

# Making Healthcare Infrastructure Work:

## Unpacking the Infrastructuring work of Individuals

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### ABSTRACT

The U.S. healthcare infrastructure is fragmented with various breakdowns. Patients or caregivers have to rely on their own to overcome barriers and fix breakdowns in order to obtain necessary service, that is, infrastructuring work to make the healthcare infrastructure work for them. So far little attention has been paid to such infrastructuring work in healthcare. We present an interview study of 32 U.S. parents of young children to discuss the work of infrastructuring our participants carry out to deal with breakdowns within the healthcare infrastructure. We report how they repaired unexpected failures happening at the individual level, aligned components at organizational and cross-organizational level, and circumvented infrastructural constraints (e.g., policy and financial ones) that were perceived as ambiguous and demanding. We discuss infrastructuring work in light of the literature on patients' and caregivers' work, reflect upon the notion of patient engagement, and explore nuances along several dimensions of infrastructuring work.

### CCS Concepts

• Human-centered computing → **Human computer interaction (HCI)**; *Empirical studies in HCI*

**KEYWORDS:** Healthcare infrastructure; infrastructuring work; patients and caregivers; patient work; new parents; healthcare consumers.

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### 1 INTRODUCTION

In many countries (e.g., the U.S. [10], African countries [50], European countries [30], Asian countries [39]), healthcare infrastructures (the underlying foundation that supports the operations of a healthcare system) are complex and fragmented [88], including numerous poorly coordinated or disjointed components (e.g., facilities, information systems, financing systems, healthcare providers) at all levels (e.g., central/national, provincial, district and community) [73]. The complexity and fragmentation raise challenges for patients and caregivers to interact with healthcare providers and obtain desired services. Taking referral process in the U.S. as an example, care provision is distributed across different entities [66]. The referral process for specialty care is often extremely disjointed. Most physicians have to use the fax machine as a primary means of communication, which often results in miscommunication, delays, insufficient data, and the lack of method for referral process tracking and reviewing [51,52]. The disjointed processes could lead to many negative consequences, such as delayed diagnosis or treatment, duplicated tests, polypharmacy, and malpractices [51]. Within complex and fragmented healthcare infrastructures, the burden of coordinating care often falls onto individual patients and their personal caregivers [25,49].

Previous HCI research has examined patients' and caregivers' care work in both clinic and home care settings, focusing on management of chronic diseases (e.g., [12,13,46,47,59,60,82,83,86,89]). However, healthcare is inherently infrastructural. Given the known fragmentation in the healthcare infrastructure, urgent attention is needed to better understand what patients and caregivers "do" to make the healthcare infrastructure work for them. With digital healthcare service systems (e.g., patient portal, online "ask the doctor" services [45]) becoming increasingly popular, understanding this question can shed light on how we can design to support the interactions between individual healthcare consumers and healthcare infrastructure.

To fill this gap, we conducted a qualitative interview study of 32 U.S. parents of children under two years old to examine how they interact with the healthcare infrastructure on behalf of their young children. Drawing on previous HCI and science and technology studies (e.g., [17,63,77]) on infrastructure and infrastructuring, we use “infrastructuring work” to highlight the ongoing work individual healthcare consumers, including both patients and caregivers, engage to make the healthcare infrastructure work for them: the practices performed by individuals’ to align different components of healthcare infrastructure and fix the infrastructural breakdowns to make the complex and fragmented healthcare infrastructure work for themselves at the micro, individual scale.

We chose parents of young children as our study participants because they are unique in experiencing a transitional status change from being healthcare service receiver to the primary caregivers for their children, which bears implications from both caregiver and patient’s perspective. We address the following research questions: 1) what kinds of infrastructural breakdowns trigger individual health consumers’ infrastructuring work? 2) what types of infrastructuring work individual health consumers have to conduct? We found that infrastructural breakdowns frequently happened at different scales. To obtain desired healthcare services, our participants often had to conduct infrastructuring work to fix breakdowns, including repairing unexpected failures happening at the individual level, aligning multiple components at organizational and cross-organizational level, and circumventing infrastructural constraints.

Our contributions to HCI research are three-fold: First, we deepen the understanding of patients and caregivers’ work by discussing infrastructuring work, a form of patients and caregivers’ work that remain understudied; Second, we reflect upon HCI research on patient engagement in light of the infrastructuring work lens; Third, our work contributes to research on infrastructuring work by problematizing and highlighting several dimensions of infrastructuring work.

## 2 RELATED WORK

### 2.1 Patient and Caregiver Work

Our work draw on sociologists Corbin and Strauss [14]’s conceptualization of “work” in healthcare settings. Corbin and Strauss conceive patients and spousal caregivers’ participation in managing chronic illness at home as work. The concept of “work” here has many facets: “what tasks, who does them, how, where, the consequences, the

problems involved” (p. 224) [14]. They focus on three interrelated types of work performed by the patients and their spouses to manage chronic illness at home, including illness work, everyday life work (“the essentially daily round of tasks that keep the household going” (p. 226) [14]), and biographical work (the effort made to control over the reconstructed life, e.g., discovering new identity and meaning of life). Each type of work consists of several subcategories of work. For instance, illness-related work is made up of regimen work, crisis prevention and management, symptom management and diagnostic-related work. Everyday life work includes housekeeping, marital work, occupational work, etc.

