Family Perspectives on Telemedicine for Pediatric Subspecialty Care

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Abstract

Background: *Children often have difficulty accessing subspecialty care, and telemedicine may improve access to subspecialty care, but information is lacking on how best to implement telemedicine programs to maximize acceptance and, ultimately, maximize impact for patients and their families.*

Methods and Materials: *To understand how subspecialty telemedicine is perceived and to identify design elements with the potential to improve telemedicine uptake and impact, we conducted and analyzed semi-structured interviews with 21 informants, including parents and caregivers of children with subspecialty care needs and adolescent and young adult patients with subspecialty care needs.*

Results: *Although informants saw the potential value of using telemedicine to replace in-person subspecialty visits, they were more enthusiastic about using telemedicine to complement rather than replace in-person visits. For example, they described the potential to use telemedicine to facilitate previsit triage encounters to assess whether the patient was being scheduled with the correct subspecialist and with the appropriate level of urgency. They also felt that telemedicine would be useful for communication with subspecialists after scheduled in-person visits for follow-up questions, care coordination, and to discuss changes in health status. Informants felt that it was important for telemedicine programs to have transparent and reliable scheduling, same-day scheduling options, continuity of care with trusted providers, clear guidelines on when to use telemedicine, and preservation of parent choice regarding method of care delivery.*

Conclusions: *Parents and patients articulated preferences regarding pediatric subspecialty telemedicine in this qualitative, hypothesis-generating study. Understanding and responding to patient and caregiver perceptions and preferences will be crucial to ensure that telemedicine drives true innovation in care delivery rather than simply recapitulating prior models of care.*

Keywords: *pediatrics, telemedicine, telehealth, policy, family centered, patient centered*

Introduction

Nearly one quarter of U.S. children in need of subspecialty care report difficulty accessing that care.[1] Numerous barriers contribute to this problem, including inadequate supply and uneven geographic distribution of pediatric subspecialists,[2–5] and inadequate communication between subspecialists and referring providers.[6–9] Telemedicine, the remote provision of medical care using real-time audio-visual consultation, is a potentially valuable strategy to address these barriers. Several studies demonstrate that telemedicine is as safe and efficacious as in-person care and can improve diagnosis and outcomes.[10–15] In turn, there is growing acceptance of telemedicine among healthcare professionals, with the American Academy of Pediatrics recently recognizing telemedicine as an important strategy for increasing access to pediatric subspecialty care.[16]

Despite this enthusiasm, experts raise concern that the expansion of some forms of telemedicine carries risks of unintended consequences, including the potential to disrupt continuity of care, depersonalize the patient-clinician relationship, and create unnecessary over-use of healthcare resources.[17,18] Although many of these unintended consequences might be mitigated by specific implementation strategies, these strategies are not well elucidated by the current literature. More broadly, much of the literature on telemedicine focuses on feasibility and acceptability of individual visits, rather than telemedicine's impact on longitudinal patient-centered measures (including process measures, intended outcomes, and unintended consequences).[18] To move toward assessing the relationship between telemedicine and patient-centered outcomes, it is first necessary to understand how patients view

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telemedicine and what they hope to gain through telemedicine-enabled healthcare. This patient- and family-centered approach[19–21] is necessary to ensure that pediatric subspecialty telemedicine programs maximize potential benefits while minimizing potential harms from the perspective of the end users.

Thus, to better understand patient and family preferences for subspecialty telemedicine and to identify relevant patient-centered outcomes for future work, we performed a stakeholder-informed qualitative analysis of semi-structured interviews. Building off prior conceptual models of subspecialty care,[6,22–24] this qualitative, hypothesis-generating study examined patient and family perspectives on the potential impact of telemedicine on care processes and outcomes, and we identified design elements and contextual factors impacting perceived usefulness.

Materials and Methods

STUDY DESIGN

We performed a qualitative study of patient and family perceptions of telemedicine by using semi-structured interviews.

