Designing for Lived Health: Engaging the Sociotechnical Complexity of Care Work

by

Elizabeth Kaziunas

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Information)
in the University of Michigan
2018

Doctoral Committee:

Professor Mark S. Ackerman, Chair
Associate Professor Renee Anspach
Professor Michael Klinkman, MD
Assistant Professor Silvia Lindtner
Professor Steven Sawyer, Syracuse University

Elizabeth Kaziunas

eskaziu@umich.edu

ORCID iD: 0000-0003-0001-355X

Dedication

For my family, who both took care of me and taught me what it means to care.

And for all the people—patients, caregivers, clinicians, and community members—who participated in this work. Thank you for sharing your stories and lives with me.

Acknowledgements

Thanks to my dissertation committee for their feedback and support throughout this thesis project. I am especially grateful to my advisor, Mark Ackerman, who is the kind of scholar everyone hopes they will get to work with when they apply to PhD programs, but too few students actually find. Thank you for being a true mentor and intellectual advocate throughout my time in Michigan and beyond. It was a privilege to be one of your students. Much thanks also goes to Silvia Lindtner, whose comments greatly improved this thesis, but particularly for her contribution in helping frame the Lived Data chapter and in influencing my thinking about labor. I am also deeply appreciative of the ongoing support from rest of my committee members, including Steve Sawyer for introducing me to sociotechnical research and always being a source of support, Mike Klinkman for sharing his medical expertise and empathy for patients, and Renee Anspach for offering her keen insights and encouragement for this work.

Thanks to all the members of the SocialWorlds lab group, especially those who collaborated on projects and completed parts of this PhD journey with me, including: Ayse Buyuktur, Tao Dong, Pei-Yao Hung, Jasmine Jones, and David Merritt. A large intellectual debt is also owed to Ayse, Jina Huh, and Xiaomu Zhou whose research on healthcare has both guided my investigations and continues to inspire. Thank you for being generous and supportive "intellectual siblings."

Thanks as well to all the members of my cohort and the wider UMSI PhD community—members past and present. I am particularly grateful to Rayoung Yang, Melissa Chalmers, Caitlin Holman, Rebecca Frank, Andrea Barbarin, and Jessica Hullman who over the years have always been available to read drafts, attend talks, work through ideas, get drinks, and give great advice. The PhD life was richer because of you. Thanks also to Sean Munson who provided helpful editorial feedback on an article published from the Lived Data chapter. I have also been extremely fortunate have collaborated over the years with a group of amazing researchers, including Sung Choi, David Hanauer, Joyce Lee, Tiffany Veniot, Charles Senteio, and Chris Wolf. I learned much from all of you. Thanks as well the UMSI staff, especially Veronica

Falandino and Allison Sweet, who provided support throughout the PhD program and could always find a solution to any problem. I am so appreciative of all that you have done over the years.

Finally, I am beyond grateful for my family who saw me through the years of graduate work and made getting a PhD possible. Thank you to my parents, Alfred and Laura, for their unceasing support and encouragement, as well as to my sisters, Anna, Marie, and Sharon, who inspired my work and cheered me on. And to my husband, Adam, a loving teammate who helped me finish strong: thank you with all my heart.

Table of Contents

List of Figures

Abstract

As healthcare is increasingly shaped by everyday interaction with data and technologies, there is a widespread interest in creating information systems that help people actively participate in managing their own health and wellness. To date, personal health technologies are largely designed as large-scale “patient-centered” systems, grounded in a biomedical model of care and clinical processes and/or commercial “self-care” technologies, that seek to facilitate individual behavior change through activities like fitness tracking. Through investigating the lived experience of chronic illness—multiple, messy, and often the site of uncomfortable dependencies—my thesis empirically and theoretically engages the limitations of such popular design narratives to address sociotechnical complexities in personal health management. My findings, drawn from people’s care practices across three distinct field sites, argue for a need to contend with *lived health*: the ways in which everyday health and wellness activities are connected to wider ecologies of care that include the emotional labor of family and friends, entanglements of data, machineries and bodies, localized networks of resources and expertise, and contested forms of information work. My thesis contributes to the literature of Information and Computer Science in the fields of Human-Computer Interaction and Computer-Supported Cooperative Work by offering an alternative analytical lens for designing health systems that support a wider range of people’s social and emotional needs.

Chapter 1 Introduction

> "How might complexities be handles in knowledge practices, nonreductively, but without at the same time generating ever more complexities until we submerge into chaos?...Answering this questions requires theoretical, but also empirical and methodological inquiry…stories about what happens to complexity in practice."
>
> –John Law and Annemarie Mol*, Complexities: Social Studies of Knowledge Practice*

As data and information technologies increasingly impact the everyday experiences of health in our society, there has been both widespread excitement and disillusionment in thinking about the transformative power of computing to facilitate new types of care. On one hand, medical organizations, government agencies, technology companies, and patient support groups alike have invested in creating systems to help people more actively participate in managing their own health and wellness. Personal health technologies designed to help people lose weight, access and maintain health records, and track everything from blood pressure and moods to menstrual cycles seem celebratory, early steps toward ushering in a new patient-centered age of medicine. Advocates maintain that increased access to personal data and health information has the potential to lead to more tailored, individualized treatments and better health outcomes. On the other hand, there have been numerous critics of technology's larger role within healthcare—often from privacy watchdog groups and concerned physicians—who have issued warnings of increased surveillance from insurance companies and the risks involved when people have increased access to medical information without advanced training. The persistent systemic barriers to clinical services and long-documented health disparities among marginalized populations, both in the United States and other parts of the world, point to the limits (and dangers) of technological solutionist rhetoric and interventions that aim to "fix" health without first contending with the costs of care.

The uncertainty with how to support the shifting role of the patient/consumer in twenty-first century medicine is tied to broader sociopolitical and technological changes and postmodernist concerns. Clarke et al. (2010), for instance, argues that the ‘biomedicalization’ of health and illness is a result of multiple, related processes including: political/economic shifts, transformations in the production, distribution and consumption of biomedical knowledges, technoscientific developments like the digitization of health information, and transformations of bodies and identities (Clarke et al., 2010, p. 47). Medical sociologists and anthropologists (Lock & Nguyen, 2010; Jain, 2013) and clinical professionals (Eiser, 2014) alike have begun to wrestle with how to (re)conceptualize the role of medicine in light of new types of patient expertise, mistrust of medical science, regulatory battles to legislate illness categories, and clashing understandings of what constitutes health itself. Medical ethicist Robert M. Veach (2009) contends that the language, activities, and very philosophical core of modern medicine—rooted in the authoritative role of doctors and an elitist Hippocratic tradition—all need to be considered anew. Indeed, for his book title, he transforms the well-known aphorism of ‘physician, health thyself’ into a neoliberal appeal: ‘patient, heal thyself.’ Such visions of self-care can be seen as equally empowering or ominous, depending on a person’s health status, access to resources, and ability to advocate for oneself, family members, or wider community.

Importantly, the unfolding processes of biomedicalization is also matter of power regarding who has the authority to make decisions about what it means to care. At first glance, the influence of biomedicine can appear unchallenged. People seek out the expertise of doctors, check into hospitals and clinics, get routine check-ups, take prescription medications, and try to follow directives to “eat healthy and exercise.” And yet, a slight shift in perspective can illuminate alternative forms of care rooted in diverse social worlds, that play out both along-side and in the shadows of traditional medicine. In recent years, for instance, school districts have found themselves on the front lines of a public health crisis in dealing with once rare diseases like whooping cough spread amongst populations of unvaccinated children whose parents fear a risk of autism and/or embrace holistic medicine. Medical marijuana dispensaries and online patient forums have become important sites of care for many people who live with chronic illnesses as they struggle to manage symptoms and side-effects over the course of a lifetime. Health advocacy movements flourish on social media, confronting the pharmaceutical industry about rising medication prices and enabling people to hack their own medical devices. While such health activities can be seen by some as an extreme or controversial form of dissent, in everyday health settings people commonly weave together disparate sources of information, technologies, local resources, and expertise in subtle and creative ways to take care of their health needs.

To date, commercial personal health technologies have largely failed to address the diversity of viewpoints and social practices found in everyday health settings, relying instead on design narratives that emphasize the needs of the individual patient or consumer. “Patient-centered” systems, for instance, typically privilege a biomedical perspective of care centered around patient privacy, professional workflows, adherence to clinical treatment regimens, and adoption of formal medical standards. Hospitals, for instance, have developed patient portals that give people to access to specific types of medical data, such as lab results pulled from the electronic medical record (EHR) systems that were designed for clinicians and hospital staff. Meanwhile, “self-care” systems frame technology through a lens of personal empowerment and the democratization of healthcare for individual consumers. Examples include commercial fitness tracking devices like Fitbits and Fuelbands that offer people the ability to monitor their heart rate, steps, and calories as a means to better understand one’s body and maximize wellness through individual behavior change. In such designs, the beneficiaries appear to be healthcare organizations (who are incentivized by reducing operating costs) and commercial entities (who along with direct sales profits often gain access to large sets of free, consumer-generated data) as often as people use them.

While the narratives of “patient-centered” and “self-care” have played an important role in shaping the design of health technologies over the past several decades, they are both limited in helping designers content with a wider range of sociotechnical[1] dimensions around health and wellness that are increasingly a part of people’s everyday lives, both now and perhaps to an even greater degree in the future. Research in fields like medical sociology and medical anthropology, for instance, have long shown that the experience of health and wellness is deeply tied to social context and cultural concerns (see Charmaz, 1997; Kleinman, 1980/1988; Faldon, 2005). Theoretical scholarship in science and technology studies (STS) and organizational studies have further argued for the necessity of addressing nonhuman actors in healthcare, viewing human-

---

[1] While there are a number of sociotechnical approaches and theoretical traditions (see Sawyer and Jarrahi, 2013 for a full historical treatment), I use “sociotechnical” in my thesis to refer to its most basic premise—the mutual constitution of people and technologies—and engage with it theoretically, drawing from scholarship in science and technology studies (STS).

machine relations as inextricably interconnected both analytically and in life (see Clarke, 2005; Mol, 2008; Murphy, 2012).

How then do we approach the design of health technologies for a world caught amid the throes of biomedicalization? While technology does not provide an easy solution to improve a broken and besieged healthcare system, seeking a path through utopian and dystopian futures calls for reckoning with realities of everyday care and grappling with the specific ways information systems are shifting relations between human and political bodies, family life, and local communities. We first need to better understand the impact of data and information technologies on everyday health practices among diverse groups of patients, families, and communities. System designers looking to support personal health—situated across a multiplicity of social worlds—need to consider these new types of interactions between people, technology, and information. As everyday health practices are intimately entangled with information technologies, data is not simply transferred, but has become the means by which people experience daily life, an integral part of how meaning is created. In this thesis, I argue that designing health systems that support diverse needs and viewpoints also calls for new sociotechnical narratives of care. This is not only a vital matter of design, but also a theoretical project and ethical imperative for all concerned with the wider impact of technology on society.

Engaging Sociotechnical Complexities and Simplifications

Among Information Science and Computing fields like Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW)— research communities where I intellectually align my work—there is a rich literature exploring different design approaches to creating systems that aim to support people in a diversity of health settings. Over the last several decades, such health-related studies have sought to better understand how we can use technology as a means of helping people navigate hospital visits, assist the elderly to live longer at home, provide tools for people living with in communities with significant health disparities, and using technologies to reduce the burdens of self-management. In HCI/CSCW, many scholars have used ethnographic methods to analyze people's practices along with participatory design approaches to develop novel systems and generate important insights for the design of future health systems. In a literature review of 25 years of CSCW health research, Fitzpatrick and Ellingsen (2013) detail these collective contributions, but also point to medical and cultural shifts—including the rise of chronic illnesses, models of self-care and data tracking, the popularity of online patient communities, and community-oriented approaches to system development—to argue for new types of design research that addresses "the broader socio-technical and policy levels" of healthcare.

To date there have been numerous efforts in HCI/CSCW to extend health technology design research in new directions (see Chamberlain et al., 2015; Churchill, & schraefel, 2015; Elsden, Kirk, Selby, & Speed, 2015; Grinter, Siek, & Grimes, 2010; O'Kane et al., 2016a; Pratt et al., 2006). And yet, while the majority of HCI/CSCW studies have accounted for many social aspects around health (such as data-sharing activities, patient support groups, and forms of collaboration), the design of technical systems and prototypes still tends to be largely framed by either clinical and/or celebratory visions of health, both of which are limited in offering a nuanced portrayal of the complex, and often contradictory, aspects of people's everyday health experiences. In this thesis, I take Fitzpatrick and Ellingsen (2013) appeal to the HCI/CSCW community as a starting point for investigating sociotechnical dimensions of care work in in three different health settings. In doing so, I articulate a design narrative of *lived health* that accounts for the practices and politics of personal health and wellness by examining how everyday health experiences are connected to wider ecologies of care include the patient-doctor relationship, but also involves new forms of information work, the emotional labor of family and friends, entanglements with data and technologies, and the shared expertise of patient networks. Health, as I will show through the following chapters, is often as scary as it is empowering, bound to cultural understandings along with clinical protocols, and the site of critical dependencies among both human and nonhuman actors.

Designing for health in this moment of cultural and political upheaval demands contending with the sociotechnical complexity but also with simplifications. In their book, *Complexities: Social Studies of Knowledge Practices,* science and technology studies (STS) scholars John Law and Annemarie Mol have written about how people live within multiple realities that overlap and coexist, each with different modes of ordering, including different logics, frames, discourses, and epistemes. These differences—be it encountered in the form of literary texts or through the practices of medicine—are not always easily discernable:

> "Often it is not so much a matter of living in a single mode of ordering or of "choosing" between them. Rather it is that we find

> ourselves at places where these modes join together. Somewhere in the interferences something crucial happens, for although a single simplification reduces complexity, at the places where different simplifications meet, complexity is created" (Law & Mol, 2002, p.11).

Care complexities can be found in formal medical intuitions like research hospitals and informal online patient forums as well as through the logics of clinical trials and the popularity of homeopathic remedies. Processes of simplification—through policies, therapies, and technology design inevitably intensify some types of health knowledge and modes of being while casting others into the shadows. Designing systems that support the practices of formal medical care, my thesis demonstrates, can leave many people's health needs unsupported and even marginalized. My findings highlight the ethical importance of considering sociotechnical complexity at the convergence of various simplifications. Reducing a person's life experience to that of a "patient" or "caregiver," for instance, draws attention to a person's role in the formal medical system while relegating other types of knowledge (such as alternative therapies, coding, or a blue-collar ethos of making do) or modes of being (a parent, innovator, worker) to the background.

When researchers and designers seek to reduce the burden of care, therefore, it is important to consider what worlds and logics are being designed for and what are left out. For instance, should we focus on the dominant discourses of biomedicine or offer support for alternative health therapies? Do we design for social concepts of illness or the scientific logics of medicine? The task, then, is to articulate a design narrative that engages health complexity and overlapping, coexisting, and conflicting worlds and logics without being as Law and Mol (2002) write, "submerged in to chaos." To answer such questions, we need to better understand both sociotechnical complexities and simplifications—how different modes of being and various care logics join together with technological artifacts and processes. In my thesis, then, I investigate people's experiences of health across multiple social worlds that are visible in situations where localized health practices meet formal medical systems and policies.

A Design Narrative of Lived Health

Focusing on health as a set of practices and narratives highlights the everyday interplay between institutions and people, data and bodies, and emotions and technologies. The rich and relatively unexplored design space that exists between the rigidity of clinical medicine and individual, idiosyncratic health practices, is what I think of as *lived health*. I draw from the framing of “lived religion” as described by Robert Orsi whose work details the everyday practices of spiritual life, such as urban shrines and religious street festivals. Orsi argues that the study of lived religion goes beyond formal theology to understand “how the dead are buried, children disciplined, the past and present imagined, moral boundaries established and challenged, the home constructed, maintained and destroyed, and the gods and spirits worshiped and importuned” (Orsi 2002, xxxi). Scholars of lived religion are thus critical of hierarchy in terms of understanding beliefs and practices, viewing theological teachings and institutional rituals as intertwined with—rather than in opposition to—people’s everyday spiritual activities. Adopting this framework for health contexts calls us to attend to how people keep their own health records, pray for healing, cook for their families, combine herbal remedies and prescription medications, and hack medical devices.

Lived health focuses on how people deal with health as situated in particular social worlds and as negotiated across the boundaries of multiple social worlds. These practices are often messy and contested. Professional medical recommendations do not always sit easily with everyday constraints (e.g. time, family obligations, limited resources), let alone when people must reflect on care options in life and death contexts, engage in new forms of information labor around personal health data, or find themselves relying on local care systems outside of the boundaries of institutionalized medicine. Lived health encompasses such tensions, bearing what religious historian David Hall refers to as the marks of both regulation and resistance (Hall, 1997). In this way, lived health does not displace institutional or normative perspectives on health and medicine but looks to include multiple, overlapping, and even contradictory meanings embodied in health practices.

There are several ways in which a lived health approach can help HCI/CSCW aesthetically and technically expand the design of personal health technologies. First, lived health opens up the design space to consider different configurations of data sharing among family, clinicians, and community members. While boundaries between social worlds are not neatly drawn, health technologies rarely help people meaningfully engage with heterogeneous, and potentially conflicting, health information. One might imagine a personal health application or managing chronic illness, for instance, being able to support expertise sharing from a range of divergent perspectives.

Additionally, lived health expands the design space of "health information" to consider what Orsi refers to the "the density of practices" that make up social worlds such as objects, gestures, emotions, and ideas. Studies of health practices in HCI/CSCW have been quick to point to the materiality of health artifacts and the embodied nature of illness, but have less often engaged explicitly with the complex *meanings* of these practices in design. Models of behavior change, while important, are not well equipped to helping designers think about how information use and behavior is connected to deeper belief systems, nor supporting new types of interactions related to human-machine dependencies, both affirming and distressing.

Since Orsi and Hall's early work, scholars of lived religion have opened up the study of religion to a wide range of contexts outside of formal religious institutions, for instance, examining the role of ritual in professional sports, acts of pilgrimage among popular music fans, and the way belief systems shape modern politics. In this way, I see lived health—the everyday practices of health and wellness—as extending not only beyond the formal intuitions of medicine such as hospital and clinic, but also the home and online patient forum. Lived health plays out across the spheres of education and politics, arts and entertainment, as well as industry and the environment. By examining the practices of health and wellness in makerspaces and BioArt collectives, farming co-ops, neighborhood festivals or faith communities, healthcare takes on new meanings beyond the biomedical as a site of innovation and resistance, cultural tradition and popular aesthetics, ethical commitment and spiritual devotion.

In the following chapters, I examine chronic illness through the lens of lived health. Chronic illness—with its highly visible sociomaterial entanglements and critical dependencies—is an important site to study the impact of data and information technologies on society and for designing alternative health technology futures. People living with chronic illness routinely engage in a wide range of care activities that are physically and emotionally difficult. Over the course of a lifetime, chronic illness often interrupts important biographical milestones and impacts the dynamics of family relationships, especially when informal caregiving assistance is needed. Comorbidities and multiple health conditions can be problematic for clinicians to diagnosis and treat given a wide range of interconnected symptoms; at the same time, people must learn how to manage different types of treatment regimens and create work-arounds to cope with the side effects of various medications. Both self-care and caregiving activities can be exhausting and tedious to perform day after day, as well medical devices and health information systems increasingly require their own forms of labor to interpret and maintain. Furthermore, systemic issues like cultural attitudes and socioeconomic status can shape both people's perceptions of and access to quality healthcare.

A goal of this thesis, then, is to improve the lives of people living with a wide range of health conditions through information technology design. In order to build systems that can help people better manage their health and wellness, the social and emotional context of everyday health needs to be better understood. Ultimately, I argue that system designers and researchers need to see care work and health itself as more than biomedical activities that require individual behavior change based on optimized data, but as deeply sociotechnical activities that draw on multiplicity of viewpoints and logics. Future designs of health technology needs to reimagine the relationships between information, people, and technologies beyond "patient" and "consumer."

Ackerman (2000) has argued that the "social-technical gap" between what we know we *must support socially* (e.g. situated, fluid and nuanced systems) and what we *can support technically* (e.g. rigid, brittle systems with limited social intelligence)—is a central challenge for the HCI/CSCW research community. Though this gap may never be fully bridged in our lifetimes, attending to social needs given the practical realities of computational systems requires the thoughtful application of innovative technologies and techniques like machine learning and data mining, but also the development of new theories and sensitizing concepts to help deepen and broaden our understanding of the relationship between people, information, technologies itself. My thesis contributes to this wider call by offering an alternative framing for designing systems that explicitly engages the social and emotional dimensions of personal health management. My work highlights emerging (and often contested) forms of information/data and labor, particularly at the boundaries of formal medical systems and the social worlds of patients and caregivers.

In the following chapter, I situate my research project within relevant literature on health technology in HCI and CSCW, discussing exemplary prototypes and sketching design themes for supporting chronic illness and care work. Then in Chapter 3, I discuss theoretical frameworks for lived health, drawing on social theory and STS sensibilities, as well as approaches to interaction design. Next, I turn to detailing people's experiences with managing chronic illness across three distinct field sites, each offering insight into dimensions of "lived health.” In Chapter 4, I share insights from a study of parent-caregivers in a bone marrow transplant unit at a children’s hospital. Chapter 5 focuses on findings around community experiences with behavioral health in the city of Jackson, Michigan. And then in Chapter 6, I discuss findings from a study on open source/DIY (do-it-yourself) online collectives dedicated to hacking and making type 1 diabetes technologies. These specific sites of care were chosen because they represent a variety of social worlds, such as hospitals, cities, and open-source software, as well as chronic illness experiences, including health conditions with a wide range of risks and different associated medical activities, such as confusing and opaque regimens, and accepted treatment protocols. These sites also highlight collaborative care activities on different scales, including families and large clinical teams, community residents and local organizations, and distributed patient groups in online spaces). I use these field sites to investigate as set of interrelated research questions, including:

- What are the everyday practices around managing chronic illness? What types of care work—visible and invisible—are performed by patients and informal caregivers to manage chronic illness?

- What are some of the considerations for designing for lived health when social worlds ***overlap*** with clinical contexts, as is the situation in pediatric bone marrow transplant? What are ways people understand “care” and how might that differ from clinicians? What types of significance do various care practices hold?

- What are some of the considerations for designing for lived health when social worlds ***coexist*** with formal health systems, such as the care experiences of residents in Jackson Michigan? What types of care practices are happening alongside (but disconnected) from formal medical systems? What types of local care resources / infrastructural health arrangements are found among people in various social worlds? What types of local cultural and political issues are important to consider in health design work?