HCI researchers have called for attention to patient work in technology design, focusing on identifying and mitigating challenges of patients’ self-management of chronic diseases (e.g., [12,21,46,47,59,60,86]). For instance, studies have found that cancer patients engage in tasks that identify, prevent, and recover from medical errors in an outpatient, cancer care setting [86]. They do significant personal health information management work over the course of cancer treatment, such as tracking side effects and preparing questions for clinicians [38].

Caregivers are heavily involved in everyday patient care activities [13]. Research in HCI, health policy, and medical fields has studied informal, unpaid caregivers of patients suffering from one (e.g., cancer, dementia, diabetes) or even multiple chronic conditions (e.g., [4,16,23,41,70]). Informal caregivers are often family members, friends, and neighbors who have personal relationships with the patients, rather than professionals who are paid or are part of a volunteer organization [79]. Informal caregivers usually engage in a range of tasks, including but not limited to helping with self-care or mobility (e.g., giving a ride, taking notes), household activities, making appointments, and medical care (e.g., giving injections), providing emotional support, communicating the patients’ needs to clinicians, guiding patients to understand their condition, and supporting patients to sustain online lives [54,64,79,85]. Informal caregivers usually experience high levels of burden, including emotional, physical, financial, and social difficulties (e.g., social isolation), and difficulties of managing their own time and coordinating their activities with others [13,70,83]. HCI researchers have explored ways of minimizing informal caregivers’ burden, including helping them track patients’ status [90], improve the relationships with patients [91], facilitate the collaboration between patients and caregivers [5] and among multiple caregivers [26,79], and maintain their own wellness by

providing social and instrumental support [13,82,83,89]. Some HCI studies [36,43,62,81,84] have focused on parents as informal caregivers. [36,43,62,81,84]

In summary, previous research on healthcare consumers' work has focused on types of care work associated with self-management of chronic diseases in home and clinic care settings. How individuals interact with the complex, often fragmented healthcare infrastructure has not yet been explored in prior literature. We aim to extend the research strand by elucidating the infrastructuring work that patients and caregivers engaged in during the encounters with different entities and actors in the large and behind-the-scene healthcare infrastructure.

## 2.2 Infrastructure and Infrastructuring

An infrastructure is conventionally considered to be a physical or technical foundation “which runs ‘underneath’ actual structures” [76], such as railroad tracks, power grid, and communication networks. In their original work, Star and Rubhleder [77] challenge this traditional view that an infrastructure is a substrate upon which something else runs or operates. They propose that infrastructure is sociotechnical and relational. An Infrastructure “becomes infrastructure in relation to organized practices” [77]. It never stands apart from its designers, users, and people who maintain it [76]. It is an ongoing alignment between contexts [3,77]. Star and Rubhleder [77] outline the following salient features of infrastructure: the embeddness of infrastructures in other structures, social arrangements and technologies; the transparency in invisibly supporting tasks; being either spatial or temporal (beyond a single event or one-site practice); learned as part of membership; shaping and being shaped by the conventions of a community of practice; plugging into other infrastructures and tools in a standardized fashion, modified by scope and often by conflicting conventions; and built on an installed base; becomes visible upon breakdown. HCI and information systems researchers have focused on information infrastructure (e.g., [33,53,74]) and human infrastructure (e.g., [11,18,80]). An information infrastructure is “a shared, evolving, heterogenous installed base of IT capabilities among a set of user communities based on open and/or standardized interfaces... [and] offers a shared resource for delivering and using information services in a (set of) community” [28]. Human infrastructure refers to “the arrangements of organizations and actors that must be brought into alignment in order for work to be accomplished” [40].

Inspired by Star and Bowker [76]’s usage of “how to infrastructure,” the notion of “infrastructuring” has been widely used in HCI and participatory design. In their article on organizational IT as work infrastructure, Pipek and Wulf highlight infrastructuring activities as the “in-situ design work of tailoring and configuring the infrastructure” [63]. They consider users as actors who have a variety of skills involving in the process of improving work information technology infrastructure. In participatory design, infrastructuring has become a common approach of designing community information technology [17]. It is “the work of creating socio-technical resources that intentionally enable adoption and appropriation beyond the initial scope of design, a process that might include participants not present during the initial design” [15]. Since infrastructure is an ongoing alignment between contexts where various contexts, practices, and technologies undergo changes, requiring continuous alignment of partly conflicting interests, infrastructuring as its design work is also an ongoing process, rather than a one-time activity or a design phase [3]. Corresponding to the features of infrastructure, infrastructuring activities have multiple aspects, such as “activities that connect different technological and social structures,” “activities that challenge and develop existing practices,” “activities that help in articulating reasons for a breakdown,” and “recovery activities after a breakdown” [17].

Previous HCI research has studied infrastructuring in different contexts, such as mobile knowledge workers’ infrastructuring practices [20] and entrepreneurs’ infrastructuring activities contributing to the Blockchain information infrastructures [33]. In healthcare settings, prior HCI work has adopted infrastructuring as an analytic lens to examine the design and implementation issues of large healthcare IT systems in hospitals (e.g., [6,27,53]). Some research focus on human infrastructure perspective, such as how hospital employees restructured the human infrastructure which was disrupted by a new healthcare IT system deployment [80] and how healthcare providers and patients co-facilitate the implementation of a telemedicine program [11]. However, little attention has been paid to the work of infrastructuring carried out by patients or caregivers to make the healthcare infrastructure work.