STAKEHOLDER ADVISORY GROUP

Before initiating our research, we convened a six-member stakeholder advisory group,[25,26] with the goal of increasing relevance and reliability of results by incorporating a range of perspectives into study design and result interpretation. This group had a balanced representation of patient representatives (patients and parents) and system representatives (payers, providers, and administrators), and it included representatives who self-reported high and low access to pediatric subspecialists. Through in-person meetings and interval e-mails, the group revised the interview guide, advised on participant recruitment, refined the preliminary codebook, and reviewed final themes, tables, and manuscript drafts. Overall, two-thirds of more than 90 stakeholder recommendations regarded methods, with the remaining recommendations related to result interpretation and dissemination.

INTERVIEW CONTENT

The interview guide was developed based on prior conceptual models of subspecialty care,[6,23,24] and it was refined through pilot interviews and stakeholder input. Telemedicine was defined as one specific form of remote care: the delivery of care through audio-visual videoconferencing. The final interview guide discussed in-person and telemedicine-enabled subspecialty care, with current analysis focused on telemedicine-related prompts. These prompts included prior telemedicine experience, perceived uses, benefits, costs, concerns, and preferences for incorporation of telemedicine into subspecialty care. The interview guide also addressed current experiences receiving subspecialty care, which were reported separately.[22] The guide was designed for interviews to last ~30 to 60 min and is provided in the *Appendix*.

RECRUITMENT

Telephone interviews were conducted from March to September 2015. We recruited subjects through Pediatric PittNet, a practice-based research network of 23 pediatric and adolescent primary care practices in a six-county region of Western Pennsylvania. Practices participating in Pediatric PittNet are primarily served by one pediatric referral center, which has pediatric subspecialty telemedicine capabilities. Eligible participants were parents/caregivers of children (ages 0–21 years old) ever referred to subspecialty care as well as adolescent patients (14–17 years old) and young adult patients (18–21 years old) ever referred to subspecialty care. To recruit a diverse representation of informants, we solicited participation from a sample of practices both near and far from subspecialty care. Clinical staff at participating sites identified eligible participants during primary care office visits and provided these potential participants with study contact information. To recruit additional caregivers, we asked participating caregivers to identify any additional potential interviewees, a strategy known as "snowball sampling." To recruit additional patients, we sought caregiver permission to contact eligible children of caregiver participants. Participants received a $25 gift card via mail. All interviews were conducted by a trained investigator with experience in qualitative data collection (L.E.A.). All subjects provided verbal informed consent or assent. The University of Pittsburgh Human Resource Protection Office provided ethical review and approval.

QUALITATIVE ANALYSIS

Interviews were digitally recorded, transcribed, and stripped of personal identifiers. Interview transcripts were analyzed by two investigators (K.N.R. and L.E.A.) using thematic content analysis.[27] A preliminary codebook was developed after reviewing the first five interviews, including *a priori* codes from prior literature and newly emerging codes. To enhance reliability, the codebook was then reviewed by the stakeholder advisory group, with revisions made based on their feedback. Subsequently, all interviews were coded by using qualitative data software (NVivo 10; QSR International, Melbourne, Australia). Interviews continued until we reached thematic saturation.[28] To increase result trustworthiness, we again reviewed key themes with our stakeholder advisory group at the conclusion of coding.

The results are organized into four domains: (1) potential impact of telemedicine on care processes (i.e., actions that comprise healthcare), (2) potential impact of telemedicine on outcomes (i.e., effects of healthcare), (3) design elements potentially impacting telemedicine acceptability and effectiveness, and (4) contextual factors potentially influencing telemedicine impact.

Results

We interviewed 21 informants (18 parents, 1 grandparent guardian, 1 adolescent patient, and 1 young adult patient; *Table 1*), with thematic saturation achieved with the 11th interview. The diagnoses that prompted subspecialty consultation included acute conditions (e.g., bone fracture), common chronic conditions (e.g., asthma and autism), and complex and/or rare chronic conditions (e.g., cystic fibrosis, genetic syndrome, spina bifida, and tumor). Self-estimated travel time to usual subspecialists ranged from 5 to 120 min. Respondents reported receiving subspecialty care through in-person visits, telephone, patient portals, and electronic messaging systems; none reported use of telemedicine. All respondents reported being either "comfortable" or "very comfortable" with technology.

