**Title**

Navigating the Healthcare Service “Black Box”: Individual Healthcare Consumers’ Practices and Design Opportunities

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**Publication Date**

2019

UNIVERSITY OF CALIFORNIA,
IRVINE

# Navigating the Healthcare Service "Black Box": Individual Healthcare Consumers' Practices and Design Opportunities

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Information and Computer Sciences

by

Xinning Gui

Dissertation Committee:
Associate Professor Yunan Chen, Chair
Associate Professor Kai Zheng
Associate Professor Melissa Mazmanian
Assistant Professor Kathleen H. Pine

2019

# DEDICATION

To

My husband, Yubo Kou, for adventuring with me.

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# ACKNOWLEDGMENTS

First and foremost, I would like to express my deepest gratitude to my advisor and best friend, Dr. Yunan Chen. Three years and three months ago, she lent me a hand and took me as her student. She introduced me to health informatics research, shared her experiences with me wholeheartedly, supported me constantly, and offered a tremendous amount of insightful advice on both my research and personal growth. Working with her has made me understand what makes an amazing advisor, which will forever guide me to be the best mentor I can be in my own professorship.

I am extremely grateful to my dissertation committee members. Dr. Kai Zheng has given me substantial support. He gave me sharp feedback on my papers and job talk, and shared a lot of valuable academic resources with me. Dr. Kathleen H. Pine is a great friend and collaborator. She was always there when I needed her help and support. Dr. Melissa Mazmanian has always been supportive when I reach out to her for help. She gave me valuable feedback on my dissertation research. As the vice chair of graduate affairs and a DECADE mentor, she helped me tackle overwhelming challenges during my Ph.D. study.

I'm also deeply indebted to other Informatics faculty members Drs. André van der Hoek, Bonnie Nardi, Gillian Hayes, Gloria Mark, Daniel Epstein. Dr. André van der Hoek has been always there for me when I needed help most. Dr. Bonnie Nardi trained me to be an ethnographer. Drs. Gillian Hayes and Gloria Mark offered timely help when I had struggles. Dr. Daniel Epstein gave me insightful guidance regarding job search. Without their support, I would not have made it this far.

I would like to extend my sincere thanks to ICS staff members Marty Beach, Suzie Barrows, Julio Rodriguez, Adriana Avina, and Wendy Wehofer. They were extremely responsive and supportive. They helped me deal with a lot of procedural issues, which made my PhD study hassle-free.

I am also grateful to all the amazing researchers and friends I have been fortunate to collaborate with: Yong Ming Know, Clara Caldeira, Tera L. Reynolds, Yao Li, Yu Chen, Qiaozhu Mei, Yue Wang, Shaozeng Zhang, Julien Forbat, Daniel Stokols, Alfred Kobsa, Xiaojuan Ma, Heng Xu, Dan Xiao, and Charlotte Tang.

Special thanks to my supportive lab mates in HAI lab, as well as other friends who accompanied and supported me at UCI: Caitie Lustig, Mengyao Zhao, Yue Rong, Jiang

Wan, Xuan Guan, Jieyun Ye, Chenying Qin, Six Silberman, Juliet Norton, Jingwen Zhang, Mustafa Ibraheem Hussain, Lu He, Mayara Costa Figueiredo, Zhaoxian Hu, Elizabeth Eikey, Brian Tran, and Mohammad Eletriby.

I am grateful to my study participants. The completion of my dissertation would not have been possible without their dedication.

Last but not the least, I would like to thank my family for all their love and support throughout so many years. Many thanks to my parents and parents-in-law who always supported any decisions that I made. And most of all, I am extremely grateful to my loving husband Yubo Kou, who has been adventuring with me since 2005.

This research was partially supported by the National Science Foundation under grant HCC-1219197.

# CURRICULUM VITAE

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## FIELD OF STUDY

Human-Computer Interaction, Health Informatics, Computer-Supported Cooperative Work, Social Media Research

## PUBLICATIONS

### JOURNAL ARTICLES

[J10] Navigating the Healthcare Service "Black Box": Individual Competence and Fragmented System

Xinning Gui, Yunan Chen, Kathleen Pine. 2018

Proceedings of the ACM on Human-Computer Interaction, Vol. 2, CSCW, Article 61

(CSCW 2018 second cycle) [Acceptance rate: 25.6%]

[J9] When SNS Privacy Settings Become Granular: Investigating Users' Choices, Rationales and Influences on Their Social Experience
Yao Li, Xinning Gui, Yunan Chen, Heng Xu, Alfred Kobsa. 2018
Proceedings of the ACM on Human-Computer Interaction, Vol 2, No. CSCW, Article 108 (CSCW 2018 second cycle) [Acceptance rate: 25.6%]

[J8] Professional Medical Advice at your Fingertips: An empirical study of an online "Ask the Doctor" Platform
Xiaojuan Ma, Xinning Gui, Jiayue Fan, Mingqian Zhao, Yunan Chen, Kai Zheng. 2018
Proceedings of the ACM on Human-Computer Interaction, Vol 2, No. CSCW, Article 116 (CSCW 2018 second cycle) [Acceptance rate: 25.6%]

[J7] Entangled with Numbers: Quantified Self and Others in a Team-Based Online Game
Yubo Kou, Xinning Gui. 2018
Proceedings of the ACM on Human-Computer Interaction, Vol 2, No. CSCW, Article 93 (CSCW 2018 second cycle) (Best Paper Honorable Mention Award) [Acceptance rate: 25.6%; , Honorable Mention: top 2.7%]

[J6] Investigating Support Seeking from Peers for Pregnancy in Online Health Communities
Xinning Gui, Yu Chen, Yubo Kou, Kathleen Pine, Yunan Chen. 2017
Proceedings of the ACM on Human-Computer Interaction, Vol 1, No. CSCW, Article 50 (CSCW 2018 online first) [Acceptance rate: 27.3%]

[J5] Conspiracy Talk on Social Media: Collective Sensemaking during a Public Health Crisis
Yubo Kou, Xinning Gui, Yunan Chen, Kathleen Pine. 2017

Proceedings of the ACM on Human-Computer Interaction, Vol 1, No. CSCW, Article 61 (CSCW 2018 online first) [Acceptance rate: 27.3%]

[J4] Managing Disruptive Behavior through Non-Hierarchical Governance: Crowdsourcing in League of Legends and Weibo
Yubo Kou, Xinning Gui, Shaozeng Zhang, Bonnie Nardi. 2017
Proceedings of the ACM on Human-Computer Interaction, Vol 1, No. CSCW, Article 62 (CSCW 2018 online first) [Acceptance rate: 27.3%]

[J3] One Social Movement, Two Social Media Sites: A Comparative Study of Public Discourses
Yubo Kou, Yong Ming Kow, Xinning Gui, Waikuen Cheng. 2017
Journal of Computer Supported Cooperative Work, 26, 4-6, 807-836.

[J2] Use of Information and Communication Technology among Street Drifters in Los Angeles
Xinning Gui, Julien Forbat, Bonnie Nardi, Dan Stokols. 2016
First Monday vol. 21(9).

[J1] Foster the "Mores", Counter the “Limits”
Xinning Gui, Bonnie Nardi. 2015
First Monday vol. 20 (8).

## CONFERENCE PROCEEDINGS

[C14] Making Healthcare Infrastructure Work: Unpacking the Infrastructuring Work of Individuals
Xinning Gui, Yunan Chen
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2019 (CHI 2019) (Best Paper Honorable Mention Award) [Acceptance rate: 23.8%]

[C13] Turn to the Self in Human-Computer Interaction: Care of the Self in Negotiating the Human-Technology Relationship
Yubo Kou, Xinning Gui, Yunan Chen, Bonnie Nardi
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2019 (CHI 2019) [Acceptance rate: 23.8%]

[C12] New to a Country: Barriers for International Students to Access Health Services and Opportunities for Design
Charlotte Tang, Xinning Gui, Yunan Chen, Mohamed Magueramane. 2018
Proceedings of the EAI International Conference on Pervasive Computing Technologies for Healthcare 2018 (PervasiveHealth 2018) [Acceptance rate: 24%]

[C11] Multidimensional Risk Communication: Public discourse on Risks during an Emerging Epidemic
Xinning Gui, Yubo Kou, Kathleen Pine, Elisa Ladaw, Harold Kim, Eli Suzuki-Gill, Yunan Chen. 2018
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2018 (CHI 2018) [Acceptance rate: 25.7%]

[C10] Playing with Streakiness in Online Games: How Players Perceive and React to Winning and Losing Streaks in League of Legends
Yubo Kou, Yao Li, Xinning Gui, Eli Suzuki-Gill. 2018
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2018 (CHI 2018) [Acceptance rate: 25.7%]

[C9] Understanding the Patterns of Health Information Dissemination on Social Media during the Zika Outbreak

Xinning Gui, Yue Wang, Yubo Kou, Tera Leigh Reynolds, Yunan Chen, Qiaozhu Mei, Kai Zheng. 2017
Proceedings of American Medical Informatics Association 2017 Annual Symposium (AMIA 2017)

[C8] Special Digital Monies: The Design of Alipay and WeChat Wallet for Mobile Payment Practices in China
Yong Ming Kow, Xinning Gui, Waikuen Cheng. 2017
Proceedings of the IFIP Conference on Human-Computer Interaction 2017 (INTERACT 2017) [Acceptance rate: 30.7%]

[C7] Managing Uncertainty: Using Social Media for Risk Assessment during a Public Health Crisis
Xinning Gui, Yubo Kou, Katie Pine, Yunan Chen. 2017
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2017 (CHI 2017) (Best Paper Honorable Mention Award) [Acceptance rate: 25%, Honorable Mention: top 5%]

[C6] When Fitness Meets Social Networks: Investigating Social and Fitness Practices on WeRun
Xinning Gui, Yu Chen, Clara Caldeira, Dan Xiao, Yunan Chen. 2017
Proceedings of the SIGCHI Conference on Human Factors in Computing Systems 2017 (CHI 2017) [Acceptance rate: 25%]

[C5] Resisting the Censorship Infrastructure in China
Yubo Kou, Yong Ming Kow, Xinning Gui. 2017
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[C4] When Code Governs Community

Yubo Kou, Xinning Gui. 2017
Proceedings of the Hawaii International Conference on System Sciences (HICSS) 2017

[C3] Ranking Practices and Distinction in League of Legends
Yubo Kou, Xinning Gui, Yong Ming Kow. 2016
Proceedings of the ACM SIGCHI Annual Symposium on Computer-Human Interaction in Play 2016 (CHI PLAY 2016) [Acceptance rate: 29%]

[C2] Sustainability Begins in the Street: A Story of Transition Town Totnes
Xinning Gui, Bonnie Nardi. 2015
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[C1] Playing with Strangers: Understanding Temporary Teams in League of Legends
Yubo Kou, Xinning Gui. 2014
Proceedings of the ACM SIGCHI Annual Symposium on Computer-Human Interaction in Play 2014 (CHI PLAY 2014) [Acceptance rate: 29%]

## WORKSHOP PUBLICATIONS AND POSTERS

[P3] The Rise and Fall of Moral Labor in an Online Game Community
Yubo Kou, Xinning Gui. 2017
ACM Conference Companion on Computer-Supported Cooperative Work & Social Computing 2017 (CSCW 2017 Companion)

[P2] Investigating Support Seeking from Peers for Pregnancy in Online Health Communities
Xinning Gui, Yu Chen, Yubo Kou, Kathleen Pine, Yunan Chen. 2017
AMIA 2017 Workshop on Interactive Systems in Healthcare (WISH)

[P1] Civic Capacity and Sustainability in a Chinese City

Xinning Gui, Bonnie Nardi. 2015
29th EnviroInfo and 3rd ICT4S Conference 2015

## DOCTORAL COLLOQUIUM

[D1] Understanding New Parents' Navigation Practices in Healthcare
Xinning Gui. 2017
ACM Conference on Computer-Supported Cooperative Work & Social Computing 2017 (CSCW 2017) Doctoral Colloquium

## WORKSHOP ORGANIZED

[W1] Unpacking the Infrastructuring Work of Patients and Caregivers around the World
Yunan Chen, Nervo Verdezoto, Xinning Gui, Xiaojuan Ma, Claus Bossen, Naveen Bagalkot, Valeria Herskovic, Bernd Ploderer
SIGCHI Conference on Human Factors in Computing Systems 2019 (CHI 2019) Workshop

# ABSTRACT OF THE DISSERTATION

## Navigating the Healthcare Service "Black Box": Individual Healthcare Consumers' Practices and Design Opportunities

By

Xinning Gui

Doctor of Philosophy in Information and Computer Sciences

University of California, Irvine, 2019

Associated Professor Yunan Chen, Chair

The U.S. healthcare system is known to be complex and fragmented. It presents as a black box to consumers as they often encounter a variety of challenges in obtaining the healthcare services they desire. To obtain a single service, patients often need to coordinate with multiple organizations, such as their employer, an insurance company, a physician practice, and a hospital. Such complexity and fragmentation manifests in isolation between patients, caregivers, organizations, and institutions. Yet little research has been done to understand how patients navigate the black box healthcare system. My dissertation research concerns the practices of parents of young children who navigated the multi-institutional healthcare system on behalf of their children in the United States. Through a narrative interview study of 32 parents from diverse racial, educational, and geographical backgrounds, I document how my participants as organizational outsiders navigated a complex system composed of diverse organizations and gain navigational competence. Building upon the empirical evidence, I conceptualize navigation practices and competence, and demonstrate multiple aspects of navigation practices. I further explore navigation practice in a concrete scenario that is choosing a provider, highlighting several factors that participants considered while making decisions. Lastly, I explore one specific type of navigation practice: the ongoing work that individual healthcare consumers engage in to make the fragmented healthcare infrastructure work for them, as a form of infrastructuring work. Building upon these findings, I discuss how navigation practice mediates the interaction between individual healthcare consumers and the "black box" healthcare system, and how design could better such interaction and help them obtain desired healthcare service.

# Chapter 1. Introduction

## 1.1 Motivation and Research Questions

The increasing specialization of labor and occupations in almost every sector of our current society makes everyday service work highly collaborative, requiring the orchestration of a network of service providers that are situated in highly complex sociotechnical system, with clearly designated roles and a defined chain of responsibilities (Hodson and Sullivan 2012) (p.4). Healthcare service delivery, the focus of this dissertation, is no exception. Across the world (e.g., the U.S. (Cebul et al. 2008), African countries (McIntyre et al. 2008), European countries (Hofmarcher, Oxley, and Rusticelli 2007), Asian countries (Lagomarsino et al. 2012)), the whole healthcare system is complex and fragmented (World Health Organization 2008), including numerous components (e.g., facilities, information systems, financing systems, healthcare providers) at all levels (e.g., central/national, provincial, district and community) (Smith and Bryant 1988). Healthcare service delivery in those countries usually involves a series of separate care settings—sometimes referred to as "silos" (Hofmarcher, Oxley, and Rusticelli 2007). These care settings are often within different organizations, operated under different budgetary regimes, and under different levels of governmental jurisdiction (Hofmarcher, Oxley, and Rusticelli 2007). At the micro-level, patients often receive services from a number of different providers including physicians, nurses, medical assistants, pharmacists, and insurance providers in different departments and organizations (e.g., emergency department, home care agency, skilled nursing facility, pharmacy, insurance company) (Bodenheimer 2008), and each often has its own legal, financial, and regulatory systems (Cantrell 2001) and does not coordinate with one another well (Bodenheimer 2008).

Taking vision care service, one relatively simple health service as an example, not only there exist multiple specialized professions with diverse expertise (Stevens et al. 2000), including but not limited to ophthalmologist, optometrist, orthoptist, ocularist, and optician, but these professionals are likely to be employed in different health organizations that each has its own legal, financial, and regulatory systems (Cantrell 2001). Such complex, often hierarchical, division of labor is often not visible to individual patients who seek for the services. Patients thus face great magnitude of challenges to navigate the network of sociotechnical system as an outsider and acquire the services they needed and preferred.

A more complicated example is how complex the referral process could be in the United States, because care provision is distributed across different entities (Reisman 2017). 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 could result in miscommunication, delays, insufficient data, and lack of method for referral process tracking and reviewing (Metzger and Zywiak 2008; Mehrotra, Forrest, and Lin 2011; Kliff 2018b). Disjointed processes could lead to negative consequences, such as delayed diagnosis or treatment, duplicated tests, polypharmacy, and malpractices (Mehrotra, Forrest, and Lin 2011).

Thus, although it is common to refer to a "healthcare system," from the perspective of patients and caregivers this is a misnomer. The siloed, fragmented healthcare system presents a multitude of challenges for individual patients and patient caregivers to find their way through to achieve desired outcomes (Hofmarcher, Oxley, and Rusticelli 2007). First, since individuals are the only ones with a holistic view of their own situations, they are responsible for interacting with each element of the service provision landscape, acquiring information from each, planning their next actions, and transmitting information and paperwork between different elements. Individuals are forced to take on the role of connecting and patching fragmented healthcare organizations. This requires them to know how organizations work on their own and with each other, and to be able to apply such knowledge of organizations to plan, negotiate, and make decisions as they navigate through the healthcare journey. It is particularly challenging for patients and caregivers, who are often consumers and outsiders of the healthcare organizations, to gain such knowledge since the complex healthcare service provision landscape is often opaque to them (Hofmarcher, Oxley, and Rusticelli 2007). Second, many service sectors are so complex that two individuals could have the same need but enter two completely different service landscapes, making it difficult for professionals to plan and seek services for them. Further, individual service seekers also have unique life circumstances. When acquiring services, people's family, work, financial and overall health situations all come into play, creating endless permutations of complex service provision landscapes that individuals must apprehend and manage on their own. Finally, service landscapes are highly situated and dynamically changing, forcing individuals to adapt their navigating as the larger service landscape as well as their needs, situations, resources and preferences change on an ongoing basis. To overcome the abovementioned challenges, individuals must carry out labor-intensive practices, like the hub of a wheel who is personally responsible for connecting multiple disconnected elements together and for navigating an ever-changing landscape of elements. It involves numerous decision-making points, and often lacks guidance or information on how to navigate. It requires extensive time and effort and often impinges on other activities, placing people under significant amounts of physical burden and emotional stress. Indeed, a recent article on the popular site Vox exemplified these issues experienced by almost everyone at some point in their lives (Kliff 2016). In the article, Aaron Carroll, a pediatrician and ulcerative colitis sufferer was quoted as saying “Every three months, I just know I’m going to lose a few days of my life” (Kliff 2016). The quote represents the deep struggles facing many patients and caregivers nowadays. In this example, Aaron Carroll, an ulcerative colitis sufferer, had to devote multiple days to the heavy workload of managing the healthcare system as a patient—making phone calls, connecting his doctor and his pharmacy to refill medications, and managing missing lab tests—in order to navigate the complex healthcare service system. A shocking fact about Aaron is that he is actually a physician who possesses a wealth of domain knowledge that one would expect would make the navigation process much easier for him. Yet even a medical doctor must devote multiple weeks of labor to navigating healthcare services each year.