In this paper, “infrastructuring work” refers to the ongoing work individual healthcare consumers engage in to make the healthcare infrastructure work for them. We choose it over the term “articulation work” (which also concerns aligning and integrating issues and concerns and fixing breakdowns) for two reasons: First, articulation work is

“cooperative work to make cooperative work work” conducted by insiders of the cooperative work [69], while our participants are not members of cooperative work, and their work is individualistic efforts rather than a cooperative one. Second, “infrastructuring” is helpful in critically examining the healthcare infrastructure to question what values are inscribed into the design of the healthcare infrastructure, and how it impacts our participants’ experience and practice [75].

### 3 METHODS

From 2016 to 2018, the first author conducted 30 narrative interviews [22,34] with 32 participants (two interviews conducted with parental dyads) who had diverse demographic backgrounds. To determine whether the participants qualified for an interview, we first asked them if they were primarily responsible for navigating the healthcare system for the young children. If not, we asked if they could refer to the person who was. When two parents shared the work of care, the interview was conducted with the parental dyad. Narrative interviewing is an unstructured approach that allows participants to tell a narrative of their experiences and elicits a naturalistic rendering of the participants’ perspectives [34]. We chose this method because it is a pertinent way to unpack participants’ trajectories [67,71] which speak directly to our research questions. We recruited participants through direct contacts and snowball sampling. To diversify our participants, we screened interview candidates based on their ethnicity, educational background, occupation, location, socioeconomic status, length of stay in U.S., and their children’s health condition(s). Our final participants include parents of children who are generally healthy and face no extraordinary circumstances, parents of children with chronic health conditions, and parents of children with rare diseases. Participants aged from 21 to 39, having children aged between one month to two years, including those who were new to the U.S., e.g. international students and new immigrants, and those who were more familiar with the healthcare system such as people born and raised in the U.S. The sample is ethnically diverse, including people from Asian, Hispanic/Latino, Black/African American, and White/Caucasian backgrounds. Their occupations included stay-at-home parent, graduate student, teacher, engineer, manager, university staff, professor, physician, model, and small business owner. In the end, we conducted 30 interviews with 32 participants, including one father, two couples, and 27 mothers.

Following the narrative interview method, the first author used the question “When was your first time navigating the healthcare system for your baby?” as “a generative narrative question” [67] to invite participants to share their personal experiences. During the interview process, the first author listened attentively to the participants, exerted no interruptions, and only probed with questions including “is there anything else you want to say,” “how did it begin,” and “what happened before/after/then?” [22,34]. The interviews lasted from 50 minutes to 2.5 hours. When possible, we conducted face-to-face interviews. Remote interviews were conducted when the participants lived too far away to meet in person. Nine interviews were conducted face-to-face, and the remaining interviews were via Skype or phone calls. All interviews were audio recorded with participants’ permission. All participants received compensation for their participation in our study. IRB approval was obtained prior to data collection.

We used thematic analysis [8] to analyze our data in a deductive approach [61]. Two researchers participated in this analysis process. We first familiarized ourselves with data with the initial analytic interests in challenges our participants faced and practices they performed to tackle the challenges. Each researcher immersed himself or herself in the data through reading back and forth and marking ideas pertaining to our two research questions: what were the breakdowns and what participants did to fix them. During this iterative process, the two researchers had regular meetings on a weekly basis to discuss ideas. Each of us then started generating an individual list of initial codes through our whole dataset, after which we compared and combined our initial code lists through discussion. Based on the initial code list, we re-focused our analysis at the broader level of themes, using rounds of discussions to consolidate our codes into an overarching theme. We sorted different codes into potential, overarching themes, and collated all the related data within the identified themes. Next, we carefully compared the identified themes to the dataset and refine the them with the goal of ensuring internal homogeneity and external heterogeneity [61]. Lastly, we defined and named overarching themes. Our final satisfactory thematic map of the data includes three primary themes concerning three distinct types of breakdowns and corresponding infrastructuring work. They are repairing failures at the individual level, aligning multiple components at organizational and cross-organizational level, and circumventing infrastructural constraints. In the following section, we present these themes. When reporting quotes from interviews, to protect

our participants' identities, we use P1, P2, etc. to denote different study participants.

## 4 FINDINGS

All participants stated that they started interacting with the healthcare infrastructure for their babies when they were planning to become pregnant or knew they were pregnant, as they perceived that the fetus' health was deeply entangled with the mother's health situation during pregnancy. Most of our participants (31 out of 32) encountered breakdowns when interacting with the healthcare infrastructure for their babies' health. They perceived the U.S. healthcare infrastructure fragmented and complex. When breakdowns happened, fragmentation and complexity became visible. In order to obtain desired healthcare services, they often had to conduct infrastructuring work to fix breakdowns. In this section, we report experienced breakdowns and infrastructuring work that our participants conducted to fix them.

### 4.1 Repairing Failures Happening at the Individual Level

The first type of infrastructuring work that our participant conducted is repairing failures happening at the individual level. Such breakdowns were caused by individuals working for (e.g., individual healthcare providers; staff of insurance company) or interacting with the infrastructure (e.g., human resources employees who help other employees interact with insurance companies).