Table 1. Informant Demographics

INFORMANTS ($n=21$)	n (%)
Child's age	
0–4	6 (29)
5–12	3 (14)
13–17	8 (38)
18–21	4 (19)
Informant's age[a]	
14–21	2 (10)
22–34	7 (35)
35–50	8 (40)
51–70	3 (15)
Informant's self-identified race[a]	
White	15 (75)
Black	5 (25)
Insurance[a]	
Commercial	5 (25)
Medicaid	9 (45)
Both	6 (30)
Travel time to pediatric subspecialists	
0–20 min	7 (33)
21–40 min	5 (24)
41–59 min	5 (24)
≥60 min	4 (19)
Number of subspecialists seen, median (range)	4 (1–21)
Number of subspecialist visits, median (range)[a]	8 (2–130)
Comfort with technology[a]	
Uncomfortable	0 (0)
Comfortable	6 (30)
Very comfortable	14 (70)

[a]One informant declined to answer the indicated questions.

POTENTIAL IMPACT OF TELEMEDICINE ON SUBSPECIALTY CARE PROCESSES

Informants discussed the potential impact of telemedicine on processes of subspecialty care (*Table 2*). Informants believed that telemedicine could increase access to care, but they described different potential implications of this greater ease of access. Some informants envisioned using telemedicine visits to replace current in-person subspecialty visits:

> *"But I think where we're at now, we're in a maintenance every three months visit to the doctor. I think it could be done on a computer versus having to drive all the way to her office for every visit."*

In contrast, others described using telemedicine to augment current in-person subspecialty visits by providing opportunities to receive care that would have otherwise been missed or delayed:

> *"There are times when she's too weak to get up, and I've had to cancel appointments. Instead of cancelling, I would have loved to have had the ability to say, 'Hey, she can't get up today. I don't want to cancel. Here…you know, let's video-conference and discuss what's going on.' And I can pull her in for the conference."*

Informants felt that telemedicine could also improve scheduling and triage processes, thereby increasing the value of in-person visits. Specifically, they envisioned telemedicine encounters before in-person visits to allow assessment of whether an in-person visit is needed, who is the most appropriate subspecialist to see, and how urgently further care is needed:

> *"A screening process method seems like a great use of [telemedicine]. Maybe she's having an issue but I'm not sure. Maybe you're the right specialist but maybe you're not. If you could do*

Table 2. Potential Impact of Telemedicine on Pediatric Subspecialty Processes and Patient-Centered Outcomes

