What makes health services usable?: Insights from a qualitative study of caregivers of children with disabilities

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Background: The concept of usability from the field of user-centered design addresses the extent to which a system is easy to use, including under extreme conditions. Apart from applications to technologies, however, little attention has been given to understanding what shapes usability of health services more generally. Health service usability may impact the extent to which patients avail themselves of and benefit from those services.
Purpose: The aim of the study was to develop the concept of usability as it applies to health services, particularly for a high-need, complex patient population.
Approach: We conducted interviews and focus groups with 66 caregivers of children with disabilities and analyzed data through inductive coding and constant comparison.
Results: We find that before health services can be rendered usable for patients with complex health conditions, work is often required to develop trusting relationships with individual providers and to manage time demands and attendant challenges of physical access. In addition, our findings show that actions crucial to receiving benefits from one service often entail difficult tradeoffs either with other services or with other important features in the patient's life-world. Finally, we propose the concept of configuration to capture the complex interdependent arrangement of connections to multiple health services, often for multiple household members, and other life-world factors (e.g., employment, transportation, living conditions). These configurations are dynamic, fragile, and vulnerable

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to shocks—events that destabilize them, often negatively impacting the relative usability of services and of the entire configuration. Collectively, these findings illustrate health service usability as a relational, situated, emergent property rather than an inherent feature of the service itself.

Practice Implications: System-centered design perspectives produce services that are usable for the mythical "ideal" user. To be truly "patient centered," designs must "decenter" the health service and recognize it as one component of the patient's life-world configuration.

What makes a health service more or less usable for patients? Concerns about usability—the degree to which a product is easy to use—have long occupied designers of information systems in the field of user-centered design (Endsley, 2016; Giacomin, 2014; Krippendorff, 2004; Nielsen, 1993). The usability of systems is crucial to their adoption and use (Brown, 2009; Nielsen, 1993) and may contribute significantly to the success or failure of innovations (Watts et al., 2007). In health care, researchers have studied the usability of clinical and information technologies (IT; e.g., Nambisan, 2011; Ratwani, Zachary Hettinger, Kosydar, Fairbanks, & Hodgkins, 2016; Watterson, Rodriguez, Aguilera, & Shortell, 2018), and some have begun to explore user-centered design approaches to the patient experience (Brown, 2009; Chambers, Benz, & Boat, 2016; Duncan & Breslin, 2009; Patel, Moore, Blayney, & Milstein, 2014). Beyond these initial explorations, the concept of usability has not been regularly or widely applied to health services. Consequently, we know little about what it means for a health service to be usable.

The usability of a health service matters because it may help explain the extent to which patients avail themselves of services and reap potential benefits. Extending the logic of user-centered design (Krippendorff, 2004; Nielsen, 1993; Spolsky, 2001), we might expect that if a health service has low usability, patients may not use it and thus not benefit from it. Consequently, usability may play an important role in shaping outcomes. As value-based payment mechanisms proliferate and providers increasingly take on accountability for health outcomes, deepening our understanding of what shapes the usability of a health service may become more crucial, particularly where the care of complex patients or particularly needy populations are concerned. Addressing the needs of such populations is central to reducing rising costs of care and enhancing health outcomes as required under value-based payment (Institute of Medicine, 2013). Lacking a better understanding of the usability of health services, however, efforts to redesign care delivery to improve value may be ineffective.

In this article, we report an inductive qualitative study of health service usability based on the experiences of caregivers of children with disabilities covered under a Medicaid-serving pediatric accountable care organization (ACO). Children with disabilities, covered under Medicaid, have health, social, and economic needs that are more extreme than children without disabilities (Council on Children With Disabilities, 2005; Simon et al., 2010). Given that user-centered design philosophies stress that in order for a system to be truly usable it must work well under extreme, nonideal conditions (Shneiderman & Hochheiser, 2001; Spolsky, 2001), children with disabilities who rely on Medicaid provide excellent context for studying the usability of health services.

Theoretical Perspective

The field of user-centered design approaches the design of products with a primary focus on the users of those products and the goal of ensuring that products are responsive to user needs and environments and conform to user preferences (Endsley, 2016; Giacomin, 2014; Krippendorff, 2004; Nielsen, 1993). User-centered design is contrasted with system-centered (or technology-centered) design, which is driven by considerations of system (or technological) characteristics and the goal of optimizing system efficiencies (Endsley, 2016; Giacomin, 2014). The proliferation of IT into everyday life during the late 20th century played a significant role in the rise of user-centered design, and thus, the field is heavily shaped by IT terminologies and metaphors (e.g., "users" and "systems"). Nevertheless, the relevance of user-centered design beyond IT is evidenced by the growing enthusiasm for applications of "design thinking" (a particular instantiation of user-centered design) in organizations more broadly (Brown, 2009). Although most applications of user-centered design concepts in health care are primarily concerned with technological usability (e.g., Nambisan, 2011; Ratwani et al., 2016; Watterson et al., 2018), some argue user-centered design approaches hold promise for improving patient experiences and the value of care (Chambers et al., 2016; Duncan & Breslin, 2009; Patel et al., 2014).

Usability

Usability, a key concept in user-centered design, is the degree to which a system (e.g., technology, product) is easy to use (Nielsen, 1993). Conceptions of usability include considerations such as how easy it is for users to learn and remember how to use the system, how well the system

helps users avoid errors or prevents inappropriate actions, how efficiently users can interact with the system, and how satisfying users find the system (Grudin, 1992; Nielsen, 1993). Most examinations of usability are concerned with the interface, the space where the user and the technology interact.