Understanding individuals’ navigation practices and designing sociotechnical solutions to facilitate them remains a critical yet challenging problem that has not been studied sufficiently. Current human-computer interaction (HCI) and computer supported cooperative work (CSCW) research has focused extensively on the study of coordination – how two or more people working together to accomplish a particular task within organizations (e.g., a workplace, home, or a particular organizational setting) or within mutual activities between organizations (Schmidt and Simonee 1996; Okhuysen and Bechky 2009). In contrast navigation practices draw individuals into a vast web of siloed organizations and resources that are across multiple organizational boundaries. Navigation practices usually involve continuous and changing situated efforts, which often go beyond coordination to include knowledge translation, sense-making, strategically planning, decision making, etc. Another rich body of work on coordination during crises also bears much in common with navigation (e.g., (Starbird et al. 2016; Huang et al. 2015; Starbird et al. 2010; Heverin and Zach 2012). However, this work focuses around discrete, acute crisis events, while navigating complex service sectors is often an ongoing, mundane activity that individuals face in many aspects of their every life. In summary, how a single person navigates the much broader sociotechnical landscape of various elements (individual providers, organizations, and information sources) has largely been overlooked in CSCW and HCI research. In addition, much research in healthcare related domains has been conducted on topics falling under the umbrella "health literacy," which focuses on a person's ability to access, understand, appraise, and apply health information (Berkman et al. 2011). Little is known regarding how individual health consumers gain knowledge and skills that specifically relates to how particular organizations and organizational groupings work and "how patients maneuver their way through the trajectory of large and complicated health systems"(Paasche-Orlow and Wolf 2007).

This work fills the research gap and answers the following research questions:

- How do individual patients and caregivers navigate complex healthcare service provision landscapes to acquire needed information and services?
- What specific challenges do individuals encounter and what specific resources (e.g. information and computing technologies, financial, skills, social connections, etc.) support their navigation practices?
- How do individuals as organizational outsiders gain competence in navigating the complex healthcare system to acquire essential health services?
- What opportunities exist for designing technologies to facilitate individuals' navigation through complex service provision landscapes, and to mitigate the navigation challenges?

To understand individual patients and caregivers' ongoing, mundane activities of navigating complex organizations from a consumer's point of view, and to explore how to design to better support individuals' navigation practices, this work focuses on a particular case—parents of young children's navigation practices to acquire healthcare services for their young children. I chose this population because it bares multiple significances: as parents of young children, individuals face radical changes in their lives and they must navigate a variety of service sectors, primarily healthcare, for the mothers and for the children, but also including various child care services, both with formal organizations and informal services offered through various means, as well as many other organizations such as employers, insurance companies, etc. It is a type of mundane everyday negotiation that many people are accustomed to, yet it is extremely complex that involves numerous service providers with different management structures, resources, and consumer interfaces. In addition, parents of young children experience a transitional status change from being the ones who receive healthcare services to the primary caregivers for their children. Thus, the study of this population has profound implications for both caregivers and patients, and generates deep understanding of the sociotechnical practices through which individuals navigate complex service sectors and provide crucial insights for design to support these practices.

## 1.2 Contributions

This research makes multiple contributions to the fields of HCI, CSCW, Organizational Science, and Health Informatics:

First, I document and present detailed practices of how organizational outsiders navigate a complex system composed of diverse organizations and gain navigational competence, which provide empirical insights that complements the existing CSCW research takes on an organizational insider's view to examine how team members or employees coordinate (e.g. (Bellotti and Bly 1996; Dourish and Bellotti 1992; Grinter, Herbsleb, and Perry 1999; Kellogg, Orlikowski, and Yates 2006)) with each other and acquire and use organizational knowledge (e.g., (Orr and E. 1986; Spence and Reddy 2012; Ackerman and Halverson 2004)).

Second, I conceptualize navigation practices and competence, and demonstrate multiple aspects of navigation practices, which render individual health consumers' such work visible.

Third, my findings in healthcare domain contain important values for developing a theoretical understanding of individual service consumers' navigation practices and competence in other domains, as many infrastructures in modern society are complex and fragmented, such as education infrastructure and immigration service infrastructure.

Fourth, I explore possible ICT design solutions, and derive implications for design based on my empirical findings to support the interactions between individual healthcare consumers and healthcare system and ease the burden of navigating to acquire essential services.

## 1.3 Dissertation Overview

This dissertation includes nine chapters.

Chapter One overviews this dissertation project, including my motivations and research questions, and contributions.

Chapter Two details the theoretical framework of this dissertation project, as well as related work in HCI, CSCW, and health informatics.

Chapter Three articulates my methodology for this dissertation project. I discuss my methods for data collection and analysis, as well as justifications for using these methods.

Chapters Four to Seven are my findings. Chapter Four addresses what I mean by calling the healthcare system a black box. Chapter Five describes the notions of navigation practice and competence in detail. Navigation practice is an umbrella term covering many more concrete forms of practices. In Chapter Six, I focus on one particular practice that is choosing a provider. In Chapter Seven, I explore another particular practice from the perspective of infrastructure and infrastructuring.

Chapter Eight builds upon the empirical findings that I have presented, and highlight theoretical insights I have obtained through my dissertation project. I also discuss design implications towards the end of Chapter Eight.

I conclude the dissertation in Chapter Nine.

# Chapter 2. Background and Related Work

In this chapter, I use practice theory as my analytic lens to conceptualize navigation as practice. I then discuss how the notion of navigation practice is related to but different from notions in HCI and CSCW such as coordination, situated action, and organizational knowledge. Lastly, I contextualize navigation practice by discussing navigating healthcare services.

I explore how the notion of navigation practice could contribute to existing health informatics literature. I discuss its difference from formal support from healthcare systems such as patient navigator' service and care coordination. I then discuss how navigation practice differs from existing concepts such as patient competence, health literacy, patient expertise, patient and caregiver work.

Lastly, because of the particular population that I focus on, I also review relevant literature on new parents of young children in HCI.

I conclude this chapter by highlighting research gaps in multiple strands of literature.

## 2.1 Unpacking the Social through the Practice Lens

Rooted in the extensive sociological and philosophical debates around the agency/structure relationship, the practice lens has garnered much scholarly attention as a means through which to explore the constitution of social life, as well as the complex interplay between individual agency and social structure. In this research, I found the practice lens to be a pertinent theoretical angle because of the scope of my academic inquiry consisting of patients' interactions with the larger service systems, as well as my core interest in understanding how patients as social agents know situations, make decisions, and carry out actions in their relationship with the structure of service systems comprised of medical policies, routines, norms, and dispositions.

The practice lens has already been valued and advocated by HCI and CSCW researchers. For example, Kuutti and Bannon called for practice-oriented research programs in HCI (Kuutti et al. 2014). Wulf et al. discussed the values and considerations of engaging with practices with designing innovative technologies (Wulf et al. 2011). In this research, when applying the practice lens, I draw from the interpretation and articulation of practice theory in organization science (Orlikowski and J. 2008), because the service systems are primarily organizational and because HCI and CSCW's longstanding overlapping interest with organizational studies.

Organization researchers Feldman and Orlikowski noted that practice theory entails a key set of theorizing moves including highlighting situated actions as consequential in the production of social life, rejecting dualisms, and stressing mutual constitution (Feldman and Orlikowski 2011). They outlined how practice theory could inform three application areas that are highly relevant to my study: how strategizing is relational and enacted, how to reformulate notions of knowledge, and how to rethink institutions from the practice lens (Feldman and Orlikowski 2011). Further, the practice lens can help interpret technology use in practice (Orlikowski and J. 2008). Technology structures are not static and fixed, but routinely enacted through everyday situated activities. This perspective is relevant to the current research since people use a variety of information technologies as part of navigating healthcare services and building navigation competence, but they do not use them in static ways—navigation practice and information technology are dynamically emergent in use.

This work also draws inspiration from information practice research to understand how my participants find, use, evaluate, and share information through their navigation practices. Information scientist Reijo Savolainen stressed that the basic characteristic of information practice research is to emphasize "the role of the contextual factors of information seeking, use, and sharing" (Savolainen 2007). The framing of information literacy could move beyond the idea of a reified and decontextualized set of skills, and be understood as a critical information practice (Lloyd 2010). Contextual factors such as access to and trust in information (Lloyd, Pilerot, and Hultgren 2017), as well as the dynamics of interdependencies between individual information workers (Nordsteien and Byström 2018), should not be taken lightly in information practice research.

## 2.2 Navigation

This research draws on prior literature on navigation from multiple domains. HCI literature on navigation has examined "social navigation," the phenomenon in which individuals' movement through an information space is shaped by social interactions with others and the structure of the information space (Dourish and Chalmers 1994; Dourish 2003). In semantic web studies, navigation research examines the process of users following a series of explicit or implicit links to move from a starting point to their desired information resource (Ding et al. 2005). Researchers of environmental sustainability use the term navigation to describe the process through which environmental stakeholders find ways to transform crisis and rapid transformations in complex systems into capacity for renewal and innovation (Berkes, Colding, and Folke 2008). The concept of "wayfinding," which focuses on successfully moving through physical space, is highly related to navigation and a plethora of research in urban, design, cognitive science, and other fields examines the dynamics of human spatial awareness and how to support it through design of tools and spaces (e.g. (Golledge 1999; Millonig and Gartner 2011)). HCI research has examined wayfinding in virtual spaces (e.g. (Wu et al. 2007)) and design of information technologies to support wayfinding (e.g. (Bradley and Dunlop 2005)).

## 2.3 Navigation's Relation to HCI and CSCW Research

### 2.3.1 Concept of coordination

Navigation centrally involves *coordination*—a core concept that has been studied extensively in HCI, CSCW, and Organizational Science research alike. Coordination is defined as "…the act of managing interdependencies between activities performed to achieve a goal" (Malone and Crowston 1990). Coordination involves "…the allocation, planning and integration of the tasks of individual group members or groups" (Andriessen 2012) and can refer to activities within organizations (e.g., a workplace, home, or a particular organizational setting) or to mutual activities between organizations (e.g., (Schmidt and Simonee 1996; Okhuysen and Bechky 2009; Bellotti and Bly 1996; Dourish and Bellotti 1992; Grinter, Herbsleb, and Perry 1999; Kellogg, Orlikowski, and Yates 2006; Cummings and Kiesler 2005)).

In the realm of HCI and CSCW, much coordination research focuses specifically on how people coordinate actions *within* organizations to achieve work efficiency and effectiveness. This research on coordination in organizations examines how individuals use information technology to communicate and coordinate in physically co-located, virtually co-located, and distant groups and increasingly across organizations (see for example (Bellotti and Bly 1996; Dourish and Bellotti 1992; Grinter, Herbsleb, and Perry 1999; Kellogg, Orlikowski, and Yates 2006)). This incredibly rich stream of research examines key aspects of coordination, such as invisible work (Suchman and Lucy 1995); articulation work (i.e. (A. Strauss 1988)); coordination mechanisms (i.e. (Schmidt and Simonee 1996)) including artifacts (i.e. (Xiao 2005)), classification systems (i.e. (Bowker and Star 1999)), standard operating procedures (i.e. (Suchman 1987)), temporal and spatial arrangement ((Reddy and Dourish 2002; Bardram and Bossen 2005)), and routines (i.e. (Feldman and S. 2000)). Many of the same mechanisms that underlie coordination also play a role in navigation. Artifacts (forms, computer interfaces for scheduling, educational resources, etc.) clearly play a large role in navigation. Another crucial reason that research on navigation must attend to coordination mechanisms is that individuals navigating complex service provision landscapes encounter the coordination mechanisms deployed by organizations they are attempting to acquire things from, and these mechanisms can help or hinder navigation. For example, an individual may encounter standard operating procedures (SOPs) of an organization, and these SOPs can dictate to a large extent how an individual interact with the organization (Hasenfeld 2010). Just as with coordination, much of the navigation work is invisible thus unrecognized and unaccounted for by service providers, policymakers, and other stakeholders of various service sectors (Unruh and Pratt 2008a; May et al. 2014; Ancker et al. 2015). Thus studying the challenges of navigation and providing opportunities through technology design can be extremely beneficial to those struggled to navigate in their everyday lives.

### 2.3.2 The Concept of Situated Action

Another core concept in CSCW workplace studies is *situated action*. Research on situated action shows that lines of action can never be fully predicted in advance, because action always occurs under particular conditions at certain places and times (Suchman 1987). Navigation of service provision is also highly situated and dynamically changing based on individuals' current conditions and needs. However, in navigation, the variables are expanded, as individuals may constantly encounter new issues, identify new criteria, etc.. Individuals must constantly ascertain the best next action in a given situation. Designing to support navigation must take into account the endless permutations of action that could exist as inevitable shifts occur in the service provision landscape and in an individual's life circumstances.

### 2.3.3 Organizational Knowledge in CSCW

In CSCW and organizational research fields, organizational knowledge refers to the capability "…members of an organization have developed to draw distinctions in the process of carrying out their work, in particular concrete contexts, by enacting sets of generalizations whose application depends on historically evolved collective understandings" (Tsoukas and Vladimirou 2001). Individuals working in organizations often face challenges in conducting collaborative work. Organizational knowledge, as a significant organizational resource (Alavi and Leidner 2001), plays a critical role in teams' performance and organizations' capacity of problem solving and innovation (Spence and Reddy 2012). There has been a substantial body of CSCW research on the creation, acquisition, and management of organizational knowledge in collaborative settings, as researchers have explored mechanisms of generation, usage, storage, sharing, and reusing (e.g., (Orr and E. 1986; Spence and Reddy 2012; Ackerman and Halverson 2004)) organizational knowledge, and how to design systems to support these mechanisms (e.g., (Ackerman and McDonald 1996; Stocker et al. 2012)). However, this research is primarily concerned with how organizational insiders (e.g. employees) gain and use organizational knowledge for better cooperative work within one organization. How organizational outsiders obtain knowledge about organizations and organizational landscapes involved in providing a service is understudied. In this dissertation, I use organizational knowledge to denote the knowledge about how organizations work.

## 2.4 Navigating Healthcare Services

For most countries, including the U.S., health care service delivery is on the basis of a series of separate care settings -- sometimes referred to as “silos” (Hofmarcher, Oxley, and Rusticelli 2007). These care settings are often within different institutions, operated under different budgetary regimes, and even under different levels of government’s responsibility (Hofmarcher, Oxley, and Rusticelli 2007). The siloed landscape of healthcare, combined with the increasing specialization of medical knowledge, creates challenges for patients and caregivers to find their way through to receive desired services (Hofmarcher, Oxley, and Rusticelli 2007). The number of venues individuals have to visit in order to treat one health condition manifests the challenges. For example, between 2000 and 2002, the typical Medicare beneficiary saw a median of two primary care physicians and five specialists each year, in addition to accessing diagnostic, pharmacy, and other services. Patients with multiple chronic conditions may visit up to 16 physicians in a year (Bodenheimer 2008). Care needs to be coordinated among “primary care physicians, specialists, diagnostic centers, pharmacies, home care agencies, acute care hospitals, skilled nursing facilities, and emergency departments” (Bodenheimer 2008). Within each of these venues, a patient may receive services from a number of different providers such as physicians, nurses, medical assistants, and pharmacists, who also need to coordinate with one another (Bodenheimer 2008).

Care coordination [1], "the deliberate integration of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of health care services" (McDonald et al. 2007), has been advocated for a long time as a bridge to connect different multiple providers (Hofmarcher, Oxley, and Rusticelli 2007). However, the complexity of healthcare service delivery raises enormous challenges to successful care coordination. Individual healthcare service providers do not generally interoperate or coordinate their activities well for patients. Failures in coordination among healthcare providers, for instance between hospital-based physicians, primary care physicians, specialists, emergency departments, and sources of diagnostic data, are common and create serious concerns (Bodenheimer 2008). For example, families of

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[1] Care coordination is similar to various other models in the sense that that all of these models provide some kinds of intervention to coordinate some forms of care at some stages, including patient navigators, community health workers, case managers, and transition coaches. These models have slightly different definitions under certain circumstances, depending on the setting, system of care using the terms, and specific services they provide (Antonelli, Mcallister, and Popp 2009). For instance, In some cases, case management is different from care coordination which often addresses a wide range of needs of patients and family. Case management tends to focus on a limited sets of predetermined diseases and guided by health care cost savings (Antonelli, Mcallister, and Popp 2009). Case managers' major role is to limit the financial risk of the payer (American Academy of Pediatrics: Council on Children With Disabilities 2005). Many times, research works and policy statements use the terms (e.g., care coordinator, case manager, patient navigator) interchangeably (e.g., (Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee et al. 2014)). In this research, to avoid confusion and complexity, I also use them interchangeably.

children with special health care needs (CSHCN) usually have to deal with a number of services and programs such as primary health care, specialty health care, educational services, and community services. These service systems are often scattered and uncoordinated, which leads to fragmentation, gaps, duplication, and conflicts in care (Nolan, Orlando, and Liptak 2007). The referral process is another case in point. In the United States, more than a third of patients are referred to see a specialist each year (Mehrotra, Forrest, and Lin 2011). However, the referral process for specialty care is often extremely disjointed. Typically, patients, referring and receiving health care providers, administrative staff, and the payer relay on paper, phone calls, and faxes to communicate and coordinate, which often results in miscommunication, delays, and the lack of method for referral process tracking and reviewing (Metzger and Zywiak 2008). Referring health care providers often know little about whether a patient has actually visited the specialist and what the specialist has done. Many referrals lack a transfer of information or sufficient data for medical decision making (Mehrotra, Forrest, and Lin 2011). The disjointed processes could lead to many adverse consequences, such as delayed diagnosis or treatment, duplicated tests, polypharmacy, meaning “the use of multiple drugs or more than are medically necessary” (Maher et al. 2014), and malpractices (Mehrotra, Forrest, and Lin 2011). There are a lot of concrete navigation tasks for patients during the referral process, such as obtaining authorization, contacting and choosing potential receiving providers within a short time, scheduling appointments, and checking the referral progress. Major barriers to seamless care coordination from the providers' perspective include overstressed primary care clinicians, lack of interoperable computerized records, and lack of integrated systems of care when health care is delivered in many small practices (e.g., emergency departments, "minute clinics," independent providers) (Bodenheimer 2008). Much research shows that healthcare information often encounters impediments to flowing across the boundaries of different entities, leading to disrupted relationships, disconnected information sharing, and jeopardized quality of healthcare (Bourgeois, Olson, and Mandl 2010; Pratt et al. 2006; Cebul et al. 2008).

Hence, the work of coordinating care and connecting different organizations and systems, including transmitting information across boundaries, falls onto individual patients and their personal caregivers (McDonald et al. 2007; Unruh and Pratt 2008b). Coordinating one's healthcare services often means individuals must understand and navigate the bureaucratic systems of insurance carriers, sign up for appropriate social services, and negotiate time off with employers. As such, individuals face numerous challenges and encounter failures at multiple points as they interface with formal organizations that are part of health care delivery, as well as the broader patchwork of formal organizations and informal entities they traverse (Chen et al. 2013; McCall, Rice, and Sangl 1986). Despite the fact that patients are often the sole connector for different clinicians and healthcare organizations, previous research has shown that individuals are not well equipped to do so: individuals often encounter challenges in seeking and integrating health information from a wide range of sources including multiple healthcare providers, various online and offline resources, as well as peer patients and family members (Halasyamani et al. 2006; Julien and Michels 2004; Pratt et al. 2006; Moen and Brennan 2005; Unruh and Pratt 2008b). Prior studies suggest that healthcare consumers struggle with even basic tasks related to seeking healthcare. For example, people are generally not knowledgeable about their insurance options and often incorrectly chose an insurance that differs from their preferences (Mechanic 1989). Patients and their caregivers often fail in coordinating care from multiple providers and agencies (Brown et al. 2014; Golden and Nageswaran 2012), which results in serious consequences including delayed care and severe mental stress.