DOMAIN	DEFINITION	QUOTES
Processes		
Accessing subspecialty care	Use of telemedicine to replace or augment in-person visits	*But I think [telemedicine] would be much more convenient, especially for people who are traveling really far to get to the hospital or people who just can't make it or, you know, if your kids are deathly ill and you don't want to take them out of the house and don't have to, so I think that would make a huge difference.*
Scheduling/triaging visits needs	Use of telemedicine for a triage encounter to determine need for subspecialty care, urgency, appropriate subspecialist, and optimal modality (i.e., in-person visit versus telemedicine)	*It's very difficult, it's a long wait for [specific subspecialty]. And I think, you know, an evaluation during that long wait period via the Internet would be a fantastic tool for that department, because if they do feel it's serious enough they could bump 'em up. You know, it's like kind of weeding it out. Triaging in a different way.*
Care coordination at the time of subspecialty visit	Use of telemedicine to incorporate additional family members or physicians into a subspecialist visit	*It would be fabulous if they could exchange information easily [through telemedicine] … Because at this point it just doesn't seem like that's how it is. You know, it just seems like that's just not the way it is…. I'm like, "Hey, can you connect with his surgeon and figure out the best way to get him to physical therapy," or whatever. But like, they just look at you like, "Well, we don't contact them. You contact them." And that's just the way it is. So it would be great if there was a way that they could more easily interact so that they would be more likely to.*
Communication with subspecialist between visits	Use of telemedicine to facilitate communication with subspecialists for questions or changes in status between visits	*Let's say … you needed an extra appointment and your therapist only had twenty minutes, but you could actually look at them in the face and talk to them via video, like that might just help you get over that whatever little issue you're having instead of having to book a whole new appointment. You know what mean? I do feel like it could help you in the gaps between when you see them face to face.*
Relationship with subspecialist	Impact on relationship between subspecialist and patient/family, potentially improved due to increased communication or potentially worsened due to reduced continuity	*Definitely not for their regular check-ups; their regular meeting of the specialists—a lot of specialists will see you back in three months, on a regular basis—I don't think that's a good time [for telemedicine].*
Outcomes		
Opportunity costs	Potential reduction in opportunity costs by reducing travel time and allowing waiting time to be spent doing other tasks	*I can't think of many parents who wouldn't be anxious to do [telemedicine] because of … people worrying about travel time and missing school and missing work, and all those complications that parents have.*
Family burden	Potential reduction in stress associated with travel and with waiting with children in a stressful environment	*I think that, especially when it's these kind of follow-up appointments where I basically go to an appointment and they say, "How's she been doing? She looks great. Okay, keep doing what you're doing; we'll see you in six months," and I had to sit in a waiting room for an hour with a child who's screaming and hitting themselves, and having an anxiety attack—yeah. If I could not do that, that would be so great. It would really—it would actually change our lives.*
Health outcomes	Potential improvement in health outcomes through increased access to care and coordination; potential worsening health outcomes due to lack of exam	*[Telemedicine] might not be as accurate only because they're not—he's not there for the doctor to physically see him. If there's new symptoms or change in care then, maybe, that wouldn't be the best.*
Parental anxiety	Potential impact on parental anxiety, including reduced anxiety due to increased communication/access as well as increased anxiety due to increased reliance on parental report	*I think in that case, a video chat would be wonderful, because it's not a—you know, it reassures the patient. It would reassure the parents. "Yes. This is absolutely common for [child condition]" … or "That also really needs to be looked at."*

[telemedicine] appointments where you could just ask some questions and it could be determined if she does need to go come in or not, or if she needs to contact another specialty, that would be helpful."

Informants also suggested that telemedicine could improve communication and care coordination during the encounter by allowing additional family members or physicians to participate.

"You could have different providers possibly all in that conference, and depending on what it was maybe you would want kind of like a whole team approach to sit down and talk about this. So that kind of gives people flexibility with scheduling and even the logistics of meeting."

Finally, informants discussed using telemedicine to communicate with subspecialists between scheduled encounters if additional questions arose or their child's status changed.

"If she's going through something, they would be able to see exactly right then and there what's going on, instead of me having to fly down there to see them, and for them to just send me home."

However, informants expressed concern about the impact of telemedicine on their relationship with subspecialists:

"But I think the biggest thing is still feeling you have that relationship with your doctor… making sure like you still within a year's time take that time and actually make an appointment to see that individual face-to-face, and kind of have that relationship then that way… like you're not losing some of the benefits that you get from going to an appointment."

POTENTIAL IMPACT OF TELEMEDICINE ON SUBSPECIALTY CARE OUTCOMES

In addition to discussing processes of care, informants discussed the potential impact of telemedicine on multiple patient-centered outcomes (*Table 2*), including family costs/burden (e.g., travel burden and foregone work), health outcomes (e.g., functional status and symptom management), and parental knowledge/anxiety.

Informants discussed the potential for telemedicine to reduce the costs of subspecialty care, particularly the "opportunity costs" from missed work and school, as well as the family burden from additional stresses such as traveling to appointments and occupying children in waiting rooms:

"It would kind of be nice to just do it by video, because I wouldn't have to take off of work or whatever—or go there. Like that would be more convenient."

"For me, with doctors' appointments, it's the waiting room that's brutal… So any situation in which I can minimize or avoid a waiting room and still get to communicate with the doctor is a win."

Among health outcomes, informants envisioned both potential benefits and harms, including not only the possibility of more timely diagnoses and more comprehensive care but also the possibility of missed diagnoses:

But there's such a fine line with that, because what I might feel is ok… just like when we took him… for his regular visit… we knew he was breathing kind of heavy, but we had no idea that it was to the extent that it was that they ended up admitting him. So, I kind of think that you still run a slight risk when you just, when you don't take your child to the doctor [in-person].