Usability is typically not conceived as a static property of the system, but rather relative to particular users (Gaver, 1991). The notion of affordance, drawn from the field of ecology (Gibson, 1979), suggests that action possibilities offered by an environment are determined by the features of the environment in conjunction with the properties of the actor. A door handle affords pulling (i.e., is "pullable") by an actor with certain bodily features. To a fish, a door handle is not pullable. The concept of affordance, widely used in user-centered design, is powerful because it shifts attention away from features of the technology or system itself toward the interaction of user with system (Gaver, 1991). It suggests that usability requires attention to the context of use.

Guidelines for improving the usability of systems and tools often stress the importance of designing for extremes rather than optimal conditions and for diverse populations of users (Shneiderman & Hochheiser, 2001; Spolsky, 2001). For example:

> *Good usability doesn't just mean "usability under the best of circumstances." It means usability under as many adverse circumstances as possible. This is a principle called design for extremes. Don't design something that can only be read in daylight: design it to be read in dim light, too. Don't design something that can only be handled by a strong, seventeen-year-old athlete; design something that an arthritic person can use as well. Design things that work outdoors, in the rain, when you're not looking, when you didn't read the manual, when you're distracted by bombs falling around you, or volcanic ash, or when you've got both arms in a cast and can't quite turn your head. (Spolsky, 2001, p. 57)*

The principle of design for extremes cautions against the common tendency to evaluate a system from the perspective of the designer of that system—that is, the way the system was intended or envisioned to be used by an "ideal" user. Designing for extremes and thus for true usability requires that system designers examine how their systems are *actually used* by real people in the context of real situations. Related, user-centered design methods stress empathy as a core value for the design of highly usable tools and technologies (Brown, 2009). Designers must develop an understanding of how others understand their worlds if they are to design systems and tools that support rather than frustrate users (Krippendorff, 2004). Failures to empathize through design are not insignificant. Estimates suggest that up to 80% of new products fail, not for lack of innovation,

but for lack of understanding of user needs and contexts of use (Watts et al., 2007).

There is a great deal more to the philosophies and methods of user-centered design than we have covered here. For our purposes, however, this brief overview provides a conceptual framing for our examination of health services usability for caregivers of children with disabilities. The concept of usability as understood in user-centered design requires that we examine how health services are (or are not) usable from the perspectives of patients and their caregivers, within the broader contexts of their life-worlds. This means that an engagement with the subjective experiences and perspectives of patients and caregivers is necessary if we are to understand how various action possibilities either are or are not afforded to individuals. The principle of design for extremes motivates analysis of usability for a population such as children with disabilities covered under Medicaid because the health, economic, and social consequences of disability are significant on both individual households (Newacheck et al., 1998; Parish, Shattuck, & Rose, 2009) and the health system (Council on Children With Disabilities, 2005; Perrin, 2002; Simon et al., 2010). Usability problems are likely to be most visible where such extreme conditions prevail (Spolsky, 2001).

▍Methods

Our data come from a larger study that examined the effects of an Ohio state policy change that moved children with disabilities from fee-for-service Medicaid to managed care and, consequently, a Medicaid-serving pediatric ACO model. Part of the study involved focus groups and one-on-one interviews with caregivers of children with disabilities. Our focus in the analyses reported here was not with the effects of or differences between the two payment systems. Rather, our goal was to theorize health service usability by analyzing the ongoing efforts of caregivers to create and maintain workable arrangements that addressed their children's needs within the context of other life demands. Our focus on health service usability was empirically grounded (Charmaz, 2006). That is, we turned to the concept of usability during analysis because it offered a lens for making sense of dynamics we observed in caregiver accounts.

Sample and Data

Our focus group and interview data come from a total of 66 caregivers. We recruited participants through multiple ways, including flyers distributed through ACO clinics and care coordinators, the patient advisory panel that guided the larger study, and a question on a survey conducted in a separate aim of the larger study. For the purposes of our study, a caregiver was an adult who self-identified as responsible for a child who qualified for Medicaid benefits under

the "Aged, Blind, and Disabled" category. In most cases, caregivers were birth mothers of these children; however, a few were grandparents or legal guardians. The average participant was 40 years old. The sample was overwhelmingly female ($n = 64$). Slightly more than one third were identified as African American ($n = 23$), and the rest were White. These racial demographics generally correspond with the larger population covered under the ACO. The average participant lived in a household of four people. Most ($n = 41$) reported household income of $21,200 or less, which was below the 2016 U.S. Federal Poverty Level for a household of four (i.e., $24,300). Our sample included a mix of physical and developmental disabilities. Table 1 provides sample characteristics.

We gathered all data between June 2015 and May 2016. We first conducted six focus groups, each 1.5 hours long, with a total of 33 caregivers of children with disabilities. These focus groups averaged roughly five participants (range

Table 1	
Caregiver demographics	
Number of caregiver participants	66
Age in years	Mean: 40; range: 25–73
Female	64 (97%)
Race	Black or African American: 23 (35%)
	White or Caucasian: 43 (65%)
Marital status	Married: 23 (35%)
	Divorced: 18 (27%)
	Divorced and member of unmarried couple: 1 (2%)
	Widowed: 2 (3%)
	Separated: 6 (95)
	Never been married: 14 (21%)
	Member of unmarried couple: 2 (3%)
Education	8th grade or less: 2 (3%)
	Some high school: 10 (15%)
	High school: 14 (21%)
	Some college, technical, or trade school: 25 (38%)
	Technical or trade degree, or certificate: 3 (5%)
	Associate degree: 8 (12%)
	Bachelor's degree: 3 (5%)
	Master's degree: 1 (1.5%)
Income	Less than $14,000: 22 (33%)
	$14,001–$21,200: 19 (29%)
	$21,201–$28,400: 9 (14%)
	$28,401–$35,600: 5 (8%)
	$35,601–$50,000: 4 (6%)
	More than $50,000: 1 (1.5%)
	I prefer not to answer: 2 (3%)
	Missing: 4 (6%)
People covered by reported income	Average: 4.9, range: 1–8
People in household	Average: 4.13, range: 1–8