- Finally, what are some of the considerations for designing for lived health when

> social worlds ***conflict*** with institutionalized medicine and regulatory health frameworks, as exemplified by the DIY/opensource diabetes collectives? What types of gaps and breakdowns in formal healthcare systems exist that these health practices address? What types of conflicts emerge when care practices don't align with dominant models of healthcare? What are some of the costs and consequences to consider in designing to support emerging forms of care work?

Finally, in Chapter 7, I pull back to craft a design narrative around lived health that contends with the sociotechnical complexity of care.

Chapter 2 Approaches to Health Technology Design in HCI/CSCW

CONCEPTUALZING HEALTH IN SYSTEM DESIGN

Designing systems to support the health needs of diverse populations has long been a goal within the HCI/CSCW the research community (Fitzpatrick and Ellingsen, 2013); and yet, over the last decade many researchers and designers have also increasingly adopted a critical stance to the promise of technological 'solutionism' both in the healthcare domain and beyond. In exploring how to create systems that are less prescriptive, more socially nuanced, and embedded in everyday life, a number of HCI/CSCW scholars have turned their attention to understanding informal care activities and the social and emotional dimensions of healthcare in the home (Aarhus and Ballegaard, 2010; Ballegaard, Hansen, & Kyng, 2008; Barbarin, Veinot, & Klasnja, 2015; Grönvall, E., & Verdezoto; Schorch, Wan, Randall, & Wulf, 2016) and local community (Parker & Grinter, 2014; Schaefbauer et al., 2015). Importantly, findings from this research has prompted HCI/CSCW scholars to reconsider some of the dominant epistemological foundations of health technology. For example, Maitland, Chalmers, and Siek (2009) have written about the limitations of designing for 'persuasive technologies' in communities with significant health disparities, arguing that technological interventions that seek to encourage people to make healthy choices first need to address socioeconomic issues around access to clinical services, exercise, and food.

While HCI/CSCW literature often implicitly grapples with the limitations of conceptualizing health solely through the lens of physical optimization and individual behavior change, to date research efforts to expand the design discourse around health are still nascent. A number of scholars have begun to apply holistic concepts like 'wellness' or 'whole-person' to system design as an alternative framing beyond rationalistic models of health (Grinter, Siek, & Grimes, 2010; Huh, Patel, & Pratt., 2010). One of more robust efforts to articulate design discourse around wellness is Elizabeth Churchill and m.c. schraefel's (2015) *Interactions* article, "mHealth + Proactive Well-Being = Wellth Creation." Arguing that designers and developers need new sociotechnical design paradigms for health, Churchill and schraefel propose the concept of *wellth* to describe a type of "proactive well-being." Churchhill and schraefel write:

> "Although much research has focused on body maintenance and repair, focusing on the achievement of fitness goals and/or following medicalized concepts of health management, there is an emerging complementary research agenda that calls for a focus on the experience of well-being and increasing quality of life. This latter research agenda focuses on the phenomenological aspects of well-being, broadening the discourse beyond health as the absence of illness and healthcare as disease and/or condition prevention/management. This is what leads us to the idea of "wellth creation," an intentional play on words to underscore our belief that personal well-being or "wellth" offers broader societal gains" (p.60).

In their article, they develop a design narrative around personal well-being that points to several grand HCI/CSCW challenges, including: (1) Better understanding how conceptions of health might shift in relation to the complexities of everyday life, especially over a lifetime; (2) Encouraging self-experiments and reflective practice through system design; and (3) Creating designing interventions as "cultural hacks" to facilitate "large-scale societal change in bottom up ways" (p. 63). In framing wellth as a positive, affirming design space, related to (but ultimately distinct from) experiences of illness, Churchhill and schraefel's article calls attention to the way design narratives can shift our expectations of what health systems might be and the types of activities that get supported or marginalized.

In the following sections, I analyze several HCI/CSCW studies on personal health systems to support chronic illness and informal types of care work. While it is beyond the scope of this chapter to survey all related health technology research, this chapter provides an overview of several key health systems upon which I draw inspiration for questions of design throughout the thesis. While not exhaustive, the prototypes I highlight here are illustrative of different ways HCI/CSCW researchers and designers have approached social concerns related to personal health. Finally, at the end of this chapter, I take a step back to describe important empirical and theoretical gaps in health technology design literature to argue for design narratives that explore post techno-solutionist understandings of care.

DEVELOPING SYSTEMS FOR PERSONAL HEALTH MANAGEMENT

Studies in HCI/CSCW discuss design opportunities in relation to various health care settings (e.g. hospital, community, and online forums), detail a wide range of patient/caregiver needs, as well as advocate for new perspectives and directions for health system research. In this thesis I situate important bodies of this growing health literature in greater detail in the chapters to come. In this section, however, I focus in on the rich literature which describes systems designed to support people's needs in living with different types of health conditions, including acute and chronic illnesses. Chronic illness, in particular, has long been a site for new technology interventions given the burdens of self-care and the opportunities enabled by sensing and tracking technologies. Chronic illness has also been viewed in HCI/CSCW as an important place to study collaboration given that medical activities often include diverse clinical teams, (Zhou, Ackerman, & Zheng, 2010), family members (Kaziunas et al., 2015; Miller et al., 2016a); and online forms of peer-support (Huh & Ackerman, 2012; Huh et al., 2014).

In what follows, I discuss several examples of novel systems designed for people living with cancer, behavioral health conditions, and diabetes. While some prototypes were designed to explicitly support biomedical concerns, such increasing patient adherence to treatment protocols or promoting behavior change, they also demonstrate an awareness of social and emotional issues that are typically missing from the design of commercial health information technologies. Emerging health technology research has also embraced more social perspectives as a starting point, as is the case with collectivist health approaches to system design. Together, these HCI/CSCW studies offer insight into how the field is navigating the social complexities of care work given current constraints of engineering and technology and also point to limitations in current health design narratives.

Cancer Support Systems

There are a number of studies in HCI/CSCW that describe innovative social approaches to cancer support systems. An early example in literature is Farnham et al.'s (2002) paper on HutchWorld, an online system that provided social and informational support for adult bone marrow transplant (BMT) patients and their caregivers. Designed as a partnership between Microsoft Research and the Fred Hutchinson Cancer Research Center, HutchWorld was conceived and developed before Internet access became the ubiquitous experience it is today via mobile devices and wifi. At this time, HutchWorld importantly acted as a portal to the Internet so that isolated patients and caregivers could connect with family and friends. The authors were especially interested to discover if HutchWorld could have a meaningful impact on the quality of life—viewed as psychological well-being—of patients and caregivers living in the hospital's outpatient apartments.

Along with providing online connections to people outside the hospital, the system was intended to serve as a means of community-building for those caregivers and patients living in the hospital itself. Farnham et al. (2002) describe HutchWorld as "a private, multiuser community environment that integrates social interaction tools, information, and diversionary activities" as well as an online, 3D community space that was modeled after the outpatient lobby in the hospital. Participants could utilize a range of synchronous (real-time) and asynchronous communication tools, including: interacting with each other through real-time, 3D chat environments, posting messages on a community bulletin board, creating personalized web pages, and sharing "egifts" with one another. The authors note that "the virtual gifts and notes could easily be exchanged, held and carried around in the 3D world, and saved in a personal area."

After deploying their prototype, Farnham et al. described the various ways people used the system. They found, for instance, that one of the most popular uses of the system was the personalized web page feature which allowed patients and caregivers to "broadcast health status" to family and friends. They suggested that future community systems explore supporting personal relationships between friends and family, as well as be private and customizable. While some aspects of the system design would now appear dated, HutchWorld is important in demonstrating early attention among HCI/CSCW researchers to social health issues even in clinical settings like the hospital. Access to clinical information is not viewed as the primary design function of the system, but sees such information as connected to wider social relations.

Klasnja et al.'s (2010) HealthWeaver Mobile project provides a more recent example of designing mobile technology systems to address patient-centered needs in cancer care. The HealthWeaver prototype focused on supporting "unanchored information work" or types of coordination work that occur away from home and have limited access to physical information artifacts like patient records, or during times when people have "diminished attention" as a result of chemotherapy or radiation treatments. Participants in the study were breast cancer patients who received a smartphone application that included a set of digital tools for managing personal health information anytime or location. The HealthWeaver application, for instance, provided several features including: " (1) daily check-ins to track well-being and symptoms, (2) calendar events (e.g., consultations with clinicians), (3) logs to monitor medications, pain, and surgery drains, and (4) notes (i.e., text, photo, and audio) for quick capture of care-related information."

While the information work described by Klasnja et al. is seen primarily through a biomedical lens, their work importantly argues that the design of health technology also needs to account for people's social worlds outside clinical settings. For instance, they argue that a central finding from their study was the importance of synching the HealthWeaver mobile application with people's current calendar systems so as to be accessible; but they also acknowledged that the design of this health information impacted other parts of people's lives. They write:

> Calendars were a primary tool our participants used to manage care-related information in their everyday lives. Thus, they expected our mobile application to integrate with their current system without disrupting it or making it more complicated. …Yet, participants wanted limits on integration. The two participants who worked in corporate environments both synchronized their work calendars to their mobile phones. Although they wanted to be able to see health-related appointments alongside work appointments, they did not want the two to mix. As P2 explained, "I don't want my colleagues to read I am going to an oncologist."

In this way, while participants in Klasjna et al.'s study valued HealthWeaver for enabling them to quickly capture information and providing easy access to health information in everyday situations, they also wanted tools for maintaining social boundaries. Sharing health information through the system information could easily lead to context collapse, a phenomenon described by danah boyd and other communication and social media scholars in speaking about the work involved in managing own's identity in relation to different online audiences. Klasjna et al.'s study points to how people have a number of social roles beyond that of 'cancer patient' that need to be considered in system design.

Jacobs, Clawson, & Mynatt (2014)'s My Journey Compass system is another mobile tool designed for breast cancer patients. They describe this prototype as a mobile, tablet-based health management aid that is integrated into people's healthcare system as well as local cancer navigation organizations. Arguing that commercial PHR technology has a low adoption rate because most of these systems are overly clinical in design and viewed as irrelevant for everyday health tasks, Jacobs, Clawson & Mynatt decided to take a different design approach to personal health technology. Importantly, instead of locking down the functionality of the tablet prototype, they conceived of My Journey Compass as a customizable personal tool that would be useful beyond dedicated cancer management tasks or health specific information work. In doing so, they found that people used the system for a wide range of activities. Some of these were health-specific such as calendar memos for medical appointments, communicating with clinicians after appointments, and writing notes about medications, but other uses included using the system for relaxation and entertainment. They write:

> "One of the most common, yet unexpected, uses of My Journey Compass was as a relaxation and escape tool. Patients used Pandora, online books, preloaded stress relief tools, and a variety of downloaded games to relax. Eight participants reported using the tool to help them alleviate anxiety."

They describe, for instance, one participant who used the mobile tablet to record sermons in her church that she found uplifting during her cancer treatments. These social uses of My Journey Compass suggest the need for supporting a wider variety of patient needs—such as the emotional labor involved in coping with anxiety and stress—in relation to chronic illness. Their work also demonstrates how people value flexibility and customization in technological tools that can be used across clinical and community contexts.

Diabetes Support Systems

There are a number of novel personal health systems in HCI/CSCW literature that aim to support people in diabetes management. One influential example is Mamykina et al.'s (2008) MAHI project, a mobile health monitoring application designed to help newly diagnosed individuals with diabetes. The MAHI system includes a commercial blood glucose meter, a Java enabled cell phone, and a Bluetooth adapter to support communication between the glucose meter and the phone. The system's goal was to help people "develop reflective thinking skills" to better understand blood glucose data and treatment options through social interaction with diabetes educators. People use MAHI to document life events (e.g. types of meals, exercise routines, and other moments when they experience a low or high) with photos and audio files along with their corresponding blood sugar levels. They can then share these personal health records with diabetes educators through a dedicated website in order to discern blood sugar level patterns, discuss specific questions about diabetes management, and discover potential health problems. Notably, in this project Mamykina et al. “adopt the view of learning as a social process and focus on social scaffolding mechanisms.” Along with specifically designing the system around social interaction with diabetes educators, MAHI’s also attends to the temporal stages of chronic illness. For instance, Mamykina et al. argue in their paper that the early days of diagnosis require more structured forms of support and guidance, but as people grow more experienced in management practices, they might increasingly require other forms of peer-support.

While MAHI was designed to primarily support interaction between clinician and patient, a growing body of HCI/CSCW work has focused on types of community participation, both in online and local settings. Grimes, Landry, and Grinter (2010), for instance, discuss the development of EatWell, a health application designed to be used in low income, predominantly African-American neighborhoods in the city of Atlanta. As a community that disproportionality experiences diet-related chronic illnesses, including type 2 diabetes, the goal of this project was to help people share locally and culturally relevant health information, recipes, and nutritional advice. The system supported the creation of audio recordings that could be saved and later accessed by other people living in the same neighborhood. Grimes, Landry, and Grinter found that residents using EatWell reported “a sense of community empowerment” as well as a “sense of hope and encouragement by seeing that others like them were trying to eat healthfully.” Along with focusing on supporting relationships in nonclinical social worlds, this project is also an example of system that uses an alternative framing for personal health technology that is collectivist in design and centered on community experiences of health and wellness rather than clinical protocols.

Behavioral Health Management Systems

There has been a growing attention on creating personal health systems for people living with behavioral health conditions. I discuss examples of that work here to consider current design approaches of personal health systems for people living with behavioral health conditions. These have been more limited in terms of social support, however, than the previous personal health systems discussed in this chapter in that they tend to have a clinical focus on a symptom tracking and/or passive sensing and monitoring approaches to care. An example of these ongoing efforts is Bardram et al. (2013)'s Monarca system, a mobile technology designed for managing bipolar disorder. Created by a team of researchers in Denmark, Monarca was conceptualized as a "persuasive monitoring system" which would use sensor data and self-reported data to support adherence to clinical treatment protocols and prompt positive behavior change. The system was designed to be collaborative and used by people living with bipolar disorder, their clinicians, as well as relatives or caregivers (if so desired by the patient).

The system had different functions for each of these user groups. People living with biopolar disorder can use an Android application to help monitor and visualize data on mood, behaviors, and activities (like exercise, sleep, and taking medications) and receive timely feedback to patients on their physical state and activities in order to help them adjust their behaviors. Clinicians and relatives can use a website which provides access to historical overviews of data for patients, clinicians and relatives to customize and review. Importantly, data sharing, clinical collaboration, and treatment transparency are central parts of Bardram et al.'s system design and are viewed as a central part of behavioral health management. They write:

> "In order to strengthen the psychotherapy relationship, data and treatment decisions should be shared between the patient and his/her clinician. Similarly, sharing data with family members or other caregivers should be supported in order to support the treatment process. Finally, sharing data among patients will help with personal coping and management efforts by re-assuring patients that they are not alone, and helping them see how others manage their illness."

While the Danish healthcare system is not described in their papers, Bardram et al.'s design importantly presupposes access to clinical delivery services for behavioral health conditions and scopes the design space for chronic behavioral health around challenges related to the complexity of the health condition and treatment process, rather than wider social considerations like access to medications.

Also of relevance is Mohr et al.'s (2015) study of MedLink, a mobile system designed to address failure points in the treatment of depression in general internal medicine. The study, conducted in Chicago, looks specifically at problems around patient adherence to prescribed medications, challenges in physician management of recommended medication regimens, and poor patient-physician communication practices. Mohr et al. argue that adherence is not an individual patient problem, but a systemic healthcare challenge. MedLink is therefore designed as a support system for people who are newly prescribed antidepressants and seeks to help guide them through the first several weeks of taking a prescription, a time when it is common to struggle with dosing issues and side-effects. The system itself consists of a patient-facing mobile app with automatic medication reminders, audio alarms, and weekly self-reported mood surveys, a Wisepill bottle which is a smart medication container that tracks medication adherence through a cellular signal when opened, and physician decision support system that generates a report with information on "depressive symptom severity, side effects, adherence rates, and a treatment recommendation based on treatment guidelines." Mohr et al. describe several infrastructural challenges with implementing their prototype, particularly in integrating new types of information into the electronic medical record (EMR) to make MedLink a scalable intervention. However, they do not discuss larger social issues like community trust in clinical care, cultural views and stigma around antidepressants, or economic difficulties many people have in affording medications.

Wang et al. (2016) report on a study of a smartphone sensing system, called CrossCheck, that uses continuous passive sensing and periodic self-reporting to monitor and assess mental health changes in people living with schizophrenia. The goal is to better predict when a person will relapse and alert clinicians to intervene in order to prevent or reduce the severity of relapse. The authors describe an algorithmic approach to behavioral health in which personal models of chronic illness are created through passively tracked data. The authors write:

> "The CrossCheck app collects sensor data continuously and does not require the participant's interaction. The CrossCheck app automatically infers activity (stationary, walking, running, driving, cycling), sleep duration, and sociability (i.e., the number of independent conservations and their durations). The app also collects audio amplitude, accelerometer readings, light sensor readings, location coordinates, and application usages."

In contrast to other systems discussed previously, CrossCheck has no social tools for patient-clinician interaction and there are no customizable features for people to review and control how data is shared. Such passive approaches, while increasingly popular, also suggest a need to more deeply consider the role of data in the relationship between clinicians and people living with chronic health conditions.

Informal Caregiving Systems

In recent years, there has been a number of HCI/CSCW researchers working on developing systems that seek to support informal care work. Yu et al. (2011), for instance, developed a mobile phone application to promote positive forms of interaction between people who were living with chronic depression and informal caregivers. Yu et al. describe this as a “care meditation system” that allows people to share information about their mood with one another digitally, thus telling people in a lightweight way when they are doing poorly and need help or are doing well and don’t need attention. It also enables people who are depressed to engage in “distraction exercises” when they are in a negative mood in an attempt to help alleviate caregiver burden. Similarly, Ghosh et al. (2018) discuss Carebit, an Android application for informal caregivers, such as a family member, friend, or neighbor that offer a means of checking in on people with chronic illness who live independently, but need occasional help.

One study that deployed a caregiving system is Güldenpfennig, Nunes, and Fitzpatrick’s (2015) ProxyCare, an “informal care technology” designed to help people who are living with dementia. Situating their study in a nursing home, they describe ProxyCare as a modular system for monitoring behavior and facilitating soothing forms of interaction between caregivers and elderly patients. Using sensors and speakers in device attached to the patient’s bed, the system detects when a person attempts to get up and plays a recorded voice message by a family caregiver to persuade them stay in bed and wait for a nurse to help them. ProxyCare is operated by the person’s family members and the design goal is to protect elderly people from injuries, such standing too soon after surgery or trying to walk without assistance. If triggered, the system notifies the nursing staff and the family member to check on the patient.

In their paper, they discuss the need to build systems for people with chronic illness that are integrated into people’s everyday life. The system was therefore designed to be unobtrusive and not add extra work for the nursing home staff, but also to provide a way to help caregivers participate in the care of their family members even though they lived away from home. The authors report on using the system with families and found caregivers needed to record different messages before finding an approach that would calm the person with dementia down when they were agitated or upset. The note that caregivers felt it was important that the system provide care that was “not cold” or look like “a standard medical device” but could be personalized to the needs of their family member.

While there are many other HCI/CSCW systems designed to support chronic illness for these particular types health conditions and others, this section highlights several innovative approaches to supporting information work, social relationships, and medical activities with technology. Many of these systems reimagined how to support the patient-physician relationship by facilitating new types of interaction (e.g. MAHI, Monarca, MedLink, My Journey Compass) or by using sensing technologies and passive data collection as a means of intervention (e.g. CrossCheck, MedLink, ProxyCare). Researchers and designers in HCI/CSCW are also reconsidering how to help people manage health activities that take place away from the clinic and are centered in the home, workplace, or community. This included the information work involved in coordinating formal care activities (e.g. HealthWeaver), as well social information sharing that is a part of everyday activities such as cooking and eating together (e.g. EatWell). Using technology to address emotional needs in chronic illness management is also an important design opportunity. HutchWorld and ProxyCare illustrate approaches for designing to facilitate social interactions where managing stress, anxiety, and finding ways of coping were central concerns. This collective work also points to designing for social roles beyond 'patient' in the ways data could be shared with family, friends, neighbors, and colleagues (e.g. EatWell, HealthWeaver, Carebit).

NEW SOCIOTECHNICAL DESIGN NARRATIVES FOR HEALTH

While far from exhaustive, the studies described in this chapter show various approaches to designing personal health systems that contend with the concerns of everyday life. For people living with chronic illness, this includes support for performing routine medical activities, but also aspects of what Churchill and schraefel (2015) position as personal wellness, such as emotional well-being. Importantly, there are few empirical studies in the field that specifically explore the intersections of biomedical settings and informal forms of care work in system design. Güldenpfennig, Nunes, and Fitzpatrick (2015) argue that understanding how such care settings are related is of critical importance writing:

> "The studies around informal care technologies are usually located around the home, or in everyday life, supporting patients and carers in the different situations of their life. It is not common though to find studies about informal care in formal settings. It is as if, when people moved to institutional settings such as a nursing home, they abandoned their informal care practices and

> devices. What happens in reality is that some informal care practices are transformed, while others continue to exist. Ignoring informal care practices in formal settings may decrease the quality of care, so it is relevant to study how the two settings can be integrated."

Along with the need for empirical studies that address how formal and informal care settings may better align, I would also argue that it is important to more deeply understand how and why care practices might diverge or even conflict. The goal of integration noted by Güldenpfennig, Nunes, and Fitzpatrick (2015) is also a value and power dynamic that needs to be carefully considered.

Conceptualizing personal health through biomedical concepts like compliance, optimization, and behavior change, along with celebratory ideas of well-being have proved a useful lens for designing particular types of technology. Yet, such narratives can also be problematic in that they leave many types of relationships, costs, and labor unaccounted for. An empirical and theoretical gap exists in HCI/CSCW health literature in articulating critical, sociotechnical alternatives to techno-solutionist paradigms. For instance, in this chapter personal health data are most often understood as a means of encouraging patient adherence or reducing anxiety, but as Grimes, Landry, and Grinter (2010) and Jacobs, Clawson, and Mynatt (2014)'s studies imply, such design framings are not always the most appropriate or desirable. The HCI/CSCW community needs research that specifically addresses diverse care experiences that speaks to the relations between new forms of labor and expertise, various nonhuman actors, and wider community concerns. In this thesis, I show how technology design would benefit from engaging with alternative theoretical traditions—such as STS and feminist sensibilities of care—in the design of health technologies. Woven throughout this thesis, then, is an alternative design narrative that looks at how researchers and designers might engage (rather fix or erase) sociotechnical complexities by studying various dependencies and uncertainties related to everyday health contexts.