Informants also discussed a potential reduction in parental anxiety due to increased access to subspecialty care:

"[Telemedicine] would definitely make our lives easier, it would reduce the anxiety."

However, some envisioned new sources of anxiety due to increased reliance on family reporting rather than direct examination:

"I suppose the fact that they can't really see him, I guess, and if I can't really say for sure what's wrong with him… if I couldn't explain what's going on with him, I might make it sound not as bad as it actually is or I might make it sound worse…"

DESIGN ELEMENTS POTENTIALLY IMPACTING TELEMEDICINE IMPLEMENTATION

Informants discussed policies and protocols surrounding telemedicine use that could influence telemedicine adoption and impact (*Table 3*). Some of these issues related to features of the technology itself (i.e., reliability, quality, and privacy):

"I would just hope that they had all of their privacy things in order, no breaches in confidentiality."

Beyond these technologic concerns, informants discussed policies and protocols surrounding how families access care via telemedicine. Several of these features related to scheduling and appointment logistics. For example, informants desired transparent scheduling processes to reduce uncertainty and time spent waiting:

"*Knowing the timeframe of those things… am I going to know when you're going to call back or is it kind of like, you know, when the refrigerator guy comes? It's going to be between 1:00 and between 8:00, good luck."*

Informants also expressed concern about the reliability of work processes associated with telemedicine visits (e.g., would

Table 3. Design Elements of Telemedicine Potentially Enhancing Impact on Patients and Families

DOMAIN	DEFINITION	QUOTES
Technology		
Quality of technology	Ability of the technology to transmit high-quality images and sound	*I'd want to know that their video technology is … advanced enough … the images they're seeing aren't those crackled, grainy pictures; that they're getting a very clear picture.*
Reliability of technology	Consistency with which the technology is available and functioning	*Something not going through, or, you know, just having difficulty with technology maybe not cooperating in your favor on a given day, like the Wi-Fi is down, or something like that.*
Privacy of technology	Security and confidentiality of transmissions	*I think probably the same thing most parents would want to know: how secure is the line?*
Policies/protocols		
Timeliness	Timeliness of telemedicine visit; timeliness of communication about scheduling telemedicine visit	*And I'll schedule an appointment, and it will be for a week or so down the line, you know, if they can—"The soonest we can get you in is in a week." I would have loved to have been able to connect—like, even if it's like a FaceTime, or something like that—through videoconferencing.*
		That you get a response quickly.
Transparency of processes	Availability of information about scheduling processes, workflow processes, continuity	*What their response time is going to be, how fast are they going to get back to me? Like I could even see avoiding an emergency room visit.*
Access without travel	Ability to connect at home or work	*To just be able to say, "Hey, here's very quick. [name]'s in bed. You know, I can take you up to see her, and this is what's going on. What do you think we should do?" I would have loved to have been able to do that.*
Reliability of processes	Confidence that care (including prescriptions, follow-up tasks) will be completed during visit	*I mean what all you have to go through to be able to do it. … It's like the Internet stuff just isn't well for me … because me doing all the online or the over the phone, stuff sometimes don't get done.*
Guidelines for when to use	Clarity of indications for using telemedicine	*I think outlining the parameters and letting people know … what that type of technology would be used for is huge. So if I could go on [hospital web]site and think, say, ok, my child needs to see, I want to switch over to their endocrinology department, let's say. What is acceptable to be using the videoconferencing versus what is expected as an office visit?*
Continuity with provider	Ability to connect with usual subspecialist or usual team	*Is it going to be our doctor who knows our son's game plan or is it going to be a resident who's like having a fun day figuring things out?*
Cost	Costs to the patient/family	*I would be worried about if it would be … like the cost of it and if it was covered by insurance.*
Culture		
Subspecialist buy-in	Subspecialist commitment to making telemedicine available	*I would want to know that that particular specialist or doctor or whoever was 100 percent on board with that because I wouldn't want to say, "Oh, yeah, this is great," and we'll go all into it and be all for it and sign up for it, and then have a particular doctor that's just not really into it, not really keeping with it, and not, you know…kind of like false hope. So if it's something that will be put in place, then it should be something that all the doctors are very hands on with and actually use and implement in their care with the parents and everything.*
Patient/parent choice	Ability of parent/patient to continue in-person care when preferred	*I would like to think that this is something that is going to be a part of the care, not is going to become the norm. So that would bother me, because I think it's still important to be able to have that option to come in and have your child seen, versus, "Oh, I think if we just do a conference call we're fine." I don't, I'd like to see, you know—I don't know. That would just be a concern of mine.*