4–8 participants). Three focus groups were conducted in Columbus, Ohio, a large metropolitan area. The remaining focus groups were conducted in three different rural Ohio counties. One researcher conducted each focus group, ensuring all participants had opportunity to share their thoughts. One or more additional research team members took notes or observed. After completion of the focus groups, we then conducted individual, semistructured interviews with 33 additional caregivers in order to obtain in-depth accounts of experiences. Sixteen interviews were conducted with residents of Columbus, whereas the remainder interviews were conducted with residents of three rural counties, which were different from those from which we sampled for focus groups. To ensure consistency, two researchers (B. H., S. T.) jointly conducted the first interview and then conferred regularly between the remaining interviews, which they conducted individually.

We preidentified a list of topics to cover in the focus groups and interviews. These included home context, impacts of disability, accessing and coordinating care, satisfaction with quality of health care, hospitalization, and overall assessments of experiences. However, we allowed focus groups and interviews to partially focus on issues that participants were keen to discuss. Throughout, we prompted for stories and specific examples to illustrate comments participants made. We did not ask questions explicitly about usability or configurations—two themes that emerged during analysis. All focus groups and interviews were recorded and transcribed verbatim.

Analysis

Throughout data collection, research team members discussed impressions and emerging interpretations. Among these impressions was the awareness of the considerable ongoing work of caregivers to find, establish, maintain, and alter connections to needed health services for their (often multiple) children with disabilities. We developed initial broad codes that related to themes in this ongoing work (e.g., finding services, physically accessing services, affording services, relating with providers). Our discussions also sensitized us to complex interdependencies among the multiple health services caregivers were accessing and many other demands in their life-worlds (e.g., employment, income, transportation, social supports). We read transcripts closely to help us conceptualize these complex interdependencies. From these readings, we developed the concept of "configuration" to capture the arrangement of many different health services and life-world factors that caregivers seemed to be constructing and maintaining. Our close readings also suggested that (a) these configurations were constructed through complicated decisions in which caregivers were trading off one need against another, including among multiple family members, and (b) the resulting configurations were vulnerable to events that destabilized configurations (e.g., loss of a

trusted provider) and required additional work on the part of caregivers. We therefore, developed additional codes for these themes (adjusting intraconfiguration, adjusting interconfiguration, reconfiguring).

One researcher (M. P.) coded the transcripts for the themes represented by the codes described above. Reading through these coded data, the lead researcher (B. H.), sensitized by his background in user-centered design, discovered that the challenges facing caregivers suggested that health services were not highly usable for this population. He then sorted through the coded data comparing coded segment with coded segment to examine what each theme revealed about the usability of health services. Other team members checked the findings and interpretations against their own understandings, which they developed from their own in-depth engagement with the data (e.g., attending focus groups and interviews, reading transcripts, conducting other analyses from these data). Feedback from these team members was incorporated into the final manuscript.

▌ Findings

We present our findings under four themes: rapport, access, tradeoffs, and configurations and destabilizing shocks (Table 2). Each theme reveals something caregivers and their children valued and/or challenges they experienced as they attempted to obtain and maintain benefits from various health services. Increasingly, the themes reveal interdependencies between the use of health services and other life-world concerns. These interdependencies have important implications for understanding health service usability, which we examine in the discussion that follows. To protect identities, we use aliases when referencing caregivers and their children.

Rapport

Caregivers spoke of the need for "rapport" and finding providers who were "compatible" with them and their children. In explaining positive assessments of many of their children's providers, caregivers said those providers listened, explained things clearly, were accessible and responsive (e.g., via e-mail or patient portals), and cared. In many instances, they linked rapport with positive outcomes they perceived in their children. Shawna explained that her son, who had autism, "started to come out of his shell" when special education teachers and therapists at a local program specializing in developmental disabilities began working with him: "They know exactly how his mind ticks and how they need to work with him to get what he needs to get done." Like other caregivers, Shawna credited her son's improvement with the fit she perceived between his specific needs and the actions of providers who had customized their approach to those needs.

Related, some caregivers reported that they had discontinued their use of certain providers when they felt rapport was missing. Laverne, for example, told a story about an unpleasant interaction her grandson Leo had with an occupational therapist. At the time, Leo, who had Down's syndrome and asthma, only ate pureed foods.

> *She takes the cookie and she tries to put it in his mouth, and I'm thinking, oh my gosh, it's going to choke him to death. Because she didn't really know, and she's supposed to be, you know, the specialist. Well she rubbed it into his mouth, and he bit his mouth down, and he would not open his mouth for her. Nothing. And then she got a granola bar, and I thought, are you kidding me? He's not even that far! (I-163)*

She explained that at Leo's next appointment, "…he didn't want to go back in that room…he turned around, fought, kicked his feet, stomped. He didn't want no part of that room. […] I thought, I'm not taking him back there…." Other caregivers spoke of observing how providers interacted with their children, including talking to the child rather than just the caregiver, and using these observations to evaluate rapport and decide whether or not to continue using a service.

In some cases, trust and rapport experienced with providers appeared to be the result of years of interacting. Jodi suggested that the well-established, positive relationship between her son and his speech therapist played an important role in his openness to participating in that therapy.