For example, P13, during her first trimester of pregnancy, was diagnosed as having a cyst on her left ovary, which needed a surgery to remove. She met a gynecological oncologist Dr. M on Nov 14th and scheduled the surgery on Dec 2nd. P13 wanted to make sure that Dr. M would have her medical records (e.g., her recent ultrasound images) from her obstetrician (OB) for the surgical preparation. She made phone calls to both offices to make sure her ultrasound images were faxed and received:

*The day before my surgery or two days before my surgery, I checked with Dr. M's office: "Did you get that fax? And they said, "yes, we received it. "*

Despite her efforts, on 7:30am the day of surgery, a breakdown still happened when she already lied on the bed and was prepared for the surgery:

*The doctor came to me and he's like, "do you know the size of your cyst? Because I was looking at your record last night. I didn't see the ultrasound report". I was pretty shocked... I was like, "okay, I remember it's thirteen by fourteen." so he took*

*the note. That's pretty shocking because I was like, I double checked ... and the doctor was like, "oh, probably it's thanksgiving. People forgot to put that in your record."*

P13 felt shocked that despite her efforts, Dr. M still did not get the information, but was relieved that she could recollect the measurement. P13's experiences showed that when multiple individuals (e.g. referring and receiving health care providers, administrative staff) were involved, the transferring process of P13's ultrasound report was uncertain. Mistake or delay at any single step could cause breakdown. In this case, although the report arrived at the oncologist' office, the staff in the oncologist's office forgot to put P3' ultrasound report in the medical record, a failure happening at the individual level. P13 was lucky to manage to repair the failure on the fly, only because she "asked for the dimensions (of the cyst) on the spot" during her OB visit, memorized the numbers, and communicated those numbers to the oncologist.

P21 and P25 also encountered the failures caused by individuals working in the healthcare infrastructure. In both cases, such individuals were staff in insurance companies. When P21 and P25 received unexpected, large bills for the health services which were supposed to be covered by the insurance, they started repairing the breakdowns by checking the policies to verify that they should not be charged, calling the healthcare providers and insurance companies to figure out what and who caused the error, asking the insurance company to fix the error (which required multiple phone calls), and confirming the error had been fixed. P21 explained her case to us:

*...I received an unexpected bill from the hospital. I called the hospital. They said it's because my insurance company didn't cover it. So I called the insurance company, and they said that the technician who took the ultrasound for me was in-network, but the person who read my ultrasound image was not. It's really weird...I said, "the hospital is in my network, how come that person was not?!" The representative said: "well, he is not. That happens." ...I decided that I wouldn't pay the bill until I figured out why...I called the insurance company for multiple times, and finally a representative admitted that it's indeed an error. Someone input the wrong bill code.... About three weeks later, I received the same bill again. So I called the insurance again, the first representative who answered my phone couldn't explain it clearly.... The second representative finally admitted the wrong bill code was still there. So the problem was, the previous representative didn't fix the error, although he found the error...Anyway, after calling them for so many times, finally someone corrected it for me. Then I called the department in the*

*hospital. I asked the staff whether the bill had been covered by the insurance. She told me, “Yes, it’s been covered.”*

In the U.S., it is not rare that a facility is in-network, while some service providers (e.g., anesthesiologists, radiologist) within the facility are out-of-network [37]. Such mysterious misalignment between physical (facilities) and human components (providers) of the healthcare infrastructure intensifies patients and caregivers’ vulnerability in receiving surprising and burdensome bills [37]. (For instance, among our participants, P13 had to pay three large bills because of this type of misalignment.) It is not surprising that the insurance company staff insisted that the bill P21 received was not an error in the beginning, as “it happens.” In addition, medical billing professionals could easily make human errors in the process of filling out, submitting, and processing a medical claim, especially when they calculate bills using insurance codes, which requires medical knowledge and extreme caution to understand physicians’ charting and make sure to input right codes. In both P21’s and P25’s cases, insurance procedural codes were messed up, leading to billing errors. Both P21 and P25 had to spend a large amount of effort into repairing such human infrastructural failures. Such repairing work consisted of multiple types of work, such as information work (e.g., checking policies) and negotiation work (e.g., calling both hospitals and insurance to explain).

For P14, the infrastructural failure at individual level was caused by an individual who connected her to the healthcare infrastructure. Below P14 described her encounters with the human resources (HR) officer in the company she was working for:

*In the first month (after birth), my baby was automatically covered by my insurance...but I had to add her to my plan within this one-month window... I asked my HR to do the enrollment in advance...I took my baby to the pediatrician for the one-month checkup. I waited for a long time and it’s finally my turn...the receptionist said, “your baby is not insured.” I was so shocked...I was already there, I’d waited for such a long time, and my baby was crying. I just wanted to finish the checkup as soon as possible. It’s ridiculous that the HR didn’t do the work.... I called her, I had to wait there, with my baby crying, I had to wait for her to contact the insurance company and enroll for me...It’s really frustrating...I couldn’t contact the insurance company directly, because the HR was in charge of insurance enrollment...*

P14 was enrolled in an employer-sponsored group plan, where the HR department was in charge of adding her newborn to the plan within a short timeframe. When this

connecting point failed, breakdown happened. Our other participants also mentioned similar failures at connecting points such as childcare facility and referring personnel.

In summary, because of the complexity and fragmentation of the healthcare infrastructure, whether the infrastructure can work seamlessly relies heavily on human components (e.g., individual provider, administrative staff). When individual(s) made mistakes, the whole infrastructure could easily fail to function properly for individual patients and caregivers. As a result, patients and caregivers were forced to repair the failures. The repairing work we identified contains three phases: 1) identifying who caused the failure, 2) negotiating with individual(s) who were responsible or could help fix the failure, and 3) confirming and reconfirming that the failure had been fixed. Because individuals who could help fix the failure can also make mistakes and delays, the second phrase was often repetitive and required a lot of attention, as manifested in P21 and P25’s cases.