In the realm of healthcare, previous CSCW and health informatics research has focused primarily on coordination activities between patients, family members, and organizational insiders such as physicians and nurses in clinical settings (e.g., (Amir et al. 2015; S. Lee et al. 2012; Unruh et al. 2010)). Because informal caregivers such as patients' family members are key stakeholders in patient health management (Chen, Ngo, and Park 2013), a large set of studies have attended to how patients and their caregivers collaborate and coordinate to manage chronic conditions or in the inpatient settings (Chen, Ngo, and Park 2013; Prey et al. n.d.; Miller et al. 2016; Mishra et al. 2016). Some research focuses on cancer navigation practices through the role of professional cancer navigators (M. Jacobs, Clawson, and Mynatt 2014; M. L. Jacobs, Clawson, and Mynatt 2014). However, little research examines informal caregivers' navigation practices outside of clinical settings and prior to entering clinical settings from the consumer's perspective.

This research builds on previous research on caregiver and patients' coordination activities, but I take the perspective of the consumer navigating a broad and complex array of healthcare service providers rather than focusing on simple, discrete interactions based in the clinic. The case of parents navigating on behalf of children is particularly rich because, in contrast to caregivers who can collaborate with patients directly, new parents need to navigate the system without clear input of patients (babies) such as verbal articulation of their health conditions. Where the focus in previous research has been squarely on clinical settings and chronic disease management, this research examines not only new parents' navigation practices in clinical settings, but also every day, mundane activities related to identifying, seeking, and obtaining healthcare services and resources for their baby's health.

## 2.5 Formal Support: Patient Navigators and Care Coordination Services in Healthcare

### 2.5.1 Patient Navigators

In the healthcare domain, the term navigation has come to denote a specific realm of practice held by an occupational group—patient navigators—who guide patients through and around barriers presented by the complex healthcare system (Freund et al. 2008). There has been increased interest in the healthcare field over the past decades in "patient navigation." Patient navigation is defined as "…the assistance offered to underserved populations in 'navigating' through the complex health-care system to overcome barriers in accessing quality care and treatment" (Fowler et al. 2006). Patient navigation was introduced more than two decades ago in response to health disparities in cancer care (Paskett, Harrop, and Wells 2011). It is conducted by professional patient navigators who serve as liaisons to help individuals obtain needed services in the health care labyrinth (Sofaer 2009; Vargas et al. 2008; Gardner 2015). Professional patient navigators serve as liaisons to help individuals obtain needed services in the health care labyrinth (Sofaer 2009; Vargas et al. 2008).

However, the role of patient navigator is not well-defined; and its key responsibilities and qualifications, such as licensure, training, and practice setting, vary significantly

(Wells et al. 2008; Parker and Lemak 2011). These differences lead to a variety of stances on who can be formally considered a professional “patient navigator,” what the duties of this job are, and what the needed qualifications for the job are. For instance, patient navigators might be individuals who have lived through the same cancer (Giese-Davis et al. 2006), oncology nurses (Crane-Okada 2013), or licensed social workers (Calhoun et al. 2010). They may be employed by healthcare organizations or directly hired by patients (e.g., http://www.ornoa.com). A patient navigator's duties may range from providing transportation and appointment scheduling to providing emotional support (Parker and Lemak 2011).

Currently established patient navigation programs and academic research on patient navigation have primarily targeted patient populations at higher risk of not receiving adequate care services, and have focused on these vulnerable populations for a limited range of conditions, primarily on cancer care and a few common chronic diseases such as diabetes, asthma, and depression (M. Jacobs, Clawson, and Mynatt 2014; M. L. Jacobs, Clawson, and Mynatt 2014; Parker and Lemak 2011). The target patient populations are usually vulnerable and underserved populations due to culture, language, or socio-economic status (e.g., (Rabiner and Weiner 2012)). Patient navigator services are only available in some geographic areas and care settings for patients with limited types of chronic diseases (M. Jacobs, Clawson, and Mynatt 2014; M. L. Jacobs, Clawson, and Mynatt 2014; Parker and Lemak 2011; Parker et al. 2010; Rabiner and Weiner 2012; Paskett, Harrop, and Wells 2011). Thus, in reality, most individuals do not have access to professional navigators. Previous HCI and CSCW research has focused on cancer navigation practices through the role of professional cancer navigators (M. Jacobs, Clawson, and Mynatt 2014; M. L. Jacobs, Clawson, and Mynatt 2014).

In contrast to research on "patient navigation" that focuses on professional patient navigators providing support to individuals, my research adopts the individual consumers' perspective of navigating the healthcare system as unpaid, untrained, and usually unprepared navigation workers.

### 2.5.2. Pediatric Care Coordination

Turning to pediatric healthcare, there have been some organizational initiatives existing to support coordination of pediatric care. Pediatric care coordination is defined by American Academy of Pediatrics (AAP) as *"a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health"* (American Academy of Pediatrics: Council on Children With Disabilities 2005). Research and practices in pediatric care coordination have focused on serving for children with special health care needs (CHSCN) (e.g., (American Academy of Pediatrics: Council on Children With Disabilities 2005; Gupta, O'Connor, and Quezada-

Gomez 2004; Looman et al. 2013; Toomey et al. 2013; Antonelli and Antonelli 2004; Stille and Antonelli 2004; McClanahan and Weismuller 2015; Taylor et al. 2013; Ranade-Kharkar et al. 2017; Antonelli, Stille, and Antonelli 2008; Amir et al. 2015)). Research shows that care coordination has the potential to play an important role in integrating health and related systems of care for children with special health care needs (American Academy of Pediatrics: Council on Children With Disabilities 2005) and could reduce health care costs and increase patient satisfaction (Barry et al. 2002). In general, care coordination is expected to be connected to or provided by "a clinician-led, proactive health care team" (Antonelli, Mcallister, and Popp 2009) to offer professional assitance. Care coordination is mainly performed by professionals such as physicians, nurses, occupational therapists and social workers, and families and children themseleves are participants and consultants (American Academy of Pediatrics: Council on Children With Disabilities 2005; Antonelli, Stille, and Antonelli 2008). For example, the family-centered medical home (FCMH) model, a core component of which is care coordination, is primarily led by pediatricians (Tschudy et al. 2016) and emphasizes the role of primary care in care coordination (Antonelli, Mcallister, and Popp 2009).

However there are significant barriers which hinder organizations from providing effective aids to families. For example, Tschudy et al. reported that even pediatricians needed sufficient personnel, communication skills, and enough time to provide care coordination (Tschudy et al. 2016). Even for those children with sepcial health care needs who have a primary care coordinator designated by their clinicians, care coordination services are often not happening. A recent survey of AAP members found most pediatricians (71.2%) report someone in their practice serves as the primary care coordinator for patients with special healthcare needs but, because of limited time, lack of sufficient personnel, and inadequate reimbursement, only a few coordinators actually provide important services for families (Gupta, O'Connor, and Quezada-Gomez 2004). Additionally there is "a lack of consensus among pediatricians about which activities constitute care coordnation" (Gupta, O'Connor, and Quezada-Gomez 2004). Despite the preliminary state of this literature, it is clear that facilitating acquisition and management of pediatric services has been identified as a pressing need or patients, which points to the potential for broad impact of research on navigation practices of pediatric healthcare services.

## 2.6 Related Concepts: Patient Competence, Health Literacy, and Patient Expertise

Patient competence refers to patients' capacity to make decisions about treatment which the provisions of informed consent are designed to protect (Kutner, Ruark, and Raffin 1991; Morreim 1983). The term has a long history in law and medical ethics. Physicians are required by law to obtain the informed consent of a patient before initiating any treatment (Appelbaum 2007). Patient competence is a prerequisite for valid informed consent. It mainly concerns legal and ethical implications, especially in terms of how to evaluate and determine individual patient competence and how to achieve the balance between preserving patients autonomy and providing needed medical care (e.g., (Tepper and Elwork 1984; Kutner, Ruark, and Raffin 1991; Morreim 1983; Appelbaum 2007)). Therefore, the concept of patient competence focuses on patients' capacity to make treatment-related decisions and the legal and ethical implications of these decisions. In contrast, the concept "navigational competence," as I define it, covers a broader set of skills and knowledge that individuals bring to bear as they maneuver complex service provision systems effectively.

Another related concept is health literacy. Nutbeam (Nutbeam 2008) reviewed past research and described two distinct conceptual meanings for health literacy: one is health literacy as a risk factor, which focuses on lack of literacy skills (numeracy and language skills) as a clinical risk factor for health. The other conceptualization is health literacy as asset, which focuses on health literacy as development of skills that enable individuals to exert greater control over their health and the factors that shape health. It is this second view that is relevant to my research. However, both conceptualizations have deep roots in educational research on literacy, emphasizing health literacy as an outcome to health and patient education (Nutbeam 2008), which is different from the perspective of individual agency I want to emphasize by focusing on practices and competence in practices. In addition, definitions of health literacy (Sørensen et al. 2012) and operational means for measuring health literacy (Nutbeam 2008) focus on a person's ability to access, understand, appraise, and apply health information, not on competence and knowledgeability about how to get desired services in a complex health service system.

An additional body of research attends to patient expertise. Patient expertise refers to "experiential knowledge" that patients have gained "…from personally managing the day-to-day experience of illness" (Hartzler and Pratt 2011). Patient expertise emphasizes patients' self-management of illness on personal aspects of health (Civan-Hartzler et al. 2010), which is different from my study's focus on health service navigation which extends beyond self-management of personal health into practices and knowledge about multiple aspects of acquiring needed services for oneself or another.

## 2.7 Patient and Caregiver Work

This work also draw on sociologists Corbin and Strauss's conceptualization of "work" in healthcare settings (Corbin and Strauss 1985). They conceived 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” (Corbin and Strauss 1985) (p. 224). 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” (Corbin and Strauss 1985) (p. 226)), 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., (Mamykina et al. 2008; Park and Chen 2015; Unruh and Pratt 2007; Chen 2011; Nunes et al. 2015; Eschler et al. 2015; Mamykina et al. 2010)). 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 (Unruh and Pratt 2007). They do significant personal health information management work over the course of cancer treatment, such as tracking side effects and preparing questions for clinicians (Klasnja et al. 2010).

Caregivers are heavily involved in everyday patient care activities (Chen, Ngo, and Park 2013). 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., (Leggett et al. 2018; Belle et al. 2006; Dionne-Odom et al. 2018; Girgis, Lambert, and Lecathelinais 2011; Schorch et al. 2016)). Informal caregivers consist of 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 (C. Tang et al. 2018). 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 (Miller et al. 2016; U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability 2014; C. Tang et al. 2018; Piper et al. 2016). 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 (Tixier and Lewkowicz 2016; Chen, Ngo, and Park 2013; Schorch et al. 2016). HCI researchers have explored ways of minimizing informal caregivers’ burden, including helping them track patients’ status (Yamashita et al. 2017), improve the relationships with patients (Yamashita et al. 2018), facilitate the collaboration between patients and caregivers (Berry et al. 2017) and among multiple caregivers (C. Tang et al. 2018; Gutierrez and Ochoa 2017), and maintain their own wellness by providing social and instrumental support (Chen, Ngo, and Park 2013; Yamashita et al. 2013; Tixier and Lewkowicz 2016, 2015).

Some HCI studies have focused on parents as informal caregivers. Tang et al., explore how to support parents to collect and track preterm infants’ health data (K. Tang et al. 2012). Liu et al. (Liu et al. 2011) designed a prototype to improve communication between parents of high-risk infants and health professionals and provide social support to parents. Toscos et al. present suggestions for the design of health monitoring technology to ease the tension between parents as caregivers and children who have Diabetes (Toscos, Connelly, and Rogers 2012). Pina et al. (Pina et al. 2017) argued for supporting distributing the burdens of tracking across family members. Kaziunas et al. (Kaziunas et al. 2015) examined the interconnections between information and emotion work performed by parents of children received bone marrow transplant. In addition, some studies have paid attention to professional caregivers’ work, uncovering the types of work that paid professional home workers carried out (Bratteteig and Eide 2017) and exploring how to improve volunteer caregivers' performance in dementia care setting (Foong et al. 2018).

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 system has not yet been explored in prior literature. This research extends the scope of patient work to include the work happening in patients and caregivers' interaction with healthcare systems.

## 2.8 Studies of Parents of Young Children in HCI

In HCI, new parents and health-related research is still an understudied field (Almeida, Comber, and Balaam 2016). Most related research has focused on designing systems and devices for maternal care. Some of the works (Enquist and Tollmar 2008; N. Kumar and Anderson 2015; Perrier et al. 2015) focused on pregnancy-related information collection, dissemination, and communication. Enquist and Tollmar (Enquist and Tollmar 2008) aimed to facilitating pregnant women's health information collection by developing a functional prototype of a healthcare device for pregnant women to collect and review clinical and personal information related to their pregnancies. Within the HCI4D field, some works (N. Kumar and Anderson 2015; Perrier et al. 2015) has paid attention to underserved pregnant women's needs of receiving information and communication in developing countries: Kumar and Anderson (N. Kumar and Anderson 2015) investigated rural Indian women (including pregnant and lactating mothers)'s mobile media consumption and sharing practices using the lens of Feminist HCI to generate insights for next steps of a project which aims to dissemination health information for pregnant women, lactating mothers, and their newborns. Perrier et al. (Perrier et al. 2015) designed and examined a SMS communication system to engage pregnant women in Kenya in health-related communication during pregnancy and postpartum phase. Sharing the interests in underserved pregnant women's needs, Peyton et al. 's study (Peyton et al. 2014) explored how to design better mobile health interventions to help lower-income women avoid excessive gestational weight gain. Another small body of research aims to develop and test computational methods to identify and predict women's behavior patterns related to pregnancy and childbirth. De Choudhury et al. developed models to characterize and predict postpartum changes in behavior, language and affect based on Twitter data (De Choudhury, Counts, and Horvitz 2013) and postpartum depression based on Facebook data (De Choudhury et al. 2014).

There has been an emerging research strand focused on designing for better experience of motherhood and parenting, mostly during the postpartum phase. Breastfeeding, an important type of postpartum experience, has gained some attention. Balaam et al. (Balaam et al. 2015) designed a mobile application to help mothers find a place to breastfeed. D'Ignazio et al. (D'Ignazio et al. 2016) discussed how to improve the breast pump design to better support new mothers' better postpartum experiences in terms of collecting and storing breast milk. Gibron and Hnason's study (Gibson and Hanson 2013), instead, focused on another vital type of postpartum experience: new mother's identity shifting experiences. They identified two themes that ICTs could support new mothers' identity shifting: the need to improve confidence and reclaiming their identity as being more than "just" a mother. A relatively rich body of the research has focused on parents' disclosure about themselves and their children on social networking sites, including lesbian, gay, bisexual, and transgender (LGBT) parents' self-disclosure practice social media (Blackwell et al. 2016), how parents decide what to disclose about their children on social networking sites (Ammari et al. 2015), new mothers' baby photos sharing on Facebook (P. Kumar and Schoenebeck 2015), new mothers' social media posts about their children (Morris 2014), and parents' and children's preferences about parents' practices of sharing about children on social media (Moser, Chen, and Schoenebeck 2017). Some research has examined types of parenting practices, which focus on how parents manage their children's digital technology use (Moser, Schoenebeck, and Reinecke 2016; Blackwell, Gardiner, and Schoenebeck 2016; Mazmanian and Lanette 2017; Hiniker, Schoenebeck, and Kientz 2016) and helping parents to track their young children's development (H. Suh, Porter, Hiniker, and Kientz 2014; Kientz et al. 2007).

Some research (Kientz et al. 2007; H. Suh, Porter, Hiniker, Kientz, et al. 2014) has investigated new parents' practices of taking care of baby's health and designing systems to support them. The focus has been on tracking their child's development. In contrast, my dissertation work aims to understand new parents' holistic navigation practices of identifying, seeking, and obtaining healthcare services and resources.

## 2.9 Gaps in Prior Research and Relevance to This Research

In summary, multiple research fields and subfields have started to pay attention to what patients do to obtain quality healthcare service. However, there are multiple research gaps in the literature.

*First*, the coordination literature has focused on activities between two or more people interacting within an organization or across organizational boundaries (e.g. (Cummings and Kiesler 2005; Kellogg, Orlikowski, and Yates 2006)). In contrast, navigation involves a much larger landscape of service providers, organizations, and information resources. The focus of navigation is on the actions that *individuals* take to acquire an essential service. To acquire services, individuals crisscross organizations in messy patchworks, sail across seemingly clear organizational boundaries, and bridge multiple sociotechnical systems. Prior HCI/CSCW literature has not researched navigation from the perspective of individuals serving as nexus connecting fragmented people, organizations, and systems. My dissertation fills this gap by examining how individuals use a variety of means at their disposal to pursue needed services and create effective networks of service provision by traversing and connecting fragmented service providers and information sources.

*Second*, much of the previous coordination research takes on an organizational insider's view to examine how team members or employees coordinate (e.g. (Bellotti and Bly 1996; Dourish and Bellotti 1992; Grinter, Herbsleb, and Perry 1999; Kellogg, Orlikowski, and Yates 2006)). Little is known regarding how *outsiders,* e.g. consumers or clients of services, coordinate and navigate the complex and fragmented sociotechnical landscape of service provision. Compared to previous CSCW research on organizational knowledge that focus on organizational insiders, my study shifts the focus to organizational outsiders' knowledge about how organizations work.

Research solely situated within organizations cannot adequately identify the normal natural troubles that organizational outsiders must work to solve as they navigate complex systems, e.g. how patients receive, understand, then pass alone information provided by professionals with limited knowledge and literacy. While research has examined coordination mechanisms between patients and informal caregivers (e.g. family members) (Chen, Ngo, and Park 2013), and the communication and collaboration between a patient and a clinician in managing chronic conditions (Chen, Ngo, and Park 2013; Prey et al. n.d.; Miller et al. 2016; Mishra et al. 2016), how individuals navigate the complex landscape of healthcare services holistically from the consumer's perspective has not been adequately addressed in prior literature.

*Third*, this research builds on previous research on both care coordination and patient navigation in the healthcare service landscape. Yet, theoretically, the literature on patient navigation is quite new and the concept is under-developed, and literature on pediatric care coordination is even less well developed. A key shortcoming of existing literature is that its focus on a limited scope of navigation activities—typically navigation occurring within a healthcare system. In contrast, my dissertation project adopts an expanded and deeply personal view of navigation. Individuals' health situations are highly diverse and are further complicated by the nuances of one's social, financial, occupational circumstances and personal values. Formal navigation programs and patient navigators may not meet individuals personalized and diversified health needs, and even where people have access to professional patient navigators, they still might need to engage in self navigation. While patient navigation programs and research focus on professional navigators' role in supporting certain patient populations to receive adequate care service, my research focuses on individual health consumers' perspective of navigating the healthcare system. My dissertation provides both empirical evidence and theoretical insights for designing healthcare services to ease the burden of navigation which individuals inevitably face amidst the complex and fragmented healthcare service landscape.

*Fourth*, existing concepts including patient competence, health literacy, and patient expertise, while related, are insufficient to describe my study's focus on health service navigation.

*Fifth,* previous research on healthcare consumers' work has focused on types of patients and caregivers' care work and burden associated with self-management of chronic diseases in home and clinic care settings. How individuals interact with the complex, often fragmented healthcare system has not yet been explored in prior literature.

*Lastly,* little HCI research examines new parents' holistic navigation practices of identifying, seeking, and obtaining healthcare services and resources. This research addresses the research gap.