> *The [speech therapist] that he sees he's been seeing since he was three. I think he's built a relationship with her. He's used to her and he likes her and he looks forward to going. Like, he's not one of them kids that gets there and is like, oh, man! He goes back really, like, easily. (I-134)*

When an opening with a different speech therapist, whose office was much closer to Jodi's home, became available, Jodi explained that she opted to stay with the initial therapist partly because she felt the relationship between her son and the therapist played an important role in his progress.

> *When we had to do some schedule changes, [the therapist] had said, like, "Oh, you know, we could let him see someone else that might have a different availability than me." But for me, I just know how my child is, and I think he's a lot like me. I'm a creature of habit. I like things, like, kind of the same and in routine, so I just felt…he would be better off staying with someone he's already started to build a relationship and bond with. (I-134)*

The belief in the importance of maintaining established connections with trusted providers was a theme that appeared in many caregiver accounts, often couched in the assumption

that change was disruptive. As we discuss below, concerns about the convenience of physical access were often important to the evaluation and use of services; however, Jodi's account, like those of several other caregivers, suggests such concerns are only part of what makes a service usable. In fact, Jodi's account demonstrates that rapport may sometimes be more important than convenience.

As further evidence of the importance of rapport to usable services, several caregivers told stories of negative ramifications when connections to trusted providers were disrupted. In one focus group, a single mother relayed her struggle dealing with her teenage son who had attention-deficit/hyperactivity disorder and weighed over 300 pounds. The loss of his trusted counselor resulted in the boy's refusal to continue taking his medications, which had in turn resulted in an escalation of multiple problems.

He won't take his meds. He don't feel he needs them. He gets in that play mode regardless of if you wanna play or not, you're gonna play 'cause he is so big. […] The fights, just because he's big. My 14-year-old goes through it. He walks around with black eyes, busted lips, swollen faces, 'cause they're big. I can't stop them. It's just me, no family support. His counselor left a year ago, and he don't really talk to no one else. He's been with her since he was five years old. So, he really got attached to her; she really got attached to him to where it was hard for her to leave, but she had to. The behavior issues I'm having now since he won't take his meds is every day is hard. Almost every day is a fight. When I say a fight, I'm talking $700 in repairs, five busted windows, two bare rooms where I had to repair the whole wall. I can't afford that. (FG-105)

Other caregivers similarly explained that their children also went without certain therapies when those services were no longer available through trusted providers.

Access

In some cases, caregivers characterized the work of connecting with a service as difficult because of challenges arising from physical distances, transportation needs, and related barriers to access. For caregivers living in rural areas, for example, the lack of local services of all sorts meant they often had to drive considerable distances. One caregiver, Karen, told us that there was no grocery store in her entire county: "For us, traveling, if it's under an hour, it's close by." Karen's son Kelvin, a 14-year-old with multiple physical and learning disabilities, had been prescribed occupational therapy (OT), which he received three times per week. Because this service was not available locally, accessing it meant that Kelvin had to miss school regularly.

…we ended up having to give up the OT because he would've been out of school so much we would've ran into some really big problems. Because in order to take him to [town where OT was available], 45-minute drive there, 45 back, 3 times a week, he'd be out of school 3 times a week at minimum half a day. (I-162)

Karen's comment suggests several important points relevant to health service usability. First, to receive benefit from the OT service, Karen and her son had to expend time and energy traveling to and from the service. Second, this expending of time and energy was ongoing. As with our findings pertaining to rapport, here again we find evidence that what made a service useable was not merely its own objective features. Rather, its usefulness and usability required action on the part of patients and caregivers, and in many instances, that action had to be sustained over long periods of time. Furthermore, Karen's remarks indicate that the time and energy required to sustain those actions were consequential not only in light of benefits received from the OT itself but also within the context of other life demands. We explore the consequentiality of such tradeoffs below.

Access challenges were not confined to rural areas nor merely a matter of physical distance or service availability. Caregivers in all locations spoke of time demands resulting from needing to access multiple services, especially when children had multiple health conditions. Tina, for example, explained how the demands of physically accessing multiple services for her son had taxed her materially and emotionally, in addition to contributing to missed appointments.

We were missing a lot of appointments…ADHD appointments, Healthy Weight and Nutrition appointments. And I seen improvement with his allergies, so I was, like: Okay, it's overwhelming for one person. He was going through the counseling then. It was just all kinds of appointments, and I couldn't afford to keep running him back and forth to the hospital. Car broke down, like I said, and just crazy. (I-137)

Others described similar challenges arising from ongoing work of managing multiple appointments. Tina's account, like Karen's above, suggests that assessments of services are not necessarily made in isolation nor based solely on features inherent to the service itself. Rather, such assessments are made in the context of other competing demands and priorities.

Just as Tina's account featured an unreliable car, other caregiver accounts revealed access challenges arising from unreliable transportation, including such services provided by managed care companies. For instance, Megan explained how managed care procedures prevented her from taking

advantage of last-minute appointments when her daughter had urgent needs.

> *…I'll have to say, "I can't take it," and have to wait a longer time for an appointment because the medical insurance says that you have to call…48 hours [in advance] to schedule transportation. So, sometimes that could hinder things. (I-140)*

In Megan's account, two services (doctor and transportation) were technically available to her. The usability of the one service (doctor), however, was shaped not only by its own features (i.e., last-minute availability) but also by features of the other service (i.e., procedures for accessing transportation). Megan also explained a slightly different but related situation.

> *And then sometimes, I'm just so overwhelmed…. I just miss an appointment because I forgot to call like 48 hours in advance because I get the text [from doctor's office] the day before…reminding me. (I-140)*

Megan's comment suggests an incompatibility between features of the two services. The doctor's office provided a 24-hour reminder, but the insurance company required a 48-hour advance reservation for transportation services. The reminder came too late to be useful. Regardless of how simply this particular problem—which other caregivers also reported—might be solved, the deeper point is that Megan's account reveals situated interdependencies among services, such that the usability of one service might only be fully understood in the context of other needed services.