## 4.2 Aligning Components at Organizational and Cross-Organizational Level

Participants encountered failed coordination (sometimes no coordination at all) within one healthcare organization or across organizational boundaries. Correspondingly, the second type of infrastructuring work is aligning multiple components of the healthcare infrastructure.

For instance, P1 (interviewed with P2 together as a couple) whose baby has diabetes explained to us how he had to put much effort in aligning their old and new insurances and different medical departments and billing systems within one medical group:

*... even though we gave them the new insurance, they were constantly billing the old policy that expired...and of course the insurance company would not honor that... the bills are very high. And the issue was I had to be the one constantly calling them, telling them that the insurance that they’re billing is incorrect... this happened at least for about fifteen months back and forth. Yes, so the baby was almost like a year and six months before we actually stopped receiving bills. ... We kept on getting bills and every department that sent me another bill, I had to call and gave them the new insurance and they billed me again and they billed me again and I still had to call and changed it again. ... And I had to be the one to keep calling and correcting it, which was frustrating... I talked with one, and someone else, the new person was not aware what I called and gave before. ...it seems as it was just not being, um, coordinated across the departments...So literally like ten different doctors are billing you separately, even*

*though they are from the same practice (medical group) ...How it works is like, because each doctor's in a different department, department of anesthesiology, department of pediatrics, department of ophthalmology... so literally, each department bills you separately. So you have to call each one and give them the new policy information so that they could bill it properly. Well, there is a central billing, but it also seems as if the department prepares their invoice and then the central billing send all to us. But it looks like there is something where the insurance information was just not available to each department, for whatever reason.*

P1's case demonstrated the nonalignment across multiple departments within one medical group. Different than the breakdowns on individual patient or representative level which a known person could be contacted to fix the error, the breakdown P1 encountered is much more elusive. It involved multiple departments within one organization, and it's invisible to P1 which specific individual might have caused such breakdown. Despite P1's baby received healthcare services from one medical organization, because of the fragmented design of the billing system, different departments failed to coordinate regarding P1's updated insurance information. P1 had to call each department constantly to correct the wrong bills again and again within a long period of time (fifteen months). It appeared as if there was no information exchange among these multiple departments, and P1 ended up updating new insurance policy with each single department. P1's infrastructuring work was not a one-time task, but involved the constant alignment of different departments, the temporality of old and new insurances, and the new insurance policy. As P1 explained, such infrastructuring work was "frustrating".

Our participants also had to do infrastructuring work to streamline failed coordination across multiple organizations. One relatively straightforward type of such infrastructuring work is transferring information or objects between organizations. For instance, P20, who suffered from rheumatoid arthritis, had to drive between two clinics to transfer her own medical records because the coordination between two clinics failed:

*When I was pregnant...my OB wanted to get my medical records from my rheumatologist.... Then they both complained to me. My OB complained that he hadn't received the faxes. My rheumatologist complained that he had faxed for so many time...back and forth for one month...In the end, I had to drive to my rheumatologist's clinic, I got my records, made a copy, then drove to my OB's clinic, handed it to him...Problem finally solved...*

P20's experiences showed that there was no interoperable medical information system between the rheumatologist and OB's clinics, which manifests the fragmentation of the U.S. healthcare infrastructure. When faxing failed for some unknown reason, P20 had to transfer the medical records from one organization to another.

Sometimes more complicated and difficult infrastructuring work was required, especially when there was no coordination between organizations at all. For instance, to manage the health plan for her baby, P8, who gave birth in a midwifery birth center, had to align disjointed organizations and temporality:

*In the hospital, you get a birth certificate in the hospital...the paperwork for a social security card is automatically done. In a midwifery, you don't have a birth certificate...You don't fill out that paperwork, you have to go do all those things. So Olivia (pseudonym) was kind of flying under the radar for the first six months of her life. We didn't even get her birth certificate until, she was way over six months old. You have to do within the first year legally, and which is a crazy amount of time. It made our paperwork more complicated. ... Uh, so I had to have like a special form filled out by the midwife to submit it to F (an insurance company). ...they're like, "we need a social security number". I was like, "she doesn't have one." Like "what do you mean she doesn't have one?" "It's like she's not born in hospital" ...they had to have the statistics of the doctor who was there at the time of the birth, the weight, the height, the heartbeat and whatever else the information was. That's like the proof of birth, and verification that I am the pregnant...So yeah, I had to get special paperwork for that. And then, actually when tax season came for that year, we still hadn't gotten her social security number...F's like we need her social security number to report to the IRS that your child is insured because otherwise we get fine. I'm like, oh, okay, we'll get the social [security number]....so later we had to do that.*

Although both hospitals and midwifery birth centers provide maternity services, their procedures are often different in providing birth certificate and obtaining social security numbers (SSN) for newborns. Hospitals usually automatically submit the SSN applications, while midwifery birth centers lack connections with social security offices. To manage her baby's health plan, P8 had to do extra work, including registering an out-of-hospital birth, getting SSN, and submitting birth certificate and SSN to the insurance company. Unlike the breakdowns caused by individuals in the previous section, in this case it was caused by the disconnection among multiple health and non-health organizations including the birth center, the social security

office, and the insurance company. P8 had to figure out which organizations were involved and the exact procedure and timeline to fix it. This infrastructuring work involved multiple organizations and the onerous paperwork that had to be done within a mandatory timeframe. It also involved careful management of ordering of actions, such as which paperwork should be done first. For P8 who was extremely stressed in dealing with her baby's health issues, the extra infrastructuring work was "additionally hard" and "complicated."