Chapter 3 Theoretical Framings

In articulating a lived health design space, I follow others in HCI/CSCW who have drawn theoretical inspiration from the humanities and social sciences to investigate the role of information and technology design in various health contexts. In this section, I review several theoretical approaches that have influenced the way HCI/CSCW research addresses social context, types of activity and relationships between actors. In particular, I examine sociological theories of interaction, science and technology studies (STS) scholarship on human/nonhuman relations, and infrastructural perspectives of information systems along with related sensitizing concepts (e.g. *social world, information work, cyborg, shadow bodies)*. This collective theoretical and empirical work points to how practices are dynamic, both shaping and shaped by a multitude of sociotechnical dimensions, including: material arrangements, social relationships, local resources, organizational processes, and political discourses.

THE LIFEWORLD & SOCIAL WORLDS

HCI/CSCW has long been interested in the ways in health information is bound up with highly-situated everyday life activities and concerns. Research in information behavior, for instance, has been influenced by the concept of the *lifeworld*, a theoretical focus in the phenomenological sociology of Alfred Schütz's *Phenomenology of the Social World* and later extended by sociologists like Luckmann and Garfinkel. In phenomenological tradition, people experience meaning, e.g. the significance of objects, events, the self, and other people, through a particular culture. One's surrounding lifeworld shapes communication practices, social interaction (including collective action) and everyday activity (Smith, 2016). Research in the area of doctor-patient communication, for instance, have investigated the lifeworld of patients to better understand how the richness of people's lives might be more meaningfully integrated with professional healthcare work (Rodin et al., 2009; Barry et al., 2001; Mishler,1984). It has often been noted, for instance, that the patient's "voice of the lifeworld" (e.g., contextually grounded experiences) is often held in tension with the physician's "voice of medicine" (e.g., technical information) (Scambler and Britten, 2001).

Numerous studies in medical sociology have demonstrated a need for health professionals to better relate clinical information to the lifeworld. This is especially important in treating people with chronic illnesses as these health conditions are inextricably woven into the fabric of daily life. For example, Barry et al. (2001) writes: "As the role of the GP [general practitioner] changes with the rise of chronic illness in an aging population GPs may have to change their notions of success from purely technical considerations to include their patients feeling understood, listened to and treated like whole and unique human beings."

Literature in medical sociology detailing the patient's lifeworld have generally critiqued professional medical practice by arguing that institutionalized healthcare too often ignores social context, dehumanizes the patient, and "depersonalizes" health information. Although the literature on medical sociology demonstrates a need to think holistically about health, the ways in which medical information might be integrated with patient lifeworlds are still not well understood (Waizkin 1989, 1991). While drawing attention to the social context of health, the medical sociology literature on the lifeworld is limited in its theoretical scope as it does not fully grapple with the complexity of how people negotiate a multiplicity of perspectives/cultures/meanings nor does it offer a nuanced understanding of the role information and data technologies play in shaping such practices.

HCI/CSCW has also drawn upon *symbolic interactionism*, a sociological approach to the study of human behavior rooted in the premise that meaning is derived from people's interaction with others in social settings (Blumer, 1969). This interpretation is fluid and ongoing, and meaning is reconstructed through repeated interactions. Through varied studies, often of medical settings, the sociologist Anslem Strauss developed a theory of *social worlds* to analyze the arrangements and processes of collective action. Unlike formal organizations with clear boundaries and known memberships, however, Strauss argued that social worlds are shaped by "forms of communication, symbolism, discourses" as well as "palpable matters like activities, memberships, sites, technologies" (Strauss, 1978). In contrast with the phenomenological concept of the "lifeworld," people participate in multiple social worlds both small and large in scale, local and international, as well as visible and hidden. Strauss maintained that social worlds have a primary organizing activity, such as art collecting, medicine, DIY repair, politics, or punk music etc., as well as have particular sites of action and technologies to carry out action.

On a theoretical level, Strauss was interested in understanding the conditions where/when social worlds *intersect*, pointing to situations where new types of skills and expertise are needed, a process made visible when technology is adopted or modified. Also of interest was when social worlds *impinge* (e.g. when actions in a social world are questioned, viewed as harmful or illegitimate) or *segment* by dissolving or splintering off into subworlds. Strauss argued that the formation of multiple subworlds, "signifies not only new activities, sites, technologies and organizations, but also signifies new universes of discourse." Social worlds in an interactionist view then can be seen as fluid sociotechnical arrangements, fragmenting and disappearing as often as they emerge and coalesce. Important analytical inquires for sociologists drawing on social worlds theory are multiple-world issues: who has the power to authenticate members of a social world? How do people manage simultaneous memberships among social worlds? What are the arenas—the debated and contested issues among members? While Strauss and colleagues pointed to the role of technology as important part in facilitating the action and making visible the movements of social worlds, is has not received much attention as an actor itself.

Although the notion of the lifeworld and social worlds implicitly underlies many HCI/CSCW studies grappling with the social context of healthcare, studies to date have focused on small and contained social worlds like a hospital floor or clinical department. This literature has generated a rich understanding of the role of technology in coordinating the clinical activities and organizational processes of medicine. For example, Xhou et al. (2009) documented the lived experience of nurses and doctors using an electronic medical record (EMR) system through an ethnographic study of a hospital. Similarly, Park (2014) investigated the relationship between clinical care and health information technologies in a local emergency room. Given an interest in personal health technologies, there has been a wide range qualitative and design studies in HCI/CSCW investigating specific types of patient-centered care relationships, technologies, and health activities, but rarely look at how all these come together in the social/subworld(s) of everyday health in the same depth as that of clinicians.

For example, studies have examined how technology might support informal caregiving relationships as partnerships (Miller et al., 2015), impact family relationships among adult children who care for elderly parents (Schorch et al., 2016), and help parents better care for the needs of young children (Kientz et al., 2009). Other studies have focused on understanding the role of artifacts as coordinating devices, for instance, Barbarin et al. (2015) examined the management of chronic illness in the home through material objects like the arrangement of pill containers and location of shared calendars. There has been a move in HCI/CSCW to study health in community settings, such as neighborhoods with health disparities (Schaefbauer et al., 2015; Parker et al., 2012); however, these studies tend to design technology as a tool to assist people in adhering to clinical treatments or promoting types of behavior change (e.g. reduce blood pressure, lose weight, eat healthier, exercise more). Although the design of HCI/CSCW health technologies are still are predominately framed around a biomedical and/or individualistic model of health, this collective research suggests that it is important to consider alternative, social directions.

The HCI/CSCW literature on online patient forums, for instance, suggests the multiplicity of socialworlds/subworlds in managing chronic illness. Qualitative studies on Chinese patient forums, for instance, have discussed the use of traditional Chinese medicine and differences in cultural attitudes in managing conditions like diabetes (Zhou et al., 2014) and depression (Li et al., 2016). Mankoff et al. (2012) discussed competing patient viewpoints for the treatment of Lyme disease in dedicated patient forums, noting this can be an opportunity for design intervention. Furthermore, Huh et al.'s (2012; 2015) work on online patient communities for those with chronic illness have documented a wide range psychosocial challenges, calling widely for the design of health technology to account for "the whole person." Design approaches for incorporating a multiplicity of meanings, discourses and belief systems in health systems, however, remains undertheorized.

My thesis, then, build on and extends this earlier work in considering how people's lifeworld (and/or a multiplicity of social worlds) might be better engaged in the design of personal health technology. Envisioning users strictly in terms of individuals, for instance, might not resonate with people for whom the family or local faith community is the most important social unit. Technology that seeks to move beyond the dualistic design narratives of "patient-centered" or "self-care" needs to account for various sets of social relationship, belief systems, and local knowledge found in people's lifeworld/social worlds/arenas. In the next section, I turn to social analyses and sensitizing concepts that investigate health and illness contexts through examining types of work practices.

SOCIOLOGY OF WORK AND CHRONIC ILLNESS

Analyzing health and wellness through the lens of symbolic interaction, the medical sociologist Anselm Strauss with others, provided insight into the lived experience of chronic illness and the contextualized activities by which illness is managed (Glaser & Strauss, 1965; Glaser & Strauss, 1968) Strauss was particularly interested in extending the concept of *work* to investigate the practices around living with chronic illness. For Strauss, and here in this thesis, work is comprised of micro-interactional activities, and is not necessarily conducted in formal workplace settings. He examined, in collaboration with others, the activities of hospital staff in caring for the chronically ill, including *machine work* (associated with using, monitoring, maintaining technology/machinery), *safety work* (associated with issues of clinical safety), *comfort work* (associated with tending to physical discomforts), *sentimental work* (associated with psychosocial issues such as trust, composure and identity) and *articulation work* (associated with the collective effort of clinicians, including planning and coordination to operationalize tasks) (Strauss et al, 1997).

Although it is undertheorized as a sensitizing concept in their writings, Strauss and colleagues also discussed *information work*, which they conceptualized in general terms as the passing or omitting of information (ibid). In their studies, they were interested in “how the flow of information is implied in and makes possible the organization of work” (p.253). Citing Gerson (1981), they maintained that the flow of information includes reflexivity and sentiment, and therefore both must necessarily be considered in analyses of information work. Additionally, they argued that information work must be related both to the illness trajectory or temporal arc of work associated with managing the illness and the contexts in which the work takes place (Strauss et al., 1997, p. 253).

Strauss and colleagues also recognized and examined the kinds of work done by chronically ill people themselves, both in hospital settings (Strauss et al, 1982; Strauss et al., 1997) and in managing illness at home (Corbin and Strauss, 1985). They noted that people with chronic illness and informal caregivers engage in the types of work undertaken by clinicians (e.g. machine work, comfort work, information work, sentimental work, etc.), as well as others that only patients can do, such as *biographical*, or *identity work* related to reconstructing one’s self (or life narrative) by and through illness. In this thesis, I refer collectively to these various types of Straussian interactional activities as “care work” to describe the practices people (and concerned others in their social worlds, such as family and friends) perform in the everyday management of health and wellness.

Furthermore, some types of everyday care work are visible (e.g. recognized by the formal medical world as "real" work), especially if it duplicates or supplements the work of clinicians (Strauss et al, 1997). For example, work done by patients in managing medications or adhering to clinical protocols. Some types of work, on the other hand, are mostly invisible and not openly or frequently recognized by clinicians as "work," such as seeking out alternative treatments, documenting one's family medical history, or learning how to provide (and ask for) information during a doctor's visit. Many types of work can go largely unrecognized by both lay people and clinicians alike; for example, reflecting on whether or not to follow a doctor's advice, advocating for patient rights, documenting an illness trajectory, self-experimentation, reducing stress, or sharing personal health data with family and friends. Strauss et al. (1997) noted that whether or not these activities are openly recognized as "work" they can influence clinicians' judgments about how cooperative/adherent people are to biomedical treatments and protocols. Grounded in these studies, the sensitizing concept of *invisible work*—those activities (often types of emotional labor and/or traditionally "feminized" occupations) not supported by organizational processes or technological systems (Star and Strauss, 1999).

Information work, as detailed in Strauss's writings, was premised on a conceptual model of straightforward information transfer that neglected to address sociotechnical complexities. CSCW and HCI, however, routinely study information behavior alongside innovative technology use in a range of health settings. Research in these fields has contributed to our understanding of issues as far ranging as collaborative help in managing individualized problems in chronic illness (Huh & Ackerman, 2012), patient work for personal health information management (e.g. Pratt et al., 2006) including "unanchored information work" that occurs when patients are away from their personal health information collections (Klasnja et al, 2010), information use in "chronic care cycles" between clinical settings and the home (Chen, 2011), and discrepancies in documenting psychosocial information by clinicians for long-term use (Zhou et al, 2010).

Types of care work described in HCI/CSCW focus on human action (e.g., what people do); and refer to the ways that people manage their health through specific, situated actions. For example, a person organizing their prescriptions on the kitchen counter in order to remember taking their daily medications. There has been a renewed interest in CSCW to articulate more contextually-situated understandings of informal care work, including information work. In this thesis, I propose to follow such extensions by further contemplating the relationship between information and emotion work, the intra-personal and inter-personal labor involved in making sense of different types of information in the management of health.

HUMAN-MACHINE RELATIONS: EMBODIMENT AND EMERGING SELVES

Another theoretical influence in my thesis work on lived health can be found in feminist technoscience scholarship broadly associated with the field of Science and Technology Studies (STS) and exemplified in the work of Donna Haraway, Annemarie Mol, Lucy Suchman, and Adele Clarke. Situated at the intersection of several theoretical areas including, actor-network theory, practice theory and sociomateriality, collectively this work articulates a sociotechnical approach to studying health technology in which personhood is inextricably entwined with the cultural and material worlds.

Posthumanist theorists like Haraway, for instance, attempt to disrupt and subvert an understanding of the body as singularly human. Her influential and enduring "Cyborg Manifesto," for instance, points to a future where people's relationship with technology is both alluring/fascinating and fearful/disturbing. Writing of the cyborg body, Haraway maintains, "Late 20th century machines have made thoroughly the difference between natural and artificial, mind and body, self-developing and externally designed and many other distinctions that used to apply to organisms and machines" (Haraway 1985/1991). Accordingly, people and technology are in a constant state of flux, shaping and (re)shaping one another through a variety of interactions with different social contexts.

This theoretical position implies an inherent multiplicity in a person's lived experience as different arrangements of technologies, processes, and people perform new self/selves. Furthermore, a growing collection of scholarship investigating information systems in organizational studies and HCI/CSCW have turned to practices as a theoretical lens and design methodology in which to understand and engage with this multiplicity (Orlikowski 2000; Suchman 2007; Danholt 2008; Nunes et al., 2015; Bjørn and Østerlund, 2014).

In *The Body Multiple* (2002), a philosophical and anthropological study of atherosclerosis, Mol conceptualizes the lived experience of a disease as "multiplicities of realities" made visible through the relations between practices of knowledge systems, the human body, and technologies. Information is not neutral but presents a version of reality that is always intertwined with practice (Mol 2002, p. 171). The patient record as an information technology includes an array of discrete logics (and realities) such as images of blood vessels, clinician notes, patient complaints, and numerical lab results that all perform a person's blood sugar levels. Although this information does not neatly align, Mol maintains that the patient record holds together as a form of coordination across the organizational contexts of healthcare institutions. In *The Logic of Care* (2008), Mol further argues that for healthcare to be "person-centered," policy-makers and practitioners need to grapple with contextual multiplicity by attending to localized health practices found both within and beyond the world of institutionalized medicine, a subject that I investigate throughout this thesis, especially around the practices of BMT caregivers in Chapter 4.

Understanding the ways in which medical and health systems are related to embodiment—how the personal is digitally performed—is also a matter of design. Berg and Harterink (2004) trace the history of medical records from the early twentieth century and demonstrate how the medical record has long conceptualized the patient as a singular, independent, and rational subject. They further argue that emerging technologies have the potential to shift our understanding of personhood to be "decentered, dispersed, and multiplied subjects" (Berg and Harterink 2004). Current personal health technologies, however, still largely design for a patient in isolation and apart from "the mess" that is a part of contextual specificity: the localized practices found in particular communities, family situations, and geographies. If one accepts Berg and Harterink's (2004) postulation that technologies can help shape and support new forms of embodiment, then the HCI/CSCW designer and researcher must also think constructively (and critically) about how to incorporate the contextual multiplicity of lived experience into the design of health systems.

In *Human-Machine Reconfigurations*, Lucy Suchman (2007) presents a practice theory approach that closely examines people's behavior in a specific context as the starting point for design work. Understanding people's practices—or in Suchman's terminology *situated actions*—helps articulate the complicated arrangements of people, social processes, and material artifacts. As with Berg's (1999) "sociotechnical" approach, Suchman holds that design should embrace, rather than dismiss, the "mess" found in people's everyday actions be they in the home, workplace, hospital, or an online forum. In the final chapter of *Human-Machine Reconfigurations*, Suchman invokes Haraway's figure of the cyborg, noting that it should not be viewed as a singular heroic, monstrous, or marginalized subject, but a "multifaceted subject-object assemblage." A cyborg sociomateriality views health information and personal data as inextricably connected to a distributed and shifting network of bodies, processes, technologies, and people. Furthermore, Suchman argues that cyborg configurations and their consequences play out in the mundanity of everyday life. Today, emerging health contexts like DIY/hacking and personal data-tracking technologies, discussed later in Chapter 6, extend as lived practice the kinds of configurations Suchman observed and theorized. They come with values, such as individual empowerment and self-care, built into the very purpose of their uses, and the consequences of such human-machine configurations are of a deep sociopolitical and ethical nature.

The notion of the postmodern/posthuman self as an assemblage of decentered and dispersed subjects argues for future design directions to help people manage a multiplicity of healthcare practices across family life, hospital floor, religious service, clashing regulatory bodies, online support groups, and neighborhood bar. That different types of personal health information may overlap, conflict, or coexist does not necessarily have to lead to technical chaos or poorer health outcomes. Disparate but meaningfully connected health information might open up new design trajectories that enable a holistic vision of health information technology that is integrated into people's everyday practices and lifeworlds. Engaging with such theoretical elaborations from feminist technoscience, this thesis will offer a situated and multi-faceted account of lived health through detailing the arrangements and configurations they entail. My thesis work will further unpack how familiar tropes of patient empowerment and user-centered mask social and economic consequences such as the wider shifts in responsibility and expertise in health care from provider to lay person (Clarke et al., 2010). My thesis draws out a lived health stance for HCI/CSCW researchers and designers that includes a critical sensibility towards the politics and ethics of care work within shifting terrains of personal data, technology, and self-care/patient-centered health narratives.

INFRASTRUCTURAL PERSPECTIVES

Grounded in STS scholarship around informational and knowledge infrastructures by Susan Leigh Star and collogues (Bowker et al., 2015), infrastructural studies of health systems have taken an ecological approach to analyzing formal medical systems in healthcare organizations, like electronic medical records in hospitals. Analytically, infrastructure is a relational process, dynamic and changing rather than a thing. One is therefore tasked with considering “when—not the what—is an infrastructure” (Star and Ruhleder 1996/2015). Star argues that infrastructure is characterized by several sociotechnical dimensions, such as: *embeddedness* (e.g. “sunk into, inside of, other structures, social arrangements, and technologies”), *transparency* (e.g. invisible in use to support task), *spatial or temporal in scope* (e.g. reaching beyond a single event or local practice), *learned as a part of membership* (e.g. shapes and is shaped by a community of practice), *embodiment of standards* (e.g. can become more rigid through process of standardization as infrastructure connects to other infrastructures and tools), and becomes *visible upon breakdown* (Star and Ruhleder 1996/2015).

Of particular interest to my thesis work on chronic illness and discussed in greater detail in both Chapter 5 and Chapter 7, is Star’s writing on “infrastructural shadows” in relation to thinking about the consequences of standardizing overly simplified models of care through system design. In “Mapping the Body across Diverse Information Systems,” for instance, Balka and Star (2015) discuss the way electronic medical records fail to connect important information across jurisdictional boundaries like regional hospitals, local clinics, and specialty services. This incomplete and partial record of the ‘patient’ illuminates particular aspects of a person’s body (and life) while casting others (perhaps equally or more important) into the shadows, underemphasized and often invisible to the medical system at large. While this example of a large-scale healthcare system highlights a breakdown in information infrastructure, the notion of shadows is more of a theoretical provocation than a fleshed-out analytical concept or thing. Star (2015) wrote of shadows, for instance, as generative spaces for “the discarded complex,” those places/relationships/selves that resist the rigid and often binary classifications problematically reified through infrastructure and (too often) in the design of smaller, less formal technologies.

Infrastructural studies have begun to gain traction as a theoretical perspective in the HCI/CSCW health community, although largely in terms of large-scale medical systems research around electronic records (see Bossen et al., 2016; Bansler et al., 2010; and Ellingsen et al., 2010; Pine and Mazmanian, 2015). My thesis goal in articulating a design space of lived health is to take seriously the rich and varied activities (and meanings) involved in how people care for themselves and others in everyday settings. I follow Star’s lead, then, in looking deeply at the “discarded complex” in healthcare. In particular, how people’s varied selves—caregiver/mother or programmer/patient—are connected to wider ecological factors and organizational policies, such as local resources and health regulations. I believe that in drawing attention to marginalized types of care work that exist in the infrastructural shadows of the formal medical system, alternative framings of sustaining health and well-being beyond individual ‘patient’ or ‘consumer’ can be revealed.

Chapter 4 Information of Bone-and Blood:
Fragile Children, Caregiving Materialities, and Technology Design

> "What does it mean for something to be information?"
> –Paul Dourish, *The Stuff of Bits*

> "With my pathology report, the material of my body (that me and not-me tumor) seemed to be literally lifted out of myself and into data."
> –S. Lochlann Jain, *Malignant*

INTRODUCTION

Pediatric hematopoietic stem cell transplantation (HSCT) is the biomedical term for a procedure more commonly known as a "bone marrow transplant" or "BMT." It is an intense treatment of last resort used to treat a range of blood disorders and blood cell cancers, such as leukemias and lymphomas. The procedure itself involves replacing unhealthy stem cells in the bone marrow with healthy ones harvested from the patient or a donor. Approximately 20,000 BMTs are performed annually in the United States and transplant recipients constitute some of the most complex clinical cases due to the nature of the treatment and the serious risks it involves, the severity of the diseases for which transplant is done, and the heavy physical and psychosocial burdens.

BMT requires prolonged inpatient care in a hospital lasting a month or more (Ford and Wickline, 2009). Furthermore, for pediatric recipients—medically fragile children—a BMT cannot be performed unless a suitable caregiver (usually a parent) is available; furthermore, children undergoing BMT remain dependent on caregivers to attend to their healthcare needs long after hospital discharge (Gremmill et al., 2011). Caregivers are often required to stay with the patient 24 h/day during the first 3 months after they leave the hospital, sometimes longer. Even before discharge, BMT– an intense and life-threatening procedure – can cause significant distress for children and parents, which impacts their physical, psychological, and social well-being (Phipps et al, 2004). Caregivers must fulfill multiple roles to properly care for a child receiving a BMT, soothing anxious children, but also tracking symptoms and medical tasks. One recent study of chronically ill children described the roles of such caregivers as being: “parents, nurses, advocates, activists, educators, and case managers in the lives of their [medical] technology-dependent children” (Rehm, 2013).