# Chapter 3. Methods

## 3.1 Data Collection

From 2016 to 2018, I conducted 30 narrative interviews (Jovchelovitch and Bauer 2000; Fraser 2004) with 32 participants (two interviews conducted with father-mother dyads) who had diverse demographic backgrounds. The narrative interview "…encourages and stimulates an interviewee....to tell a story about some significant event in their life and social context" (Jovchelovitch and Bauer 2000) (p.59). I chose the narrative interview method because people's experiences of navigating health services are deeply embedded in situated life events and people naturally use narrative to describe these events and their means for managing them. Narrative interviewing follows an unstructured approach that allows participants to tell a narrative of their experiences and elicits a naturalistic rendering of the participants' perspectives that are more valid than what can be provided by structured and semi-structured interviews (Jovchelovitch and Bauer 2000). Narratives tend to be detailed with a focus on personal experience including events, actions, contexts, outcomes, motivations, and so on. Thus, a narrative interview "...reconstructs actions and context in the most adequate way (Jovchelovitch and Bauer 2000) (p.58)" and "…reveals place, time, motivation, and the actor's symbolic system of orientation (Jovchelovitch and Bauer 2000) (p.58)."

I recruited participants through direct contacts and snowball sampling. To diversify the participants, I 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). My 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 28 to 39, including those who are new to the U.S., e.g. international students and new immigrants, and those who are more familiar with the healthcare system such as people born and raised in the U.S. My sample of parents had children aged between one month to two years. The sample is ethnically diverse, including people from Asian, African American, and White ethnic backgrounds. Their occupations included stay-at-home parent, student, teacher, engineer, manager, graphic designer, university staff, professor, physician, model, and small business owner.

Before conducting interviews, I asked whom in the family was primarily responsible for navigating the healthcare system for the young children to help them decide whom should be interviewed. When two parents shared the responsibility roughly equally, the interview was conducted with the parental dyad (each of the dyads was a heterosexual father-mother dyad, which is why I refer to "father-mother dyads" in the remainder of the paper). When one parent clearly identified as performing the majority of navigational work, I interviewed this person. In the end, I conducted 30 interviews with 32 participants, including one father, two couples, and 27 mothers.

**Table 1. Participants' demographic information**

| | Baby's Health Condition | Mother's Health Condition during Pregnancy | Location (State) | Low-income or not | Recruiting Methods |
|---|---|---|---|---|---|
| P1 and P2 | Chronic disease (Diabetes) | Generally healthy | Florida and Pennsylvania (moved during pregnancy) | Yes | Direct contact |
| P3 | Generally healthy | High risk | Washington | No | Direct contact |
| P4 | Generally healthy | High risk, being monitored with possible Zika virus infection | New York | No | Snowball sampling |
| P5 | Generally healthy | Generally healthy | California | Yes | Direct contact |
| P6 | Generally healthy | Gestational diabetes mellitus | California | No | Direct contact |
| P7 | Preemie | Generally healthy | Arizona | Yes | Snowball sampling |
| P8 | Generally healthy | Generally healthy | California | Yes | Direct contact |
| P9 | Generally healthy | Gestational diabetes mellitus | California | No | Direct contact |
| P10 | Generally healthy | Postpartum hemorrhage | California | Yes | Direct contact |
| P11 | Rare disease (Kawasaki disease) | Generally healthy | California | Yes | Direct contact |
| P12 | Generally healthy | Generally healthy | New Jersey | No | Direct contact |
| P13 | Generally healthy | High risk | California | No | Direct contact |
| P14 | Generally healthy | Generally healthy | California | No | Direct contact |
| P15 | Generally healthy | Hypothyroidism | California and Washington (moved after pregnancy) | No | Direct contact |

| | | | | | |
|---|---|---|---|---|---|
| P16 and P17 | Overlapping toes | Gestational diabetes mellitus | California | No | Direct contact |
| P18 | Generally healthy | High risk | California | No | Direct contact |
| P19 | Generally healthy | High risk | Ohio | No | Direct contact |
| P20 | Generally healthy | Rheumatoid arthritis | Washington | No | Snowball sampling |
| P21 | Generally healthy | Generally healthy | Indiana | Yes | Snowball sampling |
| P22 | Generally healthy | Generally healthy | Indiana | Yes | Snowball sampling |
| P23 | Generally healthy | Generally healthy | Florida | Yes | Direct contact |
| P24 | Generally healthy | Generally healthy | Washington | No | Direct contact |
| P25 | Generally healthy | Generally healthy | California | No | Direct contact |
| P26 | Generally healthy | Generally healthy | New Jersey | No | Direct contact |
| P27 | Blocked tear duct | Generally healthy | Pennsylvania | Yes | Direct contact |
| P28 | Generally healthy | Generally healthy | Idaho | Yes | Direct contact |
| P29 | Generally healthy | Postpartum hemorrhage | Washington | No | Direct contact |
| P30 | Generally healthy | Generally healthy | Oregon | No | Direct contact |

Following the narrative interview method, I used the question "When was your first time navigating the healthcare system for your baby?" as "a generative narrative question" (Riemann and Schütze 1991) to invite participants to share their personal experiences and elicit their perceptions of what constitutes the healthcare system in U.S. During the interview process, I 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?"

(Jovchelovitch and Bauer 2000; Fraser 2004). The interviews lasted from 1 to 2.5 hours. When possible, I conducted face-to-face interviews. Skype interviews were conducted when the participants lived too far away to meet in person. Nine interviews were conducted face-to-face, and the remaining eight interviews were via Skype. All interviews were audio recorded with participants' permission. Each interview produced a rich description of the participant's lived experience of navigating the healthcare service landscape on behalf of their children. Some participants also shared artifacts that they created to help them navigate health services, such as lists comparing OBs and pediatricians, and lists of bills. All participants received compensation for their participation in the study. IRB approval was obtained prior to the beginning of data collection.

## 3.2 Data Analysis

I conducted three rounds of data analysis, corresponding to the findings chapters in this dissertation project. Each round was started with a distinct theoretical or empirical focus. Yet insights generated from the former substantially informed the design of later analyses.

### 3.2.1 First Round of Data Analysis

The first round’s goal is to identify individuals’ trajectories. “Trajectory” is a term coined by Strauss et al. (A. L. Strauss et al. 1985) “to refer not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization" (p.8), which reflects “the complicated relationship between the development of an illness and the various types of work done to ‘manage’ that illness “ (Riemann and Schütze 1991). Schütze later developed “trajectory” as a basic concept for analyzing narrative interview data (Schütze 2008; Riemann and Schütze 1991), which refers to a biographical process of “the ordering of events for each individual” (Jovchelovitch and Bauer 2000).

I followed Schütze’s six steps (Schütze 2008; Jovchelovitch and Bauer 2000) to analyze the narrative data in an inductive approach to identify individuals’ trajectories.

The first step is transcribing detailed and high-quality transcriptions. I transcribed the interviews by herself, which helped me immerse myself within the data and re-experience each participant’s emotions (Jovchelovitch and Bauer 2000; Fraser 2004).

For the second step, I disaggregated long chunks of talk into segments of narratives, and separated the text into indexical and non-indexical materials. Indexical statements refer to “who did what, when, where and why,” while non-indexical statements go beyond events and express values, judgements and any other form of generalized “life wisdom” (Jovchelovitch and Bauer 2000). Non-indexical statements include two types: descriptive, and argumentative. Descriptions refer to “how events are felt and experienced, to the values and opinions attached to them, and to the usual and the ordinary” (Jovchelovitch and Bauer 2000). Argumentation refers to “the legitimization of what is not taken for granted in the story, and to reflections in terms of general theories and concepts about the events” (Jovchelovitch and Bauer 2000).

In the third step, I used of all the indexical components of the text to analyze the ordering events (“trajectories”) for each participant.

In the fourth step, I analyzed each participant’s self-understanding about their trajectory by examining the non-indexical components such as opinions, concepts, and reflections.

In the fifth step, I compared the trajectories between different participants, in search of similarities and differences.

The last step was to construct a theoretical model which established similarities to recognize collective trajectories.

### 3.2.2 Second Round of Data Analysis

Informed by the first round of data analysis that participants had to juggle a wide array of interactions with healthcare systems, I found it important to focus on individual type of interaction and further explore its associated navigation practice, because this would allow focused insights into how we could design to better such interaction. I decided to focus on choosing a provider, because this was an important first step towards dealing with healthcare systems. I used thematic analysis (Braun and Clarke 2006) to explore how participants chose a provider. To be more specific, I coded all my interview transcripts to explore what factors participants considered important to their decision-making process. The coding process was inductive, as I initially assigned basic codes to each idea participants described as relevant in helping them choose a provider. Then I iteratively combine the codes into higher level concepts, until I was able to develop a coherent thematic map, where the overarching themes were mutually exclusive but also complemented each other, empirically and theoretically.

### 3.2.3 Third Round of Data Analysis

I used thematic analysis (Braun and Clarke 2006) to analyze my data in an inductive approach (Patton 1990). I first familiarized myself with data with the initial analytic interests in challenges my participants faced and practices they performed to tackle the challenges. I immersed myself in the data through reading back and forth and marking ideas. During this iterative process, I started generating an individual list of initial codes through the whole dataset. Based on the initial code list, I re-focused my analysis at the broader level of themes, using rounds of discussions to consolidate my codes into an overarching theme. I sorted different codes into potential, overarching themes, and collated all the related data within the identified themes. Next, I carefully compared the identified themes to the dataset and refine the them with the goal of ensuring internal homogeneity and external heterogeneity (Patton 1990). Lastly, I defined and named overarching themes. My 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, I present these themes. When reporting quotes from interviews, to protect my participants' identities, I use P1, P2, etc. to denote different study participants.

## 3.3 Methodological Considerations

Per the nature of qualitative research, my dissertation project does not make generalizing claims about the concrete experiences of larger populations in the United States. The retrospective style of narrative interview means that participants might miss details such as the exact hour they visited a medical facility. However, they were all able to articulate major frustrations, encounters, and strategies in their interactions with healthcare systems. These memories of lived experiences do not fade away easily, as they involved so many emotional burdens and cognitive investments. While coding these data, I also checked their logical consistency and coherency for each individual participant so that each individual's experiences could deliver a convincing narrative. For example, when a participant had a rather pleasant experience with a medical visit, I would try to explain why by referring to their previous frustrating experiences and identifying positive factors.

I envision my dissertation project as a starting point of exploring contemporary healthcare challenges from the healthcare consumer's perspective. It started from a small-scale interview study but was able to point out critical issues within the healthcare system. It successfully executed my research efforts in a delineated conceptual space that is navigation practice in the context of healthcare. It also pointed to many unanswered questions in an outer research space that warrants many future research endeavors.

# Chapter 4. Healthcare System as a Black Box

All participants stated that they started navigating the healthcare system for their babies when they were planning to become pregnant or knew they were pregnant. Participants saw no real distinction between the antepartum and postpartum period, but already started navigation during pregnancy when the fetus' health was still dependent on the mother's body. All participants reported that they could not fully understand the internal workings of the healthcare system, and felt that mechanisms and processes were extremely complex.

I use the classic metaphor of the "black box" (e.g., (Wiener 1961; Latour 1988; Suchman 1987)) to capture the lived experiences of participants encountering the healthcare system: the inner mechanisms of the health system took inputs from participants (health needs, money, and other resources) and produced outputs (health services), but the inner processes were not transparent. Participants felt they were dealing with a number of unknown variables and were often surprised and taken off guard by unexpected requirements and breakdowns. They generally felt lost as to how the healthcare procedures related to them succeeded or failed. For instance, P10, a PhD student born and raised in U.S., explained:

> *I had to go to (the) student health (center) to get the pregnancy confirmed. And that's when they gave me a referral...because of the student insurance, they require a referral for everything…The doctor gave me the referral, and I found another doctor at XX medical center…I did follow the steps, they had like, if you do this, whatever it was paperwork and stuff. And then they still messed up my insurance, and I still had to call the insurance, because they sent me a bill…They fixed it eventually. But yeah, I still don't know what or who caused the mess-up.*

For P10, since she followed the procedures and sent the referral, ideally there should not be a bill. Even though she contacted the insurance company and got the mess-up fixed, no one explained to her what issues caused the 'mess-up,' who was responsible for fixing the issue, or what they did to fix it. P10 was left not knowing what she could do to prevent similar issues in the future.

Similarly, P12, a teacher who had lived and worked in New Jersey for six years, found the healthcare system difficult to understand. One incident she described relates to understanding and managing bills:

> *I have been very confused during the whole process…I am still receiving bill(s). However, I don't really understand what those items are, because these items are usually listed only*

> *using abbreviations or acronyms. Sometimes...I could make a guess. But most times, I just can't make sense of those abbreviations and acronyms. Also, the bills contain too little useful information...Sometimes, the hospital…sent my samples to some outside labs to analyze and didn't notify me. Then when I received bills, I was totally puzzled…I don't know whether and how the hospital and insurance company communicate. It seems that the hospital sends bills to the insurance company, and the insurance company calculates then list the bills on its website. But sometimes the hospital directly mailed me bills. Most of the time, it's like I downloaded bills from the insurance company and paid. I'm not even sure whether there are overlaps between bills mailed by the hospital and bills on the insurance website.*

P12 was extremely puzzled about how the hospital and the insurance company handled her bills, especially when numerous bills started to arrive. To avoid paying a same bill twice, P12 started carefully managing bills from the hospital and insurance company. She categorized the bills into different folders and named each bill with labels such as "fully covered," "not paid," "over paid," and "new not paid" to avoid missing or paying a bill twice (See Figure 1.).

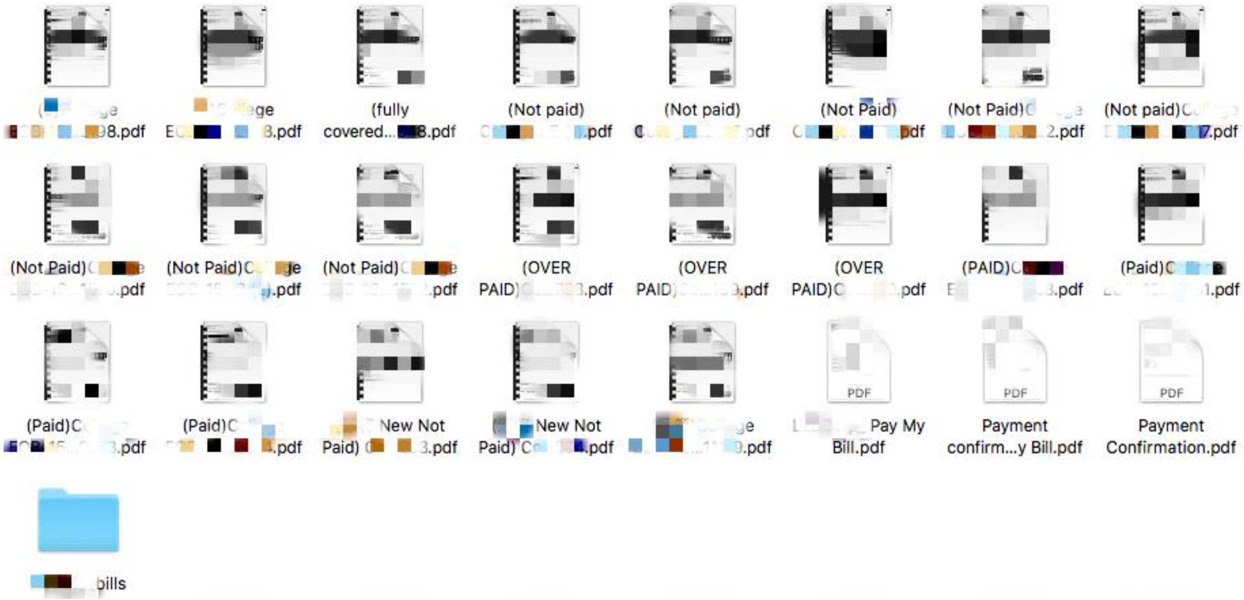

**Figure 1. P 12's way of managing bills**

The health services black box departs from classic examples of black boxes. This is because despite the opacity of the processes contained in the box, my participants are often required to engage with health services organizations at multiple points to get what they need—yet they do so with little available information and no formal training in how the organizations work. For example, P15, an engineer from Seattle, expressed her confusion regarding how different sectors of healthcare system might disconnect or connect with each other, and lamented that as an individual consumer she bore the responsibility to navigate health services almost entirely alone:

> *I don't know how the whole healthcare system operates. It's not transparent at all. Everything relies on one's own effort to search, to understand…Every time my OB*

> *ordered blood tests, I needed to drive to another clinic to draw the blood. I feel very confused about this. Why cannot those related facilities be in a same building? I don't know what organizes them together. I mean, there must be some kind of network, or system, but I just don't know…Even now, I can only say I kind of understand the OB/GYN and pediatricians related services, but everything else is still unclear to me.*

My participants identified a range of issues that they must manage in navigating the healthcare service. These issues related to clinicians, clinics, hospitals, insurance, billing, referrals, medications, diagnoses, treatments, and many others. Participants felt that specific healthcare organizations, and the healthcare system as a whole, are opaque and difficult to understand. Participants reported lacking an understanding of how health services worked, how different elements connected to one another, or how errors occurred and how they could be corrected and avoided in the future. Perceiving the lack of transparency and complex nature of the healthcare system, as P15 so clearly expressed, patients must seek information and get what they need on their own. Participants felt as if they were grappling in the dark as they struggled to navigate through a non-transparent set of complex processes.

The emotional ramifications of this work are very real: participants reported a wide range of overwhelming negative feelings such as confusion, frustration, distress, anger, and loss of control. They also had to exert a large amount of time and energy attempting to obtain and manage health services for their children.

# Chapter 5. Navigation Practices and Navigational Competence

My participants found the U.S. healthcare system opaque and complex. Gaining a full understanding of the health service landscape can be incredibly difficult. Yet, over time my participants reported becoming more adept at understanding and navigating the black box of healthcare services. In this chapter, I describe knowledge and skills participants gained that enabled them to navigate health services for their young children. I use *navigational competence* as a working definition to denote a set of integrated capabilities consisting of knowledge and skills for individual healthcare consumers to go through complex service provision systems effectively. Because different participants had their own unique life circumstances, including location, health needs, and financial factors, their service provision landscapes and specific experiences of encounters with service providers varied.

## 5.1 A Common Trajectory

Despite their different circumstances, 31 out of 32 participants [2] experienced a common process in becoming more knowledgeable about the health system and gaining

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[2] Only P7 felt that he had never encountered challenges in navigating the healthcare system to obtain desired services, because he had a dedicated social worker who helped him navigate through the services for his wife's pregnancy and his preemie. Despite that, he felt the healthcare system was a black box to him, as he believed he knew little about how the system

adeptness at navigating health services for their young children. The process that I constructed based on diverse participant accounts involves multiple stages, and is inherently iterative in the sense that each of the stages is typically revisited multiple times (see Figure 2). First, individuals seek and combine information from various sources including their own pre-existing knowledge to make decisions regarding what services they need and which providers to choose. Each of my participants described putting a large amount of effort into seeking information and making informed decisions related to selecting insurance, selecting clinicians, evaluating clinician diagnoses and treatment options, and so forth. However, despite the large amounts of information seeking and integration that went into decision making, participants all reported breakdowns of various types that they encountered while using health services. When they encountered breakdowns, they exerted their agency to figure out how to repair the breakdowns and reflect on what should have been done or what lessons they could learn for the future. Breakdowns prompted gains in knowledgeability and competence about how to navigate, which in turn informed future service use.

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work. In addition, he felt unsure about the quality of the services he received. Having no navigational issues does not equate with the high quality of services.

Next, I present two "typical" cases, that share insights common to all interviews in the study, to demonstrate the process through which participants gained competence to navigate health services.