In some cases, our participants had to align different levels (e.g., national and local) of components. For instance, P4, who was monitored for suspected Zika virus infection during her pregnancy, explained:

*I got pregnant in September, then I went to Cancun in December. That December was exactly when the Zika virus became a concern. So when I came back, I was notified that every pregnant woman who went to the Caribbean should visit their OBs...Because of this, during my pregnancy, I had to do ultrasounds every two weeks. My OB checked my baby's development, to confirm whether she got infected by Zika or not...I was worried, because my insurance plan only covered three ultrasounds. Then who should pay for the rest? ...I called the insurance company and negotiated. I said it's CDC's requirement that my OB had to order many ultrasounds for me. It's a national policy, then the insurance company should adjust the coverage to follow the national policy.... So the insurance company agreed to cover partial cost for me. It's like, every time when I was about to do an ultrasound, my OB asked my insurance company for preauthorization, then I paid for the copay, it's like \$90 each time. It was OK, at least I didn't need to pay for the full amount.*

P4 had already encountered several breakdowns related to insurance prior to the pregnancy. Thus, she proactively checked the insurance policy this time. In this case, P4's OB (local level) followed the CDC (Centers for Disease Control and Prevention) (national level)'s recommendation to order additional fetal ultrasounds for P4. P4 had to negotiate with the insurance company to adjust the coverage in response to CDC's recommendation and OB's actions.

In summary, different entities within the healthcare infrastructure are often disconnected or poorly coordinated, which is further entangled with non-health organizations (e.g., social security offices) which are loosely connected to the healthcare infrastructure. Thus, organizational and cross-organizational breakdowns easily happen and force individual healthcare consumers to conduct burdensome infrastructuring work. Such infrastructuring work involved

identifying relevant entities, locating the problems, paying painstaking attention to figure out the course of actions, dealing with multiple entities repetitively, and finally connecting them together. It is worth noting that, it was sometimes extremely complex and ambiguous for our participants to figure out which entities caused the failure and how to fix it, and actually conduct the work. Thus, some participants chose to give up under certain situations which were elusive or required extremely demanding work.

### 4.3 Circumventing Infrastructural Constraints

The third type of infrastructuring work is circumventing structural constraints embedded in the healthcare infrastructure, such as spatial constraints, temporal constraints, seemingly inflexible policies, and financial constraints.

For example, P6 encountered spatial and temporal constraints during the first trimester:

*I started bleeding ...I was worried that it's a miscarriage sign... But my OB refused to do anything... About two weeks later, I was still spotting...I couldn't bear it anymore. I asked my OB to do ultrasound for me. He told me that he could not do it for me, because his office didn't have the equipment, and if I insisted, I should make an appointment with the hospital (where the doctor was affiliated) and at least wait for one or two weeks, because large hospitals are usually very slow...I was very anxious. I didn't want to wait.... So I used my husband's insurance. His insurance plan also covers me, so I used his insurance and found a small clinic.... It's a small clinic, but it has the equipment, and it's not busy. They did the ultrasound for me the same day. They tested my baby's heartbeat....The doctor said, "it means your baby is fine. Don't worry." I felt so relieved.*

P6 faced spatial (OB's clinic having no equipment) and temporal (long appointment waiting time) constraints. She circumvented the constraints by using her secondary insurance plan to maximize the coverage of healthcare facilities, calling many clinics to check for the equipment and waiting time, and obtaining desired service from another facility.

Healthcare policies, especially billing policies, often seem rigid and impose constraints to individual health consumers. However, our participants managed to strategically circumvent the constraints. For example, P15 talked about how she worked around the referral procedure to get her the needed medication on time.

*I have underactive thyroid... I searched online, I knew I should take medications immediately, otherwise I might miscarry...I*



*made an appointment with a specialist immediately and visited him...The right procedure should be, I ask the student health center (in her university) to provide a referral letter, then I visit the specialist. Otherwise my insurance won't cover the cost. But I was really worried and just wanted to get the medications as soon as possible. So I was like, whatever, I will just visit the doctor and take the medications, then I will deal with the insurance issue. I remembered that I called to schedule the appointment on Friday, and then on Monday, I visited the doctor and got the medications. After that, I called the insurance person in the student health center...I said I had a pregnancy emergency. I had to visit the doctor as soon as possible, I didn't have time to contact you.... He told me to appeal and fill out a form...Then the cost was covered...my intuition told me that although the insurance policies were strict, there must be some room for negotiation...so I tried.*

In the face of a pregnancy emergency, P15 realized that time would not allow her to follow the exact procedures articulated in the policies. Instead, P15 prioritized her and her baby's health, and put the constraints of insurance policies aside. It was fortunate that her later negotiation worked in eventually circumventing the constraints and the potential high cost.