prescriptions really be sent to the pharmacy?). Informants desired telemedicine visit options that were potentially timelier than their experience with in-person care (i.e., same day), and the ability to engage in visits with little or no travel (i.e., from work or home). Some informants also requested guidelines for telemedicine use to reduce uncertainty about when to use it:

> "*I think a clear-cut outline of the tool that it's going to be would be very useful on [hospital web]site, and even having a toll-free number where you could discuss it with somebody to see if it is something that qualifies for that type of environment.*"

In addition, informants desired access to telemedicine that enhanced, rather than undermined, continuity with specific providers:

> *"I would want to know that it's someone in that practice, someone who's familiar with them, and not just like an answering service type thing … I would want to know that it's not generic people, but people who were apprised of his individual case."*

Additional design elements discussed included family cost, subspecialist buy-in, and family ability to exercise choice regarding telemedicine use.

CONTEXTS POTENTIALLY IMPACTING TELEMEDICINE ADOPTION BY PATIENTS AND FAMILIES

Informants discussed the potential for chronic diagnosis and acute medical needs to impact the appropriateness of telemedicine for a given child, a given diagnosis, or a given visit (*Table 4*). For example, informants suggested that

Table 4. Contextual Factors Impacting Telemedicine Perceived Usefulness by Patients and Families

DOMAIN	QUOTES
Patient contexts	
Medical complexity/technology dependence	*Especially when you have a little guy like mine where a ton of equipment comes with them everywhere they go so it's not easy to just pack them up and take them somewhere, so like I said, just having that option would be really, really great.*
Developmental needs	*Especially when it's these kind of follow-up appointments where I basically go to an appointment and they say, "How's she been doing? She looks great. Okay, keep doing what you're doing; we'll see you in six months," and I had to sit in a waiting room for an hour with a child who's screaming and hitting themselves, and having an anxiety attack—yeah. If I could not do that, that would be so great. It would really—it would actually change our lives.*
Communication needs	*It's important not to go like behind her back. So that's why face-to-face are good for her because of her being deaf.*
Immune status	*I would absolutely be open to it as an option because I do know that especially when your child is immunosuppressed from chemotherapy, you're exposing them to potential germs and viruses by going to an emergency room or a doctor's office, and if that could be avoided, that would be great.*
Acute illness	*But I think that would be much more convenient, especially … if your kids are deathly ill and you don't want to take them out of the house and don't have to, so I think that would make a huge difference.*
	Obviously if it's something really, really serious, you have to take them in in person, but there are a lot of times with especially preemies, they—I mean, every day it's something, so it's not always something that you have to hop in the car and run to ER for. And to have that option to be able to [teleconference] with a doctor that day rather than freaking out and trying to decide how to get your kid to the ER … that would make a big difference.
Goals of encounter	*Let's say, you want to have a more of like a discussion of kind of maybe where you are in the process, you know, are we kind of making those, making the strides in areas we want to, you know, that could be something that's done over a video chat. I think it all really kind of centers still around what do you hope to get out of that appointment.*
	Usually there's a necessity to see him physically because of needing x-rays and things like that.
Family contexts	
Travel time	*I don't see the need really for teleconferencing for myself. I mean, I am within easy, have very easy access, it's pretty much a direct route, maybe 20 minute's traffic.*
Comfort with technology	*I like to really like see my doctors. Me, email, and via text, and all that stuff, like, I'd rather do a face-to-face than any of that.*
Internet access	*A lot of households might not have Internet connection. Like we don't have the Internet. And it's just not something we can financially do right now.*
Insurance coverage	*I would be worried about if it would be … like the cost of it and if it was covered by insurance.*

telemedicine might be particularly advantageous for children dependent on technology (i.e., chronically ventilated), immunocompromised, or with developmental/behavioral concerns. Parent/family factors impacting appropriateness or interest in telemedicine included travel time, comfort with technology, Internet access, and insurance coverage.