Tradeoffs

Above, we provided a few examples of tradeoffs caregivers reported facing, including Karen, who pulled her son out of OT because it conflicted with his school schedule. Similarly, we quoted Tina above when she spoke of the emotional and material demands she faced in her efforts to keep up with the many appointments required for her son's care. When she perceived improvement in his asthma, she chose to discontinue his weekly allergy shots, not because the doctor had determined the boy had fully benefited from the therapy but rather because Tina found her son's many appointments "overwhelming," particularly at a time when her car broke down and she was dealing with "a domestic violence situation with his father." These examples reveal that caregivers often could not manage connections to individual resources in isolation because the work of managing those connections was interdependent with work of managing other connections and entangled with other life events, giving rise to difficult tradeoffs. Thus, to make use of one service, adjustments

to other services or life-world factors were frequently required.

Tradeoffs often involved caregivers' own employment. Jared, a single father raising a daughter (Anna) with epilepsy, said that Anna's frequent seizures meant that he had to be readily available to attend to her, which in turn led to him having "to bounce in and out of jobs." Jared said staff at Anna's school called him almost daily because of his daughter's frequent seizures, and if he was not immediately available, the school would call an ambulance and send Anna to the emergency department (ED). Jared, who worked odd jobs as a handyman, found it difficult to maintain steady work given this situation: "It's like, every day, if I attempt to get a job, I'm going to have to, you know what I mean, end up leaving to go pick her up." Jared's solution to this dilemma highlights poor usability. If part of what makes a system usable is that it prevents users from making errors or taking improper actions and if a goal of value-based care is to reduce unnecessary ED utilization, then the ease with which his daughter could wind up in the ED suggests a system that was not affording desirable outcomes—at least not without sacrifices to Jared's employment.

We found other consequences of adjusting employment to address the needs of children. For example, when asked about the impacts of her 8-year-old daughter's autism, Beth explained that, because few people are able to care for such children, she had to do it herself rather than work. "So, it affects your income. Your income affects how you live, where you live." Others suggested a similar causal loop: Efforts to manage their child's condition prevented them from working or otherwise earning needed income, which in turn negatively impacted their abilities to effectively manage their child's condition, including make use of needed services. For example, Yvonne, a mother of a 13-year-old boy with seizures and muscle problems, explained:

> *They [welfare office] were telling me that they wouldn't even help me get my car fixed because I'm not working. So, I told them, I understand that, but how do I get him to the doctor's appointments to get him better to be able to even get a job that's maybe even four hours a day? (I-139)*

Among study participants from rural areas, a few talked about making significant adjustments to their family life in order to improve access to the services their children needed. Tina explained that she moved from a rural area to Columbus to get better care for her son's asthma. She said that, "he was hospitalized every year for the past three years before the move, with pneumonia, bronchitis, asthmatic bronchitis, and it was really affecting his health." Others had considered similar adjustments but found them impossible, indicating that there are limits to the adjustments that caregivers can or will make. Karen had considered but rejected the idea of moving.

	Table 2
	Themes and example quotes
Theme	**Example quotes**
Rapport	"I really liked the doctor. He had a great rapport. He worked well with Jason. He asked questions. He talked to Jason, not me. He let it know, 'How's Jason feeling,' and he let Jason answer for himself, not me…it made him comfortable with the doctor." (I-137)
	"Fred is the case manager who comes to the house and it just works out great. He does awesome with him. They do the therapeutic while he's doing whatever he needs, you know, just bouncing around. He's taken him fishing, he's taken him to play basketball. It's stuff that I can't get out there and do or I don't have time to do. That's been one of the best things that's come along." (I-154)
	"My kids are: if I see you, you better be there the next time I come, and don't give me somebody else. We don't switch chairs at the table. They're very hard to get out of the house and stuff like that." (I-149)
Access	Interviewer: "Where did he receive the surgeries?" Caregiver: "Nationwide. Yeah. Which is two hours or so—for all those trips. Yeah. So, for 14 years, we've been up and back. I could drive there in my sleep." (FG-125)
	"…the cab people that [the managed care company] be calling, sometimes they be late, man. I remember one time I was late to an appointment, I almost had to—her psychology appointment, I want to say her first one. I almost had to reschedule. And then one time, luckily, they called me and rescheduled that morning. My appointment was at 9:00, man. The [driver] didn't even come until, like, 9:45." (I-160)
	"We did live in other parts of Ohio where it wasn't as easy, that it was scattered. You went to a clinic, and then they sent you to maybe the hospital for an X-ray, or to a different [diagnostic testing facility] for blood work." (I-138)
Tradeoffs	"He used to go (to OT/PT) once a week, two sessions back to back, and we liked it, but when we got into school and realized, you know, with me working full-time and dad never has time to do anything like appointment-wise, it's all me, so working full-time and then having him going to school, it was just easier to get the OT/PT in school than it was to, you know, try to rush around and get him to an appointment every day." (I-150)
	"I think she spent 28 days in the hospital. It was a lot of doctors' appointments. It was hard to find a job that's gonna let me leave all these days. At any given time, somebody can call and they're like, 'I need you to come get her.' […] I've quit a couple jobs because I did too much running." (I-138)
	"His condition has…impacted me greatly. I had to deal with the emotional stuff of him being diagnosed, and the fear for him, and then trying to get him in to as many intervention services as possible trying to figure out what worked. Having to quit school and having to wait to be able to go back when he was older and I was able to. It basically made me a hermit for five years because I couldn't leave the house. I really couldn't be around anyone because no one really could watch him for very long because they couldn't control him." (I-152)
Configurations and destabilizing shocks	[School speech therapist failed to renew license] "School started. They had to fire her, okay? They did not have speech therapy at that school. And it's in their IEPs. […] There was not a speech therapist at that school until January. They did not notify us. They were having the teachers give the speech therapy—which, the teachers have enough to do to begin with." (FG-116)
	"He was getting home health before the switch [from fee-for-service to managed care], he was, and then as soon as the switch was made, they took him off of that [home health]…." (I-143)
	"We had a trouble with therapy there a few months ago and it wasn't—it was more a staffing issue on their half. People had quit, people had went out for medical reasons and this and that and they just didn't have the staff to cover what he needed." (I-153)