As an HCI researcher, I encountered BMT through fieldwork for a hospital-led design project aimed at supporting caregivers. The medical community has increasingly seen caregiver engagement—often defined in terms of access to information, health literacy, and agency in shared medical decision-making—as the optimal model for healthcare delivery to pediatric populations, particularly for children facing life-altering medical treatments (Mead & Bower, 2000). Looking for strategies to enhance this partnership, medical institutions have recently begun to develop technology systems to support caregivers in a wide range of medical contexts (Hibbard et al., 2007). The pediatric BMT unit at Hemphill Children’s Hospital, part of a large, university-based medical system in the midwestern U.S., was creating one such system, a mobile application to support the BMT caregivers during their inpatient stay. As part of the project design team, I was invited to spend time with families both in the hospital’s inpatient unit and outpatient clinic to learn more about their information needs, a process that involved observing daily clinical rounds in patient rooms, sitting in on outpatient appointments, and interviewing families both about their medical experiences and lives.

My first trip to the hospital’s inpatient BMT unit was on a sunny spring day. I walked across the sprawling medical campus where fruit trees were bursting into bloom and blankets of pollen covered parked cars—it was a day when anyone with seasonal allergies was caught between bouts of sneezing and rubbing itchy, watery eyes. As one such allergy sufferer, I gripped a pack of tissues in my hand and walked into the hospital’s main entrance knowing that I wasn’t sick or contagious, but nevertheless nervous that an ill-timed sneeze could put someone in the BMT unit at risk. I had been warned before my arrival that the children I would be visiting were highly vulnerable to the exposure of any type of germ or bacteria.

As an advanced biomedical research and clinical space built to treat immunosuppressed compromised children, the BMT unit occupies the entire eastern side of the hospital’s 8th floor. Traveling up an elevator from the lobby, the BMT unit sits behind a locked door with its own security guard. Past the door, long hospital corridors branch out. The walls are decorated with framed, colorful pictures drawn by children, wobbly rainbows and favorite nurses scrawled in crayon, that occupy places of honor next to specialized scales and other medical equipment temporarily stashed outside of patient rooms. I recall taking a hesitant breath, ready for what I think of as "hospital smell," that mixture of cleaning product, dishes of lukewarm food, and illness—and was pleasantly surprised. The air here smelled new and clean. I later learned that the BMT unit has specialized air purification and filtration systems silently at work behind the walls—technology that eradicates dust, mold, and pollen, but also an array of nanoparticles and tiny microbes that wouldn't be caught by a typical commercial HEPA filter. Its effect on my allergy-weary body was immediate: I could breathe again.

Talking about my instant allergy relief with a nurse, she also explained that fresh-cut flowers weren't permitted in the BMT unit. The floral arrangements and get-well plants that decorate countless hospital rooms were dangerous here, carrying containments in their water and soil that could hurt transplant patients waiting for their blood cell counts to return to normal and fight off everyday infections. Fresh fruit baskets, also full of get-well germs, were not permitted; although fruit (with a peal) could be eaten from the hospital cafeteria. According to the Pediatric Blood and Marrow Transplant Program Patient Guide, a thick booklet given to each family upon beginning their hospital stay, "artificial flowers and cards are welcome."

This initial visceral encounter with BMT, witnessed (albeit in a minor way) through my own weakened immune system, later became amplified through the experiences of families I spent time with at the hospital. From the artificial air circulating the rooms to the artificial food protecting inflamed guts, transplant patients were dependent on a myriad of technologies to keep themselves functioning. BMT (by design) is a totalizing experience that profoundly alters aspects of a child's body—even changing their blood type—but also the lives of their entire family who rally round to take care of them, living in and out of the hospital. It is a matter of blood-and-bone in the most literal biological sense, but also in terms of the deep social and emotional impact it has on pediatric patients and their parent-caregivers, who are often tasked with routine monitoring responsibilities as well as making life and death decisions on behalf of their children. People in the BMT unit—clinicians and families alike—were always on alert, the risks of the medical project they were engaged in emphasized by the material arrangements of a sanitized hospital floor. Fake flowers and no fruit.

MATERIALITIES OF INFORMATION + MATTERS OF CARE

BMT is therefore of considerable interest to HCI not only in terms of health system design, including creating tools and technologies to support a range of challenging health situations such as chronic illness management, rare diseases and extended hospitalization; but also, for what it can tell HCI designers and researchers about the nature of information through highlighting very human (i.e. vulnerable) moments of interaction.

People's experiences with personal data is an area of increasing interest to HCI in designing systems to support a wide range health and wellness contexts, but also in terms of everyday activities like going to school, shopping, banking and travel etc. In a specialized treatment like pediatric BMT, families must engage with a tremendous amount of clinical information and personal health data to take care of their children. To help them, families are given a wide variety of resources, including clinician time, as BMT caregivers must collaborate closely with a team of healthcare professionals, learning the specialized language and the technical practices of medicine. This information-rich and high-risk setting makes visible the many challenges parents have in understanding and acting on health information, providing a richer depiction of caregiver engagement in practice. Furthermore, BMT also intimately and profoundly shapes the everyday lives of patient, caregiver, and family (Büyüktür & Ackerman, 2014; Büyüktür, 2015). The medical procedure, but also the types of information people interact with, shift social, financial, emotional, and temporal realities, but also material relations.

Information, in this caregiving context, has a deeper significance than a numerical representation of a lab result or the probabilities of clinical trials. What to treatments to try? What hobbies and activities to give up? What foods to keep away from (no matter how hungry)? What people to leave behind (no matter how loved)? Information was a caregiving practice that required real labor: monitoring and tracking their child's response to medications, but also researching and reflecting on possible outcomes. Living with information was a social as well as technical activity for parents, negotiated through clinical tests, treatments, and protocols; but also, relationships with nurses, doctors, and family and friends. Importantly, information for BMT caregivers was also always material, taken from *bodies* and bound up in *things:* blood bags and beads, sketches and spreadsheets, patient records and Facebook posts. These physical and digital artifacts held a multiplicity of meanings for families facing life and death: Information for bone marrow transplant families was a site of hope and despair and a matter of daily survival.

In this way, information work in BMT can be seen as a site of complex sociotechnical relations and materialities, a matter of care that necessitates weighing the risks of medical decisions and multifaceted human needs. Taking the lived experience of BMT information seriously, in its various practices and forms, shows the unexpected ways care is enacted through interactions with digital records, but also fragile bones, family life, and cups of tea. Information of bone-and-blood complicates a narrative of straight-forward information transfer, a model of interacting with health information that underlies the design of many information systems developed to help people engage with health settings. BMT, then, also becomes an important site for investigating a number of wider sociotechnical issues currently being explored by HCI, such as how labor, power, and values are embedded into information systems and design processes.

This chapter, then, has two overarching goals. First, I explore the lived experience of pediatric BMT caregivers. Drawing on findings from an ethnographic engagement with families whose children were undergoing a bone marrow transplant, I detail everyday caregiving practices and the meanings those activities hold for parent-caregivers. This includes looking at medical tasks, but also a wide range of information work and emotional labor. Second, this chapter also considers the materialities of health information in the process of design. As mentioned, the ethnographic work detailed here was part of a larger design project for a BMT caregiver support system to be used in Hemphill Children's Hospital. Analyzing this design work through what Dourish (2018) calls "a lens of materialities," I seek to draw attention to the types of data that are represented, where they come from, and the significance of those digital representations.

In the following sections, I first outline what is known in HCI/CSCW literature about healthcare management with children, and with caregivers (especially parents). I then discuss the theoretical framework I use in my analysis, focusing on Strauss et al.'s interaction work. I follow with a description of the field site, my data collection, and the BMT process. Next, I present study findings about the medical/ information/emotional labor parents performed, detailed in relation to caregiving practices, to argue that care should be seen as a negotiated activity between a multiplicity of logics and materialities. Finally, I explore the representation of information of bone and blood in design, the meanings of that data, reflect on how we as HCI designers and researchers might attend to some of the costs—social, emotional, physical—in designing for caregiver engagement.

RELATED WORK

Health Management in CSCW

There has been increasing interest in the HCI/CSCW communities to design systems that better support the social and emotional dimensions of managing health conditions in a range of care settings (Grimes et al., 2010; Huh et al., 2012; Liu et al, 2013; Mamykina et al., 2008). In particular, the hospital context has long been of interest as a site of collaboration between clinicians and patients. Paul and Reddy (2010), for instance, have described practices around collaborative sensemaking on healthcare teams. Zhou, Ackerman, and Zheng (2010) studied how doctors record psychosocial information from patients in electronic health records (EHR) systems, finding that this data is recorded selectively and from a medicalized view point. Importantly, they argue that "missing or problematic representations of a patient affect work activities and patient care." Jacobs et al. (2014, 2015) have investigated the collaborative arrangements and needs of cancer patients; while Mishra et al. (2016) have investigated forms of patient engagement in a hospital setting. Recent work has focused on the information work that occurs in hospitals such as health tracking (Mishra et al., 2018) and in transitions to self-management (Pollack et al., 2016).

Caregiving has been of increased interest to the HCI/CSCW health research community (Bernadina et al., 2016; Hong et al., 2016; Miller et al. 2016a; Miller et al., 2016b). Yunan Chen (2011), and in particular, Chen et al. (2013), which presented a qualitative study of caregivers and highlighted the need in CSCW and HCI to better understand the situated practices of caregiving in people's everyday lives. Drawing on Strauss, the authors discussed the 'identity work' caregivers engage in as they manage multiple 'selves' (e.g. physical, emotional, and social selves). Furthermore, the authors found that caregiving is both a collaborative and reflective endeavor calling attention to the need for management in 'social-emotion work' and reflective learning.

Furthermore, a number of studies in the HCI/CSCW literature have looked at the needs of parents and families in a variety of healthcare contexts as a space for technological support (Farnham et al., 2002; Liu et al., 2002; Pina et al., 2017; Tixier et al., 2009; Toscos et al., 20012). Although such studies have examined technologies to augment or facilitate consumer health, there are only a handful of caregiver-oriented studies that document everyday practices, especially for a pediatric patient population. Important studies include Kientz (2010), which examined the interactions between parents and pediatricians, describing tensions and challenges in this communication dynamic, including parents who had difficulty recalling and remembering details after consultation and asking questions of clinicians. Based on the study findings, Kientz recommended systems that help track information and include family members in shared health experiences via social media. Toscos et al. (2012) described how health-monitoring technology affects the parent-child relationship and highlighted the conflicts that can occur in the parent-child relationship in caregiving work. In a study of caregivers and high-risk infants, Liu et al. (2002) noted that currently little has been done to design collaborative systems for parents of pediatric patients. In their discussion of information-sharing challenges, Liu et al. pointed to social isolation as a problem for parents of ill children and suggested social support tools for networks of friends, family members, and health professionals.

Ayşe Büyüktür's ethnographic research on adult BMT is also of particular relevance to this study (Büyüktür & Ackerman, 2014; Büyüktür, 2015, and Büyüktür & Ackerman, 2017). Focuses her inquiry on the various temporalities in the transplant experience for patients and caregivers Büyüktür draws attention to the significance of transitions from specialty care (e.g. going from hospital to home). Büyüktür's collective work demonstrates how the BMT process is challenging on many levels even for adult patients, both medically and also in terms of the emotional and information work required by the wider care team. My study draws from and extends this foundational work through grappling with the specifics of contextualized caregiving work in a pediatric setting and by exploring the materialities and meanings of information in both everyday practice and design.

Framing Care Work

In this chapter, I draw upon the work of Anselm Strauss and colleagues for a general theoretical framing. Strauss contributed to many areas within health informatics and CSCW, the best known of which is articulation, or coordination, work. Strauss and colleagues (Strauss et al., 1982; Strauss, 1993; Wiener et al., 1997) described not only articulation work but also additional kinds of work in interaction and the social activity in medical settings. (For Strauss, and here in this chapter, work is micro-interactional work, and is not necessarily conducted in formal workplace settings.) Strauss largely analyzed the activities of clinicians, such as safety work, or making sure that clinical processes wouldn't cause harm. As neither patients nor caregivers were the focus of Strauss' theoretical analysis, the two types of work in Strauss upon which I draw heavily for my analysis are 'patient-centered' in that they can also be performed by patients and/or caregivers. The first is *sentimental work*, also called *emotional labor* (Hochschild, 2012); it is the intra and inter-personal work involved in maintaining one's composure and self-control.

The second type is *information work*, which is generally under-theorized in the writings of Strauss and his fellow co-authors. Information work, as detailed in this writing, was premised on Shannon & Weaver's (1949) mathematical model of straightforward information transfer that did not address social complexity. There has been a renewed interest in CSCW to articulate more contextually-situated understandings of information work (Ackerman, 2000; Kaziunas et al., 2013; Mentis et al., 2010). I follow these extensions of information work here, further contemplating the relationship of information and emotion in health settings as a type of *reflection work*. This sensitizing concept highlights the personal and collective labor involved in navigating and negotiating the multiplicity of meanings (biomedical science, parental instinct, alternative therapies) and materialities (fragile bodies, information artifacts, and digital apps) that information holds in high risk and chronic health contexts like BMT. Reflection work offers a way for designers to better understand how competing care logics operate alongside, against, and with the logic of biomedicine, as well as the significance they have for caregiving.

RESEARCH SITE AND STUDY METHODS

This ethnographic study was conducted at Hemphill Children's Hospital, a large research and teaching hospital in the U.S. Midwest. The specific site was the hospital's pediatric bone marrow transplant unit and outpatient clinic.

Data Collection

Data included 17 semi-structured interviews I conducted with caregivers of pediatric BMT patients. These data were also informed by approximately 40 hours of observing hospital rounds and BMT consults. Observations included attending meetings between caregivers, patients, and clinicians, as well as informal conversations held among BMT team members that included nurses, doctors, dieticians, pharmacists, and social workers. Observational data were recorded as fieldnotes and later transcribed. Additionally, the analysis of personal blogs and social media sites maintained by my interlocutors added to my understanding of the pediatric

BMT experience. Three Facebook profiles and five distinct websites (with a total of 371 distinct posts), shared with me over the course of my ethnographic engagement, were analyzed and used to triangulate interview and observational data.

The interviews were conducted with primary caregivers for BMT pediatric patients. Participants were recruited through referrals from the BMT clinical team and included caregivers at varying stages of the BMT process. Interviews were approximately 1-2 hours and were recorded and transcribed; children were recorded with the permission of their parents. These semi-structured interviews took place in patient rooms in the hospital and in a private conference room at the outpatient clinic. Semi-structured interviews explored (1) the caregiver's experience with BMT, (2) everyday caregiving practices, (3) the impact of BMT on family life, and (4) information needs in the BMT process.

Interview participants included mothers, fathers, and a grandmother who acted as caregivers. Caregivers came from a wide range of socio-economic backgrounds and family structures. Some caregivers were single parents working full-time to maintain insurance coverage, while other families had the support of two full-time adult caregivers for the patient. Age and education also varied as a number of caregivers had little or no higher education, while others had several degrees and professional training in the sciences. Acknowledging that such demographic data shapes the BMT experience, in this paper I have limited myself to reporting findings commonly articulated by caregivers across demographics.

At the time the interviews were conducted, 7 of the study participants were in the hospital recovering from BMT, and 10 of the study participants had recently been discharged following a BMT and were being treated in the outpatient clinic. During interviews, other family members and occasionally children going through the BMT process, would join the conversation and provide additional insight. While caregivers were the main focus of this study, I routinely observed an intimacy in the communication between children and their caregivers to the point where they would often finish one another's sentences. While acknowledging the child's role as a BMT patient as a unique experience unto itself (caregivers, in fact, often deferred to the patient's interpretations of medical events), it is also important to note that caregivers often spoke about the BMT experience in terms of 'we' and 'our family.' This collective language perhaps points to the deep social impact of BMT and the close relationship between parent and child amplified by long days spent together in the hospital and clinic.

The ethnographic work detailed here was part of a design project for a BMT caregiver support system to be used in inpatient settings. This chapter also describes data collected during design activities with caregivers and children; including two participatory design workshops with BMT caregivers and patients that I helped organize and lead using low fidelity and high-fidelity prototypes. A total of 11 caregivers and 8 patients attended the workshops representing 5 households in each design group. In two cases the caregiver participated alone because their child was too young (ages 2 and 3 years old). In one case a patient was joined by 2 caregivers. There was a gender mix in both caregiver and patient populations. Caregivers were between 34 and 69 years of age. Families included patients with varying times removed from BMT, between 3 months and 5 years post-transplant. Most were from the southeastern Michigan region. There were diverse socioeconomic responses, reflected by variable household health insurances. These workshops and interviews were recorded and later transcribed.

During the course of their interviews, four of the seven inpatient participants were also shown a paper prototype of a personal health system designed to support BMT patients and caregivers during their inpatient stay. The prototype was used as a design probe to help understand patient and caregiver informational needs during the BMT process. The resulting prototype, an iPad application called the "BMT Roadmap" was created with a development team of clinicians, professional engineers and designers, as well as participation and input from BMT caregivers and patients.

My analysis was also informed by my participation in a larger research project aimed at understanding the BMT experience. In this collaborative research role, I have also have analyzed 3 focus groups of 26 individual participants involved in BMT that included 6 caregivers of BMT pediatric patients. As part of a study led by clinical BMT researcher, however, these data are not used in this chapter. IRB approval for data collection was obtained along with participant consent.

Data Analysis

Data analysis followed grounded theory (Corbin & Strauss, 1998; Glaser & Strauss, 1967) in that my data collection and analysis mutually informed one another. Four initial interviews were transcribed and analyzed using an open coding method to identify significant concepts. During data analysis, new codes were generated as significant concepts became identified, compared, and revised. These codes were later used as probes in subsequent interviews. The second stage of data analysis with new data resulted in consistent themes and confirmed findings. Fieldnotes, design workshop transcripts, and blog posts were read, coded, and analyzed in a similar manner during data analysis sessions. Analytical memos were also written as theoretical insights emerged from the ongoing data collection.

The BMT TREATMENT PROCESS

In this section, I outline the biomedical BMT process and draw attention to two important sociotechnical factors that impact caregiver experiences: 1) the many risks and uncertainties that families must consider when consenting to a treatment protocol; and 2) the roles of the BMT clinical team and caregiver and how they inform each other in the medical decision-making process. As a treatment of last resort, many BMT medical technologies from chemotherapy drugs to GVHD prevention strategies were still in development and taking part in clinical trials at Hemphill was common. BMT, therefore, can be best understood as series of ongoing clinical adjustments rather than a straightforward intervention. In this setting of uncertainty, families found themselves under-siege by many opposing forces: cancer and chemo treatments, prescription drugs and their innumerable side-effects, unruly stomachs and fresh foods that could kill, implanted technologies buried beneath the skin and large medical machineries that swallowed up tiny bodies, the treat of invisible pathogens and long stretches of isolation. In this complex medical environment, clinicians and caregivers worked closely together to develop protocol, but also to manage the physical pain and emotional fall out that comes with waiting weeks to see if the transplant will take.

Physical Risks and Technical Uncertainties

The BMT treatment takes a substantial toll on the body. Children are first admitted to the hospital for pre-transplant conditioning therapy which involves high doses of chemotherapy and sometimes also radiation therapy in order to wipe out their bone marrow and destroy diseased cells. As both chemotherapy and the transplant process require numerous IV treatments and transfusions, children are fitted with a central venous catheter or “central line,” a special tube that is surgically inserted into a large vein in the arm or implanted into the chest and allows for the administration of routine blood draws and medications without repeated pokes with a needle (a painful and dreaded process with young children). Importantly, in being connected to the child's heart, these medical devices (called PICC lines and ports) need to be kept clean to prevent a deadly infection, a task referred to as "flushing the lines." While nurses take charge of line care in the hospital, it becomes the responsibility of the caretaker upon discharge.

During the transplant itself (referred to as "day 0") new stem cells[2] are infused into the child in a process similar to a standard blood transfusion. As a medical technology, the transplant is sometimes seen as anti- climactic. There are no whirling machines or digital scans to show parents something is happening; instead, stem cells drip slowly from a bag of blood over the course of a few hours while children watch TV or even eat to distract themselves. In the weeks of that follow, families must wait patiently (and anxiously) to see if the body has accepted the transplant and if the donor cells will start to grow and make new blood cells, a process called engraftment.

On average, families remain in the hospital between 4 to 6 weeks waiting for engraftment. During this time, children are prescribed a strict regimen of antibacterial, antifungal, and antiviral medications to prevent potential infections that requires careful monitoring by a clinical team. Medications like Neupogen are taken to help stimulate new bone marrow cells to grow and ward off rejections. Absent complications after engraftment, the child is discharged from the hospital (typically around "day 30"). Since the child is placed on anti-rejection medication for months, however, the risk for infections continues for much longer and families have ongoing follow-up appointments in the hospital's outpatient BMT clinic to monitor the child's progress.

Complications are common during the engraftment process and even after discharge. The high doses of chemotherapy from preconditioning therapy wipe out the body's own bone marrow, and children's blood counts become very low. They are often dependent on red blood cell and platelet transfusions for long period of times. Chemotherapy can also lead to its own set of complications, such as Veno-Occlusive Disease (VOD) which affects the functioning of the liver, lungs and kidneys. Treatment for VOD requires additional medications, blood transfusions,

---

[2] Stem-cell donation involves a surgical procedure where special needles are inserted into the pelvic bone to withdraw liquid marrow (where blood-forming cells are made). Many find the process painful. Transplant recipients may find the best donor matches among other siblings, who may also be children. While a close match is celebrated, it is also important to note that donation can result in another child's medical procedure and requires additional difficult decision on behalf of BMT families. For those families dependent on finding a match from a volunteer BMT donor database, donation can also be a nerve-wracking experience.

and in severe cases, ventilators and dialysis machines. Secondary cancers can also be caused by chemotherapy or radiation given prior to the transplant.

Furthermore, since white blood cells are killed off, children are at high risk for several types of bacterial and fungal infections that can be life threatening. Pneumonias are common for several months after the transplant and can be difficult to manage in immune suppressed children. Treating a condition like Idiopathic Pneumonia Syndrome, for instance, can require a breathing machine, bronchoscopy (an invasive procedure where a periscope device is put into the lungs), chest X rays and CT scans. Cytomegalovirus, another common complication with BMT, is a virus that can cause severe infections in the lungs, gastrointestinal track or liver. Regular blood draws are given to monitor for such infections.

Graft versus host disease (GVHD) is a particularly dreaded complication that can affect up to 40-60% of some transplant patients. GVHD occurs when the stem cells (the graft) react against the body (the host). It can range from mild symptoms to a life-threatening condition affecting the child’s skin (itchy rash), liver (jaundice), intestines (diarrhea), lungs (scar tissue and loss of lung capacity) etc. GVHD can be an acute as well as chronic condition lasting for several weeks, months or even years. Several medications are used to prevent severe GVHD from occurring, including tacrolimus, which is started prior to the stem cell infusion. Prevention is key, so parents are tasked with careful monitoring of their child for potential signs of GVHD.