Discussion

Through stakeholder-guided qualitative analysis, we identified patient and family perspectives on telemedicine for subspecialty care, including potential impact on processes and outcomes, design elements modifying potential impact, and child and family factors influencing perceived value. These perspectives may be valuable for developing and implementing telemedicine-based subspecialty services and in guiding assessment of such services.

In terms of implementation, our results suggest that the use of telemedicine should be considered more broadly—not only as a replacement for in-person visits but also for other uses. At present, outpatient telemedicine often follows similar scheduling processes and visit expectations as in-person visits,[18] and informants identified potential advantages of using telemedicine in place of some in-person visits. However, they also discussed more innovative uses of telemedicine. Specifically, they spoke of using telemedicine not to replace an in-person visit but to optimize the value of an in-person visit through previsit telemedicine communication and postvisit telemedicine follow-up. These findings suggest that telemedicine programs may be missing opportunities to improve care if they are neglecting these potential uses. Notably, regulatory issues such as whether telemedicine can be used in the absence of a preceding in-person visit to establish a doctor-patient relationship[16,29–31] may create barriers to some more innovative uses of telemedicine.

It is worth noting that other communication strategies such as telephone consults and store-and-forward telemedicine might achieve these same goals of enhancing previsit and postvisit care coordination. Our results emphasize that families desire greater accessibility of subspecialists outside of in-person care and that they view telemedicine as one potential means of achieving this. Our results cannot determine which strategy is optimal for enhancing family-subspecialist communication, but differences in reimbursement across these strategies may influence which strategy is sustainable.

Informants also discussed other key aspects of implementation. Optimizing the technology itself was of interest to patients and their families, and it is a shared concern of pediatric providers.[17,32–34] However, informants were also interested in nontechnological aspects of implementation, including timely and transparent scheduling, reliable workflow, continuity with trusted providers, clear indications for use, and preservation of family choice. Although some of these concerns have been raised by providers,[33] others have not been described, such as preserving family choice and providing families with guidance on appropriate indications. Attention to these concerns has the potential to influence not only the effectiveness of telemedicine but also whether it is used in the first place.

Our results also provide guidance for evaluation efforts. Past evaluation of outpatient subspecialty telemedicine often compared telemedicine visits with in-person visits,[10,11] and such head-to-head comparisons have been important for establishing safety and efficacy. To understand the overall impact on patients, however, a more salient comparison may be longitudinal comparisons of care where telemedicine is an option (i.e., both telemedicine and in-person encounters available) versus care where telemedicine is not an option. This evaluation paradigm acknowledges that, at least from the perspective of parents and patients, telemedicine's greatest value may not be in directly replacing in-person subspecialist visits but instead in providing more comprehensive, continuous communication and care before, during, and after in-person visits.

Also related to evaluation efforts, our study expands the domains by which telemedicine should be evaluated beyond those often examined in prior outpatient subspecialty telemedicine studies. For example, informants emphasized the potential reduction in opportunity costs, family burden, and family anxiety. Patient and family opportunity costs have traditionally been unvalued or undervalued,[35] although they are clearly substantial.[36] Incorporating a fuller range of outcome measures in evaluation will provide a greater understanding of the benefits and harms of telemedicine for those seeking pediatric subspecialty care.

Our study has several limitations. First, as a qualitative study, our results should be viewed as hypothesis generating, with further work needed to test and prioritize the preferences identified. Second, we recruited more caregivers than patients, but our analysis was not intended to compare these groups, and it instead focused on summarizing the range of perspectives among patients and caregivers, which our sample allowed us to do. Third, although we did not exclude participants with telemedicine experience, our sample consisted entirely of individuals experienced in the receipt of subspecialty care but without telemedicine experience. As such, informants may overestimate or underestimate the strengths and weaknesses of telemedicine. However, because potential users of pediatric subspecialty telemedicine far exceed actual

users currently, we believe that the perspectives of these potential users are particularly valuable. Fourth, we recognize that our analysis is limited to telemedicine as defined for our informants ("audio-visual videoconferencing") as opposed to other forms of telemedicine. Finally, our analysis cannot comment on the feasibility of informant recommendations from the viewpoint of subspecialists and healthcare systems.