That decision [to move] is non-decision…. I bought my house when the market was high, and I didn't have a child with autism [laughs]. And then the market crashed. And I can't sell my house. And we live paycheck-to-paycheck. So, I can't leave a house that I still owe 70-some thousand dollars for…. So yeah, if it wasn't for that, I'd be gone. […] I'd go out of state if I could to get him help. But, you know, I owe $74,000 on a house that would probably sell for $40,000 right now. (I-162)

Many caregivers reported that more than one member of their household had a disability or other significant health condition. For example, among our 33 interview participants, 10 reported having more than one child with a disability, whereas 11 of those 33 caregivers self-identified as having health conditions that compromised their abilities to work and care for their children. For example, they reported suffering from manic depression, lupus, cancer, herniated discs, carpel tunnel syndrome, and social anxiety. In many instances, because multiple household members had multiple

health needs, caregivers reported interdependencies between the work of addressing a given child's care needs and the work of addressing the needs of someone else. For example, Karen lived with her husband and three children: a 16-year-old with migraines and posttraumatic stress disorder; a 14-year-old boy with multiple conditions, including a learning disability and physical disabilities affecting his feet, hips, and back; and a 3-year-old with autism. She explained how managed care restrictions had introduced difficult adjustment dilemmas to her household.

> *So, you're doing a lot more doctor searching, which isn't that big of a deal if it's just a primary physician. But when it's: Okay, I found an ortho that will take [insurance]. Well, this [child] needs counseling. Because my 16-year-old has PTSD.... Trying to find a counselor that would take this insurance versus that insurance. And then you have to weigh out: which is more important? This doctor or this doctor? Because this insurance will pay for this [service], but not this one. Yeah, they're used to this [provider]; they're more comfortable with this [provider], but their physical health kind of comes before their counselor. So even though she's closer to this one, they no longer take that insurance, so we're gonna have to find her a different counselor, start over on that, in order for my son to keep his ortho or his therapist. (I-162)*

She explained that the state's Medicaid rules required the entire family be covered under the same insurance plan, forcing her to decide, "Which child needs it more? Which one is more serious?"

Karen's experience highlights a key challenge for obtaining usable, useful services: optimal arrangements may be difficult if not impossible to achieve in many cases because connections to care services cannot be established, maintained, or assessed in isolation. Rather, adjustments regarding the connections to one service may have consequences for connections to other services and for other priorities in the patient's larger life-world. Optimizing matters to enable one person to fully benefit from available services may result in suboptimal arrangements for another.

Configurations and Destabilizing Shocks

The tradeoffs caregivers faced—and the adjustments they made as a result—characterize the connections between children and health services as interdependent with other life demands. Consequently, each family's life-world can be seen as a complex "configuration" of connections to (typically) multiple services, often for multiple family members. Furthermore, as we have demonstrated, these multiple connections were interdependent with many other processes and priorities in the family's life-world (e.g., employment, transportation, housing). Most caregiver narratives suggested

that these configurations were hard-won. For example, many told of "fighting" with providers, insurance plans, schools, and other services, often over extended periods of time, in order to obtain what they felt their children needed. The difficult decisions made to manage tradeoffs described above also demonstrate the work of establishing configurations that were usable in the broader context of the family's life-world. Indeed, these configurations were workable, if not optimal. As Shawna put it: "It's not perfect, but it works for the time being."

Shawna's comment that the configuration worked "for the time being" points to the temporal, changeable nature of the configurations of services and life-world factors that caregivers constructed. This relates to the fourth theme we found through our analyses. Caregiver narratives described shocks, that is, events that interrupted or destabilized configurations. Some shocks were relatively small events, creating isolated breakdowns in usable care arrangements. For example, in both focus groups and interviews, caregivers said their children missed or were late for appointments because transportation services provided by managed care companies were often late or failed to show up at all. Some caregivers reported finding out that services they thought their children were receiving at school, typically speech and occupational therapies, were either being provided irregularly or not at all for some time. Although these may have been relatively minor shocks in terms of noted impacts, they demonstrate that the usability of a health service is an ongoing accomplishment, dependent on the continued performances of various actors.

One reason that many shocks had apparently minor impacts may relate to the ways that caregivers stepped in to manage discontinuities in care. In some instances, caregivers reported coping with shocks to established connections by providing the services themselves. For example, Susan and her husband were raising five children—their two granddaughters and three adopted boys—four of whom had one or more disabilities. When the family's trusted occupational therapist quit and the children were averse to seeing someone else, Susan picked up the slack, increasing the frequency of OT exercises the therapist had taught her.

> *The therapist would send home a paper to color, so we would sit down and do something like that, or they would send a rubber band thing to where she would try to pull it from me and stuff and, you know, work her hands. She's got fine motor problems. So, we did a little bit, but now I do a lot more, because she doesn't get it very much as school, maybe 20 minutes every two weeks, something like that. (I-149)*

Some shocks, however, were not so easily accommodated. The move from fee-for-service Medicaid to managed care brought changes that disrupted configurations that some participants depended upon. Claudia, caregiver to her grandson

Carlos, an 11-year-old with severe asthma, and her daughter, Carlos' mother, a 35-year-old with "mild Down's syndrome," explained how she experienced the insurance change: "Everything went downhill. Everything." In particular, she talked about the impact of losing home health services.