In this risky medical context, transplants not always successful and hospital stays can last much longer than the hoped for 30 days. Sometimes the transplant does not cure the underlying disease and the child experiences a relapse as those conditions return. Engraftment can also fail and new stem cells will not develop or mature. Sometimes patients will opt for a second (or even third) transplant following non-engraftment. In a number of cases following a failed transplant, however, children are classified as terminal. In such situations, knowing when to stop treatment and leave the hospital is a decision that can result in distress and conflict between clinicians and family members. Death and dying are part of BMT realities, but there is no protocol for giving up on a child’s life, and clinical opinions on end-of-life care are often resisted by determined parents.

The BMT Care Team

At Hemphill, each child remains under the care of one primary BMT physician throughout the transplant process, however, a large number of other clinicians and medical staff are also involved, first during the stay in the hospital and then again as outpatients in the clinic. A specialized “BMT Team” was comprised of medical professionals included physicians, nurse practitioners and nurses, physical therapists, dieticians, pharmacists, psychologists and social workers, among others. Some of these clinicians remain constant through a family’s stay in the hospital, while others rotate through the hospital ward every two weeks. In outpatient care, parents work with the primary BMT physician as well as other clinic staff such as physician assistants, nurse practitioners, and infusion nurses.

In the hospital, the BMT physicians and nurse practitioner used a small office staff room on the floor that was crammed with whiteboards, a large table, and several computer terminals. Here clinicians would gather daily to update electronic patient medical records, research treatment protocols, eat a quick snack between consultations, and gather to discuss difficult patient cases before rounds began. During daily rounds in the hospital, parents and patients would typically meet with a physician, resident and nurse practitioner to go over lab results, answer questions, and tweak the treatment protocol. Additional BMT clinicians and staff also attended rounds depending on what doctor/nurse was on call and what types of special services were needed by patients, such as dietitian guidance or pharmacy expertise.

The BMT clinicians, both in the hospital and outpatient clinic, come to know the patients, caregivers, and often their extended families very well. Several team members (including physicians) explained how important it is for them to interact with their patients and their families on a personal, as well as clinical level. Likewise, families often spoke positively about the clinical team and were generally happy with the level of expertise and commitment the BMT clinicians demonstrated to their children. Nurses, in particular, were often referred to “as family.” Indeed, along with performing medical tasks, the pediatric BMT nurses often assumed roles as teachers, advocates, and friends to both children and their families as they explained medical procedures, shared jokes, intervened with physicians and social workers on behalf of families, and generally bonded over the long hours spent in the hospital together.

The Role of the Parent-Caregiver

As noted previously, an adult acting in a designated caregiver role, is required to stay with the patient essentially 24/7 during the first 2 to 3 months following hospital discharge, or as long as medically required by the BMT physician. In fact, in this hospital no transplant is approved without a satisfactory and formal caregiver plan. According to hospital policy, it is acceptable for the caregiver role to be fulfilled by multiple people; however, usually only 1 or 2 people (almost always a parent) perform these duties for pediatric patients.

In the days before admission, the hospital also requires the caregiver to undergo an orientation where nurses educate the family on the BMT treatment process and any clinical trials in which the child is eligible to participate once admitted. Although this initial training is clearly important, its success depends on the ability of parents to absorb and process a large amount of detailed medical information before they gain first-hand experience with the clinical context. Further adding to the complexity of the situation, BMT is often a treatment of last resort and, as such, caregivers and their families often experienced heightened anxiety around their child's health, making it difficult to process and retain information at that time. Many caregivers, in fact, could not recall what clinical trials they had signed their child up for during this stage of the BMT process. A caregiver-mother, for instance, recalled that she and her husband had to make the decision of participating in a clinical trial very quickly after learning her son needed a BMT:

> "When we made a decision about being in a clinical trial it was right after we found out he was diagnosed…I know people told me a lot of this information, but like I said, you are already on information overload and you really aren't thinking as clearly as you might be able to at some points…and almost you are not capable at the moment… I think we had determined that we would just sign on for it and let God make the decision, but looking back, I do not think I had enough information on it and I'm glad it worked out like it did."

In the first year of transplant, much of the caregiver's time is spent in clinical settings involving visits with the BMT team and other specialists, various tests and procedures, and blood transfusions or other infusions. Once the patient is discharged from the hospital following transplant, much of patient care falls to the caregiver alone. Caregivers are responsible for managing medications, infusions and sometimes injections, following infection precautions, and adhering to strict dietary and lifestyle restrictions. Household routines must change and many typical aspects of family life with children is put on hold while the child's immune system is vulnerable. Arrangements must be made with school and employers, and social life is severely limited. The BMT treatment process can also put caregivers under a great deal of financial strain with families utilizing a mixture of private, federal (Medicaid) and state-funded insurance (a special insurance to cover the costs of acutely ill children). Community fundraisers are common occurrences for BMT families who use donations to help cover the wide-ranging expenses needed to supply additional housing near the hospital, travel, time away from work, as well as medical supplies like prescription medications or nutritional supplements.

In all, BMT is an exhausting experience for patients as well as for caregivers. The treatment is highly technical and physically demanding, which brings with it anxieties about understanding critical health information and how well one will be able to cope with pressing day-to-day concerns. There is also much uncertainty about the future and fear associated with these unknowns. In the following section, I discuss how the clinical BMT process is experienced by families during their hospital stay.

Hospital Days: "The life of having a sick child"

The hospital's BMT unit was centered around a busy nurses' station which connected two long hallways lined with private patient rooms. Each family had access to a small refrigerator, a bathroom with shower, a bedside stand with a few drawers, and a small closet. A large flat panel monitor (that doubled as a TV/video game console and interface for the hospital's inpatient portal system) faced the bed. Internet was available and families could even check out personal computers from the hospital to use if they didn't have their own. Every room also had a couch that converted into a small single bed for a designated caregiver to stay overnight. There were also spaces for families to gather, play, and relax during their stay in the hospital, including a transplant unit lounge and a meditation room, although most people stayed in their rooms.[3]

---

[3] According to caregiver interviews, the BMT unit at Hemphill had been recently renovated and the old hospital space had shared patient rooms. Interestingly, with the new private rooms, some of these interlocutors expressed regret in no longer having as much social interaction with other BMT families. Sharing rooms, for instance, enabled children to make friends with kids who shared the BMT experience, as well as enabled families to trade stories, tips, and information with one another about medications and treatments. At the time of my study, the formally designated common spaces in the BMT unit had not yet become everyday gathering spaces for BMT caregivers.

The first days at Hemphill Children's Hospital often elicit hopeful feelings among BMT caregivers. The transplant represents the chance for a healthy life for the admitted child. Many of the obstacles families have faced—from the child's chemo regimens to finding a willing and healthy donor match—have at this point finally been overcome. This cautious optimism for most families, however, was quickly tempered by the pressing cognitive, physical, and emotional demands that come with their new reality of living day-to-day on the hospital floor.

Due to the length of the inpatient stay, families are informed by BMT staff to expect considerable disruptions to family life. Caregivers are often separated from significant others and other children in order to stay in the hospital. This separation can last even longer if the caregiver needs to geographically relocate near the hospital while the child is an outpatient. At times, these household disruptions can be quite emotionally burdensome. A mother from out-of-state explained:

> "There's five in my household...We have two other kids, 17 and 15. So I'm leaving kids in the highlight of their high school year...I miss my husband, my older son, and my youngest daughter...Medical stuff ain't nothing."

It should also be noted that learning the "medical stuff" is far from trivial as it requires an in-depth knowledge of the healthcare system. Early on in their BMT hospital stay, caregivers described challenges in their communications with doctors who relied upon technical medical language. During rounds, for instance, one participant noted that doctors would speak "book talk": "All the fellows [doctors] would be all like book talk, 'Oh, your creatinine levels are at such and such.' I'm like, 'Excuse me?' They're like, "Liver is doing fine.'"

As caregivers lived on the hospital floor, they came to understand more medical terminology and gain confidence in communicating with and questioning clinicians. This confidence was especially important during rounds, a time when caregivers and patients met with the core BMT team to share information and get feedback on the child's status. During this brief daily interaction, caregivers felt the need to have questions formulated in advance in order to competently speak to the BMT clinical team. Participants likened this experience to preparing for class:

> "I suppose it's a learning curve ... We didn't know Day 1 what to track. And there are times we are just dead wrong. We were talking about cholesterol when LDH is not cholesterol, it's acid created by your muscles when they are injured. At the time, I was thinking …

> you know, one kind of cholesterol and then there is the other kind of cholesterol. Like, no, that is not what it is."

Clinical rounds happened each morning around 9:00 AM. In these early hours, the BMT unit was a hushed space. Rooms were dark with lowered shades, and parent's couch-beds still unmade from the night before. A group of clinicians would knock quietly and often walk in to find a weary mother or father, who had been up all night with a restless child, still in a bathrobe or with wet hair from a hasty shower. Sometimes the child would still be sleeping and everyone spoke in soft tones around the bed. The nurse would relay the lab results from yesterday's blood work to parents who were clutching at cups of coffee and would then mark the results on a personized BMT calendar hanging in each room. There was an intimacy not only in entering rooms where children lay exhausted and often in pain, but also through sharing the spaces where families were living (sometimes for months). Coming upon people in these domestic situations —disheveled and sleep-deprived, eating breakfast—contributed to rounds as a time full of awkward vulnerabilities, as well a shared moment of humor and a sense of bonding between clinicians and families.

The story of Eric, a teenage transplant patient, and June, his mother and caregiver, exemplifies how rounds allows clinicians and families to share important clinical information and work through emotional challenges that come with BMT hospital life.

Eric and June's Story

Eric's room is quiet when the BMT team comes in. In the dim light from a morning news program (muted) on the TV, it's possible to make out a lanky teenage boy cocooned in blankets in the hospital bed. On the team's arrival, June stands up from her couch/bed where she's been camped out overnight (blankets and sheets still rumpled). Hellos are quietly exchanged. For a moment, it seems likely everyone might all shuffle back out into the brightly-lit florescent hallway to talk, but then the unit's longstanding nurse practitioner, Alisha, an energetic woman who maintains a strong rapport with patients and families, suddenly flips on the light above the bed. Eric opens his eyes and groans dramatically. Alisha grins at him. Dr. Garcia, a hematologist-oncologist, chuckles: "Alisha, you are really tough."

With the light on, one can see Eric's room is decorated with the treasured possessions of a 13-year-old football super fan. Cristiano Ronaldo's Real Madrid jersey with a "number 7" hangs on the door and a big poster of Ronaldo caught in a mid-goal score is positioned on the wall next to a chart given to all the patients to keep track of blood counts. Alisha jokes about being able to take Eric on in soccer soon and gives her grief as the other BMT team members—physician, intern, and mother—watch the performance with a smile. It has quickly become an ongoing bit between Eric and Alisha since he came to the unit a week ago to receive a BMT to treat Hodgkin's lymphoma, a cancer of the lymphatic system. Eric's protestations cut through the atmosphere of anxiety: Alisha gives him a hard time and he plays the moody teenager.

June, gathering herself, updates the BMT team on Eric's appetite, pain and sleep patterns. She's kept a careful record of every treatment, symptom, and calorie consumed in a growing binder filled Eric's transplant information. June is concerned that Eric has been bothered by pain post-transplant: his bones hurt. "You don't know," she explains, "But he complains about it day and night." "Is this normal?" she asks the team.

Dr. Garcia explains that the aching discomfort Eric feels is a reaction to the Neupogen, a medication given to transplant patients that stimulates new bone marrow cells to grow. June asks about his blood cell counts, her pen hovering above her notebook to record the results. Alicia reports that it has risen and June smiles broadly. "The fact that he is in pain is a good sign," Dr. Garcia explains. "It means that the graft is working and the blood cells are reproducing. It's kind of a paradox. We are very happy with these numbers." Eric takes a big bite of carefully peeled banana and June carefully transcribes the new blood counts. Things are going well.

The next morning on rounds, the team finds Eric in a lot of pain again. Unlike yesterday, however, when the team left him sitting up eating a banana, today he is laying on the bed awake but zoned out. He has painful ulcers in his mouth and can't eat. Dr. Garcia puts on a pair of plastic gloves and gets a light to inspect the ulcers more closely. June watches nervously as Eric has a hard time opening his mouth. Dr. Garcia spots some ulcers in the back of his mouth and tells Alisha that they will need to be swabbed. She mentions to make a note in his medical record of herpes. Then Dr. Garcia asks June if Eric had canker sores. "No," June says, clasping her binder, "He had been doing well." Alisha interjects to ask if Eric *ever* had a canker sore even before coming to the hospital, to which June quickly replies: "Oh, yes!" Dr. Garcia tells Alisha to notify the pain management team coming in later that Eric might need his dosage altered and Alisha updates the electronic patient record using the computer system next to Eric's bed. "His pain meds are at one of the lowest levels," Dr. Garcia, explains to June. "The fact that he is awake and alert right now means that we can adjust his pain medications many times before he reaches the highest dosage." As the BMT team left everyone told Eric to hang in there and hoped he felt better soon.

Fluctuations

On the team's next visit, a week later, Eric is awake and joking with Alisha again. The mouth sores are gone and June reports on Eric's appetite and diet, telling the team what he ate that day. Alisha noted they could start weaning him off one of the anti-nausea medications because his appetite was coming back. June, however, is not convinced this is the right step. She asks Dr. Garcia if they could wait to take Eric off the medication because his appetite (while better than it was) is still not great. June finds it difficult to get him to consume enough calories since eating tires him out. "My stomach feels weird when I eat," Eric chimes in. "That might be because your stomach is small," explained Dr. Garcia, "It will get better." Alisha types a note into the patient record and tells June and Eric that the nursing staff will check back in with them during the day to see if his appetite was holding steady and they could make the decision then.

"Any other questions?" asks Dr. Garcia before the team leaves. "Can I go home?" asks Eric. Dr. Garcia smiles at him, "You are doing good. Keep eating. Let's see how things go."

This time on rounds, Eric is out of his room for physical therapy, but June is there waiting for the BMT team. Eric's blood counts look good, he is eating and managing his medications. The team wants to discharge Eric later this week, much earlier than expected because he is doing so well. He is scheduled to go to the emergency room later in the next day to get his port removed—a medical device inserted into the body to administer chemotherapy treatments and medications—a final step in preparing to go home. All looks well for hospital discharge as long as he doesn't get a fever. It's good news, but June still looks anxious: "Is it normal his weight is still fluctuating?" "When patients are released home, they tend to gain weight" Dr. Garcia reassures her. "We try, but hospital food is hospital food." "Have you been trained on home line care yet?" Alisha asks. June shakes her head no. Alisha tells June not to worry and that training will be scheduled with a nurse before discharge. "You'll have a chance to practice before you leave," she explains to June.

Postponed

The next day, however, the team finds Eric in a lot of pain again. He's spiked a fever overnight and won't be going home as hoped for. "Will we be able to go home for Easter?" June asks the team. "He wanted to be able to go home. We have all these relatives coming in from out of state for Easter." Dr. Garcia speaks to June and Eric gently: "Well, you might have to postpone Easter for a while."

Eric and June's story exemplifies how BMT families begin to adapt to their new daily existence of medication regimens, lack of sleep, and anxiety that make up their hospital life. Holidays, birthdays, and anniversaries come and go while in the hospital. A family whose child had severe GVHD described their "new normal" as a family disrupted:

> "This starts the sixth week of admission. The walk to the car is getting longer and the camaraderie with the nurses grows, because this is the new normal. The life of having a sick child, the life of a sick child."

As caregivers adjusted to life on the floor, they found ways of bridging the space between the social worlds of hospital and home. They talked to other parents over endless cups of coffee, connected to family with Skype, and learned the new routines and rhythms of the hospital. This adjustment, however, is often far from seamless. While clinicians were relied upon for their medical expertise, parents were experts in their children. Parent-caregivers occasionally pushed back on recommended clinical treatment protocols, especially as they spent longer periods of time in the hospital, asking for children to be taken on and off medications for a variety of medical and emotional reasons.

Going "Home"

When a child's blood counts rebound and the medical team deems the child ready to leave the hospital, it is cause for celebration, but also (as in June's case) a time of anxiety. Due to the extensive follow-up outpatient appointments, however, families must remain located within commuting distance. Even local families, however, never really go 'home,' at least as it existed pre-BMT. The child is now also a 'patient.' As mentioned, the transition between hospital and home also heightens anxieties for caregivers as they take on the routine medical work once performed by nurses in the hospital. Many caregivers described this anxiety:

> "It's just like when you have your first child, and when you first leave the hospital, it's kind of scary, but you've got your in-laws or your parents usually to fall back on. Well, you ... don't have that."

Although caregivers are trained by medical staff to perform routine tasks like cleaning incisions and doing IV magnesium infusions, caregivers often still expressed being overwhelmed because the risks were so real. The sentiment in the following quote was echoed by many parents:

> "I was just scared…scared that you are going to do something wrong. Am I going to remember everything that I have to do? What if I forget to do this and he gets sick, or I don't do it right? Those are the scary things."

Indeed, many caregivers mentioned they did not want to leave the hospital at first, uncomfortable about returning to their former life without the "backup" of the medical team.

Caregivers reported that their family life changed dramatically. Children who had the BMT procedure often had to be kept away from friends for fear of infection. One 8-year-old girl recalled that going home was a difficult experience after her transplant: "[C]ertain people could come in the room and everyone else had to stay out. They could talk to me through the screen door: "I love you from a distance." The risks of contracting a cold or the flu can make families overly cautious and wary of visitors. Another mother described how BMT impacted her relationships with family and friends after leaving the hospital:

> "Even when you go home you're kind of secluded, because we disinfected the whole house...you don't really have visitors. You don't have family over because they could potentially have a cold or a virus that they don't even know of...[I]t stays that way for like the first whole year."

Some parents take clinical guidelines to extremes out of fear or anxiety and become isolated from their previous social lives. The experience of being between social worlds may continue upon returning home as friends and extended family cannot grasp the new reality of the caregiver and patient.

CARING FOR FRAGILE CHILDREN

In this section, I turn to detailing the everyday activities parent-caregivers engaged in throughout the BMT process necessary for their children's welfare. Routine medical tasks, like monitoring for symptoms of GVHD, for instance, often required information work but also emotional labor. First, I discuss the various types of information work and emotional labor caregivers commonly performed in BMT. Then, I discuss the significance of seeing information and emotional work as inextricably connected through looking at BMT caregiver coping mechanisms.

Types of Information Work

Information work includes activities such as learning how to perform medical procedures, understanding and organizing medication regimens, tracking a child's diet, fluid intake, exercise, and bowel movements, interpreting blood counts, researching treatment options and medication side effects, and becoming adept at conversing with and questioning medical professionals. Caregivers described "following protocol" in relation to the various medication and treatment regimens as generally "overwhelming," even in the best of times. For the majority of caregivers, clinical protocols were viewed as important to understand and follow closely (often as a matter of life or death). As a mother explained: "Everyday we're still very cautious about, you know, follow[ing] what they tell us to do to the "T" or we try to at least. We don't want any setbacks." Parents expressed that this information work, especially in the initial weeks, took a great deal of attention, diligence, organizational skill, hands-on training and research into medical terminology so as to perform the necessary tasks.

Learning at the Hospital

The weeks spent living at the hospital during the BMT procedure was spoken of by caregivers as a rich informational experience. It was during their hospital stay that they learned the skills and knowledge needed to do medical tasks. While there were varying levels of training offered to caregivers before discharge, parents pointed to the informal education they received through watching and chatting with nurses day to day. One father discussed how he and his wife learned through careful observation: "I pay attention to everything, and my wife is the same way, with what they are doing…You just learn by watching, it's just repetitive nature."

Caregivers also received more direct instruction from clinicians. For example, many caregivers explained that they learned proper line care, medication regimens, and wound care through promptings and encouragement by the nursing staff. Sometimes the BMT team used medical models like fake skin to practice giving injections and a "Chester Chest" lifelike model of a human torso, for demonstrating insertion care and line work. Others shadowed nurses as they took care of their children. One caregiver explained how BMT nurses provided both her and her partner with hands-on line care training at the bedside of their son who had a catheter inserted through the veins in his chest.

> "Like with flushing his lines and stuff like that; you know, cleaning when he had his [port]…When we were in the hospital, the nurses … they were always asking, 'Do you want to do this?' They'll watch you and train you like right there. Changing the bandages and stuff."

Despite this hands-on training, parents struggled with retaining medical information when they left the hospital. For instance, another mother explained that remembering the proper steps for line care is a constant struggle:

> "Sometimes you might do something over and over. But when you get home, it's like you never did it before. Or it is so many steps, did I get it right? Even if you have it right, you just might want to make sure because you don't want to give your child an infection. It's like the biggest thing you think about: Am I doing something wrong?"

Anxious about getting any (potentially fatal) information wrong, parents utilized a wide range of information artifacts as educational support tools throughout the BMT process. Often, instead of referring to generic, hospital-provided orientation materials, caregivers relied upon informal documentation like graphs or charts created by clinicians during their hospital stay. For example, several participants showed me hand-drawn diagrams from a much beloved older BMT physician, Dr. Lambert, that resembled a kind of personal health infographic. The hospital staff jokingly dubbed these drawings "lamb-o-grams;" but they were treasured by families (see fig. 1). A mother explained how she preserved and saved several sketches drawn by Dr. Lambert from her early days in the hospital:

> "His diagrams were amazing. He drew everything out for my husband, myself and [son], and just laid it all out. I laminated his drawings…When I explained BMT to family members I would pull them out. It helped everybody understand it."

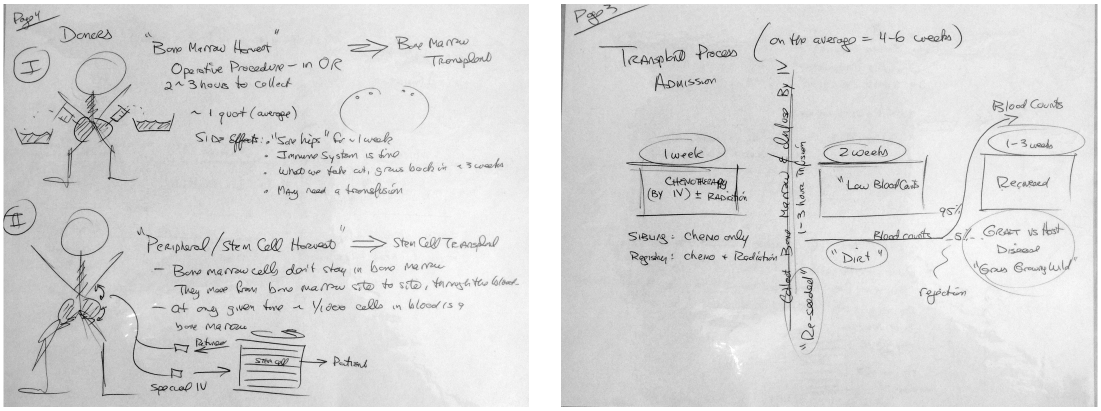


Figure 1:Hand-drawn educational diagrams given to a family by BMT physician. The family laminated the diagrams to save them and referred to the sketches throughout the child's hospital stay. The top diagram describes the process of collecting the stem cells for the transplant, and the bottom diagram provides a high-level overview of the transplant process itself.

