart contained bad news or worsening laboratory results. Furthermore, many adolescents with chronic illness still demonstrated little interest in using their portals, despite their ongoing health needs ([Table IV](#)).

**Adolescent's Curiosity.** Adolescents described how curiosity motivated them to access the portal. For some, this curiosity related to their health or disease. For others, this curiosity reflected an interest in what results looked like and how doctors wrote notes. Adolescents without chronic illness also shared this interest. This curiosity was often unrelated to practical healthcare needs, but rather an interest in the novelty of seeing results and reading notes.

**Ease of Technology Use.** A small number of parents and adolescents described how accessing the portal after initial enrollment was simple, which encouraged portal use. Parents also described how portal use was easy for adolescents because their generation has been raised with similar technology.

### Barriers to Adolescent Portal Use

**Lack of Awareness or Interest.** Twenty adolescents (39%) were not aware that they could access the portal. Two parents

**Table IV.** Facilitators and barriers to adolescent portal use

Facilitators	
Severity of illness	"I would definitely look at it just to see, especially if I had some sort of medical issue that was reoccurring. I'd wanna see what the doctors were putting in there." [Adolescent 29 – No Chronic Illness] "I think I definitely would not think about it as much. I probably wouldn't even care. I probably wouldn't have my chart." [Adolescent 4 – DM] "I think if I had cancer or some long-term disease, I probably wouldn't wanna see my doctor's notes." [Adolescent 47 – No Chronic Illness]
Curiosity	"Just curiosity. I mean it's something—diabetes is something I have to deal with forever, so it's just kind of cool to read about." [Adolescent 4 – DM] "I wanted to know what she said. I was curious as to what doctors write down. I want to learn how to speak doctor that way I can understand it when they talk to me in the office face-to-face." [Adolescent 7 – DM] "I did the first time just to see what it was about, see what it was." [Adolescent 40 – No Chronic Illness]
Ease of technology use	"It's actually really easy because I even made it so that I can just log in with my touch ID, so it's really easy to get on." [Adolescent 4 – DM] "It's a pretty easy navigable website. It's pretty user-friendly." [Parent 13 – IBD] "Our adolescents are completely digital native. They're more adept, honestly than their parents, especially if their parents are in their late thirties and early forties. I think it's a great tool for our young adults to be using." [Parent 42 – No Chronic Illness]
Barriers	
Lack of awareness or interest	"[Adolescent] don't wanna. That's why he told them I can have access to it... He really didn't want to be bothered right now." [Parent 21 – SS] "My mom just does it. I don't really think about it." [Adolescent 50 – No Chronic Illness] "I just don't think I ever have the time to seriously sit down and read that just with all of the things that I have going on." [Adolescent 29 – No Chronic Illness]
Complexity of information	"Well, I try to encourage him to read 'em every time, but he doesn't always. [Laughs]" [Parent 5 – IBD] "I've looked at it a couple times, but some things I don't really understand completely, so I just stay away." [Adolescent 17 – IBD] "It seems more adults are using it and I'm not using it. There's a, I don't know, it just doesn't seem something that is directed at me." [Adolescent 15 – No Chronic Illness] "Make the wording a little bit easier for kids to understand. Because we don't understand some of the terms in the app. Maybe make a dictionary or just change the words." [Adolescent 40 – No Chronic Illness]
Access difficulties	"We had to basically make a fake email account, use my phone number, it was really a lot of hoops that just didn't apply to her. She was so young, at the time, that she didn't have the things that it assumed that she had." [Parent 15 – No Chronic Illness] "The signing on process was a challenge, and it was aggravating. She was aggravated. I was aggravated. I just wanted to schedule a doctor's appointment with her. I really didn't want to worry about MyChart. I just wanted to call someone and schedule an appointment, and they are very—her endocrinologist is 100 percent MyChart." [Parent 26 – No Chronic Illness] "The mobile version and the desktop version are pretty different. The desktop version—it doesn't feel as organized as the mobile version, so it was kinda hard to navigate." [Adolescent 10 – DM]

DM, Diabetes mellitus; IBD, Inflammatory bowel disease; SS, Sickle cell.

described their adolescent lacking this awareness. Of these adolescents, 8 had chronic disease, and 12 were without chronic illness.