> *Before the change…I could get a nurse to come in and help me out with Carlos, help him manage his medications and stuff…getting us to the grocery stores and getting what he needed. […] And [losing that service] kind of put me off a little bit, because I have the house to tend to, trying to deal with his mom, making sure the bills are paid and everything, and I would forget to set up his medications. So, having someone there to do it for me kind of lifted up the burden a little bit off of me. (I-144)*

Claudia's account describes a configuration that had been stabilized and made usable, in part, through the ongoing use of a home health nurse. The home health service became an important resource as the nurse took on certain recurring activities (e.g., managing medications). When that resource was suddenly removed, the configuration destabilized. Like other accounts described above, Claudia coped with the shock by absorbing the reverberations and taking on herself the work that the nurse had formerly done. Pointing to her own forgetfulness and the additional "burden," Claudia suggested the new configuration might be less reliable than the previous one.

Claudia's account, like many others, further illustrates the complex interdependencies among care services and features of the life-worlds of children with disabilities. As a result of these interdependencies, caregivers were necessarily central to the ongoing management of configurations. Because of their positions at the center of their children's life-worlds, caregivers, more than anyone else, were positioned to perceive and manage complicated tradeoffs. In fact, caregivers in our study uniformly identified themselves as the primary coordinators of their children's care. This central position allowed caregivers to step in and make up for lack of usable services, but it also revealed a vulnerability. For example, later in the interview Claudia said, "God forbid if I get sick now. I can't lay down. I've got to be up moving around there with a mask on."

Other caregivers told stories of shocks to established configurations happening when trusted providers changed the insurance plans that they accepted, rendering their services unusable. For instance, Karen said, "you pick a certain managed care [plan] because your child's physician is covered, and they decide to switch. And now they're covered under a different managed care [plan]."

In other cases, established configurations fell apart as children aged and lost eligibility for certain programs. For example, several caregivers reported experiencing losses of valued services when their children turned 18 years old.

But the need to reconfigure care arrangements brought on as children aged was not confined to the transition into adulthood. Karen explained the difficulty she was having finding tools to provide additional OT at home for her son with physical and learning disabilities. Whereas she had previously relied on a state-sponsored child development program for needed resources, her son had aged out of that program, leaving Karen uncertain where to turn: "So, whenever they turn five years old, they age out. So, it's just kind of hard finding the resources to be able to go to sometimes." These accounts suggest that usability—of both individual health services and configurations—changes over time.

Many caregiver accounts indicated they experienced stress regarding the uncertain futures of the configurations they had constructed. For example, Beth described the impact that a recent reduction of allowable hours of home health services had on her family, as well as the continued stress she experienced from worrying about the possibility of additional coverage changes.

> *You know, when [my daughter] lost those hours for like a couple of months there…I mean, you could really tell…. Not only did it affect her, but it affected all of us. So, it's just—I guess, I'm worried all the time, and it's a hell of a life to live. You know? You're always worried, am I going to lose this? And am I ever going to get approved for this? (I-159)*

Susan, the grandmother raising four children with disabilities, described herself as "worried" and "petrified" about the future. She said of her granddaughter Saskia, "My concern is I will die, and she won't know what to do." These comments, as well as many examples above, clearly demonstrate the perceived fragility and impermanent nature of the working (i.e., usable) configurations that caregivers had constructed among valued care services and particular features of their life-worlds.

DISCUSSION

The four themes identified in our analyses provide evidence regarding what makes health services more or less usable for caregivers of children with disabilities. The theme of rapport reveals the importance of an interpersonal dimension to the interfaces between patients and providers of care services. Others have shown rapport to be crucial for productive patient–provider relationships, including by building trust, facilitating information sharing, and increasing patient compliance with therapies, among other effects (e.g., Barnett, 2001; Hoff, 2017). The emphasis on rapport in our analyses suggests that, at least for some, the work of establishing and maintaining trust-based ties between provider and (caregiver and) child is central to rendering a service usable. That

is, evaluations of services, at least in some cases, entail not only an assessment of objective features of those services but also of dynamics that emerge out of interactions, as others have also found (e.g., Hoff, 2017). The reports of children refusing to engage with or being unable to benefit from alternate providers following the loss of a trusted one illustrate that services of a single type are not necessarily interchangeable from the perspective of the patient. They are not equally usable. Thus, our findings suggest that part of what makes a service usable to a patient—perhaps primarily patients with more complex needs—is an interpersonal dimension that cannot be easily replicated, in part because of mutual adaptation over time of patient and service.

The importance of access has long been recognized in health care (Fein, 2005). As many examples from our data show, services were often available but not usable, at least not without considerable effort on the part of caregivers. The theme of access provides evidence of the considerable work involved in converting an available service into a useful resource. In other words, we make an inductively derived analytical distinction between a service and a resource. In our conception, the former is the product of an activity or set of activities that have the *potential* to provide some benefit or use to the patient, whereas the latter is the product of *actual* use of a service. This distinction is important because it highlights the fact that the availability of a needed service, though important, is not sufficient to make that service usable.