These diagrams functioned as quick reference guides to their child's BMT treatment plan. In learning about the BMT process, contextualized information—be it in the form of charts, calendars, lists, spreadsheets or pictures—was similarly valued and used by participants to help educate and re-educate themselves about what to expect while undergoing such a medically complex and emotionally difficult treatment process.

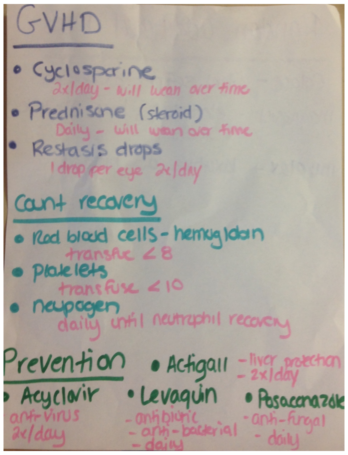
A common information challenge expressed by caregivers was learning to manage their child's medication regimens. Pediatric BMT patients were usually prescribed 15 or more medications and were required to take them multiple times each day. Close monitoring was required and, in preparing for discharge, parents were tasked with making sure they could properly administer medications orally and intravenously through a central line. Managing medication regimens was confusing and caused anxiety for caregivers leaving the hospital and oversight of the BMT clinical team. A caregiver-mother explained some of the medication challenges she faced in regards to her daughter:

> "She is on so many medications as most of these kids are. And it constantly changes as their needs change. Day-to-day it's different and I feel I'm constantly asking about that …I find myself writing it [new medication] down then looking online...She had dry mouth and that wasn't mentioned, so we had to ask: 'She's got dry mouth. What is that from? Is it from the transplant or is it from the medications?' We found out it was from the medication."

To manage medications, parents relied on a combination of observation, informal clinician tutorials and personalized information guides. Caregivers articulated designing elaborate organizational charts and routines to help them remember the ever-changing details of medication. Often this was done in collaboration with clinicians. For example, a father explained how nurses in the hospital trained him to administer his child's medication regimen so that he could continue to follow it when the family was discharged and returned home.

> "He [child] had like six or seven oral medicines to take each day; and so, they [nurses] made you do it. Well, they give you the option. They ask the parents to do it…. We had to do it at a certain time each day. Some of the pills were time-sensitive; some of them just were day pills. So that routine is what we still follow."

Along with learning a medication routine while in the hospital, he further described how the BMT nurses helped his family prepare for discharge by creating a short-hand list of types of medications that they could use as a reference (see fig. 2).



GVHD

- Cyclosporine
  2x/day - will wean over time
- Prednisone (steroid)
  Daily - will wean over time
- Restasis drops
  1 drop per eye 2x/day

Count recovery

- Red blood cells - hemoglobin
  transfuse < 8
- Platelets
  transfuse < 10
- neupogen
  daily until neutrophil recovery

Prevention

- Actigall - liver protection - 2x/day
- Acyclovir
  anti-virus
  2x/day
- Levaquin
  - antibiotic
  - anti-bacterial
  - daily
- Posaconazole
  - anti-fungal
  - daily

Figure 2: A medication list prepared by a BMT nurse to help a caregiver understand the purpose of each of the patient's medications. Note that this page also includes other clinical parameters describing criteria for transfusing red blood cells and platelets.

Charting and Tracking

Along with medication management and noting symptoms and side-effects, caregivers were also charged with tracking the patient's food, fluid, and even bodily emissions like urine and bowl movements. Parents also tracked of changes in a child's skin texture or color, sleep patterns, and energy levels. This information is clinically important, as transplant patients need to maintain specific caloric and fluid intake not only to avoid malnutrition and dehydration, but also to prevent complications, such as GVHD. One mother explained that the high risks of complications associated after the BMT require hyper-attention and discipline in tracking:

> "People don't die from the transplant, I feel like. I think a lot of times it seems like they have like the secondary things that come with it, the infections and all those things. It's very, very hard to be…not that I'm tooting my own horn … but it's hard to be disciplined in those things."

This type of discipline and training, though, begins in the hospital as caregivers are provided official forms to guide them through aspects of this work. For instance, one father-caregiver noted how he and his wife first started recording nutritional information for their son when he was an inpatient: "We had to write down what he was eating, how much he drank … In the hospital they dropped off a sheet every day, a nutrition sheet, and we just filled it out." When families return home, the responsibility of tracking is left solely to the caregivers. One mother noted that the labor involved with such detailed tracking is like a full-time job that she and her husband did together. They also noted that it became "a way of life":

> "It's almost like a job every day, because you're taking medicine four different times of the day, ... writing down what you eat every second, keeping track of, you know what I mean, everything! Even the water he had to drink, like two liters of water per day … We needed to track and make sure that he was going to the bathroom enough … It just becomes a way of life."

Many families spent considerable time and effort devising their own methods of tracking various BMT information using paper notebooks, excel spreadsheets and iPhone apps. One mother, whose teenage son and been in and out of the hospital for two years, shared her detailed organizational system for several binders worth of personal health data and BMT clinical research information she had collected on behalf of her son. One much-relied upon information artifact she created was a paper calendar (see fig. 3) to keep track of important medical events and medications, as well as significant personal milestones in the BMT process (e.g. going home).

Figure 3: A calendar maintained by a BMT parent-caregiver. It was used to keep track of multiple medications and other medical events relevant to their child.

In her personal BMT information system, a detailed list of medications, including names, routes, and days of administration, can be found at the bottom of the document. Other medications, as well as other procedures (e.g. platelet transfusion), are listed on particular days in the calendar itself. Importantly, complications with medications are also recorded, such as the five anti-nausea medications that were tried unsuccessfully by her son over the course of his BMT treatment.

Emotional Labor

People, not unexpectedly, experience a great deal of fear, anxiety, and stress throughout the BMT process due to the uncertainty of the procedure's success (e.g. child's ability to engraft new cells) and risk of potentially fatal complications (e.g. infections and GVHD). Caregivers often described the frustration, anxiety, and even panic they felt when trying to replicate medical regimens at home.

One overarching concern was not only remembering how to do line care properly, but also how to manage fear of possibly doing it wrong. Line care, as previously noted, involves cleaning the lines of the child's implanted port or doing IV infusions. "It was nerve wracking!"

was a common refrain among caregivers, especially in the first weeks home from the hospital. One mother tried to convey the risk involved in line care work. “It's scary,” she explained, “that line goes right into your child's heart… I'm not a doctor or a nurse, but you have no choice, so you do it.” A grandmother, who acted as a caregiver for her grandson a few days a week, struggled to remember all of the steps involved in line care. She expressed feeling at times guilty and inadequate for not being able to remember these important details: “It was learning how to do all that IV stuff. I was nervous, very nervous … I had a hard time remembering. It’s like he [the grandchild] had to talk me through it.” While many children (even teenagers) were content to let their parents perform many of these medical tasks for them, we also heard from parents who eventually encouraged their older children to participate or even take over line care for themselves. Relinquishing control of such critical medical tasks required families to negotiate care responsibilities with their children, as well as learn how to trust in their child’s abilities, and respect their agency in everyday care decisions.

Another major source of emotional labor was dealing with medication regimens. One often repeated difficulty was trying to get children to swallow the necessary large number of pills prescribed. Caregivers used expressions like “exhausting” and “hissy fits” to describe how time-consuming and emotionally draining these events were. For example, one father discovered his 7-year-old son hiding his pills because of the unpleasant taste and side effects.

> “So, we actually have to physically watch him take his pills. I don’t blame him, I wouldn’t really want to take them either. They don’t taste good ... I’m a blunt person, so I just told him, ‘You want to die? This is how serious it is.’ And he cried or whatever, but we still make sure we watch him take them and let him know how serious it is.”

Another caregiver-father echoed similar struggles with getting his 10-year-old child to take oral medications. He described this as a “battle” that could last hours. “I mean, literally…it would take 12 hours sometimes to get him to take his medicine,” he explained. “And it sucked. It sucked really bad, really bad. You don’t want to fight with your kid about anything.” Unable to get their son to swallow pills, the family tried liquid versions of the medication unsuccessfully before eventually resorting to the invasive placement of a Nasojejunal Tube, a medical device which runs from the nose into the intestines, that would allow them to inject medications.

All these daily trials appeared to feed into a constant anxiety for caregivers, especially as they contemplated the uncertain outcome of the transplant. As one mother of a 5-year-old boy explained, BMT caregivers must constantly navigate uncertainties:

> "The unknown. The most difficult part of the process, because it's a life or death process. And do you want to subject your child to chemo? And will your child survive? What type of complications will he face? Is it worth it? Do the benefits outweigh the costs? That's the most difficult thing, is the unknown."

Many parents noted they try to remain strong for their children and deal with their stress internally. When asked how she manages her life as a caregiver, a mother responded that she simply has not stopped 'going' since her son's diagnosis of leukemia 3 years ago. "I don't know how to answer that," she confessed in a shaky voice, tearing up:

> "I think God gives you the trials he gives you for a reason. This was just one I was made to handle. I mean honestly, I don't know…there are other parents that have cried on my shoulder…I just keep going. I don't know how or why…I don't know."

Many caregivers echoed the need to "keep going" and "put one foot ahead of the other." The experience of living with anxiety, fear, stress and near-constant exhaustion led to complicated feelings about information, especially during rounds or clinic visits. There were times, for instance, when caregivers didn't want to hear any bad news and were reluctant to ask too many questions of the clinical team. There are other moments, however, when caregivers dealt with "the unknown" through increased engagement in the clinical process. Parents were often legitimately concerned about prescribed drugs or curious about alternative treatments, looking to clinicians for both information and assurance. Despite their best intentions, however, the medical staff could not always offer the certainty that the anxious caregiver longs to hear. Maya and Yasmin's BMT story, detailed below, provides a deeper glimpse into the care complexities that face parent-caregivers and clinical teams as they seek to collaborate in managing medical uncertainties across different social worlds.

Maya and Yasmin

One Friday on rounds, the BMT care team stops in the hallway outside of a closed door with a printed sign that has 'Maya' written on it. Next to it, a neat handwritten note is tapped to the door, asking men to knock and wait for an answer before entering. Although the clinical team members all are women, they knock anyway, but find the room is empty. A floor nurse stops by to tell them that Maya is out getting tests. The team stays in the hall as Alisha, the nurse practitioner, runs through some of the medical details around Maya's transplant case: Five-year-old girl. Readmitted to hospital over the weekend due to ongoing medical complications from transplant 4 years ago. Maya has a GI track inflammation and possibly GVHD in her gut. The family returns every few weeks due to ongoing infections (blisters) in Maya's mouth and insufficient weight gain. Alisha notes that the family sometimes lances these blisters on their own which may contribute to ongoing infection. This weekend, the big concern is that Maya is not absorbing enough food and is severely undernourished. The family has made it known, however, that they don't want Maya to have a feeding tube put in. Dr. Garcia, the physician on call, shakes her head: "She looks like a little hundred-year-old woman."

Shifting feet on the hard hospital floor, the BMT team debates this being a case of "failure to thrive." "I just want to throw it out there," says the floor nurse to the group, cautiously, "But do we need a 3200?", referring to paperwork that must be filed with the state when clinicians suspect neglect of a child. Alisha vehemently rejects this idea, pointing out the family's diligence: "The mom is trying to keep her safe by consistently bringing her back to the hospital."

Negotiating the Protocol

Saturday, Maya and her mother, Yasmin, are both present when the team stops by on rounds. Maya's tiny frame is curled up in the middle of the large hospital bed. She lies very still. The TV is off and Yasmin sits on the couch waiting expectantly for the BMT team, blankets from the night before neatly stacked on the couch. Beyond the handwritten note still taped to the door, there are no personal effects or decorations in the room. This is one just of the many hospital visits Maya's family has had over the years to deal with an array of medical complications. To add to the complexity of the case, Dr. Johnson, Maya's primary BMT doctor who supervises her care post-transplant, can't be reached by the hospital today. The BMT team tries to figure out what his instructions are for Maya as he is very invested in her care and doesn't want the inpatient BMT team changing the protocol without consulting him.

In the confusion, Yasmin takes charge. She has prepared a list of questions in a notebook. As a large BMT team assembles around Maya's bed—Alisha, Dr. Garcia, and Peter the pharmacist—Yasmin tells them all that she is very concerned about the various antibiotics Maya has been prescribed this winter and their long-term side-effects. Apparently, Maya has suffered for months with chronic diarrhea and has no appetite. It has been an ongoing struggle for her family to get her to her to gain weight after the transplant, but recently she is getting smaller and smaller. Yasmin and her husband are scared.

As Dr. Garcia gently examines Maya, Alisha tries to capture her attention by making a funny face. Maya lays listless on the bed, unresponsive to both of them. Yasmin took a deep breath and faces the clinical team: “It is my feeling, my intuition, that all the antibiotics are not helping her diarrhea. Her body is worn out from all these medications. It has had enough.” Dr. Garcia nods and offers a solution: “Antibiotics can lead to diarrhea. We could have her eat yogurt with probiotics.” “No.” Yasmin is adamant. “I’ve given up with yogurt. I could only get her to eat 2 bites of it.” Yasmin presses on with her main concern, “What about the MRI results?”

Alisha looks up the lab results on the computer, but the test has come back with inconclusive results. “See!” exclaimed Yasmin. “All the tests are coming back negative. I don’t want to put her on more medications for things she “might have.” Peter, the pharmacist, jumps into the conversation: “The problem is that no tests are 100%...” “No tests are!” says Yasmin, visibly frustrated. “Not blood work! Not MRI! Not biopsies!” Dr. Garcia speaks calmly: “We would feel better if we try this antibiotic. It has a very low absorption; it coats the GI track. She would be put on a low dose once a day for a few weeks and we could test for absorption.” Yasmin considers her proposal and acquiesces. “Okay. But if this doesn’t work,” she tells the BMT team, “I am worried you will put her on another one and then another one.”

Peter nods as Yasmin speaks: “I am worried about that too. I will speak to Dr. Johnson.” At his words, Yasmin claps her hands together. “Will you?!” she exclaims, happily. “Thank you! He doesn’t listen to me when I start talking. It is like when I talk to my mother.” She moves her hands so they slowly pass by one another without touching. “I appreciate that he talks to me this way though,” she explained. “He doesn’t always listen to me, and if he thinks it is not right for Maya he says, ‘No.’ That means he cares.”

Building the Immune System

Maya and Yasmin are getting ready to leave the hospital on Sunday. Their bags are packed and piled near the door. The BMT team (today comprised of Janet the dietician, Dr. Garcia, Peter the pharmacist, and Alisha) smile as Yasmin talks about being home for dinner. Maya looks up from a puzzle she is playing with in her bed, livelier after a weekend with an IV of TPN (artificial food). "I can see my daddy?" she asks. "Yes," Yasmin responds to her daughter and the clinicians in general: "We need to go home. We are exhausted."

The conversation turns to how to best take care of Maya once she is discharged. The BMT team is concerned about her diet. Janet goes over some ground rules for preparing food. Yasmin nods having been through this before and then turns the conversation to supplements: "What about…I bought at the natural store, a mushroom supplement?" Peter quickly answers her query: "So, mushrooms can have nasty stuff in it, dirt and fungus. It can easily lead to fungal infection and those are really, really hard to treat. We ask that the patients not be exposed to any mushroom for at least 3 to 4 months after the transplant." Yasmin nods her head. "I also do an aloe vera and honey drink," she tells the team. "I know the honey has to be pasteurized. We used it before during chemo, but I don't know now if…?" Peter shakes his head. "Yeah, honey can be problematic," he cautions. "It's hard to find pasteurized honey. We'd recommend you stay away from it." Undeterred, Yasmin presses on with her list of questions, "I have special teas, too. I know you doctors don't believe in all of this, but I see her every day and her energy levels go up."

Peter looks relieved at this question: "Well, teas are usually okay because the boiling water kills off any of the problematic parts. But you should bring it in to show us." "Okay," Yasmin agrees before voicing one of her main frustrations: "It's just that you doctors give us all these medications, but there is nothing you give us to build back the immune system, to strengthen the immune system. I mean, why don't you study this as well?" Dr. Garcia, a researcher at Hemphill studying probiotics as a prevention for GVHD, jumps in to explain the clinical research process:

> "We do. We do. But clinically, a lot of the supplements you've mentioned have only been studied a little. They haven't been found to be clinically effective in building back the immune system. Some of the supplements can help the immune system of a healthy person, but the supplements can also have other stuff in them, and for the BMT, the best way is to let the immune system rebuild over

> 3 to 4 months on its own. Some of the stuff you find on the Internet, it has human growth hormone in it, and that can be dangerous because it can actually bring the tumor cells back. So, we ask that anything supplement-wise that you want to try that you bring it in so we can have a look at it. We know that it can be important to the families, I don't have a problem with it, but we just ask that before you take it you talk to us first."

As the visit wraps up, Yasmin thanks the clinical team for their help with Maya and gives them a homemade date and pistachio cake. Alisha hugs them both goodbye on the way out.

Despite the warm farewell, the consultation with the family has left the BMT team unsettled. Janet, who has worked with the family for a few years on dietary issues, reflects: "The mom is confused and afraid. She makes a lot of correlations that aren't medically accurate but derived in part by fear." Janet discovered, for instance, that Yasmin believes using TPN (e.g. artificial food) makes Maya septic, so now she is afraid to put her daughter back on TPN even though she is malnourished. "The mom has been dealing with this for 4 years and is tired," sympathizes Janet. "She wants a normal kid who can eat regular food." Despite her concerns, Janet maintains that she can help the family adhere to the medical protocol with attention and information: "I wish I could be by her side 24/7 and talk through each concern as they come up."

Peter has a slightly different take on the situation. Over his years working as a pharmacist at Hemphill Children's Hospital he's seen numerous families struggle like Yasmin and Maya. In particular, it is common for families to use various supplements and holistic treatments long before they get to BMT, especially during previous chemotherapy treatments. "It starts in the Peds HemOnc," Peter notes, explaining that the medical risks in the Pediatric Hematology/Oncology unit are not the same as with BMT. This causes confusion about what types of treatments are acceptable and what supplements pose a serious risk to immune compromised patients. One ongoing information challenge as a pharmacist is, then, to find out what types of home-based treatments families are using and tell them if it won't work for BMT. Importantly, however, Peter also accepts that many parents will always need to add something extra to the clinical protocol. "I think families want to do something," he reasons. "And some of the supplements are benign and others are very problematic. I try not to discourage it completely, because I think it has a psychological benefit. I don't want to take away how they are engaging, but I try to steer them to something that at least won't hurt the patient."

Given the uncertainties and high risks in BMT (Yasmin's frustration that no test is 100% accurate), people rely on many different care logics to take care of fragile children. In considering his experience with helping families manage a mixture of prescription drugs and supplements, Peter reflects: "It's funny. At some points they go off everything and just do the holistic stuff, but they come back and want the medications too. And it's never that the natural supplements didn't work; it's that they didn't work *enough."*

Despite the clinical team's considerable efforts and support, the information work and emotional labor of the BMT process takes a heavy toll on the caregivers and on the family as a whole. Many medical tasks—from medication management to treating chronic GVHD—require caregivers to collaborate closely with a team of clinicians and learn much of the specialized language of medicine and the technical practices of care. This is anxiety producing and requires a great deal of effort. Even after becoming semi-fluent in the clinical processes of BMT, however, caregivers can experience ongoing frustrations with the limitations of biomedicine.

As highlighted by Yasmin and Maya's story, caring for fragile children is a risky medical project and the BMT treatment process can begin to feel like a series of endless corrections to an ever-shifting protocol. Lab results often are inconclusive and treatments to fix one pressing medical complication have their own troubling side-effects. Likewise, holistic therapies and cultural health practices, while giving parent-caregivers much needed sources of hope and spaces for agency, also don't work *enough*. Yasmin and Maya's experience points to the sociotechnical complexities in supporting caregiver engagement when a child is critically ill. In this context of vulnerable children, engagement is not a straightforward process of information transfer from clinician to parent nor a rejection of biomedical expertise, but rather a negotiation between multiple care practices, each with their own logic. Supplements and special teas; blood work and biopsies: each plays a critical part of care work.

Yasmin and Maya's story also demonstrates the limitations of biomedicine are not only a challenge faced by caregivers, but for clinicians as well. Close collaborations with families led to thorny clinical (and ethical) questions: When to provide families with guidance and support; and when to intervene and stop parents from potentially dangerous care practices? As with Yasmin's grudging approval of Maya's skeptical doctor, care sometimes needed to be expressed as 'no.' Other BMT situations were less clear-cut. Families whose children were dying, for instance, often embraced forms of care work that were unsettling to clinicians by operating outside of protocols. One mother with a two-year-old child who had two failed transplants, told about how the doctors eventually ran out of treatment options and sent her son "home to die."

Without clinical treatment options, families looked to holistic therapies and alternative medicine, such as medical cannabis growers, energy healers, and massage therapists and chiropractors to treat children and manage care on their own. Instead of relying on doctors, they heeded the recommendations of family members and friends and crowdsourced advice among networks of parents with critically ill children on social media. They did so to find management strategies and potential cures for their children's end-of-life challenges, including pain management, sleep problems, and lack of appetite. While some clinicians were skeptical of these care practices, others nurses and physicians were supportive, understanding a families' need to exhaust every possibility in the pursuit of a cure.