Twenty-three adolescents (45%) and 18 parents (35%) described the adolescents' lack of interest in the portal. Of these adolescents, 7 had chronic disease and 16 were without chronic illness. Some adolescents lacked interest because they could rely on their parents. Others expressed a general disinterest in healthcare participation. Some adolescents described how they might become interested in the future, but they were not interested right now. Other adolescents described competing priorities that occupied their time, such as school activities or sports. Several adolescents recognized the value of the portal and even advised that other adolescents should access the portal, but they did not have a personal interest in using the portal. In some dyads, adolescents stated that every teen should have access, but their parents described the adolescent's lack of interest (Table IV).

**Complexity of Information.** Adolescents found some contents of the portal difficult to understand or intimidating, leading them to avoid portal use. Others expressed that the portal is not intended for them, but for adults and parents. One adolescent suggested that using simpler language or including a glossary in the portal could support better understanding.

**Access Difficulties.** Parents and adolescents described how enrollment in the portal was complicated and onerous for the adolescent. This process was further complicated when adolescents did not have personal email accounts, which was a requirement for portal enrollment. Their parents listed their email account as the adolescents', or they made "fake email accounts." After enrolling, some adolescents experienced challenges with the interface, or with logging in. These barriers were problematic when physicians relied on the portal as the primary means of communication.

### Lack of Parent-Adolescent Collaboration in Portal Use

Parents and adolescents seldom discussed the portal, and many parents were unsure whether their adolescent had accessed the portal. "I didn't talk to her about [using the portal]. I felt like I take care of her, and so it was access for me." [Parent 47—No Chronic Illness] In several dyads, parents recalled in depth conversations with their adolescent about portal use, but the adolescent did not recall having these conversations. One parent described how her adolescent "still wanted me to [use the portal], but she also liked the idea of being able to [access the portal]—she's very computer savvy." [Parent 26—No Chronic Illness] Yet, the adolescent told us she was not aware that she could access the portal. In other dyads, adolescents were very active on the portal, but not in coordination with their parents. Overall, parents and adolescents in this study seldom used the portal as a collaborative tool, and instead were engaging with the portal independently. We did not identify any clear relationship between the adolescent's age and their interest

in discussing portal with their parents, or their interest in the portals in general.

## Discussion

Parents and adolescents believe that adolescents should have access to online portals. The benefits of portal use related predominantly to health-related knowledge that could improve understanding, support adolescent autonomy, and encourage self-management. The problems with portal access also centered on knowledge, including misunderstanding, misinterpretation, and resulting distress. The complex language of clinical notes and test results made some adolescents feel like the portal was not intended for them. Such misunderstandings might further encourage adolescents to rely on their parents to manage their healthcare needs.

Given the centrality of knowledge to the benefits and problems with adolescent portal use, healthcare systems and electronic health record vendors should prioritize making the portal useful and understandable for adolescents. Yet, few studies have aimed to engage adolescents' in using or understanding the portal. One study piloted a portal specific to sickle cell disease, showing that the portal was acceptable to adolescents and improved communication.<sup>26</sup> Another study found that portal message-based advertising for COVID-19 vaccination was unsuccessful.<sup>27</sup> A final study piloted an educational program to teach adolescents about online portals; participants became more confident in their ability to use the portal.<sup>28</sup> Our prior work found that informatics administrators have focused most efforts on ensuring confidentiality and encouraging enrollment, rather than making the portal useful for adolescents.<sup>15</sup>

Future efforts to make the portal understandable might focus on incorporating novel technologies. One adolescent recommended a glossary within the portal to provide definitions to complex terms. Given the rapid advancements of large language models (LLM), future studies might develop LLM-powered chatbots to provide explanations for contents of the portal. Prior studies have suggested that ChatGPT can provide lay summaries of radiology results.<sup>29</sup> By fine-tuning LLMs with curated data, future chatbots might provide high-quality disease-specific output.