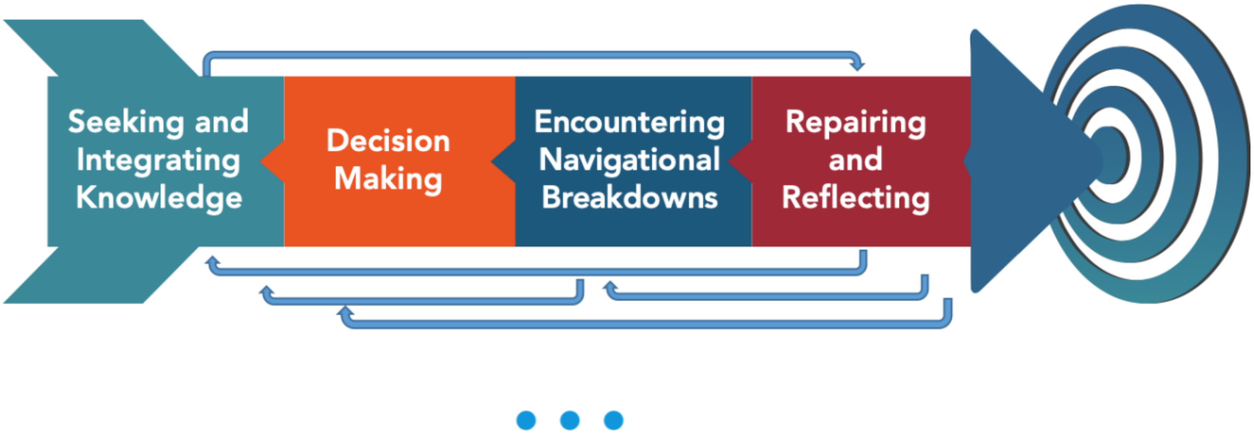

**Figure 2. Process of gaining competence for health services navigation, triggered by breakdowns**

### 5.1.1 Case 1: Dealing with Insurance

The first case is an episode where P4 had to put much effort into figuring out how to coordinate a hospital, the Human Resources (HR) office of her employer, medical labs, and an insurance company. Similar to most of my participants, this was just one of the many stressful incidents she encountered in getting desired health services for her child.

At the time of interview, P4 was 39 years old with a seven-month old baby. She received a Master's degree in Economics in Japan. She moved from Japan to the U.S. seven years ago, where she worked in a company in New York City as a business development manager, and married an ophthalmologist who was born and raised in the U.S. Although her husband worked in the healthcare field, his professional knowledge was not helpful for P4. Navigating the healthcare system was still a significant challenge for P4.

### ***Seeking and Integrating Knowledge***

P4 encountered insurance difficulties prior to planning for pregnancy, such as choosing doctors who were not in-network and having reimbursement mistakenly denied by the insurance company. From these past experiences, she possessed pre-existing knowledge regarding how to deal with insurance in the U.S. She said: *"Ever since I came to the U.S., I knew that the healthcare system, especially the insurance, is a very tricky part. Because of the past experiences, I know whom I should call when there's an issue and how to explain the cases."*

She told me that the first time she started navigating insurance services related to her child was actually one year before she started trying to conceive. Because of her past difficult experiences with insurance companies, she felt that understanding and choosing an insurance plan was the most important thing she could do to prepare for having a baby. She wanted to know which obstetricians (OBs) her insurance would cover, what hospitals particular OBs were affiliated with, whether her insurance would cover certain hospitals, which insurance plan would be ideal for the pregnancy (in case she needed to plan a switch from her current plan), what pregnancy-related tests (e.g. ultrasound, amniocentesis) different plans would cover, and so forth. Meanwhile, she posted on online forums asking for new moms' recommendations of OBs in her local area. She combined these recommendations with personal research on other factors such as the reputation of OB's affiliated hospitals and OB's educational background and compiled a list of potential OBs. She then compared her list with insurance companies' coverage of OBs.

As an ophthalmologist, her husband was *"very sensitive to the insurance issues"* and *"didn't want any problems of that kind."* However, he could not offer useful suggestions to P4, because his medical knowledge was highly specialized, and he had limited knowledge regarding things such as insurance and billing.

To understand the couple's complex insurance policy and make informed choices, P4 spent much effort seeking information. She sought information from various sources, including the HR office in her company, the insurance company, and online information in peer message boards. She typically approached the HR office in her company with questions first, but the information provided by the HR staff was too basic for her to make decisions and focused on issues such as copays, not the specific information she needed.

To gain more detailed information, P4 called the insurance company many times, which was time-consuming and not informative. It took around *"ten minutes"* to reach a real customer service representative every time she called. Despite the wait, P4 described how the customer service representatives gave standardized, shallow answers that did not adequately answer her questions and spoke in vague generalities beginning with the phrase *"it's our policy"* rather than providing detailed, relevant answers to her questions. P4 felt frustrated and even expressed a suspicion that such frustrating service was perhaps by design: *"I think they intentionally design the customer service system in this way, so the customers will just give up."*

P4 then started searching online extensively and posted questions on online forums to gain as much knowledge as possible about which insurance carrier and plan would be ideal for pregnancy, childbirth, and pediatric care. After finally figuring out the optimal plan provided by her employer's insurance provider, she started considering whether to continue partaking in the insurance through her company and only changing the specific plan, or switching to her husband's insurance. To make an informed decision, she asked her husband about his plan, and used the online benefit guide and quotation system for his insurance so she could compare both insurances based on a range of factors.

### ***Decision Making***

After spending *"half a year"* figuring out these *"complex"* things and integrating pre-existing knowledge with new knowledge, P4 was finally confident that she was ready to make the best decision. P4 decided to continue partaking in insurance through her company, but she changed to another plan within the same insurance company because the plan covered more of the providers on her list of preferred OBs, had more coverage for pregnancy-related expenses than her previous plan, and was cheaper than the dependent insurance plan of similar coverage scope offered through her husband's workplace.

### ***Encountering Navigational Breakdowns***

Even though P4 tried her best to make an informed decision regarding insurance, she still encountered multiple breakdowns related to insurance service. I only describe two breakdowns here. The first breakdown related to the insurance company's refusal of coverage. When her OB was planning to order a genetic test for her, P4 called the insurance company to check whether the test would be covered by the insurance company (something she knew to do based on her pre-existing knowledge). The insurance company confirmed that it would be covered. She felt reassured and did the test. However, a breakdown still happened when the company later refused to cover it:

> *When I received the bill provided by the insurance company, I found that it's full-price. It's very expensive. They didn't cover it at all. I was shocked. I contacted the insurance company. I asked them, "it's like this, you told me that it would be covered, so I accepted the test. I only did it after confirming with you. Why didn't you cover it?" The insurance company said, "because your OB or the lab didn't contact us to ask for pre-authorization. Your OB's billing office should've asked for that from us first.... It's not your fault, but your OB's billing office or the lab missed one step..." You see, the insurance company was so evil. They could've just told me that I should ask my OB to request a pre-authorization.*

Understandably, P4 felt extremely upset when confronted with this surprise bill despite taking action to ensure the test would be covered. P4 was not sure how she could verify the insurance company's explanation for the bill. Moreover, even if the explanation was valid, the insurance company did not provide sufficient actionable information in response to her initial inquiries that would have allowed P4 to take a different path or anticipate the expense.

Another major breakdown occurred when P4's employer notified her that they decided to change to another insurance provider. P4 was forced to revisit her process of extensive information seeking and comparison of plans once again. Even worse, the employer decided to officially switch to the new insurance on June 1, when P4's estimated due date was June 3. P4 experienced a lot of stress and worry regarding the temporal implications of her delivery since she knew full well that the due date was *"just an estimate."* P4 spent a lot of time worrying about what would happen if she went to the hospital *"on May 31"* and delivered *"on June 1,"* and had a number of nagging questions about the change to insurance, including: *"Which insurance company will pay for me? How am I going to explain this to the hospital? How should I ask the hospital to separate each day's bills for me? What if I don't receive my new insurance ID number and other details before going to the hospital?"*

P4 was literate in pregnancy information and aware that her due date was simply a guess. She was also aware that inducing delivery early could have negative implications for herself and her baby. Despite this knowledge, P4 was at a loss about how to ensure she would get the insurance coverage she needed amidst her company's change.

### *Repairing and Reflecting*

P4 had to repair the breakdowns described above by herself. To fix the first breakdown, she first tried to appeal the company's decision not to cover her test, which failed. Then she joined an online mommy's group, seeking advice from those moms:

> *There were quite a few moms younger (in the group than 35 years. Some of them did the test too, because they were concerned about baby's health. Of course, insurance companies didn't cover the tests ...They shared how they negotiated with the lab. They told me, "you can directly call the lab to bargain, then the expense will be reduced from about $2000 to around $200...." Some moms even told me that they negotiated more aggressively and only paid $150....I got such information through such private communication in mommy's group. It's not like you can easily get this kind of information by searching online, and some people may not tell you so frankly.*

P4 followed the advice. She called the lab and explained the situation, which resulted in positive movement:

> *I called the lab. The lab is in California. ...Maybe because this lab is rich and they had witnessed so many similar cases, they didn't care anymore. So they said, "OK, it's our*

> *fault. We should've communicated with your insurance company first..." Then they waived the bill for me. They waived the full amount!*

P4 reflected on the experience. She told us that she gained skills and knowledge about how to manage health tests and procedures: *"you have to take care of all the procedures in advance. Before doing any examination or test, even if it's a simple blood test or urine test, always call the insurance company, ask as many details as possible."* P4 reported that she had developed a new process since this specific breakdown occurred. From then on, she always calls the insurance beforehand and asks about specific procedures that have been recommended or ordered. She asks whether the insurance company covers specific laboratory tests, what the procedures for reimbursement are, and so forth.

To fix the second breakdown, P4 acted proactively and contacted the insurance company, the HR office, and the hospital. She reported calling the insurance company *"almost everyday"* to ask them to provide her ID number and other essential information. She also brokered contact between her employer and the insurance company, saying *"I also pushed the HR office to push the insurance company. The HR office helped this time. They kept requesting the insurance company. "* This was successful: *"at the last week of May, the HR office got all the information I needed."* P4 then *"immediately called the hospital, explained the situation, asked which insurance I should use and provide when staying in the hospital."*

P4 reflected on the experience, and drew two lessons. The first one *was "You need to manage the timing issues carefully, because pregnancy is very time-sensitive.... You have to connect these institutions by yourself, proactively!"* The second one was *"You should seek help from whoever may help you, like the HR office."* As part of learning to "seek help," P4 had to identify sources of help, and obtain crucial information like which departments to contact at her work and at the hospital, how to actually get into contact with them, (e.g. key phone numbers and extensions), and who are the key people she should speak with. P4 gained working knowledge of her micro health service system, comprised of her HR, insurance, clinician, lab, and so forth, and learned who, what, when, where, and how to contact each of these entities. Crucially, P4 not only gained knowledge about her current micro-service system, she also gained capacity to identify and create other health micro-service systems in the future.

While P4 managed to deal with these breakdowns and simultaneously gain skills and knowledge that will help her prevent or address future breakdowns, these gains were not without cost. P4 continuously suffered from severe worries about the breakdowns, and performed intense labor, such as daily phone calls. Even after the breakdowns were repaired successfully and multiple months had passed, she still occasionally relived past frustrations about the fact that she had to take care of so many procedures with so much effort completely alone: *"I am so mad that I pay money for insurance, I pay money to hospitals. Then everything falls on my shoulders. I have to guide them to sort out things.... I was quite experienced. I still had to spent so much time to fight ...."*

### 5.1.2 Case 2: Treating a Baby's Acid Reflux

At the time of interview, P8 was a PhD student in California, born and raised in the U.S. Her baby was close to two years old. Similar to other study participants, she encountered many challenges in finding and receiving desired healthcare services during both the antepartum and postpartum periods. Below, I present one episode related to treating her baby's infant acid reflux, a common condition in babies.

#### *Seeking and Integrating Knowledge*

When her baby Emma (pseudonym) was about two and a half months old, Emma started screaming and crying a lot. P8 searched online. Based on the information she gained by searching, she suspected that something must be wrong. She talked to her parents and friends, as she thought they had experiences of raising kids and must know what was going on. However, her parents and friends did not offer any useful advice or understand how severe the situation was: *"…my parents were like, 'oh, you know, it's a baby. Yeah, they cry.' and I was like, 'No, you don't understand, she's screaming constantly, something is wrong'."*

P8 took her baby to the pediatrician. The pediatrician diagnosed Emma with infant acid reflux, a condition occurring when the stomach contents reflux or back up into the esophagus and/or mouth. Because the pediatrician and P8 shared a similar value of not using pharmaceutical solutions as *"the first line of defense, unless it's like something that's very serious,"* they decided P8 should do an elimination diet to try eliminating food that "could possibly be causing reflux," since P8 was breastfeeding. The elimination diet, it was hoped, would allow them to identify and eliminate the food(s) responsible for Emma's reflux (possibly because she was allergic to them). Based on the pediatrician's advice, P8 stopped eating a number of foods that might be problematic for the acid reflux and allergies. However, Emma did not get better. P8 started searching online, reading books, and integrating her and the pediatrician's pre-existing knowledge regarding herbal medicine to make a plan of using herbal remedies. P8 tried different types of herbal medicine. Unfortunately, none of them worked well.

### *Decision Making*

After the alternative medicine failed, the pediatrician suggested using Prilosec, a pharmaceutical medicine administered in liquid form, to treat the baby's reflux. P8 decided to try the treatment because both she and her baby had been suffering a lot. The medicine turned out to be helpful:

> *And at that point it's just there's something called Prilosec, which is on the adult market, and there is essentially a baby version. After not sleeping and listening to your child cry for like twelve to sixteen hours a day, and I'm not exaggerating. Like screaming not just like crying, but like screaming in horrible pain and doing that for months, we were like OK, let's try the medicine... We tried everything that you could do, and so we tried the medicine, and it didn't make it go away, but it helps. And that was nice.*

### *Encountering Navigational Breakdowns*

Even though P8 found a knowledgeable and helpful pediatrician, chose an expensive insurance, and found an effective medicine, she still encountered breakdowns in receiving desired healthcare services. Although things went smoothly with the pediatrician, P8 encountered problems with the pharmacy and insurance company.

P8 said that getting Prilosec was *"perfectly easy"* the first time: the pediatrician sent the transcription to the pharmacy and they just went there and picked it up. Problems arose the second time P8 needed to get the prescription filled when she was about to leave for a week to visit her parents for a holiday in another state. P8 wanted to get a refill in advance to prepare for the upcoming trip. However, when she attempted to do the refill, the pharmacist told her that the insurance company rejected to cover the cost because of *"policy constraints"* which stated that a patient could only get one refill *"every 30 days."* Worse still, because the insurance's rejection, the pharmacist did not prepare the medicine. However, the pharmacist did not notify P8 of the issue until P8 went in at the scheduled time to pick up the medicine:

> *... He (the pharmacist)'s like, "oh the insurance rejected us, so we didn't make it". And I was like "well, why didn't you call me and tell me that, because we have to leave in the morning and...it was like 6pm or something, like the insurance company is not doing anything now." ... He's like "people usually call and check to make sure it's ready beforehand". And I was like "you told me it would be ready, and so I came" ...*

Since they needed to leave the next morning and the medicine was urgently needed, P8 was forced to pay for Prilosec out of pocket, which *"was well over one hundred dollars."*

Three weeks later, P8 accidently spilled her baby's medicine. The remaining medicine could only last for one week. Because she paid out of pocket for the last prescription, it had been more than 30 days since last time the insurance covered the prescription. Thus, she felt relieved. She believed that according to the insurance policy, the insurance would cover the medicine this time. Because of the negative experience with the previous pharmacy (which did not notify her of the insurance's decision in a timely manner), to avoid potential issues, P8 asked the pediatrician to write another prescription. Then she went to a different pharmacy to fill the prescription. However, she still ran into problems:

> *The pharmacist was like "oh OK, well, the compounding pharmacist isn't in until Monday. Can you wait until then?" ...The compounding pharmacist came in ... (and provided the medicine). ...so we got it and it's in this really weird bottle, and then they were like "oh your insurance didn't cover it ", and I was like "This is strange." I said, "First of all, being in this bottle is weird and then the insurance not covering is weird, because they should have, as they covered it before... I had the same prescriptions filled at R (the previous pharmacy), and they were just rude, so I came to you guys."*

### *Repairing and Reflecting*

To repair the first breakdown, P8 called the insurance company the next day:

> *And then I called the insurance company the next business day. We were already on the road. And the insurance company said, "oh well, you know you only cover it once every thirty days." And I was like "OK, so what happens if I have to leave, how does that work", and they're like "well, it's just the policy" and I said "well can you please make an exception for this? You know how am I supposed to afford to give my daughter this*

> *medicine which was well over one hundred dollars for it. You know if I have to travel and I have to buy some in advance or like." "well then you should have your prescription transferred to where you're going". And I was like "OK thanks buddy".*

Although her efforts in communicating with the insurance company failed to resolve the issues, P8 reflected on the experience and shared the lessons she learnt with us: always check beforehand with the pharmacy before going in for the pick-up, check with the insurance company in advance, manage the timing and geographic issues in advance when planning travel, and ask the doctors to send new prescriptions to another location beforehand.

To repair the second breakdown, P8 decided to find out why the insurance did not cover the medication anymore. She suspected that the pharmacists made the medication without knowing the insurance would not cover it: *"It was just lags in communication between pharmacy and insurance company."* To understand the reasons why the insurance did not cover it and avoid running into similar issues in the future, she urged the pharmacist to call the insurance in front of her, and initiated communication among herself, the pharmacists, and the insurance company: *"They (pharmacists) were very cooperative….So they called the insurance again...then they actually, even though we're on the scene like me and pharmacists were in the same building and we're right next to each other, they* *had to call me and do a three way call to talk about it. Anyway, it was just weird. Very very strange…"*

Through the effortful three-way conversation, the pharmacists and P8 were able to figure out the reason why the insurance did not cover the medicine this time: *"Well, it turned out that the pharmacy wasn't aware that there was a premade version of this, that's covered by insurance, and they made it completely from scratch, ...so they're like "you know, we're willing to throw it away, and order it for you, but that's going to be several more days." And at that point... "I don't have several more days," and so I paid for that one again. And it was even more expensive…."*

Thus, P8 learned that the insurance companies differentiate between commercially available and customized medications. She told me that since then, she always double checks with pharmacists about the form of a medications (commercially available or compounded).

Similar to other participants, P8 managed to fix breakdowns and gained skills and knowledge through the process, while simultaneously suffering a from a large amount of stress and worry and taking a weighty financial loss. When *"not sleeping and listening to"* her baby *"cry for like twelve to sixteen hours a day,"* she still had to take care of breakdowns. When she shared the process during her interview, she cried and said, *"I'm crying because it was hard."*

In summary, both cases brought to the fore the fragmentation and lack of transparency that characterizes the U.S. healthcare system. P4 and P8 were located in different states, but experienced similar navigational breakdowns despite conducting prior research. Both were damaged by breakdowns, and were forced to conduct extensive repair work to get what they needed for their infants. The breakdowns they experienced were primarily interorganizational. For example, organizations might have miscommunication or disregard each other's decision. In the table 2, I compare the similarities and differences between the cases of P4 and P8 along several critical dimensions.

Notably, similar episodes happened to 31 out of 32 participants in the study sample. Even when navigation was shared by two people (as a shared the responsibility of a couple), navigation was still incredibly fraught with frequent breakdowns, which induced stress and loss of time and money. For example, P1 and P2 expended a lot of effort to enroll in insurance in a timely manner and find a good medical daycare for their baby, who has Type 1 diabetes. P16 and P17 who were small business owners had to read academic articles to figure out how to treat their baby's overlapping toes, because all the pediatricians they visited either did not notice the problem or simply told them "it doesn't matter."