The theme of tradeoffs adds further insight into what shapes the usability of a service. Specifically, the theme of tradeoffs suggests that the usability of a service and the impact that it is ultimately able to have on the child may be shaped not only by its own features but also by features of other needed services and factors in the child's life-world. Our findings demonstrate that the ways in which caregivers and children with disabilities engaged with services (e.g., making or missing appointments, dis/continuing with therapies) was not merely or even necessarily primarily a function of the features of those services or perceived benefits. Rather, engagement with services was interdependent with a host of other life-world priorities and concerns that produced complicated tradeoffs for caregivers. Decisions to engage with a given service—and thus the potential for that service to benefit the child—were made not in isolation but within the context of complicated adjustments that attended to concerns about income, employment, transportation, physical distances, the health needs of others in the household, and the relative availability of support networks, among other interdependent factors. To the extent that caregivers and patients must trade off one service or life-world concern (e.g., employment) for another, the action possibilities and benefits that any single service affords will, again, be determined not by its own features alone but also by the relative compatibilities of those features with the features of other needed services and life-world priorities.

The final theme of configurations and destabilizing shocks builds on the three previous themes. It suggests that the primary system important to any single patient is not the "health system" so much as it is a complex arrangement that is worked out among the multiple service needs—sometimes of multiple household members—and other life-world factors. The finding that ongoing work was necessary to maintain configurations and events could destabilize them illustrates the impermanence and fragility of configurations. Furthermore, in terms of usability, we found that shocks that destabilized one part of a configuration sometimes altered life-worlds in ways that impacted the usability of other services. This finding points to an interdependency between particular configurations and the usability of individual health services. To some extent, health service usability is relative to the individual patient's configuration of services and life-world factors.

Health Service Usability

Collectively, these themes illustrate health service usability as a relational, situated, emergent property rather than an inherent feature of the service itself. Health service usability is relational in the sense that it is determined by the relationship, broadly defined, between the patient and the service. This means that a service that is highly usable to one patient may have low usability for another patient with similar health conditions. Health service usability is situated in the sense that it is shaped by the social, economic, and other features specific to the patient's life-world. This means that a service's usability for a particular patient can only be understood in context. Finally, health service usability is emergent in the sense that it arises out of interactions of patient, service, and other life-world processes. This means that the usability of a service may change over time as inputs to those interactions change. For example, we found that temporary and permanent changes to employment status or the availability of one service impacted the usability of other services because of the complex interdependencies in the configurations that caregivers had constructed.

These complex interdependencies and their impact on usability have implications for how we understand the interfaces of health services. Whereas traditional approaches to design emphasize the interface at which the user directly engages the system or technology (Gaver, 1991; Nambisan, 2011; Nielsen, 1993; Watterson et al., 2018), some scholars have problematized static, fixed, atemporal notions of user–system boundaries (Suchman, 2007). Similarly, our findings imply that if we conceive of health system interfaces only as those sites of care where patients directly engage with providers and services, we will miss much of what shapes usability for many patients.

Caregivers in our study explained non- or discontinued use of services by pointing to difficult or time-consuming

access, incompatibilities with other needed services, reliance on unreliable human memory, or conflicts with other life demands. If patients do not use services, they cannot benefit from those services. Therefore, understanding what makes health services usable to individual patients is important because we would predict that patients are less likely to benefit from services that have low usability compared to services with high usability.

Regarding limitations and the transferability of our findings, our study provides an initial conceptualization of health service usability. More work is needed to further develop the properties and dimensions of health service usability and to develop means for evaluating it. We also note that the experiences of our participants represent extreme cases. Although examination of extreme cases may be important for understanding system usability (Spolsky, 2001), the specific challenges and experiences we report may be most readily transferable to other low-income households where children or perhaps adults with disabilities are covered under Medicaid managed care plans. We propose, however, that the concept of health service usability as relational, situated, and emergent may apply broadly to other groups of patients dealing with chronic health conditions. As is typical of extreme case analyses (Flyvbjerg, 2006), the extremity of the cases we studied may simply bring the otherwise invisible interactions of service features and patient life-worlds into sharper relief.

Practice Implications

In some sense, the work of care coordinators may be understood as efforts to improve the usability of services for individual patients within the specific contexts of their lives (Clark, Parker, Battaglia, & Freund, 2014; Parker & Lemak, 2011; Piper, 2014). Implementing care coordinators for large populations of patients with complex needs, however, is not economically feasible (Antonelli & Antonelli, 2004). In fact, for all the complexities of their life-worlds and health needs and despite being part of an ACO, only a few participants in our study said they had been offered care coordination services. Beyond coordinators, health care providers and managers may be able to enhance usability through many current improvements being spurred by value-based payments. Improved coordination and information sharing, medical homes, more same-day appointment options, among a host of other changes, will likely improve many patients' perceptions of usability.

In redesigning clinical processes and services to improve value, however, provider organizations may be well advised to avoid system-centered design perspectives, which tend to produce technologies that operate efficiently only for the mythical "ideal" user (Endsley, 2016). To be clear, improving clinical integration, work process efficiencies, and technologies of coordination (e.g., electronic health records)

are important for improving usability for clinicians and may generate usability gains for patients as well. Nevertheless, our findings suggest that, in order to design truly "patient-centered" (Berwick, 2009) services that are highly usable for patients, deeper understanding of patient life-worlds may be necessary. Just as user-centered design entails more than asking users what they want and giving it to them (Endsley, 2016), provider organizations will need to think beyond what they can learn from surveys of patient experiences that tend to focus on interactions at sites of care. We have shown that usability is shaped by factors beyond those sites. Our findings imply that, to be truly patient centered, we have to decenter the health service and recognize it as but one component of the patient's life-world configuration. Perhaps instead of—or in addition to—assessing the patient's engagement with the health system, we ought to assess and look for ways to redesign health services to flexibly adapt to the complex configurations of patient lives. This may be a tall, if not impossible, order. Anything less, however, is still a system-centered design.

Acknowledgments

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