Because of the high cost of the U.S. healthcare, some participants faced financial constraints which prevented them from receiving desired services. Nevertheless, they managed to conduct strategic infrastructuring work to work around the constraints. For instance, P28, a low-income mother, explained to us how she made expensive services affordable by requiring hospital services through a birth center, which suggested by another low-income mother in her extended family. She described:

*When I found out I was pregnant, I knew that I had to have an insurance to cover the cost. we didn't have [it], uh, actually we had an insurance, but our insurance was Christian Healthcare Ministries...but you have to pay the Gold program to get the pregnancy covered. Mine was bronze program, I called them and checked, it didn't cover anything....I wanted to do the 4d ultrasound (Note: four-dimensional ultrasound).... We only have two large hospitals...They said my out of pocket expense would be more than \$1000...I couldn't afford that...I requested the 4d ultrasound in the birth center, then the hospital sent someone to the center, with their equipment, and did the ultrasound for me...Because the birth center had a good business relationship with the hospital...It only cost me around \$250...It's unbelievable how much differed even it's the same hospital, the same service.*

Similarly, P26 successfully reduced the cost of a desired test by not using her insurance and asking for her OB's help,

*There's a test....it cost around \$6000 in total and copay should be around \$1000...but I really wanted to do it....my friend suggested me ask my OB to negotiate for me...I talked to my OB, I told her that I would rather not go through my insurance... My OB called the lab for me...it only cost me \$200 in the end, much cheaper than the copay.*

In P28 and P26's cases, their infrastructuring work were proactive rather than reactive, which prevented breakdowns of receiving large bills from happening.

Our participants' experiences manifest the constraints imposed directly by the infrastructural design, such as timeline (waiting time, when to see an OB, how long it takes to get a referral), cost (birth center vs. hospital), and equipment (having the ultrasound service in OB office or not). For example, the billing mechanism of a same service can differ for different insurances, different facilities, with or without insurance, and oftentimes is negotiable. However, because the behind-the-scene operation of infrastructure is not transparent, how to circumvent infrastructural constraints relies on individual healthcare consumers to figure out, as shown in the above cases, either through obtaining advice from other consumers or by trying all different possibilities, without knowing whether they could succeed. For those consumers who did not know there might be ways of circumventing (e.g., negotiation), they had to bear the negative outcomes (e.g., large bills). In addition, the outcomes of this type of infrastructuring work are uncertain. Not all of our participants' infrastructuring work succeeded in bypassing the constraints. For instance, P24 also tried to negotiate with the lab and insurance company regarding the cost of an expensive DNA test after she received a large bill, however it did not work.

## 5 DISCUSSION

In this paper, we reported the infrastructuring work our participants conducted in order to deal with the infrastructural breakdowns happening at different levels and scales. Next, we unpack properties of such infrastructuring work and derive design implications.

### 5.1 Unpacking infrastructuring work

The breakdowns our participants encountered manifest the vulnerability of the healthcare infrastructure. The healthcare infrastructure is fragmented and complex, and relies heavily on the human infrastructure to function. Whenever there is a human error, breakdowns happen and invisible infrastructural components reveal [77]. We

identified internally infrastructural misalignments and nonalignments at different levels and scales, such as the misaligned information systems within and between different entities, misaligned physical facilities and healthcare providers, and nonaligned working mechanisms of different organizations. These misalignments and nonalignments were often unexpected and unprepared for by patients and caregivers, imposing more challenges for them to obtain timely, high-quality, and affordable healthcare services. In addition, the healthcare infrastructure directly imposes structural constraints because of the inconsistent design of facilities, policies, systems and its inherent constraints on time, space, and other resources. Our participants had to wrestle with various infrastructural breakdowns, and conduct their own infrastructuring work to make the infrastructure work for them at a micro scale.

Patient work has long been studied in HCI, with an emphasis on the work involved in self-care or clinical treatment processes (e.g., [38,70,86]). Our findings on infrastructuring work extend the scope of patient work to include the work happening in patients and caregivers' interaction with a healthcare infrastructure. Infrastructuring work is different from previously studied patients and caregivers' work in multiple aspects. First, patients and caregivers' care work is mainly concerned body (patients' body), aiming to care for patients' health, while infrastructuring work goes far beyond self-management of medical conditions and interacting with individual clinicians; instead, it involves many organizations and entities direct or loosely connected to support clinicians' work. It is about dealing with the artificial and organizational components. Second, patients' and caregivers' care work is mostly scaffolded by personal relationships (e.g., relationship between caregiver and patients; relationship between patients and their primary physicians) and situated in home care or clinical settings, which usually involves planning and maintaining routines (e.g., housekeeping work, making appointment). The infrastructuring work is mostly institutional rather than personal, and happens when individual healthcare consumers interact with different healthcare institutions. Third, infrastructuring work is emergent rather than routinized, which only become visible when breakdowns happen. Fourth, infrastructuring work is usually full of confrontation, arguments, negotiation, finding proof, and rational choices. Last, infrastructuring work is forced by the problematic or imperfect infrastructural design. It is nearly always needed by individual healthcare consumers when they interact with healthcare infrastructure, not just by

chronic patients and their caregivers, "because the complex, messy, and unevenly distributed nature of infrastructure requires that individuals be in continuous negotiation with it" [20].

## 5.2 Infrastructuring work as invisible labor

It is important to note that patients and caregivers carry out infrastructuring work not only because they want to make the infrastructure work, but also because they will otherwise be the bearers of any negative consequences of the unfixed infrastructure failures (e.g., misdiagnosis of babies and unreasonable bills). While healthcare already occupies a significant portion of economy [68] and large healthcare corporations have sophisticated their ways of profiting and avoiding liability [57], the profitable healthcare infrastructure rides upon the work of individual patients and caregivers who are unacknowledged and inescapable. The infrastructuring work is beyond the neoliberal ethos that demands individual healthcare consumers to be rational actors responsible for their own health [44], and should be analyzed as a form of invisible labor [19,65]. Such labor upholds a functioning healthcare economy, but remains unacknowledged by healthcare companies and rests largely with healthcare consumers who are isolated from each other.