**Table 2. The comparison of Case 1 and Case 2**

| | P4 | P8 |
|---|---|---|
| Dealing with multiple organizations | OB, Hospital, HR office, medical lab, insurance company, pharmacy | Pediatrician, insurance company, pharmacy |
| Breakdowns (relational) | Insurance company vs. OB and lab vs. P4<br>Insurance company vs. P4 and Hospital (temporality) | Insurance policy and pharmacy vs. P8's travel plan (temporality and location)<br>Insurance vs. pharmacy vs. P8 |
| Pre-existing knowledge | A lot about the healthcare system; a husband who was a healthcare provider | About treatment; little about insurance |
| Gained Competence | Know-what and know-why:<br>• Knowledge about some specific plans and insurance choices<br>• Expenses are negotiable<br>• Some tests may need preauthorization<br>Know-how:<br>• Always double check with organizations and ask for as many details as possible<br>• Take care of all the procedures proactively<br>• Manage the timing issue carefully<br>• Seek help from others (e.g., HR)<br>• Negotiate with providers | Know-what and know-why:<br>• Insurance companies differentiate commercially available and customized medications.<br>• Prescription can be transferred to another state<br>Know-how:<br>• Always double check with organizations<br>• Manage the timing and geographic issues in advance |

During these stressful processes, my participants' navigational competence continuously increased, but this increased competence came at a steep cost since they also suffered from severe stress, worry, loss of productive time, and financial loss.

## Summary

I used the term of "U.S. healthcare system" to represent a totality of techniques, people, practices, and institutions. But in reality it is fragmented, lacking coordination between resources and organizations (Enthoven 2009). My participants had to perform coordination work to connect poorly coordinated organizations, such as their employer, insurance company, pharmacy, and hospital. For example, they need to coordinate with their employer's human resources office, insurance company, and hospital to make sure their employee health benefits could over their newborn babies. They performed negotiation work with service providers to obtain affordable, high quality services. They performed complex informational work to identify a proper course of action in dealing with service providers when breakdowns happened, e.g., when bills were calculated wrong.

The healthcare system disciplined my participants into acting as obedient workers. Often the bill was a primary instrument of coercion. In prison systems that Foucault studied (Foucault 1977), rules and constraints are visible and clear, disciplining people through instructions and punishments. In healthcare, coercion through billing was effected through a web of institutions such as debt collection and credit history services which ensured that patients and caregivers were forced to be responsible for errors and mistakes that originated from within the healthcare organizations.

Acts of coercion have a normalizing effect. For instance, P15 said, “Everything relies on one’s own effort to search, to understand.... I guess that’s just how it works.” By accepting their invisible work for the healthcare industry as normal, the participant was subjected to the neoliberal logic and its further developments that count on patients and caregivers to take upon more responsibility.

The healthcare system was an opaque and dysfunctional one where breakdowns frequently happened at different scales, with causes that were unknowable to participants. My participants observed that breakdowns could result from errors of many kinds, miscommunication across multiple departments of one organization or failed coordination across multiple organizations.

My participants faced tremendous difficulties in making sense of an opaque healthcare system with invisible rules and practices. Participants recognized that they must take initiative in fixing breakdowns, or they would be the ones to suffer. They thus sought to discover knowledge about the healthcare system. They would carefully ask questions of staff members regarding procedures and policies. Even with this knowledge, more was needed and had to be obtained through connections with a larger network of resources. For instance, my participants mentioned that they compared the websites of various healthcare providers' websites to learn whether their own provider had outdated information. They checked reviews of doctors and facilities on websites like Yelp. They consulted medical journals to check a doctor's diagnosis and medical suggestions. They gathered experiential knowledge from other parents on social media. For example, they learned that certain bills were negotiable if they told the healthcare providers they did not have health insurance or could not afford co-pay.

Participants discussed the importance of self-reflection in learning. Whenever breakdown took place, they reflected upon what they already knew, and what else they needed to know so that such breakdowns would not happen again. For example, in the U.S., in-network means healthcare providers have contracts with insurance companies, and consumers can pay much less. Out-of-network means no contract and consumers have to pay the full amount out of their own pocket. It is common that a medical facility is in-network but that certain specialists, such as pathologists, are out-of-network. However, patients are not necessarily aware of this nuance, and because of this, a substantial portion of emergency room visits could lead to high bills (Garmon and

Chartock 2017). My participants learned about this knowledge from their own unexpected bills as well as others' experiences shared on social media. They knew they must be attentive to any service or interaction that they would have in medical facilities. One participant mentioned that when her doctor said she would need an ultrasound, she asked, "Is the radiologist in-network?"

In the fragmented and complex system of healthcare, parents and caregivers were embedded in a power arrangement that they could not escape and must manage so the system remained functional for them and their families. Although parents' primary concern was their children, rather than themselves, I argue that their actions are a form of care of the self. Care of the self entails care of others as a person recognizes their rightful social role in their family, community, and society, according to Foucault (Foucault 1998b). Taking actions on behalf of their children demonstrated participants' continuous work on renewing their knowledge of the healthcare system, or mastery over the self.

In summary, in this chapter, I reported on how my participants navigate the complex, opaque, and fragmented healthcare service system in the U.S. I analyzed a common process shared by 31 out of 32  participants which consists of four stages. The process is inherently iterative in the sense that each of the stages is typically revisited multiple times. I further illustrated the process using two distinct cases. I highlighted the challenges and struggles that my participants went through in their navigation practices. As breakdowns became frequent as even mundane to my participants who navigated the healthcare service system, growing micro healthcare service system and cultivating navigational competence in a bottom-up fashion became urgent and essential. I analyzed my interviewees' navigation practices as to how their recurrent, situated actions and their navigation competence co-constructed each other through their repeated, and often exhausting, encounters with the U.S. healthcare service system.

In the next two chapters, I will focus on two specific types of navigation practices: one is choosing providers as situated actions, and the other is my participants' infrastructuring work of fixing breakdowns to make the healthcare system work for them.

# Chapter 6. Navigation Practices: Choosing Providers as Situated Actions

As demonstrated in Chapter 5, providers are the immediate contact points of healthcare systems where breakdowns happen; but they are also challenging to deal with because of various issues. In turn, participants had to rely on their own to make sense of providers' practices and fix breakdowns. Many participants were relatively inexperienced when they first chose a provider. However, they increasingly gained insights into healthcare systems and grew expertise in choosing providers. Such insights enabled to make more informed decisions when they needed to choose providers again.

Understanding the navigation practice of choosing providers holds important implications for information design that could support patients and caregivers to more efficiently locate ideal contact points (providers) of healthcare systems. In this chapter, I will cover multiple factors my participants considered important in deciding which provider to choose, including individual attributes of a provider, organizational features, and external reviews. Some factors were articulated retrospectively when participants reflected upon their frustrations. Some factors were highlighted as important in the screening of next providers. These factors together signify choosing providers as situated action where participants took into consideration various types of contextual information beyond the performance of a provider.

## 6.1 Individual Attributes: Balancing Between Personality and Professionalism

All of my participants mentioned how they paid attention to a provider's individual attributes such as personality, background, experience, age, and expertise. Two primary categories I identified were professional attributes and personal attributes. Professional attribute refers to a provider's adherence to professional ethics and procedures as perceived by participants. Personal attribute means a provider's nonprocedural qualities such as personality and background. There is not always a clear line between these two major categories, especially as the common understanding of what constitutes work in professional settings is constantly evolving (e.g., emotional work). However, I found it helpful in stressing these two ends on a spectrum to characterize what participants valued in their providers as individual professionals.

Several of my participants stressed the importance of professionalism when determining the quality of a provider. For example, P6 told me a story about how she and her husband dealt with their newborn baby's ankyloglossia (or tongue-tie). She said:

> *Our baby had tongue-tie when he was born. It was a common condition where the tongue was connected to the mouth. We went to Kaiser and two different doctors told us the condition was serious and a simple surgery would be necessary. When we went into the surgery room, we saw a very young doctor there. We were surprised but thought it would be fine. However, the way she did this surgery was careless and brutal! She just used a scissor to cut the tissue in my baby's mouth, without other advanced equipment. My baby's mouth started bleeding right away and would not stop. We questioned the hospital and they just kept saying they did nothing wrong. We later found out online that the young doctor was in residency. We were very angry and questioned the hospital why they randomly picked someone. They just said this was always the way they handled small surgeries and they did nothing wrong. Later we went to another hospital, and a senior doctor told us that the former cut was at a wrong place and left a scar. We had to wait for the scar to heal before another surgery… Later we filed a complaint against the doctor in residency, but Kaiser did nothing about it. Not a single person said sorry to us through the whole incidence. Because of all these, we now become extremely careful about choosing a good provider. We must find the best one through our extensive research.*

P6 observed unprofessional deeds of the young doctor in residency. What she learned from the hospital later confirmed that the doctor's practice was indeed contrary to the standards. Such negative experience motivated she and her husband to dedicate more work to choosing a provider, because otherwise her baby would be the bearer of any repercussions of choosing a "subpar" one.

P12 also cross compared multiple providers to locate the ideal one for her baby. She told me:

> *We tried several pediatricians. The last one was the best. The first three were simply ridiculous! The first one checked my baby's mouth with a stick to press his tongue. In the middle he took the stick out and put it on the bed. But later he picked the stick again and put it directly into my baby's mouth! I was shocked, but it happened so fast that we didn't even have time to stop him. The second one did not even use a stick. She just used her bare hands after washing them.*

To my participants, an appointment with providers was not limited to following standard medical procedures such as taking lab test, being diagnosed, and receiving prescription. Besides professionalism, participants also cared a lot about providers' individual attributes. For example, P15 mentioned how she also considered the age of a provider. She believed that age indicates experience. She explained:

> *The obstetrician for our first baby was very young for this profession. She just had her own baby. I felt she was rather inexperienced, and knew that I could not count on her for everything. I also decided to switch to another obstetrician in three or four months.*

P4 was blatant about why professionalism was not sufficient. She shared this story with me:

> *I care about the pediatrician's attitude, like whether he pays enough attention to you, and whether he actually listens to you and tries to answer your questions. When I had my first baby, I had no experience. My doctor was very patient and I felt comfortable asking him about all the details. I don't like doctors who only give perfunctory answers. I know when they do because I can compare them with good doctors. And I search online to learn about what a good doctor should do when interacting with patients… later I relocated to another city and had to switch to a new pediatrician. So in total I had experienced three pediatricians. I noticed that good ones and bad ones had totally different ways of handling my daughter's injection. With good ones, my daughter never cried. The pediatrician I disliked, made my daughter cry every single time. She used two hands to operate two injection needles at the same time, and upon finishing, she just told me: "mom, give her a hug!" That's it! I was really pissed off by that experience, and would never visit her again, because I could tell she didn't care about my daughter at all.*

P4's account indicated that medical encounters were not purely procedural. An important part of patient experience is the extent to which the provider carries out and performs concern and care for the patient. Such care, to participants, was not just performative. Rather, it encompasses a range of details, conscious and unconscious actions that providers carried out, which all together helped form participants' perception of how much care the provider had for their patients.

In addition, the value held by a doctor also matters. The process of choosing a doctor was also a value matching process to my participants. For example, P8 explained how she cared about whether the doctor's value matched hers,

> *I wanted to just like have a doctor that I felt comfortable with. I felt like we could, you know, talk about alternative medicine, not like immediately pharmaceutical medicine at the first line of defense.*

While it is infeasible to provide an exhaustive list of all the possible individual attributes, such is not the goal of this chapter. Rather, my goal is to illustrate the variety of individual attributes, as well as how they played a role in the practices of choosing a provider.

## 6.2 Organizational Features: Seeking a Sense of Space

Participants also mentioned providers' organizational features as a factor in their consideration. Here organizational features refer to characteristics of providers' medical facilities. Providers might have rather different relationships with medical facilities: some work at several facilities at the same time, while others stay and also own a clinic. P1 and P2, a couple, described their perceptions of organizational features. They said:

> *Mainly the location, the ratings, the medical records issue, and sometimes even the atmosphere of the place. Uh, some places felt more welcome. Like for instance, when we were in Miami, it built like a more well-kept facility than the place that we went here initially. The place that we went here was fine, but it just wasn't that the standard of the one in Miami. And the one in miami. It really felt as if it was like really a first class facility. This facility here just feels like it was a doctor's private practice. Um. The one that we moved into here recently since his diagnosis ,actually feels like the one that we went to in Miami.*

Their description did not locate any particular individuals that appealed to them. Rather, it was the place that made people "felt more welcome," appeared "well-kept," and felt like "first class." P8 echoed this sentiment, saying:

> *And it was a doctor, like the people that we knew, who they were at the UCI Center here. You know it was fine. They were fine. There were a lot of doctors in one practice, and I was like it was like extremely busy. Like you know, I just felt that the Sears office was just, there were fewer doctors. Yes, there were like four doctors on staff, but there was only like two doctors in the office at once. There were only you know a handful of patients in the office at once, so you were given a lot of attention by everyone. Everyone was extremely, so friendly, like some of the nicest people I've ever met. And so you know it's not that there was anything inherently wrong with the other office, but it was just everything was right. That we choose, so yeah.*

Even when participants sought standard procedures handled in professionalism, they still looked for a sense of place at medical facilities. A place has its unique culture, history, and set of values that could play an important role in patients' decisions of choosing a provider. P8 elaborated on how she cared a lot about the organizational values when choosing a provider:

> *Another thing that was really important to me were medical records. You know, some doctor's offices think of medical records as a way to make for the revenue, and they charge significantly to give your medical records. And so that I actually kind of eliminated some potential doctors because of that. Because it was important to me to be able to have access*

> *to medical records and myself having, I had found out that I had like, just weird weird genetic condition that like we wouldn't have been able to figure out without being able to access like a lifetime of medical records for myself. Like my current doctor being able to kind of deduce and say like you know this makes me think it might be this weird rare thing, maybe we should test for that. And so just because from personal experience and knowing like the importance of having your medical records, that was a big thing for me. So some doctor I called him just like "what's your process of medical records?", so actually a lot of them were eliminated just through phone, and so we actually only saw one other doctor in person. And they were perfectly fine and in fact if we hadn't gone to Sears (their current doctor), we'd probably have gone to them.*

As P8 explained, the particular way providers worked could reflect the organizational value they held. Such value may or may not be in direct conflict with healthcare consumers. However, value clash will definitely turn healthcare consumers away. In the example above, a value clash occurred around the ownership of medical records: whether providers treated patients' data as their private property.

## 6.3 External Reviews: Knowing from Outside

Participants also consulted other healthcare consumers to learn more about providers. Although participants were oftentimes isolated individuals wrestling with healthcare systems, they told me ways to identify a good provider through social networks, both offline and online. They obtained external reviews of providers from their social networks, to facilitate their decision making. For example, P8 explained how she found a pediatrician:

> *We chose the pediatrician based we learned from my midwife, that pediatrician' s books we had been reading. He had a practice in Orange County. And then again, I asked them (Note: staff members in birth center) for recommendations. I also asked, asked me general doctor if she would take her, because but she said that, even though she was trained in pediatrics, she says her practice isn't for pediatrics, unless they have like a special condition that has to do with their gastrointestinal system and we're not, like a life-long condition that they'll have, because that's like her specialty now. So you know I was just kind of finding our pediatrician just like a magical coincidence, like, wow this person who we've been reading and thinking, like hey this is stuff making sense, and they actually have practices here?! And my older sister and I told her about it. My older sister has a thirteen-year-old right now. she's thirteen. I told my older sister about it, she's like, wow, you're going to Dr Sears' practice, that's amazing! I would like to go there! I feel very kind of privileged actually, like lucky to live in an area that's close enough, that you know even though it is a thirty-minute drive in a really good traffic, it's still like it's it's doable. You know and it's cool.*

P8 relied upon multiple offline contacts to choose a provider, including her midwife, staff members at the birth center, general doctor, and even her older sister. Although it seems P8 had already did considerable amount of information work, she still found much uncertainty in choosing a provider, reflected in how she considered finding a pediatrician as a “magical coincidence” and felt “privileged” and “lucky” to live close to a good pediatrician.

Participants also mentioned how they utilized online review platforms such as Yelp and Google Review to examine reviews of providers. For example, P8 told me:

> *After like being super annoyed about that about that woman, the receptionist. I checked everybody on Yelp at the very least, and then I like went on to websites and just like searched the doctors' names or practices... Yelp was, I think, the thing that we liked the most, and actually surprised me, Yelp would be such a good resource. And I also like to try to find doctors backgrounds. You know, like trying to find personal Web sites, and then towards the end, I don't have Facebook, but M (P8's partner) does. And so when we were having trouble finding the doctor profiles about the Sears' office. I called them, they were like," Oh, they should be on there". and they decided that there's something wrong with their website. They're like, but if you want one of the doctors Dr. VB's, she has a very active Facebook page, and she got there. and so we used M's Facebook. We went*

> *there and so we ended up getting her that way, and really she's an amazing person, and we like, he (M) follows her on Facebook and say Dr. VB posted this really interesting thing. So even though that wasn't like part of our process until the very end. I can see that being a good thing to do. I don't think all doctors do that though, I think she was, maybe, a little unique.*

In P8's account, she and her husband actually went through several online platforms such as Yelp, Facebook, and doctors' websites to better evaluate their options. What is unique in P8's case is that she also sought opportunities of interacting with the doctors to determine their fitness.

While participants praised online reviews for their usefulness, they also further explained how to effective evaluate those reviews. P15 described:

> *Yelp review is a bit tricky, but the stories below each doctor are worth reading. You could get a sense of whether the story is real or not, as well as detailed pros and cons of a doctor. When I selected my doctor, we found that she had a one-star review. But this review was focused on the clinic, not her, so I just ignored this review. After reading all the stories about my current doctor, I started to like her, and thought that I could make an*

> *appointment with her. She was available then and it turned out she was indeed pretty nice, both professional and personally.*

According to P15, Yelp reviews, especially the ratings, could be misleading because oftentimes people visited Yelp only to left emotional reviews that were often skewed towards the absolutely positive or negative ends. Therefore, P15 stressed careful assessment of those reviews. One way to do this, according to P15, was to read through the stories, because of the higher level of authenticity embedded in stories. Participants also mentioned how they used online reviews in their decision-making processes. To them, the role of online reviews was helpful but not determining. P8 elaborated on this point:

> *Regarding Yelp, the way I look at Yelp, because or like Amazon or whatever or any review system, is that there is going to be bias in every direction. Everybody's story is like should be legitimately considered, but it shouldn't be the sole reason, you know, that you make a decision to do or not to do something, it should be like a collective thing, not one story should influence you that much. And so when there is an overwhelming response about something, then I tend, that means, then I may be like, OK I don't like the vibe that people get from that, at least like if these are people who are going there, and they're like, if they are generally angry, and not good people and that sucks them, or*

> *they're just like raging people, then I don't want to be around them. So for me, you know, seeing things and finding out information just about like immunization practices, and like some doctors not just, immunization practices, records stuff like that, you can find a lot of that information through people on the Yelp. And like, when people have problems, or when people are finding that their process is good... So I I think I learned things from their reviews and I didn't necessarily like use them like I'm not going to this group, in most cases, I'm not going here because all these people hate them, and but I would say that I just like to get everybody's story for how they feel it is, and you know, sometimes if something's like really egregious. I'm just like, " Do I believe that? that really have happened?" And sometimes doctors respond to the reviews, and that was actually really telling like I am really sorry that you had this experience. You know sometimes seeing the doctor response was very interesting too. But ultimately Yelp didn't help me choose the doctor I chose, it just kind of helped me eliminate other doctors, which is interesting.*

Like P8 articulated, external reviews like those on Yelp provided a useful source of information. Participants could analyze a wide range of information to make a final decision.