The possibility of death was an underlying, although largely unspoken, part of the BMT experience for caregivers. Most parents opted to be relentlessly positive about treatment progress for their child, adopting the language of 'fighter' and 'survivor.' When one caregiver's son experienced a failed transplant, he opted for transparency with his child. He also noted, however, that some parents didn't even tell their child they had cancer: "I have met parents that absolutely didn't even tell their child what was going on" A long-time BMT physician, Dr. Lambert, noted that some parents adamantly refuse to have the clinical team mention the 'the d-word' in front of their child, even at the end of life; and yet; he maintained that helping these families process the probabilities of death was an essential part of his clinical responsibilities. After walking through the halls of the BMT unit on rounds on day, he somberly shared with me that many of the children we had just visited, particularly those with complex, chronic complications would most likely die within the next few years. While BMT has high success rates for particular types of cancers and blood disorders, he outlined the limited treatment options they have as physicians when engraftment never comes or children relapse: (1) a second BMT transplant; (2) more chemotherapy; (3) BRM (biologic response modifiers) or immunotherapy; and (4) a depressingly empty category of "other," that might be filled one day by a successful clinical trial. Sometimes sending a child home to die is seen by parents to be needlessly cruel; however, Dr. Lambert sees another type of cruelty in needlessly extending a child's stay in the hospital. He has witnessed children go through (often painful) therapies and treatments, for instance, because they don't want to upset or disappoint their parents who can't deal with the possibility of death.

Along with taking on the pressing information work and emotional labor that came with performing daily medical activities, caregivers weighed and wrestled with ongoing concerns about future outcomes. The management of continuous anxiety is an important part of the lived experience of caregiving. I now describe the various coping mechanisms caregivers relied upon to get through the BMT process.

Making Coping Mechanisms

Coping was a widely recognized as an important part of the caregiver experience at Hemphill. There were professional resources at the hospital dedicated to helping families navigate a wide range of stressful situations. Social workers and physiatrists on the extended BMT care team, for instance, routinely helped parents try to find healthy ways of managing common challenges, such as: pressing financial burdens, lack of family understanding and support, guilt, future losses such as a child's infertility from chemotherapy, depression and anxiety issues, as well as discussions of death and dying. Figuring out coping strategies was an element of the hospital's formal caregiver plan, such as having a back-up plan and building a network of community support.

Many parents found that talking with other BMT caregivers was an important part of learning how to manage the life of having a sick child. Informal networks of peer-support formed at the hospital or clinic as caregivers chatted with each other in the halls or waiting rooms, sharing stories and offering advice to one another. One father, whose daughter had a bone marrow transplant, recounted how friendships with other BMT families helped his family adjust to life in the hospital. "How do you survive the hospital room for months at a time? They said, 'Oh, this is how you can survive at the hospital," he recalled. "Because they had been here … like buckets of toys by the windowsill." This father also spoke about the close personal relationships forged with other caregivers who shared similar risks in going through the same treatment: "Even across diseases, making friends with families and knowing where they're at and their struggle…you know everybody, and know who's dying and who's not dying." Coping, as described here, was a social activity, both in terms of dealing with the mundane stresses of cooped-up children, and in sharing the heartbreak of transplant failures and engraftment complications.

Along with offering emotional support, caregivers also tried to help each other manage "the unknown" by sharing their experiences with particular medications or information about medical procedures. One father spoke about how after their children bonded on the hospital floor, his family came to rely on another caregiver-mother, who was also a trained nurse, as a trusted guide to the medical world. "And so, while the kids play Legos," he explained, "mom and dad sit and talk:

> "What drugs your kid on? Watch out for Reglan [type of drug]! You know, Don't ever let any family member get Reglan. Why? Well the old docs love to prescribe it, but it can destroy your bladder."

In this way, some families helped one another manage the overwhelming information work, but also distribute the burden and responsibility of asking all the right questions and knowing when to challenge clinical protocols prescribed for their children.

Parents who were not socially inclined found other ways of coping. One form of information-based coping involved caregivers performing tasks that exceeded the already rigorous clinical recommendations. A few caregivers, for example, spoke of doing extensive remodeling to their home. These families installed new flooring, repainted, and threw away furniture in an effort to eliminate germs, mold, and dander that might negatively impact their immune-suppressed child. One mother of an 8-year-old patient described her cleaning regimen as "extreme" noting that she and her husband researched extensively how to minimize risk of infection on the Internet and "ran with it."

> "We might be extremist... [We have] no carpet in our house, no fabric curtains. I mean, if there was anything that could be done, that's what we did…And I think we took every bit of information that we found and we ran with it. You know, new furniture, nothing on the walls. I mean, I washed the walls every day; there was no dust. It was insane."

As the interview progressed, the same participant noted that this flurry for research and cleaning also reflected her family's emotional state, noting, "Maybe that's how we coped … I think it's probably a coping mechanism for us, now that I think about it."

Many parents also took on the role of a biographer of their child's medical experience. Along with capturing images and videos of their children visiting with relatives or celebrating a birthday in the hospital, caregivers also often took photographs related to medical procedures from transplant itself to routine line care activities to bags of blood and pill containers. Other common subjects included documenting potential medical problems like a rash on the skin. Many parents also noted how they routinely collected and shared clinical information artifacts, from photographs of a nurse's scribbled notations of a patient's blood work counts on a white board to a doctors' hand-drawn diagram of GVHD, through blog posts, Facebook page updates, and various social media. Often these information artifacts were deeply meaningful to the caregivers and their families as testaments to particular moments of triumph or loss. These artifacts have a practical importance, but their symbolic nature was critical to caregivers. Indeed, there were many small, ritual-like interactions with information artifacts in much of the caregiving work performed by parents.

One coping ritual that highlighted the deeply symbolic nature of information in the context of BMT is the hospital's "Hope Beads" program in which children, caregivers and their families are given a set of beads to make a personalized BMT memento (see fig. 4-5). Each style of bead represented a different type of medical activity, important person, or life event; and in stringing them together, families created a symbolically-rich information artifact that represented their "BMT journey." On rounds, I met a young mother staying in the hospital who had recently used the hope beads to document her infant son's BMT experience. Holding up the long strands of multi-colored beads, maroon for blood transfusions, crystal for IV treatments, and glow-in-the-dark bead for radiation therapy, for me to see her work, one saw medical data take on new form and meaning. On a practical level, the beads gave her something to occupy her mind with during the long days. Creating a material manifestation of her child's protocol, however, also emphasized just how much pain and prodding this small body had endured in a few weeks of life. The hope beads connected information work and emotional labor in an embodied representation of care itself.

Blood Draw/Transfusion	Maroon Bead
Chemotherapy	Yellow Bead
School	Lime Bead
Radiation	Crystal (clear) heart
Bone Marrow Asp	Root Beer Bead
Going Home	Ceramic House Bead
Favorite Staff	Ceramic Smiley
Coping Technique	Baby Blue Heart
Breathing Treatment/Oxygen	White Bead
IV	Crystal (clear) Bead
Oral Med	Glitter Gold Bead
NG/G-Tube	Purple Bead
Pokes	Crystal (Clear) Blue Bead
Radiology	Glow in the Dark Bead
Good Day/Difficult Day	Yellow/Black Bead
Port/PICC Access	Shiny Pink Bead
Chest Tube	Star Bead
ER/Ambulance/Survival Flight	Glitter Green Bead
Heart Cath	Pink Heart
Surgery	Ceramic Rainbow
Birthday (in hospital)	Ceramic Happy
Intubation/extubation	Dark Green Bead

Figure 4: Hope Bead key given to parents and children in the hospital. Medical procedures, life events and BMT milestones are represented with different types of colored beads.

Figure 5: BMT beads as information artifact and coping mechanism. Blood work here is represented by red beads.

Information, transformed into a coping mechanism, led to parents create extreme protocols, but also a wide range of BMT artifacts. Some of these types of caregiver practices were often not well understood by clinicians, who were concerned about parents misunderstanding clinical guidelines or "going too far." Others were viewed as therapeutic, providing parents with an opportunity to create new meaning out of clinical information.

In this section, I have shown through the various stories of transplant families, that the caregiver experience of BMT is quite different from that of the clinicians', even when medical tasks are collaborative in nature. While nurses trained parents in line care and medication regimens, this clinical information was transformed through caregiver engagement, taking on new material forms and meanings. Importantly, for caregiver-parents, information work and emotional labor were inextricably connected. As exemplified by varied uses of caregiver manuals and medical devices, sketches and patient records, beads and calendars, health information took on a heightened significance for parent-caregivers in the process of making medical decisions and following treatment protocols that might save their child's life.

Along with the types of caregiving activities described in this section, the complex sociotechnical nature of care work is most clearly visible in the emotionally-laden rituals developed around blood data. In the next section, I examine the blood work practices among

BMT caregivers as an important site of caregiver engagement and discuss the specific materialities and multiplicity of logics that go into producing and interpreting bone-and-blood information. I then reflect on several design challenges in digitally representing clinical information like blood data in the context of caring for fragile children.

BLOOD WORK: CAREGIVING MATERIALITIES AND COMPETING LOGICS

One of the most important types of information discussed during hospital rounds are the lab results that provide daily blood counts, the clinical data which are used to track engraftment and determine the ongoing success (or failure) of the transplant. The daily routines of blood work highlight its central organizing role in the life of the BMT unit. During rounds, for instance, caregivers eagerly wait for doctors to share their children's lab results. Blood counts were typically hand-recorded by the BMT team on a large, hospital-issued calendar that is hung in each patient room and personalized with the child's name across the top. Most caregivers also routinely tracked and recorded blood count data on their own, creating home-made information artifacts such as spreadsheets and lists. It was also common to see families posting regular blood work updates and sharing photographs of lab results through social media. To explain how significant blood work is on the hospital floor, a BMT caregiver explained, "Every person's day revolves around blood products."

There are several informational and emotional challenges that come with this tracking of blood data. Blood counts for BMT patients can often go up and down significantly throughout the treatment process in a matter of days for a number of clinical reasons. Despite the medical complexity for this fluctuation, rising blood counts typically indicate to a caregiver a positive trend that the BMT treatment is working. If blood counts are lower than expected, however, caregivers and children alike often experience tremendous anxiety waiting for the next round of tests to bring better numbers. The BMT team tried their best to caution families to expect these ups and downs; nevertheless, the clinical context for interpreting blood counts, while critical, was often poorly understood by caregivers and their families.

The hospital's BMT training program and caregiver booklet provides information on blood work to help educate families about what to expect, including basic definitions for common medical terms and tests. This information, however, is given to caregivers upfront at the beginning of the BMT process when many parents are too overwhelmed to process it.

Furthermore, as a general introductory guide to BMT, the information provided by the hospital is often too general to be useful for parents in figuring out the questions that arise in a day-to-day hospital setting. One mother, whose daughter had recently started the BMT process, shared that she didn't always understand what the platelet counts meant for her child:

> "The platelets are confusing to me sometimes. Now over the last few weeks over 50,000 is where they [doctors] like her to stay at. But before then, I probably wouldn't know. All the numbers are confusing…They give you paper, a lot of paperwork, but I'm pretty sure a lot of parents don't go through all the paperwork. I didn't. I kind of skimmed through it and read what I think is important."

Caregivers mentioned they were sometimes cautioned by clinicians not do their own research, such using the Internet to look up laboratory blood tests, because it was difficult for lay people to understand the types of clinical information doctors were looking at in regards to the specificities of their child's case. A father explained that he relied on the BMT team to provide him with the necessary information he needed on his son's blood counts:

> "I've been told don't go online. There are so many different outcomes and you might be getting too much information that you don't want to. I think if I went online I would just keep reading and of course they go into 'this could happen' a lot of times, the prognosis and that."

Given the complex treatments and unpredictable complications in going through a transplant, many caregivers were content to be given enough information that they were knowledgeable, but not so much that they had to deal with additional information work and unnecessary anxiety.

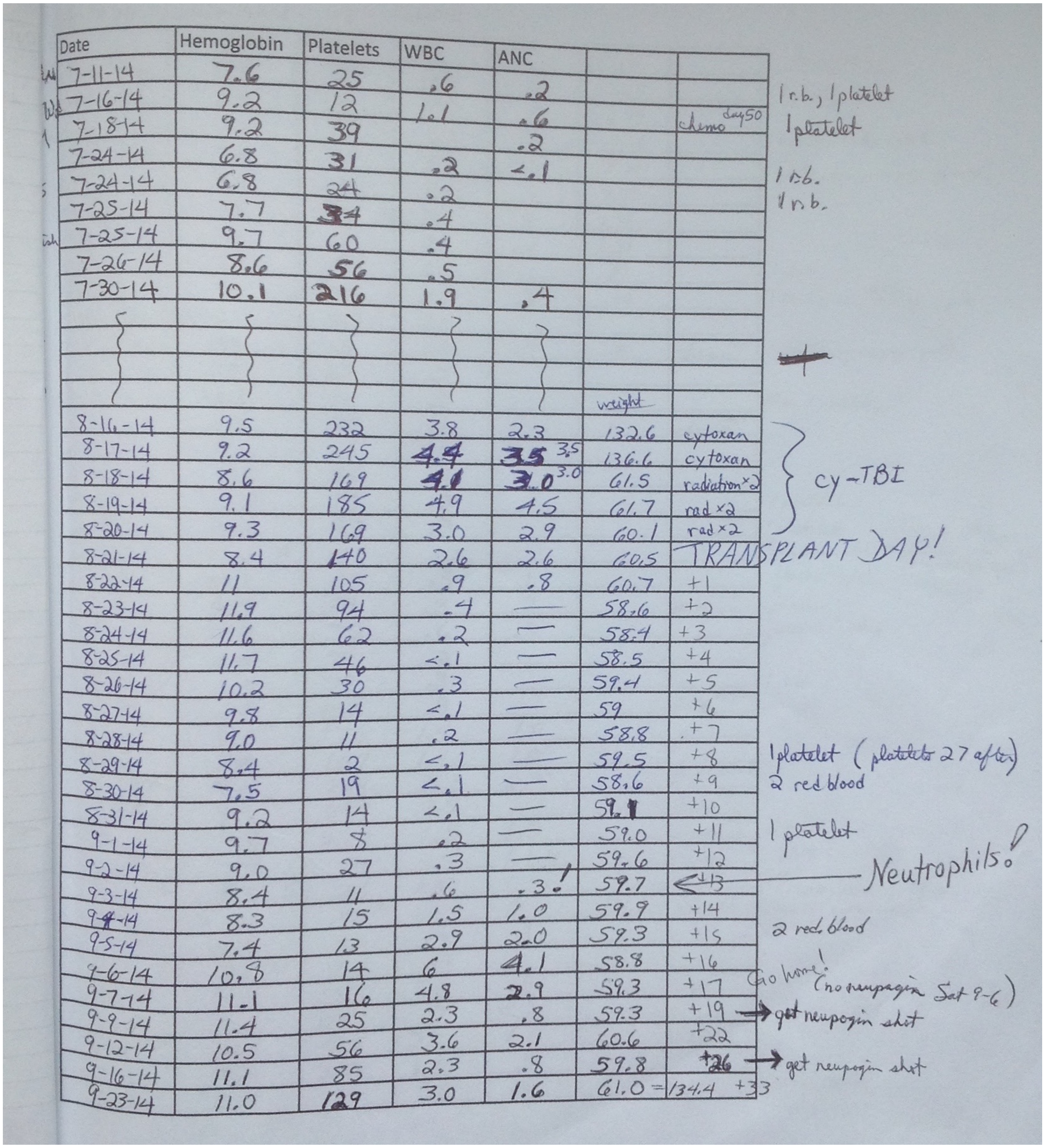
Despite such warnings, there were a number of other families who sought to learn every detail about blood work and became adept at interpreting lab results. Many of these information-seeking caregivers would petition nurses on the floor to share the laboratory results as soon as they came in (even in the middle of the night); question doctors about clinical data; comb through PubMed for new research on clinical trials; and sometimes look for supplemental treatments to add to the clinical protocol. Such activities were rooted in a range of personal impulses; for instance, some parents expressed a curiosity in the science of biomedicine, while other families viewed vast knowledge of BMT as a part of being responsible caregivers and advocates for their children in the medical system.

With a fragmented clinical understanding, however, blood work took on multiple meanings for caregivers. A father-caregiver explained that he has been keeping track of his daughter's blood counts from the beginning of her BMT treatment. While he doesn't understand the clinical significance of the data, his interest is in how the blood counts correspond to the types of treatments his daughter will need.

> "I just look at how it is trending mostly. And do I understand the details of that? No, not really. I know they [clinicians] think about infusing platelets if it gets, I think, at 10 or something. And [she/daughter] needs Hemoglobin at 8. So, when I'm recording things, I record if [she/daughter] had any infusions or a Neupogen shot to stimulate the white blood count. … I don't know what that means exactly."

The various infusions, transfusions, and shots can cause physical as well as emotional discomfort for children. Caregivers used blood data to prepare their children for unpleasant procedures that might result in a long night; or conversely, plan a special activity if the child is feeling well after a transfusion. One mother articulated her experience of blood work was connected to a finely-tuned sense of her son's well-being: "I pay attention to everything that is done with him, every movement…Any bruise, any mark, you know, he doesn't even have to have labs done for me to tell you if his platelets are low."

Above, I showed that information was infused with emotional work. Blood work also highlights that information, in the context of BMT, is always a material matter for parents. The physical nature of the medical technologies that produced blood counts—the embedded ports, daily drawing of vials of blood and weekly transfusions—takes a substantial toll on children's bodies. Blood counts tell many stories to parent-caregivers. Sometimes a child's bruised chest will make a parent question the treatment protocol and other times it will persuade a caregiver to press for a cure so that their child's suffering was not in vain. Importantly, the multiple meaning(s) of clinical data, for BMT caregivers, were bound up in these material arrangements of care. In this way, blood counts for caregivers are not only clinical facts or representations of medical complexity, but sites of emotional labor: the matter and means for caregiver engagement.



Date	Hemoglobin	Platelets	WBC	ANC			
7-11-14	7.6	25	.6	.2			
7-16-14	9.2	12	1.1	.2			1 r.b., 1 platelet
7-18-14	9.2	39		.6		chemo day50	1 platelet
7-24-14	6.8	31		.2			
7-24-14	6.8	24	.2	<.1			1 r.b.
7-25-14	7.7	34	.2				1 r.b.
7-25-14	9.7	60	.4				
7-26-14	8.6	56	.4				
7-30-14	10.1	216	1.9	.4			
					weight		
8-16-14	9.5	232	3.8	2.3	132.6	cytoxan	
8-17-14	9.2	245	4.4	3.5 3.5	136.6	cytoxan	
8-18-14	8.6	169	4.1	3.0 3.0	61.5	radiation×2	cy-TBI
8-19-14	9.1	185	4.9	4.5	61.7	rad×2	
8-20-14	9.3	169	3.0	2.9	60.1	rad×2	
8-21-14	8.4	140	2.6	2.6	60.5	TRANSPLANT DAY!	
8-22-14	11	105	.9	.8	60.7	+1	
8-23-14	11.9	94	.4	—	58.6	+2	
8-24-14	11.6	62	.2	—	58.4	+3	
8-25-14	11.7	46	<.1	—	58.5	+4	
8-26-14	10.2	30	.3	—	59.4	+5	
8-27-14	9.8	14	<.1	—	59	+6	
8-28-14	9.0	11	.2	—	58.8	+7	
8-29-14	8.4	2	<.1	—	59.5	+8	1 platelet (platelets 27 after)
8-30-14	7.5	19	<.1	—	58.6	+9	2 red blood
8-31-14	9.2	14	<.1	—	59.1	+10	
9-1-14	9.7	8	.2	—	59.0	+11	1 platelet
9-2-14	9.0	27	.3	—	59.6	+12	
9-3-14	8.4	11	.6	.3!	59.7	← +13	Neutrophils!
9-4-14	8.3	15	1.5	1.0	59.9	+14	
9-5-14	7.4	13	2.9	2.0	59.3	+15	2 red blood
9-6-14	10.8	14	6	4.1	58.8	+16	Go home!
9-7-14	11.1	16	4.8	2.9	59.3	+17	(no neupogin Sat 9-6)
9-9-14	11.4	25	2.3	.8	59.3	+19	→ get neupogin shot
9-12-14	10.5	56	3.6	2.1	60.6	+22	
9-16-14	11.1	85	2.3	.8	59.8	+26	→ get neupogin shot
9-23-14	11.0	129	3.0	1.6	61.0 =	134.4	+33

Figure 6: Tracking a child's blood counts by a caregiver-parent. Many of the numbers have additional annotations recording notable events (e.g. TRANSPLANT DAY!) that occurred at the time of recording.

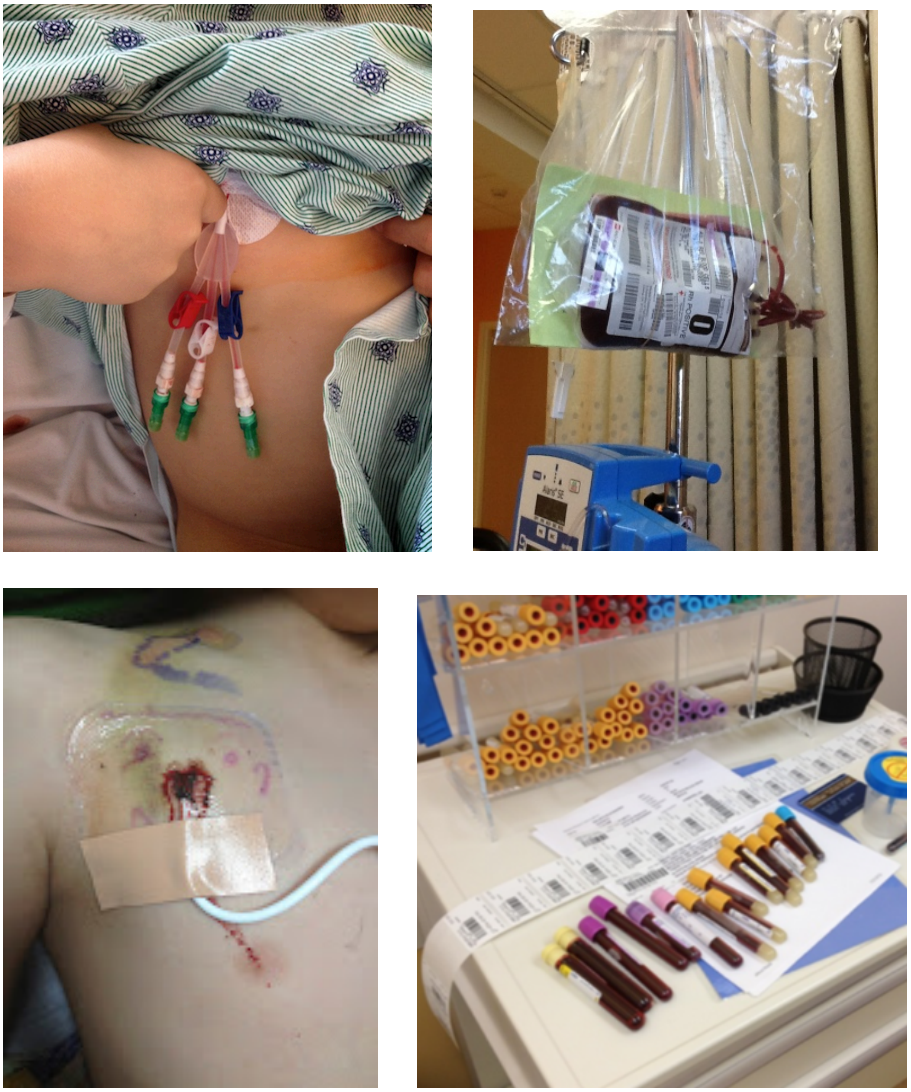


Figure 7: Materialities of blood work in the hospital. The top left image shows a central line with multiple sites for blood draws and treatments. The bottom left image also shows a child's central line that has become infected. The top right image is a bag of stem cells used during a BMT transplant; the bottom right image shows an array of test tubes of blood with different colors tops indicating a variety of hospital lab tests, including daily blood counts and clinical trials.