Many participants viewed the portal as a tool to support transitions to self-management of healthcare needs. Parents play essential roles in supporting these transitions, including collaborative communication with clinicians, helping adolescents to understand their healthcare needs, and providing oversight to ensure safety.<sup>7,11,12</sup> Portals could facilitate this collaborative management and support transitions, but few families seem to use the portal collaboratively. Few parents and adolescents had discussions about the portal, and parents were seldom aware if adolescents were using the portal. To maximize the utility of portals, clinicians and researchers should develop and evaluate efforts to engage parents and adolescents in shared use of the portal. Given the necessity of maintaining adolescent confidentiality,<sup>30-32</sup> such efforts will require close collaboration with vendors and informatics

teams to balance the tension between supporting portal utility and incorporating restrictions for confidentiality.

Despite these potential benefits, many adolescents were uninterested in using the portal. Surprisingly, age was not clearly related to whether adolescents in this study wanted to engage with the portal, although many acknowledged that young adolescents are not equipped to manage their healthcare needs. This finding could reflect that most adolescents in this study had little interest in using the portal, regardless of their age or maturity level. In part, this lack of interest seemed related to a reliance on their parents for medical management. For adolescents who demonstrated interest, curiosity relating to the novelty of the portal was a motivating factor. Several adolescents were interested to see how doctors wrote notes, or what results looked like. This curiosity was not rooted in a desire for self-management or a need to act upon information. It was an interest in the novelty of the tool and information.

Most efforts by healthcare systems to increase adolescent enrollment in portals have focused on educating adolescents about the portal and their health.<sup>15</sup> Our results suggest that such approaches are not leveraging these adolescents' underlying motivations or interests. Future efforts to engage adolescents in using portals might leverage this interest in novelty to draw more adolescents into using the portal. Messaging and advertising might leverage this role of curiosity. Furthermore, portal design or plug-ins might include tools that adolescents find interesting. For example, adolescents might want to access their portal if a novel chatbot has been integrated into it, or if the portal tied into popular culture, such as providing information about celebrities who have similar medical conditions to the adolescent. Developers and researchers should engage adolescents in generating ideas and co-designing these tools to best leverage the interests of adolescents.

The lack of adolescent interest and engagement with portals could also reflect a general lack of interest and engagement in communicating with clinicians. Clinicians and parents contribute most to verbal communication during clinical encounters,<sup>33-39</sup> and some adolescents prefer their parents to serve as a conduit for their questions and concerns.<sup>38</sup> In addition to improving the user interface and targeting curiosity, portals should be viewed as one component of a concerted effort to engage adolescents in communication and care.

This study has several limitations. There were few Hispanic participants, which reflects the population of St. Louis. Despite efforts to purposively recruit fathers, nearly all participating parents were mothers. This finding is similar to multiple prior studies of communication,<sup>40,41</sup> suggesting that mothers often play a more active role in clinical communication. We observed a higher rate of parents declining participation when their child did not have a chronic illness, which could introduce a selection bias for parents who are more active or engaged in portal use. Participants were recruited from a single Midwest city. Given the variability in adolescent privacy laws and institutional policies and priorities across different health systems in the US, these findings

might not reflect the perspectives of families from other regions of the country. Furthermore, adolescents who were seeking reproductive healthcare or participating in high-risk behaviors might have preferred more privacy, and perhaps were less likely to enroll in this study. Additionally, we are uncertain if any participating parents had been denied access to the proxy portal by their adolescent. No parents reported that their adolescent had declined permission to them. This finding could mean that parents who were denied access were less likely to participate in our study, that parents were not aware that their child had withheld permission, or that adolescents in these patient populations seldom restrict parental access. If all adolescents in our sample were willing to provide parental access, then our findings might not represent the experiences of those adolescents who would decline parental access to preserve privacy.

Parents and adolescents believe that adolescents should be permitted to access their online patient portals, and they identified several benefits and problems with this portal use. However, lack of interest was a major barrier to adolescents engaging with their portal. As such, adolescent online patient portals represent a largely untapped resource to support adolescent education, self-management, and transitions to adulthood. Ensuring adolescents are aware of the portal and targeting adolescents' curiosity about the novelty of the portal could be successful approaches to engaging adolescents in the future. ■

## CRedit authorship contribution statement

**Bryan A. Sisk:** Writing – original draft, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Alison L. Antes:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Christine Bereitschaft:** Writing – review & editing, Formal analysis, Data curation. **Fabienne Bourgeois:** Writing – review & editing, Supervision, Conceptualization. **James M. DuBois:** Writing – review & editing, Supervision, Conceptualization.