## Summary

In this chapter, I reported three levels of factors my participants would consider when they chose a provider. I showed that participants as the outsiders of healthcare systems had to utilize available information to make informed decisions. Such available information exists either at the contact point of or external to healthcare systems.

Choosing a provider was to search and analyze such information, oftentimes in an iterative fashion precisely like the common trajectory I described in Chapter 5. Importantly, I observed a mismatch between the many factors that my participants came to learn about and the reality of choosing a provider while juggling many other tasks as new parents. Many constraints existed that prevented participants to use an ideal provider as they wished. P15 described this dilemma well. She said:

> *Perhaps my choices were not the best, even if I could do it all over again. I was always wondering maybe I should have picked the most popular obstetrician. But it was so hard to make an appointment with her. But the one I stuck with was doing fine in most of the ways so I was happy with that. But it was always so hard to know which choice was the best at that moment. I guess we could only make decisions that could work, instead of insisting on finding the best.*

Clearly, direct patient-provider interaction was only part of how participants chose a provider. Like P15, many participants had to consider many practical factors when choosing a provider. Circumstances such as money, timeline of provider, location, value, and availability were all factored into their decision making. It was all too common for participants to claim that their choices were not the optimal ones. Choosing providers is a highly personalized, dynamic, situated process. My participants kept refining, identify new criteria, and then changed the plan or compromised because of emerging constraints. For example, P4 talked about how she had to change the original plan due to the tight schedule of the OB she planned to choose,

> *I'd like to choose that OB... But he was super busy. He could only take me after week 12. So I had to choose another one first…*

P 21, who lived in a rural area, also told me how she had to compromise and stick to the OB she did not like because of resource constrains: *"We don't have many choices here..."*

In summary, choosing providers is a situated and dynamic process, and a lot of factors collectively influence the process. Much more research and work could be done to improve this situation, helping patients and caregivers more efficiently locate satisfactory providers. Health informatics system designers could consider how to present providers’ healthcare performance, and how to support patients to review healthcare performance. External reviews could be enhanced so as to enable peer support and support sense-making, and help healthcare consumers identify and understand criteria for choosing a provider.

# Chapter 7. Navigation Practice: Infrastructuring Work

In this chapter, I further adopted an infrastructural perspective to unpack one particular aspect of navigation practice — the infrastructuring work that individual health consumers carry out to align different components of healthcare infrastructure and fix the infrastructural breakdowns to make the fragmented healthcare infrastructure work for themselves at the micro, individual scale. My study identified different types of breakdowns (e.g., unexpected bills, failed communication and coordination between different providers, and conflicting policies between different levels of institutions) and infrastructural constraints (e.g., policy and financial ones) caused by the fragmentation of the healthcare system, happening at the individual, organizational, and cross-organizational levels. I found that individuals had to put much effort in repairing unexpected breakdowns and circumventing infrastructural constraints. Infrastructuring work is a form of invisible work that is seldom acknowledged or supported by service providers or ICT interfaces for service provision.

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., (Mamykina et al. 2008; Park and Chen 2015; Unruh and Pratt 2007; Chen 2011; Nunes et al. 2015; Mamykina et al. 2010; Chen, Ngo, and Park 2013; Yamashita et al. 2013; Tixier and

Lewkowicz 2016, 2015)). 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 (Ma et al. 2018)) 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.

Drawing on previous HCI and science and technology studies (e.g., (Star and Ruhleder 1996; Pipek and Wulf 2009; DiSalvo, Clement, and Pipek 2013)) on infrastructure and infrastructuring, I 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. I 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?

By unpacking individual healthcare consumers' infrastructuring work, my contributions to HCI research are three-fold: First, I deepen the understanding of patients and caregivers' work by discussing infrastructuring work, a form of patients and caregivers' work that remain understudied. 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. This chapter extends 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. Second, I reflect upon HCI research on patient engagement in light of the infrastructuring work lens; Third, this chapter contributes to research on infrastructuring work by problematizing and highlighting several dimensions of infrastructuring work.

## 7.1 Infrastructure and Infrastructuring

An infrastructure is conventionally considered to be a physical or technical foundation "which runs 'underneath' actual structures" (Star and Bowker 2002), such as railroad tracks, power grid, and communication networks. In their original work, Star and Rubhleder (Star and Ruhleder 1996) 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" (Star and Ruhleder 1996). It never stands apart from its designers, users, and people who maintain it (Star and Bowker 2002). It is an ongoing alignment between contexts (Star and Ruhleder 1996; Bannon, Ehn, and Ehn 2012). Star and Rubhleder (Star and Ruhleder 1996) 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., (Jabbar and Bjørn 2017; Soden and Palen 2016; Meum 2012)) and human infrastructure (e.g., (C. Tang et al. 2015; Dye et al. 2018; Chandwani and Kumar 2018)). 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" (Hanseth and Lyytinen 2008). Human infrastructure refers to "the arrangements of organizations and actors that must be brought into alignment in order for work to be accomplished" (C. P. Lee, Dourish, and Mark 2006).

Inspired by Star and Bowker (Star and Bowker 2002)'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" (Pipek and Wulf 2009). 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 (DiSalvo, Clement, and Pipek 2013). 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" (Dantec and DiSalvo 2013). 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 (Bannon, Ehn, and Ehn 2012). 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" (DiSalvo, Clement, and Pipek 2013).

Previous HCI research has studied infrastructuring in different contexts, such as mobile knowledge workers' infrastructuring practices (Erickson and Jarrahi 2016) and entrepreneurs' infrastructuring activities contributing to the Blockchain information infrastructures (Jabbar and Bjørn 2017). 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., (Hanseth and Lundberg 2001; Meum 2012; Bossen and Markussen 2010)). 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 (C. Tang et al. 2015) and how healthcare providers and patients co-facilitate the implementation of a telemedicine program (Chandwani and Kumar 2018). 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 chapter "infrastructuring work" refers to the ongoing work individual healthcare consumers engage in to make the healthcare infrastructure work for them. I 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 (Schmidt 2011), while my 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 my participants’ experience and practice (Star 1999).

## 7.2 Unpacking the Infrastructuring work of Individuals

Most of my participants (31 out of 32, except P7) 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. Next, I report experienced breakdowns and infrastructuring work that my participants conducted to fix them.

### 7.2.1 Repairing Failures Happening at the Individual Level

The first type of infrastructuring work that my 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, at 7:30 AM on 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 (Kilff 2018). 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 (Kilff 2018). (For instance, among my 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 automictically 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. Similar failures at connecting points also occurred to other participants, including HR, childcare facility, referring personnel, indicating that what makes the medical treatment possible reach beyond those medical treatment facilities and include many other connecting organizations as well.

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 I 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.

### 7.2.2 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 that P1's baby received healthcare services from one single medical organization, its different departments failed to coordinate regarding P1's updated insurance information because of the fragmented design of the billing system. 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".

My 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, my 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' 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 my 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.

### 7.2.3 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, my 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 me 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. She said:

> *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.

My 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 my 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.

## Summary

In this chapter, I reported the infrastructuring work my participants conducted in order to deal with the infrastructural breakdowns happening at different levels and scales. I analyzed the types and characteristics of such infrastructuring work. I hope to render patients' and caregivers' labor of infrastructuring visible and acknowledged. I believe that more research on infrastructuring work in various domains are needed, as many infrastructures in modern society are complex and fragmented, such as education infrastructure (Mueller and Buckley 2014) and immigration service infrastructure (Ashar et al. 2016; Silkenat 2013).

# Chapter 8. Discussion

Building on my findings presented in the previous three chapters, I present empirical evidence on what constitutes navigation practice and competence, discuss choosing providers as situated actions, unpack properties of infrastructuring work, and derive design implications for supporting individual healthcare consumers' navigation practices. In this chapter, I will first conceptualize navigation practices and discuss the accumulation of navigational competence. Next I will discuss the design problems of current physician rating websites which are common venues that individual healthcare consumers turn to when choosing providers.  Further I will reflect on the current advocacy of *self-care.* I will list design implications under corresponding sections.

## 8.1 Conceptualizing Navigation Practices and Accumulation of Navigational Competence

### 8.1.1 Conceptualizing navigation practices

My research uncovered the specific practices that individuals engage to maneuver the healthcare service provision landscape. Individual health consumers engaging in navigation are "groping in the dark" since tasks and elements are often impossible to know fully in advance and these tasks are situated with the specific context of their health conditions, geographic areas, and resources and constraints related to healthcare services. Even those participants who have pre-existing knowledge and skills and prepare carefully often encounter numerous navigational breakdowns, and have to seek or devise solutions to repair breakdowns.

Navigation practices encompass multiple inter-related activities, including (but not limited to): seeking domain information, identifying key organizations and providers (e.g., OB, hospital, pharmacy, pediatrician, insurance company, employer), making choices from an array of options (e.g., P4 carefully reviewed and chose an optimal insurance plan), advocating for particular resources or courses of action (often in the face of adversity) (e.g., P8 advocated for receiving timely pharmaceutical service), transmitting information from one organization to another (e.g., P4 requested a new ID number from the insurance company on her own and passed it to the hospital), connecting organizations and providers who need to speak but are not connected (e.g., P8 initiated the phone call between the pharmacy and insurance company), negotiating with service providers (e.g., P4 negotiating with the medical lab for a cheaper, affordable price), and doing all of these things on an ongoing basis in the face of uncertainty and breakdowns. Thus, navigation practices include not only information practices where interviewees sought, analyzed, and shared information, but also coordination and negotiation with organizations just to make things work.

Navigation pertains to how individuals move from touchpoint (the contact points between the customer and the service providers (Patrício et al. 2011)) to touchpoint to get what they need. It also pertains to how individuals connect and coordinate different service providers to create a functioning micro-service system that meets their needs through acquiring and transmitting information from one service provider to another. Previous research in CSCW has extensively studied how people coordinate actions within and across organizations to achieve work efficiency and effectiveness. This research on coordination in organizations focuses on coordination within the organizations or across the organizations, examining how organizational insiders use information technology to communicate and coordinate in physically co-located, virtually co-located, and distant groups and increasingly across organizations (e.g., (Bellotti and Bly 1996; Dourish and Bellotti 1992; Grinter, Herbsleb, and Perry 1999; Kellogg, Orlikowski, and Yates 2006; Cummings and Kiesler 2005)). Different from the coordination widely studied, navigation in this research is about individual consumers as organizational outsiders who must learn about organizations, coordinate with multiple complex organizations on their own, and fix breakdowns. Drawing on my empirical findings, I conceptualize navigation practices as the means through which an organizational outsider who has a need(s) traverses a metaphorical "landscape" of elements, interacting with a variety of touchpoints in the process of acquiring a resource(s) or accomplishing a needed task(s) by patching different organizations to create a functioning micro-service system.

As my findings revealed, navigation is often (and sometimes incredibly) time-consuming, labor-intensive, and uncertain, imposing emotional distress, financial loss, and time loss on individual health consumers. It is a form of invisible work that is seldom acknowledged or supported by service providers or ICT interfaces for service provision. Unlike the invisible patient work described in relation to self-managing health conditions (Unruh and Pratt 2008a; Ancker et al. 2015; Klasnja et al. 2010), such as obtaining and managing information about current health status and resolving clinicians' inconsistent recommendations, navigation is the invisible work that patients and caregivers have to conduct in order to obtain desired services from a large and complex health service delivery system. Nevertheless, both types of invisible work to some extent align with contemporary biopolitical rationales and neoliberalism that promote citizens' self-responsibility (Foucault 2008; Lupton 1995), so much so that citizens can take care of their own health as long as they follow official procedures and recommendations defined and maintained by healthcare authorities and institutions. However, it is exactly those authoritative communication and coordination logics that failed my participants, yet formalized means of repair were missing. Against this backdrop, navigation is the invisible work that patients and caregivers are forced to do beyond official, authoritative procedures in order to receive seemingly passable services from a large and complex health service delivery system.

Intense navigation through a fragmented landscape of service providers is an everyday necessity in many domains besides healthcare. For example, parents of children with disabilities face a huge burden to acquire special education services (Mueller and Buckley 2014). Immigrants have to navigate complex application processes and the endless bureaucracy of government entities and the legal system to acquire and maintain legal status (Ashar et al. 2016; Silkenat 2013). Thus, designing service systems, which are by and large embedded in ICTs, to facilitate navigation practices and reduce the burdens of navigation is an important issue for HCI and CSCW researchers to explore. More empirical studies are needed to generalize insights regarding the "overall structure of the multi-interface service system (Patrício et al. 2011) and service consumers' navigation practices, which can help HCI designers to design technologically embedded systems to support individual consumers. My work also contributes to the ongoing discussions around ethics and values in the design and implementation of large socio-technical systems in relation to the humans they are meant to serve (Veale, Kleek, and Binns 2018; boyd and Crawford 2012). My work demonstrates the need to investigate the practices and associated struggles of individuals to better diagnose urgent challenges and identify design opportunities facing these large and complex “black-box” service systems.

### 8.1.1 Accumulation of navigation competence

The involvement of patients has been widely noted as a determining factor for their overall health quality and health outcomes. For instance, some studies (Civan-Hartzler et al. 2010; Civan et al. 2009) have examined patient expertise—their experiential knowledge related to self-management of illness on personal aspects of health (Civan-Hartzler et al. 2010)), and believe it can help patients manage their health conditions. Another rich research strand focuses on health literacy: a person’s ability to access, understand, appraise, and apply health information (Sørensen et al. 2012; Berkman et al. 2011). Health literacy enables individuals to exert control over their own health. Both strands of research stress the importance of patients’ knowledge, skills, learning and empowerment in the scope health management and care. In relation to these streams of research, my study points to one previously untouched area, the navigational aspect of knowledge and skills patients must have in order to effectively seek appropriate and timely health services in the larger healthcare service landscape. Taking the perspective of consumers, it becomes clear that competence is not narrowly related to health behaviors or adherence to treatment; it involves a broader organizational context where consumers must both gain acumen in managing health information and health conditions as well as ability to navigate a larger organizational landscape and create their own functioning micro-health service system. This is a patient skill that is often overlooked but is critical to successfully acquiring healthcare, and sometimes critical to staying alive or keeping a dependent alive.

In navigating the complex healthcare service landscape, participants gained competence through encountering and repairing inherent breakdowns in the fragmented systems they encountered. Navigational competence is a set of integrated capabilities consisting of knowledge and skills for individual healthcare consumers to go through complex service provision systems effectively. My findings revealed different types of knowledge and skills that constitute navigational competence. For instance, for P4 and p8, navigational competence includes technical knowledge and skills to maneuver Internet and phone interfaces, and search and transfer information; organizational knowledge to know where, who and how to seek services, make requests, and manage an ongoing trajectory of organizational interactions; domain knowledge permitting an individual to understand the information they acquire from a service organization and ask for clarifications; articulation knowledge and skills to coordinate complex tasks together; and social knowledge and skills to advocate for oneself in the process of pursuing and receiving services and to seek for help from formal and informal social resources.

The organizational knowledge participants gained contains both explicit and tacit knowledge. The rich body of research on organizational knowledge has argued that the duality of explicitness and tacitness is an important dimension to examine the organization knowledge creation process (Nonaka 1994). Explicit knowledge refers to knowledge that is transmittable in formal and systematic language (Nonaka 1994). Tacit knowledge is highly personal, deeply rooted in action, commitment, and involvement in a specific context (Nonaka 1994). Previous research has mainly examined tacit and explicit organizational knowledge in corporate organizational settings, focusing on organizational insiders' creation and transmission of such knowledge. In my study, organizational knowledge gained by participants who are organizational outsiders manifested similar dimensions. For example, insurance policies that my participants referred to are official forms of explicit knowledge that is relatively easy for my participants to find out and learn. The fact that expense of lab test, in P4's case, can be negotiable and even waived, is tacit knowledge that is not readily accessible for organizational outsiders.

I have shown that participants gained navigational competence through their various interactions with the healthcare system. In an ideal scenario, people deal with the healthcare system in a smooth fashion, as designated by health authorities and institutions, without much necessity to understand how the healthcare system actually works. Their navigational competence would be limited to how to interact with the healthcare system as a unit. However, because of the fragmentation and complexity of the U.S. healthcare system, reality is much messier. Breakdowns to navigation are rampant for individual consumers, and inter-organizational disconnections and conflicts emerge frequently. Consumers in my sample had no choice but to buildup navigational competence due to these circumstances.

The accumulation of navigational competence is a spiral path consisting of numerous breakdown-reflection-repair loops: first, pre-existing knowledge and skills constitutes pre-existing navigational competence, which help individual consumers to interact with the healthcare system. To make better decisions and interactions, individuals often seek new information and knowledge, as my participants did, which increases their navigational competence. Second, during interactions with the healthcare system, breakdowns occur, triggering 1) additional information seeking, 2) attempts to rectify the problem, and 3) reflection about what could be done differently in the future to prevent the same breakdowns from occurring.  As a result of information seeking, rectification attempts, and reflection about what they could do differently, individuals' navigational competence increases again, as my participants' trajectories show. Then, the increased navigational competence becomes the pre-existing competence for individual's future navigation. Thus, the buildup of navigational competence is a continuous process.

My participants learned knowledge and skills in various ways such as searching information online and asking for authoritative explanations and recommendations (e.g., in P4's case, calling the insurance company explanations regarding insurance plans). In particular, participants acquired tacit knowledge through probing into organizations, negotiating with organizational insiders, learning from people in their offline and online social networks, and exploring different possibilities. For instance, in P4's case, she gained such tacit knowledge only through asking in a large social media group and thus encountering people who had survived similar situations.

A large stream of CSCW research has focused on supporting organizational insiders' knowledge acquisition and sharing in formal organizational settings (e.g., (Ackerman and McDonald 1996; Stocker et al. 2012)). In addition, some researchers (Civan-Hartzler et al. 2010; Civan et al. 2009) have explored how to design systems facilitating patient expertise locating practices and sharing in everyday life to help patients who have similar health situations and contexts locate and share experiential knowledge they have gained through their own treatment experience about symptoms, treatments, side effects, prognosis, clinical terminology and so on (Civan and Pratt 2007). However, little attention has been paid to how organizational outsiders gain and share tacit organizational knowledge. Because of the difficulty in accessing such tacit knowledge, it is worth exploring how to help service consumers share such knowledge.

### 8.1.3 Design for navigation and navigational competence overall

My work has important implications for the design of healthcare systems and large socio-technical systems to facilitate individual healthcare consumers' navigation practices and buildup of navigational competence:

First, the "black-boxness" of the healthcare system that all my interviewees struggled with points to the necessity of design interventions that could make the internal workings of both individual healthcare organizations and interconnections between organizations more transparent and support individuals to learn about how these organizations and organizational "tangles" work. While computational methods to improve transparency and accountability in online systems have been explored for many years in the HCI and CSCW community (e.g., (Stuart et al. 2012; B. Suh et al. 2008)), the peculiar challenges in improving the transparency of healthcare systems lie in many service providers' lack of digitalization and organizational inertia. More work needs to be done in improving service providers' consumer-facing digital interfaces, providing powerful user interface for patients to understand the internal workings, as well as the interoperability between service providers' digital systems.

Second, I pointed to the need to the sharing of tacit knowledge (e.g., help individuals to find peers who have the needed tacit knowledge regarding navigation) and assistance to avoid or prepare for potential breakdowns (e.g., help individuals know what bills will arrive and how much money they may be for). This work thus augments an existing line of research that explores existing online platforms in supporting patients to meet, support each other, and share knowledge (Unruh and Pratt 2008a).

Third, my interviewees' self-initiated (or, one may see it as forced) exploration of the healthcare system indicates design opportunities for both empowering patients and facilitating their exploration practice. Novel systems could be designed that help raise awareness of possible issues and breakdowns and recommend preemptive actions patients may take to prevent breakdowns. Social networking platforms can be designed to promote collective sensemaking and problem solving among patients facing similar health conditions.