Moreover, such labor is usually performed under the conditions of fatigue (i.e., exhausted parents of young children juggling a variety of tasks and contingencies). Human cognitive capacity is significantly constrained when they experience fatigue and cognitive overload [78]. For instance, we have several participants who admitted that they did not have sufficient mental capacity to handle conflicting bills and ended up paying all of them. Therefore, what participants went through can be seen as a form of institutional cruelty on individuals and an existential crisis, to rephrase from Light et al.'s analysis of how institutions design to manage, exploit, and "humiliate" individuals [42]. By stressing infrastructuring work as labor, we hope to engage in what Bowker called "infrastructural inversion" [7], to render patients' and caregivers' labor of infrastructuring visible and acknowledged.

The infrastructuring lens differs from what previous HCI work (e.g., [55,56,92]) has discussed as patient engagement (patients and caregivers' involvement in their own care), which has been advocated by government agencies and many researchers as a critical factor in improving healthcare outcomes (e.g., [9,48]). First, engagement implies that patients have choice: They could for example use self-tracking devices to monitor health indicators at home [2] or

participate in online communities connect with those with similar experiences [24,31,32]. However, our participants did not have choice to not participate. As our study shows, participants' engagement with health services often occurred in the form of forced engagement, wherein they had no choice but to expend their own efforts to ensure proper healthcare delivery. Second, engagement does not account for the political economy of the healthcare industry that is hugely profitable and yet fails to deliver satisfactory healthcare service. Persuading healthcare consumers to do more burdensome work is not going to improve the fragmented healthcare infrastructure. Thus, rather than promoting patient engagement, HCI researchers should ask critical questions about the nature of engagement, the outcomes of the engagement, who benefits from patient engagement, and the political economy of engagement.

### 5.3 Infrastructuring work: why and for whom?

Infrastructuring is an elusive concept started by Star and Bowker's use of infrastructure as a verb [76]. Following research has generally revolved around the idea of making infrastructure work, and several particular scenarios: developing and implementing infrastructure, upgrading infrastructure by adding new content or modifying existing content, or fixing breakdowns [17,33,63]. By investigating infrastructuring in the context of healthcare, our work adds to this line of research by problematizing and highlighting several dimensions of infrastructuring work:

First, the structure and purpose of existing infrastructure impacts how infrastructuring work is carried out. Previous work has largely examined infrastructures at a relatively small scale with users and designers organically integrated into their internal workings. The U.S. healthcare infrastructure consists of numerous localized sub-infrastructures, with rules and policies which often constrain individual health consumers. Our participants are from diverse locations with different local healthcare infrastructure, most of them had to make localized and individualized endeavor to make the infrastructure work for them. At a much constrained role, individual health consumers could not in any meaningful way impact the structural content of the healthcare infrastructure. Knowledge they obtained through fixing breakdowns is likely to stay with individual health consumers, rather than being utilized to improve the healthcare infrastructure.

Second, making infrastructure work also entails the question of "for whom," where asking positionality becomes meaningful. The U.S. healthcare infrastructure can be considered as highly successful for healthcare industry,

because they successfully and secretly move the burden of labor onto individual health consumers and exploit them. But for health consumers, it fails in numerous places. Therefore, whether an infrastructure is functioning also rests upon the positionality of the observer, and impacts the nature of infrastructuring.

Third, regarding the outcome, previous research mostly presented infrastructuring work as a "continuing design in use" activity and intended to have a long lasting improvement on the infrastructure [35,63]. By contrast, the infrastructuring work conducted by patients and caregivers is temporary and ephemeral, only produced "fleeting moments of alignment" [87] suited to individual needs at a micro scale, without changing the healthcare infrastructure itself. The outcomes of such infrastructuring work are temporary or even ephemeral. Thus, there is a need to truly improve the infrastructure to enable more smooth interactions within the infrastructure, and between individual healthcare consumers and healthcare infrastructure.

## 6 LIMITATION AND FUTURE WORK

This work focuses on understanding individual service consumers' interaction with the U.S. healthcare infrastructure, thus, we selected study participants based on who was/were primarily responsible for interacting with the infrastructure for the young children. Those partners not involved in such practices were excluded from our study. The imbalanced gender ratio in our final sample struck us as a possible indicator to the invisible work of caring for babies frequently carried out by women [29]. However, our sample size is limited in reaching a definitive conclusion about this issue, and our data is limited in terms of inferring how and why the issue happened. We believe it will be fruitful to investigate this issue in future work at a larger scale from a feminist stance or a feminist political economy perspective.

## 7 CONCLUSION

In this paper, we reported on the healthcare infrastructural breakdowns that 32 parents encountered and their infrastructuring work that made the infrastructure work for them. We analyzed the characteristics of such infrastructuring work. By analyzing the work of patients and caregivers in the context of healthcare infrastructure, we seek to render their labor of infrastructuring visible and acknowledged.

Like the healthcare infrastructure, many infrastructures in modern society are complex and fragmented, such as the

education infrastructure [58] and the immigration service infrastructure [1,72]. More research on infrastructuring work in various domains is needed to explicate how

ordinary individuals could obtain desired outcomes against complex service systems.

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