## Declaration of Competing Interest

The authors declare no conflicts of interest.

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## References

1. Department of Health and Human Services. 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program. Published May 1, 2020. Accessed July 28, 2023. <https://www.federalregister.gov/documents/2020/05/01/2020-07419/21st-century-cures-act-interoperability-information-blocking-and-the-onc-health-it-certification>
2. Delbanco T, Walker J, Bell SK, Darer JD, Elmore JG, Farag N, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Ann Intern Med* 2012;157:461-70.

3. Weinert C. Giving doctors' daily progress notes to hospitalized patients and families to improve patient experience. *Am J Med Qual* 2017;32:58-65.
4. DesRoches CM, Bell SK, Dong Z, Elmore J, Fernandez L, Fitzgerald P, et al. Patients managing medications and reading their visit notes: a survey of OpenNotes participants. *Ann Intern Med* 2019;171:69-71.
5. Mishra VK, Hoyt RE, Wolver SE, Yoshihashi A, Banas C. Qualitative and quantitative analysis of patients' perceptions of the patient portal experience with OpenNotes. *Appl Clin Inform* 2019;10:10-8.
6. Lam BD, Bourgeois F, DesRoches CM, Dong Z, Bell SK. Attitudes, experiences, and safety behaviours of adolescents and young adults who read visit notes: opportunities to engage patients early in their care. *Future Healthc J* 2021;8:e585-92.
7. Lerch MF, Thrane SE. Adolescents with chronic illness and the transition to self-management: a systematic review. *J Adolesc* 2019;72:152-61.
8. Sisk BA, Keenan M, Schulz GL, Kaye E, Baker JN, Mack JW, et al. Interdependent functions of communication with adolescents and young adults in oncology. *Pediatr Blood Cancer* 2022;69:e29588.
9. Sisk BA, Schulz GL, Blazin LJ, Baker JN, Mack JW, DuBois JM. Parental views on communication between children and clinicians in pediatric oncology: a qualitative study. *Support Care Cancer* 2021;29:4957-68.
10. Stein A, Dalton L, Rapa E, Bluebond-Langner M, Hanington L, Stein KF, et al. Communication with children and adolescents about the diagnosis of their own life-threatening condition. *Lancet* 2019;393:1150-63.
11. Sadak KT, Gameda M, Grafelman MC, Aremu TO, Neglia JP, Freyer DR, et al. Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative interview study of parents. *Cancer Med* 2021;10:6239-48.
12. Sadak KT, Neglia JP, Freyer DR, Harwood E. Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative study of survivorship providers. *Pediatr Blood Cancer* 2017;64. <https://doi.org/10.1002/pbc.26587>
13. Murugan A, Gooding H, Greenbaum J, Boudreaux J, Blanco R, Swerlick A, et al. Lessons learned from OpenNotes learning mode and subsequent implementation across a pediatric health system. *Appl Clin Inform* 2022;13:113-22.
14. Lee J, Yang S, Holland-Hall C, Sezgin E, Gill M, Linwood S, et al. Prevalence of sensitive terms in clinical notes using natural language processing techniques: observational study. *JMIR Med Inform* 2022;10:e38482.
15. Sisk BA, Antes AL, Bereitschaft C, Enloe M, Lin S, Srinivas M, et al. Engaging adolescents in using online patient portals. *JAMA Netw Open* 2023;6:e2330483.
16. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-57.
17. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM. Qualitative methods in public health: A field guide for applied research. 2nd ed. San Francisco, CA: Wiley; 2016. p. 452. xxvi.
18. Sisk BA, Keenan M, Goodman MS, Servin AE, Yaeger LH, Mack JW, et al. Racial and ethnic disparities in communication study enrollment for young people with cancer: a descriptive analysis of the literature. *Patient Educ Couns* 2022;105:2067-73.
19. Robinson J, Huskey D, Schalley S, Wrtchford D, Hammel J, Weaver MS. Discovering dad: paternal roles, responsibilities, and support needs as defined by fathers of children with complex cardiac conditions perioperatively. *Cardiol Young* 2019;29:1143-8.
20. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 2006;18:59-82.
21. Sisk BA, Lin S, Balls-Berry JJE, Servin AE, Mack JW. Identifying contributors to disparities in patient access of online medical records: examining the role of clinician encouragement. *JAMIA Open* 2023;6:ooad049.
22. Sisk BA, Bereitschaft C, Enloe M, Schulz G, Mack J, DuBois J. Oncology clinicians' perspectives on online patient portal use in pediatric and adolescent cancer. *JCO Clin Cancer Inform* 2023e2300124.
23. Sisk BA, Antes AL, Bereitschaft C, Enloe M, Bourgeois F, DuBois J. Challenges to developing and implementing policies for adolescent online portal access. *Pediatrics* 2023;151:e2023061213.
24. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Q* 1989;13:319-40.
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
26. Kidwell KM, Peugh J, Westcott E, Nwankwo C, Britto MT, Quinn CT, et al. Acceptability and feasibility of a disease-specific patient portal in adolescents with sickle cell disease. *J Pediatr Hematol Oncol* 2019;41:561-7.
27. Burkhardt MC, Berset AE, Xu Y, Mescher A, Brinkman WB. Effect of outreach messages on adolescent well child visits and COVID-19 vaccine rates: an RCT. *J Pediatr* 2023;253:158-64.e1.
28. Allende-Richter S, Benitez AD, Ramirez M, Rivera W, Liu S, Gray KP, et al. A patient portal intervention to Promote adolescent and young adult self-management skills. *Acad Pediatr* 2023;23:1252-8.
29. Li H, Moon JT, Iyer D, Balthazar P, Krupinski EA, Bercu ZL, et al. Decoding radiology reports: potential application of OpenAI ChatGPT to enhance patient understanding of diagnostic reports. *Clin Imaging* 2023;101:137-41.
30. Pasternak RH, Alderman EM, English A. 21st century cures act ONC rule: implications for adolescent care and confidentiality protections. *Pediatrics* 2023;151(Suppl 1):e2022057267K.
31. Lee JA, Holland-Hall C. Patient portals for the adolescent and young adult population: benefits, risks and guidance for use. *Curr Probl Pediatr Adolesc Health Care* 2021;51:101101.
32. Carlson J, Goldstein R, Hoover K, Tyson N. The 21st century cures act & adolescent confidentiality. 2020. Accessed April 1, 2024. [https://www.adolescenthealth.org/Advocacy/Advocacy-Activities/2019-\(1\)/NASPAG-SAHM-Statement.aspx](https://www.adolescenthealth.org/Advocacy/Advocacy-Activities/2019-(1)/NASPAG-SAHM-Statement.aspx)
33. van Staa A. Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: the added value of mixed methods research. *Patient Educ Couns* 2011;82:455-64.
34. Savage E, Callery P. Clinic consultations with children and parents on the dietary management of cystic fibrosis. *Soc Sci Med* 2007;64:363-74.
35. Wassmer E, Minnaar G, Abdel Aal N, Atkinson M, Gupta E, Yuen S, et al. How do paediatricians communicate with children and parents? *Acta Paediatr* 2004;93:1501-6.
36. van Dulmen AM. Children's contributions to pediatric outpatient encounters. *Pediatrics* 1998;102:563-8.
37. Sisk BA, Friedrich AB, DuBois J, Mack JW. Emotional communication in advanced pediatric cancer conversations. *J Pain Symptom Manage* 2020;59:808-17.e2.
38. Sisk BA, Keenan M, Kaye EC, Baker JN, Mack JW, DuBois JM. Co-management of communication and care in adolescent and young adult oncology. *Pediatr Blood Cancer* 2022;69:e29813.
39. Sisk BA, Friedrich AB, DuBois J, Mack JW. Characteristics of uncertainty in advanced pediatric cancer conversations. *Patient Educ Couns* 2021;104:1066-74.
40. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in pediatric oncology: a qualitative study. *Pediatrics* 2020;146:e20201193.
41. Sisk BA, Bereitschaft C, Kerr A. Communication with parents and young adult patients affected by complex vascular malformations. *Pediatr Blood Cancer* 2023;70:e30158.