Fourth, my findings about interviewees' management of inter-organizational communication points to new design opportunities for socio-technical systems that could help individual service consumers and providers to both monitor and coordinate the communication between different service providers. One unique challenge is that my interviewees had to switch between multiple communication channels such as email and phone to contact different service providers, which is inefficient for wrangling inter-organizational communication. To overcome this challenge, a multi-party platform could be designed that mediate the inter-organizational communication so that patients and their service providers could use the same channel to exchange information and discuss issues.

## 8.2 Designing for service choosing

The findings in Chapter Six about factors participants considered when choosing a provider yield sufficient insights into design that could facilitate service choosing. I showed that the design for service choosing should take into consideration that choosing a provider is a situated action, rather than a one-time encounter. The situated-action perspective could leverage to redesign current ways of service choosing.

Information design of providers could be improved so that healthcare consumers could more conveniently identify each provider’s characteristics. For instance, so far there’s no system taking a holistic view towards possible factors to facilitate individuals write reviews and make sense of reviews quickly and holistically. The popular physician rating websites (e.g., Vital.com, RateMD.com) have predefined criteria for physician reviewing, which are limited. It’s hard to individuals to determine what factors they should consider when reviewing and selecting providers. For instance, it’s challenging to know what values a physician may hold. Technology design could take a holistic view towards the factors that matter to individual health consumers in deciding which doctors to choose, for instance, support customization of criteria and integrate information from multiple sources (e.g., physicians’ website, insurance company websites’ information regarding the coverage of specific physicians). In addition, realistically speaking providers might not be motivated to provided up-to-date information. They would rather operate in a secretive way in which the healthcare consumers must individually seek desired information. This is highly connected to the overall low digitalization of the healthcare industry.

Alternatively, online platforms like Yelp are already used for provider reviews, supporting the sharing of insights, experiences, and information about providers. These platforms were considered beneficial for a few participants to cross-compare providers and make decisions. However, there are much space for improvement for these online platforms. For example, the aggregation and visualization of provider reviews should prioritize authentic experiences rather than reductive ratings. According to my participants, the latter was hardly informative when reviewers could not represent the whole population.

Moreover, the value of online platforms could be beyond the practicality of information sharing. Online platforms could also support collective actions of healthcare consumers, who could collectively identify challenging issues, and devise social solutions to problems that the healthcare system simply could not fix by itself.

## 8.3 Unpacking infrastructuring work

The breakdowns my 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 (Star and Ruhleder 1996). I 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 constrains because of the inconsistent design of facilities, policies, systems and its inherent constraints on time, space, and other resources. My 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.

### 8.3.1 How infrastructuring work differs from care work?

Patient work has long been studied in HCI, with an emphasis on the work involved in self-care or clinical treatment processes (e.g., (Unruh and Pratt 2007; Klasnja et al. 2010; Schorch et al. 2016)). My 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. Differently, care work could be routinized, planned, and scheduled by patients and caregivers.

Fourth, infrastructuring work is usually full of confrontation, arguments, negotiation, finding proof, and rational choices. To the opposite, care work mostly involves coordination and collaboration.

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" (Erickson and Jarrahi 2016).

### 8.3.2 Infrastruturing 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 (Schatz and Berlin 2011) and large healthcare corporations have sophisticated their ways of profiting and avoiding liability (Morozov 2013), 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 (Lupton 1995), and should be analyzed as a form of invisible labor (Ekbia and Nardi 2016; Raval and Dourish 2016). 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 (Sweller 1994). For instance, I 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 (Light, Powell, and Shklovski 2017). By stressing infrastructuring work as labor, I hope to engage in what Bowker called "infrastructural inversion" (Bowker 1994), to render patients' and caregivers' labor of infrastructuring visible and acknowledged.

The infrastructuring lens differs from what previous HCI work (e.g., (Mishra et al. 2016, 2018; Zhu, Luo, and Choe 2017)) 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., (Carman et al. 2013; Maurer et al. 2012)). First, engagement implies that patients have choice: They could for example use self-tracking devices to monitor health indicators at home (Ayobi et al. 2017) or participate in online communities connect with those with similar experiences (Gui et al. 2017; Huh 2015; Huh and Ackerman 2012). However, my participants did not have choice to not participate. As my 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.

### 8.3.3. Infrastructuring work: why and for whom?

Infrastructuring is an elusive concept started by Star and Bowker's use of infrastructure as a verb (Star and Bowker 2002). 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 (Jabbar and Bjørn 2017; Pipek and Wulf 2009; DiSalvo, Clement, and Pipek 2013). By investigating infrastructuring in the context of healthcare, my 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. My 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 (Pipek and Wulf 2009; Karasti 2014). By contrast, the infrastructuring work conducted by patients and caregivers is temporary and ephemeral, only produced “fleeting moments of alignment” (Vertesi 2014) 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.

### 8.3.4 Designing for infrastructuring work

Making individual healthcare consumers’ infrastructuring work visible and acknowledged has implications for design and research. Next, I list out the characteristics of infrastucturing work and related implications.

#### ***Burdensome but always needed***

As evidenced by my findings, infrastructuring work is burdensome. It requires great effort to identify and solve the problem. It is indispensable for us to design to ease individual health consumers’ burdensome infrastructuring work. Considering that a large infrastructure is almost impossible to be perfect, and thus infrastructuring work is nearly always needed, it is necessary to attach importance to individual healthcare consumers’ agency. In health and biomedical informatics fields, much work has been done to design, implement, and improve large technological systems (e.g., electronic medical record system) from supporting infrastructure insiders' perspective (e.g., (Ajami and Bagheri-Tadi 2013; Lorenzi et al. 2009; Adler-Milstein et al. 2017; Gagnon et al. 2016)), it is also urgent to pay sufficient attention to designing and implementing systems that empowers patients and caregivers (e.g., personal health record system which gives individual patients more power of control) to procatively prevent and reactively fix breakdowns, instead of  instead of bringing in utopianly perfect infrastructure.

### ***Heterogeneous, and individualized but learnable***

Infrastructuring work is heterogeneous. As my findings uncovered, it consists of heterogeneous types of work, such as information work, negotiation work, and coordination work. It also involves connecting with heterogeneous resources, people, and organizations. Considering the heterogeneity and complexity of infrastructuring work, research can further examine specific subtype(s) of infrastructuring work (e.g., information work), and design can focus on supporting and easing the burden of conducting specific subtype(s) of work. Infrastructuring work is individualized in the sense it is situated within specific contexts (e.g., health conditions, financial situations, location, service needs, timing). Each individual may have different experiences and needs of interacting with the healthcare infrastructure. Nevertheless, different individuals' experiences can also have something in common, and the knowledge about the healthcare infrastructure they discovered and the lessons they learnt can be transferable. For example, as my findings show, my participants performed self-learning work, and learnt the fact that bills might be negotiable and the ways of negotiating from their friends and relatives.

### ***Emergent and uncertain***

Infrastructuring work is emergent in the sense that it is not prescribed by the infrastructural design. My participants could not fully anticipate when and where breakdowns would happen. Therefore, their infrastructuring work is largely triggered by the potential and already happened breakdowns. Because infrastructuring work is emergent and uncertain, and breakdowns are hard to be fully anticipated, one design direction can be to support individual healthcare consumers' work in preparing and preventing breakdowns. For example, as my findings show, some kinds of breakdowns (e.g., unexpected or large bills) can be prevented by proactively circumventing the infrastructural constrains. Some of my participants mentioned that if there was a system which crowdsourced patients' bills of similar services, it would have been easier for them to estimate how much they should expect and how to prepare for that.

Uncertainty exists both in the outcome of infrastructuring work, as well as during the process of infrastructuring. First, infrastructuring work may fail, regardless of individuals’ endeavors (e.g., P24’cases). Therefore, infrastructuring does not necessarily succeed. Second, some participants were never successful in acquiring sufficient knowledge about the inner workings of the healthcare infrastructure. There was uncertainty in how they could structure their infrastructuring work. This characteristic points to the need of supporting individual healthcare consumers sharing and learning how the infrastructure works and how to conduct infrastructuring work. A case in point is that a recent Vox article points out that patients in the U.S. often encounter mysterious emergency visit bills that they often had no clue about, and urged patients to submit their bills in order to collectively puzzle out how medical payments work (Kliff 2018a). It is a way to collectively make the infrastructure visible and transparent to individual healthcare consumers.

### *Temporary and ephemeral*

Previous research mostly considered infrastructuring work as professional designers and users’ deliberate, creative design activities of creating, tailoring, and (re)configuring the infrastructure which create, change, or maintain specific infrastructural characteristic (Jabbar and Bjørn 2017; Pipek and Wulf 2009; DiSalvo, Clement, and Pipek 2013). Such infrastructuring work is a “continuing design in use” activity and intended to have a long lasting improvement on the infrastructure (Pipek and Wulf 2009; Karasti 2014). By contrast, the infrastructuring work conducted by patients and caregivers only produced “fleeting moments of alignment” (Vertesi 2014) 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.

## 8.4 Rethinking Self-Care

Researchers at the intersection of HCI and health informatics have long studied self-care (Bickmore, Pfeifer, and Jack 2009; Nunes and Fitzpatrick 2018). Here the notion of self-care, much disputed as Nunes and Fitzpatrick noted (Nunes and Fitzpatrick 2018), stresses mostly how people manage their health conditions. Self-care has focused specifically on health, and the utilities of technologies in this practice. In a way, what I have described so far about parents’ care of their children is much in line with the idea of self-care, because they initiated care practice in a bottom-up fashion without much support from the healthcare system. At a deeper level, self-care in health is concerned with the neoliberal rationality that expects individuals to be responsible for themselves.

However, the current notion of self-care adopted in HCI is both problematic and insufficient in capturing what my participants experienced when they interact with the healthcare system to care for their young children in several ways. First, it reduces the plethora of work that parents are forced to undertake to basic forms of care work. In so doing, it keeps making invisible that burdensome navigation work of parents. Second, it ignores the organizational and interorganizational aspects of work in interacting with healthcare systems. Such organizational work could be overwhelming for organizational outsiders. Third, it resonates with, and to some extent, celebrates, the neoliberal ethos of demanding more responsibility and work from individual patients and caregivers. Therefore, my dissertation project points to the need of rethinking the notion of self-care in health.

I argue that the current notion of self-care could be productively expanded in light of Foucault's discussion of care of the self. Care of the self, denotes "an exercise of the self on the self by which one attempts to develop and transform oneself, and to attain to a certain mode of being" (Foucault 1998b). The certain mode of being refers to "a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1998a). The notion of care of the self, by stressing self-transformation in response to external structure, is highly relevant to critically examine individual healthcare consumers' navigation practices. Care of the self, as Foucault noted (Foucault 1998b), reflects people's concern for the truth, or knowledge of the self. My research on parents of young children negotiating a fragmented healthcare system through constructing situated knowledge illustrates care of the self in healthcare. It demonstrates how people individually carried out constant examinations of the self as well as their relations to their surroundings. Participants' practices of the self reflected their acute awareness of the predicaments in a network of power relations and their will to self-transformation in order to obtain a better mode of being. Care of the self appears evident in the doings of patients and caregivers enmeshed in a complex healthcare system.

Next, I will elaborate on the practices of self-care among my participants, how the expanded notion of self-care allows critical examination of the relationship between self-care and technology, and how HCI researchers could investigate self-care.

### 8.4.1 Self-care in interactions with the neoliberal healthcare system

The healthcare system disciplined participants into acting as obedient workers. Often the bill was a primary instrument of coercion. In prison systems that Foucault studied (Foucault 1977) , rules and constraints are visible and clear, disciplining people through instructions and punishments. In healthcare, coercion through billing was effected through a web of institutions such as debt collection and credit history services which ensured that patients and caregivers were forced to be responsible for errors and mistakes that originated from within the healthcare organizations. Acts of coercion have a normalizing effect. As P15 said that, "Everything relies on one's own effort to search, to understand.... I guess that's just how it works." By accepting their invisible work for the healthcare industry as normal, the participant was subjected to the neoliberal logic and its further developments that count on patients and caregivers to take upon more responsibility. The healthcare system was an opaque and dysfunctional one where breakdowns frequently happened at different scales, with causes that were unknowable to participants. My participants observed that breakdowns could result from errors of many kinds, miscommunication across multiple departments of one organization or failed coordination across multiple organizations.

Participants discussed the importance of self-reflection in learning. Whenever breakdown took place, they reflected upon what they already knew, and what else they needed to know so that such breakdowns would not happen again. For example, in the U.S., in-network means healthcare providers have contracts with insurance companies, and consumers can pay much less. Out-of-network means no contract and consumers have to pay the full amount out of their own pocket. It is common that a medical facility is in-network but that certain specialists, such as pathologists, are out-of-network. However, patients are not necessarily aware of this nuance, and because of this, a substantial portion of emergency room visits could lead to high bills (Garmon and Chartock 2017). My participants learned about this knowledge from their own unexpected bills as well as others' experiences shared on social media. They knew they must be attentive to any service or interaction that they would have in medical facilities.

In the neoliberal system of healthcare, parents and caregivers were embedded in a power arrangement that they could not escape and must manage so the system remained functional for them and their families. Although parents' primary concern was their children, rather than themselves, their actions are a form of care of the self. Care of the self entails care of others as a person recognizes their rightful social role in their family, community, and society, according to Foucault. Taking actions on behalf of their children demonstrated participants' continuous work on renewing their knowledge of the healthcare system, or mastery over the self.

### 8.4.2 Entanglement between self-care and technology

According to Ellul (Ellul 1964), digital technologies, institutions, and organizations are all forms of technique that represent gradually revised and refined systematic, rational, and efficient means of problem solving, very much in a modernist sense. Technology is not necessarily neutral nor does it always serve human well-being (Light, Powell, and Shklovski 2017). My research demonstrated how parents of young children wrestled with healthcare techniques such as healthcare systems, medical facilities and procedures, and insurance procedures exactly because of technological developments centered on efficiency, systematicness, and rationality. In healthcare, people encountered a “too-big-to-fail” neoliberal system (Minhas, Wendt, and Wierzibicki 2008; Hartung et al. 2015) sophisticated at self-preservation and deflection of responsibilities onto individual patients and caregivers. What technology creates, in this case, is a form of existential crisis (Light, Powell, and Shklovski 2017). Participants were entangled with the technologies and it was legitimate for them to question the meaning of such entanglement: Why do I have to do so much work just to make the healthcare system work?

What is technology in relation to self-care, then? Ulrich Beck said we are in late modernity now, which means all the old social institutions that create meaning, such as villages and the Church in traditional societies, no longer do so (Beck 1992). To create meaning, we are “condemned to individualization,” taking responsibility, making choices, and responding to a rapidly shifting environment. Digital technologies displaced existing social structures with networks and flows. My participants were indeed individualized into finding their own meanings through interactions with technologies. However, they were also compelled to generate meanings about their own selves with the presence of powerful entity—the healthcare system. The healthcare system is a system of governance that my participants were subjected to and transformed by. To some extent, as modern individuals, we are condemned to take care of ourselves, because no other external agents or structures can or will.

Mainstream HCI has prioritized technical transformation, i.e., novel technologies, and social transformation, i.e., how to effect positive social changes. Ideas driving these transformations mostly operate at the structural level, focusing intensively on the environment external to the self, while paying little attention to self-transformation. A few topical areas in HCI have focused on the self, such as self-enhancement (Zimmerman 2009; Carmien and Fischer 2008) and self-tracking (Li, Dey, and Forlizzi 2010). But it would be deterministic to assume that designed technology would certainly empower self. Our study of quantification (Kou and Gui 2018) shows that tools intended to measure player performance could discipline players, and in some cases, do harm. My research emphasizes that the healthcare system as technology, even if designed with sound intentions, is itself a source of disciplinary power. Therefore, discussions of structural transformations need to involve considerations of self-transformation, and vice versa.

### 8.4.3 Investigating self-care in HCI

The expanded notion of self-care offers much more to study in health informatics. Foucault foregrounded the importance of practice in constructing the self by noting that when he talked about care of the self, it's always practices of the self (Foucault 1998b). Therefore, to study the self is to study practices of the self. This is similar to Kuutti and Bannon's call for the turn to practice in HCI, locating the origin of the social in practices (Kuutti et al. 2014). In practical terms, we should examine what practices patients and caregivers perform to cultivate selves to achieve self-transformation. However, I also share Kaptelinin's concern that detailed empirical studies of situated, real-life processes can be insufficient in discovering very personal choices and experiences such as the meaning of one's life (Kaptelinin 2016). This is especially true when patients and caregivers exercise individualistic practices of care of the self and thus constantly ask existential questions about the meanings of their actions and technological engagements. While Kuutti and Bannon stressed that "practices are a shared resource among a community of people" (Kuutti et al. 2014), what I am concerned with is the individualistic aspect of practices of the self that pertain to different individuals' internal properties such as capacity, mentality, and reflexivity. Each patient or caregiver might encounter uniquely challenging healthcare situations, and how they cope with these situations could form their own uniqueness of self-care practices.

In certain ways, a few HCI research methods such as interviews allow the opportunity to engage in dialogues with participants, where “contemplation of self and care of self are related dialectically” (Foucault 1998a). The goal is not necessarily to discover a true, static state of participants, but to work together, reflexively and introspectively, to explore critical aspects about the self and meaning-making, such as existential questions like “who am I?” and critical questions such as “do you take care of yourself?” In this context, studying self-care in HCI entails methodological commitment to identifying patients’ and caregivers’ experienced struggles and cultivated practices. HCI researchers need to remain humble and acknowledge patients’ and caregivers’ own perspectives instead of attempting to apply pre-conceived mental models when interpreting their data.

# Chapter 9. Conclusion

My dissertation project is concerned with how individual healthcare consumers navigated through the “black box” healthcare system in the United States. Navigation practice occupied the central place in my analysis, because it seems that the systematic black-boxness, fragmentation, and discoordination will continue to stay, and, to some extent, exist by design. Resolving these issues from within seems futile; and systematic changes are unforeseeable in the near future. Meanwhile, individual healthcare consumers have to develop their own ways of coping with and bypassing the healthcare systems.

However, I do not necessarily see individual navigation practice as a solution to those systematic issues. Rather, such practice is simply a reality where the healthcare system continues to push more burdensome work onto individual healthcare consumers. I suspect that to some extent such practice will only worsen the situation, as individual healthcare consumers are systematically integrated into the service production of healthcare systems: they contribute enormous amount of invisible labor but are not acknowledged.

Where is hope, then? Hope has been a theme that I have shied away from in most of the chapters. My empirical descriptions and theorizations of the past sought to contribute deeper insights into modern day healthcare consumers' experiences and practices. What is most concerning is how healthcare systems could effectively isolate individuals and alienate them, who contribute free labor, from the production mechanisms of healthcare systems. If hope exists, perhaps we can locate it in possible scenarios of collective actions where individual health consumers could find ways to wrestle with the healthcare enterprise. My studies of novel ICT platforms that connect health consumers and doctors point to possible ways in this direction. For instance, my study (Ma et al. 2018) of an innovative "Ask the doctor" (AtD) platform showed how answer providers on AtD platforms can collectively play the role as a patient navigator, helping individual health consumers navigate their way through the complex and fragmented system in a cost-effective way. Admittedly, such solution also rests upon many healthcare-related policies and regulations. Nevertheless, my goal of this project is to render individual health consumers' labor of navigating the fragmented healthcare system visible and acknowledged. What is actionable for HCI researchers and designers is to collectively explore what we can do from patients' side.

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