Conclusions

Overall, families and patients identified uses for telemedicine that went beyond replacement of traditional in-person visits, resulting in a vision of telemedicine-enhanced pediatric subspecialty care that is vastly more responsive to patient and family needs than current systems. Much of this vision hinges on implementation details: how families access telemedicine and for what purpose. Informants identified design elements with the potential to impact the effectiveness of telemedicine programs, including timeliness, location, transparency, reliability, continuity, cost, family choice, and guidelines for use. Integration of telemedicine offers an opportunity to transform pediatric subspecialty care, but understanding and responding to patient and caregiver perceptions and preferences will be crucial to ensure that telemedicine is used in ways that take advantage of its strengths instead of simply repeating prior models of care delivery.

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Appendix: Parent Interview Script

Introduction

We're interested in understanding how the healthcare system is working for children and their families. We want to hear about your experiences—and especially when things have worked well for you and when they have not worked well for you.

I'll be asking about your experiences with different providers in the healthcare system, and I will be asking about your experiences with specialty doctors and primary care providers.

Specialty doctors are doctors who take care of one part of your child's care, such as cardiologists, dermatologists, eye doctors, ear nose throat surgeons, and allergists.

A **primary care provider** is the doctor, nurse practitioner, physician assistant, or practitioner who your child sees for his or her check-ups.

We're also interested in your thoughts on what needs to be made better—please feel free to think big and tell us how the system can work better for patients and their families.

I will begin recording now.

To start, I am interested in learning about your experience using specialty care.

Please tell me about the specialty doctors who have been important to your child's care over the past 2 to 3 years.

Tell me what has worked well in your experiences with (this/these specialty doctor(s)).

What has been frustrating, disappointing, or inconvenient about your experience with (this/these specialty doctor(s))?

The next few questions will ask you to think about specific parts of the process of seeing a specialist.

How did you decide to first involve this specialist in your child's care?

What were your expectations or hopes in involving this specialist in your child's care?

How has your experience with this specialist compared with your hopes and expectations?

Tell me about your actual visits with this specialist—what has been good or bad?

What is it like when you need to communicate with this specialist before or after your visits?

What do you think about how your primary care provider and this specialist communicate with each other?

What would exceptional specialty care look like?

To learn more about how to help patients receive the care they need, we want to hear more about times where you had difficulty obtaining the care that your child needed.

Tell me about a frustrating, disappointing, or confusing experience with specialty care.

Have there been times when you were told to see a specialist for your child but ended up not seeing that specialist? Tell me about that.

Have you and your primary care provider ever had different opinions on whether your child should see a specialty doctor? Tell me about that.

What factors are important to you when you are deciding whether your child should go to another appointment?

We're interested in understanding what patients and parents think about new ways of delivering subspecialty care. Many patients receive care through face-to-face visits with their specialty doctors. Sometimes, patients connect with their specialty doctors through other options, such as telephone conversations, emails, Web sites (sometimes called Web portals), or videoconferencing (sometimes called telemedicine or e-visits).

Other than face-to-face visits, how else have you connected with your child's specialty doctor?

What would you think about being able to connect with your child's specialty doctor more readily through email, Web sites, phone, or videoconferencing?

Additional prompts if needed:

Can you **describe a time** where you would have liked to use email, Web sites, phone, or videoconferencing?

What **benefits** do you think email, Web sites, phone, or videoconference visits could provide compared with face-to-face visits?

What **concerns** might you have about using email, Web sites, phone, or videoconference visits with specialists?

Imagine a specialist's office is set up to provide care to your child through telephone, email, Web sites, and videoconferencing. How would you like to see these options being used?

What would you want to know more about before deciding whether to connect (more) with your child's specialist through email, Web sites, phone, or videoconferencing?

What would you think about your child's primary care provider and specialists using email, Web sites, phone, or videoconferencing to discuss your care with each other?

Do you have any additional comments on any of the topics we have discussed?

Thank you so much for your time and sharing your experiences.