Martin, Beth and Oliver

Martin and Beth's caregiving experience illustrates how parent-caregivers interpret blood counts in practice, and also highlights what is at stake for families engaging with clinical data. After watching their 10-year-old son, Oliver, go through two transplant rejections and spend multiple birthdays in the hospital, however, they found themselves weighing clinical data and recommended protocol against Oliver's deep desire for a "normal life." I recount this family's BMT story, one of three transplants and countless hard decisions.

During Oliver's first transplant, Martin and Beth (his parents) had started out full of optimism for the procedure, learning complex medical terminology with enthusiasm and following every detail of the clinical treatment protocol to the best of their abilities. Martin researched countless clinical studies online and used his engineering background to dive into the data, creating spreadsheets to track possible correlations between blood counts, treatments, and his son's symptoms. Beth took on the job of documenting every lab result, keeping meticulous records of the Oliver's BMT journey and sharing them through their social media accounts. Her Facebook posts tracking the counts during Oliver's first transplant were hopeful. A typical post in these early days included celebratory exclamations:

> Counts are doing great (we are expecting the decrease in WBC and ANC due to lack of Neupogen, and now steroids)!
>
> WBC: 6.3
>
> ANC: 4.3
>
> Hemo: 8.3
>
> Platelets: 50 (WOOT!)

As the weeks in the hospital continued, however, Beth's posts on his blood counts grew more subdued as the counts did not grow as quickly as expected. Sometimes Beth annotated the lab reports, providing extra information for family members who were following her updates to explain the clinical data. For instance, Beth began to note the impact of various medications and treatments on the blood counts:

> Even through these myelosuppressive medications, Oliver's counts are doing well.
>
> WBC 3.9 (fine)
>
> HGB 12.6 (good)
>
> PLT 48 <- got transfused on platelets today
>
> ANC 3.0 (fine)
>
> Lymph 0.4 (great, we want these low to reduce gvhd)

After weeks of waiting, however, engraftment ultimately failed. The family quickly decided to pursue a second transplant. This time, however, Oliver quickly had a number of complications, including GVHD. They shared the toll waiting on the numbers was taking, both on their son and larger family:

> "He's had a lot of complications along the way. His numbers aren't coming up like they should. We're here longer than we expected… We're just waiting for the numbers to come up. That's the hardest part is the waiting. The waiting and if it's going to happen."

All the information they had gained from the first failed transplant provided a clinical explanation for Oliver's blood cell counts going up and down but did little to lessen the emotional challenges that came with waiting for engraftment. This time, even when Oliver's labs would come back in the middle of the night, the BMT floor nurse would immediately walk in to their room with a printout of the results. "She'd know Emily and I wanted a copy," explained Martin. "She'd hand us the labs. If we had questions, we'd ask her."

As Oliver's medical complications continued, the tests multiplied. Every day he got blood drawn. "There's time periods during transplant that you're getting labs three times a day," recalled Beth. "Let's also be clear about that, at least for us, they were just terrible, terrible times." Living hooked up to various BMT technologies and medical machineries at times felt unbearable for Oliver. Suffering from severe GVHD in his gut, he wasn't permitted to eat food. At night, he tossed and turned restlessly while 14 pumps hung from his IV pole, dispensing medications, TPN-liquid (artificial food), and blood transfusions. "All of the machines," Oliver shared, "I couldn't sleep with the lights."

During rounds, a sleep-deprived Beth and Martin questioned the doctors rigorously about the blood counts. Martin worried it was taking longer for the transplant stem cells to graft because Oliver had such trouble with chemo in getting his own cell numbers down to an acceptable level. Dr. Garcia explained that there was no clinical correlation between the two but could offer few assurances about Oliver's engraftment. Beth often referred to her detailed research notes and quizzed the nurses to make sure they would "wash" platelets[4] before Oliver's blood transfusions. Alisha reassured her each time that the order was put in correctly. Despite Beth and Martin's close collaboration with the BMT team Oliver's counts continued to fall and

---

[4] "Washed blood" refers to red blood which have most of the plasma, platelets and white blood cells removed and replaced with an electrolyte solution. Plasma contains substance that may interfere with antigen-antibody reaction.

the family experienced their second failed engraftment. Martin and Beth were devastated. They spoke with the clinical team somberly about Oliver's options (another transplant) and went home to let their son experience some of the rites of childhood: playing with friends, being with family, and going to school. Eventually, however, Oliver decided he wanted to pursue BMT one last time. As Martin explained:

> "The first two transplants were really, really difficult. We went through a lot to decide to do the third. Oliver was prepared to die. He knew the ramifications of not having the third transplant and would rather have died then go through that. But then he got a taste of school and wanted nothing more than to go back to school, even if it was for a short period of time. And so, we did the third transplant ..."

Coming back to the hospital, Beth and Martin took a radically different approach to the third transplant. They decided to let their son live as full of life as possible, even if his blood counts weren't "good." Although Oliver was still severely immune compromised, they refused to completely isolate him from friends and family like before, and they allowed him get a much longed for dog as a pet. Sometimes these family care decisions led to conflicts with the BMT team:

> "They [Oliver's doctors] told us we couldn't have pets because it would cause an immune system problem. But here you have a child who has a 6% chance at living, and the docs just sent him home and said, 'You can't go to school, and we don't know when you will be able to because you are so immune compromised.' And so, what do Mom and Dad do? ... We got a beautiful German Shepherd dog ... He's just the best dog ever and my son's best friend ... And we haven't had any problems."

This time the transplant worked, although Oliver continued to struggle with chronic GVHD. Beth updated Facebook posts to celebrate Oliver's new blood counts, noting that his platelet counts were the highest they had been in two years. Martin semi-jokingly credited the family dog with raising Oliver's counts in giving him a reason to live. As Martin reflected on his family's transplant experience, he viewed BMT as a seasoned caregiver, but also as a parent. While the doctors' interpretation of clinical information continued to be important in making decisions about the management of his son's health, it did not necessarily trump a father's concerns for his son's pain and loneliness. As Martin summed it up: "The human perspective versus the textbook perspective is two very, very different things."

As demonstrated by Martin and Beth’s ongoing engagement with blood data, care in a critical health context like BMT is never solely clinical; rather, it is grounded in moments of life and death, sleepless nights in the hospital, the frenzied washing of walls, a child’s bruised body, and the ritual archiving of blood counts. The practices of caregiving for those in the pediatric BMT unit was fundamentally tied to the experience of being a parent. Caregivers, especially those who have had years in and out of medical facilities, spent considerable time reflecting upon how different treatments affect their child, not just medically, but as a human being. These caregivers weighed clinical information from the BMT team against their past experiences and insight from other families, often carefully deliberating treatment decisions with a range of more humanistic concerns, such as quality of life.

The daily trauma of being a caregiver was one of warring sensibilities between fighting for survival and easing suffering: Will my child’s present pain be worth it? Care, for Martin and Beth and many others, required navigating a multiplicity of care logics: biomedical science, alternative therapies and cultural understandings of care, faith, and parental instinct. While the BMT treatment process at Hemphill Children’s Hospital was centered around treatment protocols and clinical trials, these competing logics operated alongside, against, and with the logic of biomedicine. Practices like documenting blood work are grounded in a kind of embodied ‘ritual logic’ that may offer solace and hope. Other logics, such as those that argue for alternative therapies, make sense for parents seeking to provide a child with a whole and happy life, but perhaps not for clinicians who see these practices through the biomedical lens of clinical risk and noncompliance.

Importantly, information work and emotion work are understood by families within these various competing logics and caregiving materialities. Drawing on the theoretical framings of both Mol (2002, 2008) and that of Strauss (1993) and colleagues (Strauss et al., 1982a; Strauss et al., 1982b; Wiener et al., 1997), I argue that navigating the multiplicity of logics inherent in BMT requires real labor on the part of caregiver-parents, an additional labor that should be seen as an analytically distinct activity called *reflection work*. What looks like intransigence, or even anxiety on the part of caregivers, may be better viewed as the ongoing navigation, reconciliation, and even superimposition of various care logics. In this view, information work and emotion work in BMT are part of processes in which people make connections between differing logics (reconciling them) or generating alternatives (challenging or even rejecting a dominant logic).

Indeed, ‘reflection work’ can be seen as the labor involved in managing the utility of both information and emotion work when a person is confronted with differing care logics. Information, literally extracted out of bone and blood, was embodied in a wide range of physical and digital artifacts, many of which hold different meanings for clinicians and parent-caregivers. A blood count in BMT is more than a numerical representation of a lab result; for caregivers it is also a sociomaterial practice, a form of engagement comprised of blood bags and beads, sketches and spreadsheets, patient records and Facebook posts. In detailing the materialities of blood work, I have shown how parents wrestled with their hybrid roles as clinicians acting “in loco medicus” and as advocates protecting their dependent (and fragile) children from the logics of clinical data and the tyranny of medical technology. Reframing such activities from acts of noncompliance to an essential aspect of care itself, I argue such practices should be understood and supported as an important and generative form of reflection work: making sense of not only what information means, but finding ways of living with information materialities.

So far, I have discussed a number of complex information and emotional challenges for BMT caregivers. Some of these difficulties are also encountered in a range of other chronic and acute health conditions, such as medication management issues and the adherence to clinical regimens. The nature of BMT, however, draws out the emotional issues and highlights ways in which information is often invested with additional symbolic meaning(s) and carries heavy physical costs. In this final section, I reflect on findings from a technology design project that created a digital application to support BMT caregivers. In analyzing the digital representations of bone and blood information, I draw attention to the important sociotechnical complexities (and simplifications) that arise in designing systems to support the diverse informational and emotional dimensions of care work.

DESIGNING A BMT ROADMAP: DIGITAL REPRESENTATIONS OF CARE

In his book, *The Stuff of Bits*, Paul Dourish argues for HCI as a discipline to contend with the materialities of information. This includes the various components that make up widescale digital infrastructures (such as the servers, protocols, and software that make up the Internet), but also the materialities of digital representations (like spreadsheets and databases). Significantly, Dourish maintains the materialities of information should not be seen as separate from the design process itself:

> "The relevance of materialities of information…is in how they manifest themselves within the design, application, and use of information systems. They are a part of interpretive and cultural processes that produce digital systems as objects in our world…What does it mean for something to be information…Similarly, what we expect that computers can do, what information can represent, how we can have access to it or make it do something for us, are evolving ideas, shaped as much by institutional conventions and social norms as by technological arrangements." (Dourish, 2018, p. 208)

In articulating a sociotechnical design space around information materialities, Dourish tasks HCI researchers and designers to investigate "the particular materialities that come to matter in different settings" (Dourish, 2018, p. 57). These insights and provocations offer a starting point for articulating the importance of bone-and-blood information in technology design. For instance, in the course of my ethnographic engagement, I participated in project to develop a digital system aimed at supporting pediatric BMT caregivers. The resulting iPad application, called "the BMT Roadmap," was to be given to families in Hemphill's BMT unit as an educational resource and information guide through the BMT process.

By examining the BMT Roadmap through what Dourish calls 'the lens of representation materialities,' I seek to document "the particular materialities that matter" in the context of BMT, including: the types of information and data that are represented, where they come from, and the significance of those digital representations. As information of bone-and-blood, the context of BMT (where data is often painfully extracted from the body), highlights the lived experience of turning materialities into digital representations. Along with Dourish's query, "what does it mean for something to be information," I would also ask: *what does it cost for something to become information?* And, more specifically, how might health technology researchers and designers attend to the costs of care—social, emotional, physical—in design?

The BMT Roadmap Project

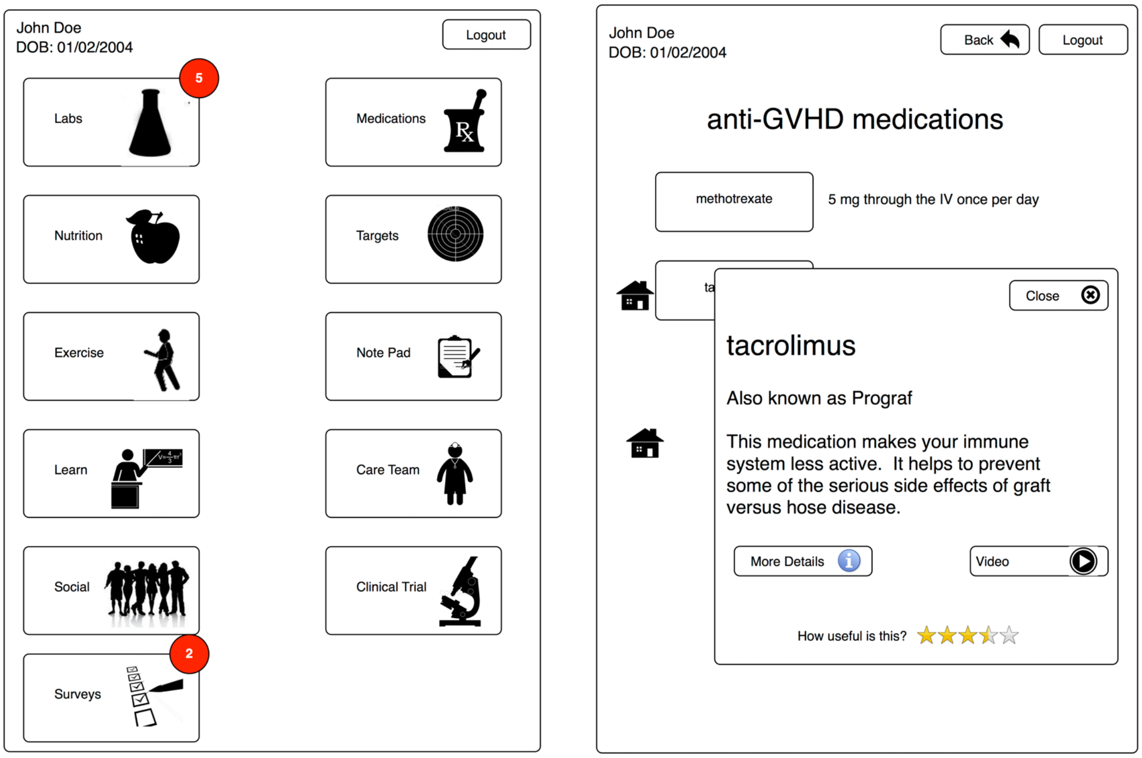
The creation of the BMT Roadmap involved a larger research team of doctors as well as a university-based development team comprised of a professional software engineer, project manager, UX designer and graphic artist. It is important to note that the team behind the BMT Roadmap was aware of the emotional as well as information needs of caregivers and that various psychosocial factors were taken into consideration throughout the design process. In particular, the BMT doctor spearheading this project was driven by a deep empathy for caregivers, many of whom she routinely witnessed struggling on rounds and in consultations. The BMT Roadmap thus marked a significant investment on behalf of the hospital and participating clinicians (in terms of clinical resources, research time, and personal energies) to figure out how to develop a system that would help lessen the substantial burdens of caregiving. A stated goal of the project was to increase caregiver engagement in the BMT process.

In the capacity of a graduate student HCI researcher, I participated regularly in team development sessions. During these meetings the overarching goals of the application and design concept, as well as specific tools and application functionality, were brainstormed and discussed. My role on the team was to advocate for the needs of the users (caregivers) based on my findings from observations and interviews described in this chapter, and to help developers translate some of those needs into design. I also engaged in a series of design activities with caregivers and BMT patients. For instance, I used low-fidelity prototypes (paper mock-ups of the app) as design probes in interviews with BMT families to elicit feedback on the application design, but also as a prompt to help people articulate some of the (often invisible) information work and emotional labor they routinely performed. I also led a design workshop with BMT caregivers and their children that let families both use and respond to a high-fidelity prototype of the BMT Roadmap (i.e. iPads running an early version of the application that had limited functionality) (Maher et al., 2015; Maher et al., 2016).

Prototypes

The design of the BMT roadmap went through several iterations, as is typical in system development. Early prototypes, for example, showed a series of icons and screens that caregivers could explore to find information on types of medications (antibiotics, anti-nausea, line care, pain management, and supplements), nutrition, members of the care team, etc. Caregivers could also look up personalized patient information, such as laboratory results and up-to-date blood counts, or the clinical trials they were enrolled in at Hemphill. General information on common complications like GVHD were also provided in text and video formats. In this early design stage, a social feature was included in the application to help connect caregivers to other families to share experiences, although later this was dropped from the design in order for some of the core application features (medication, lab results) to be more fully developed.

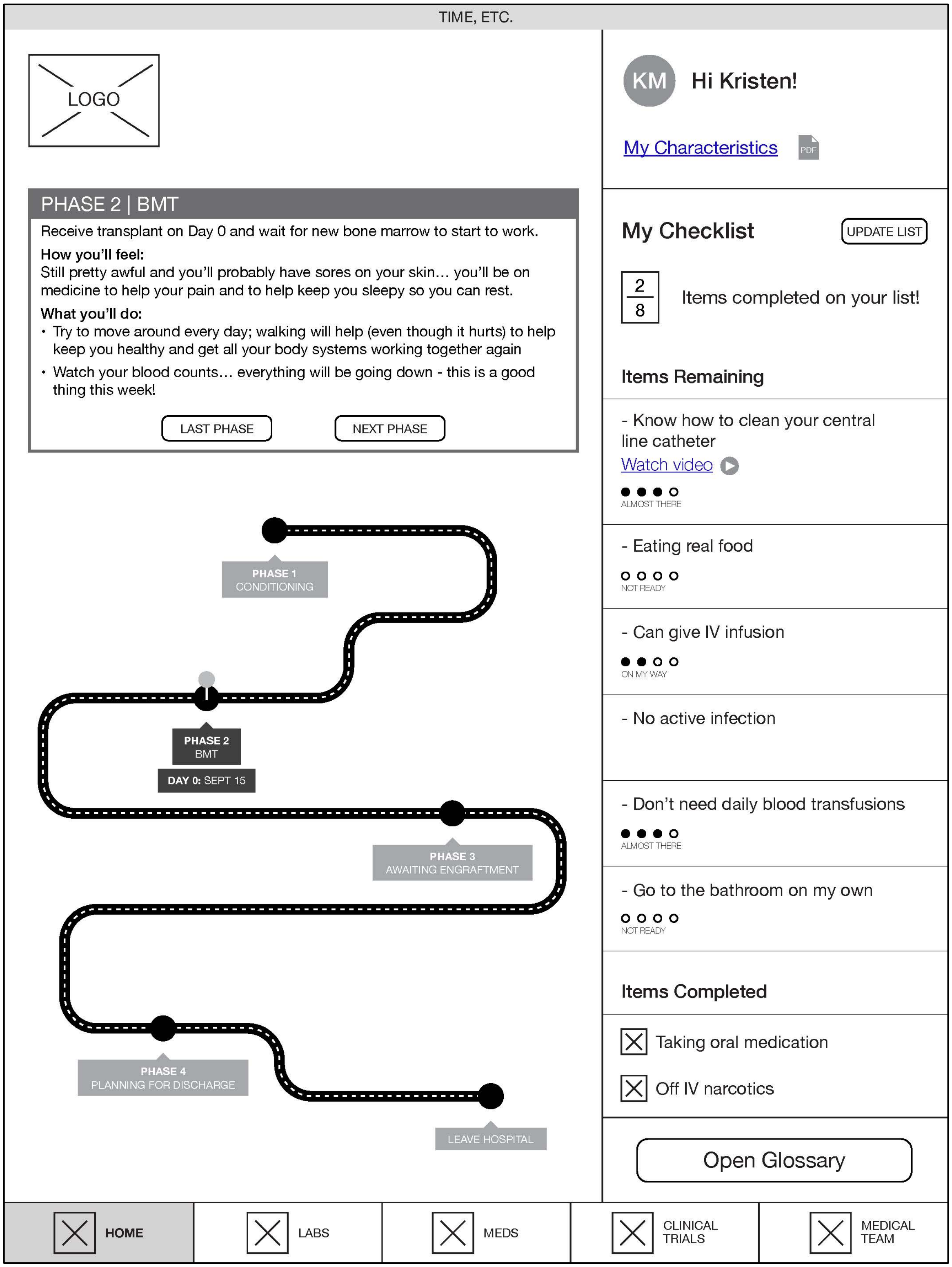
As the project developed, the various types of information were designed to be displayed with icons and visuals that represented a roadmap that would help families navigate through the four main phases of the BMT process. Starting with a pre-conditioning therapy phase, families moved on the actual transplant, and then next to a waiting engraftment phase, until finally, they returned home. The design team created different styles of buildings and houses along a road to represent types of medications and major BMT milestones. This the information included in the application was intended for adult caregiver-parents, the roadmap design also aimed to appeal to an older pediatric audience who might use the application with their families. Caregivers could touch different icons to get pop-up windows with more detailed information, for example, if the user touched "Phase 2 BMT" they could read a brief description of "What you'll do" during the transplant process, as well gain some insight on "how you'll feel." The application, notes, for instance that on transplant day, or "Day 0," the patient will most likely be in pain and have sores on the skin. The application reminds families to "watch your blood counts…everything will be going down—this is a good thing this week!"



Also known as Prograf

This medication makes your immune system less active. It helps to prevent some of the serious side effects of graft versus hose disease.

Figure 8: Low-fidelity (paper) prototypes used during caregiver interviews as design probes. The image on the left shows various modules for iPad application, such as lab results and tracking nutritional information. The image on the right shows how caregivers can search and find information on different kinds of medications.



PHASE 2 | BMT

Receive transplant on Day 0 and wait for new bone marrow to start to work.

How you'll feel:
Still pretty awful and you'll probably have sores on your skin… you'll be on medicine to help your pain and to help keep you sleepy so you can rest.

What you'll do:

- Try to move around every day; walking will help (even though it hurts) to help keep you healthy and get all your body systems working together again
- Watch your blood counts… everything will be going down - this is a good thing this week!

My Checklist

2/8 Items completed on your list!

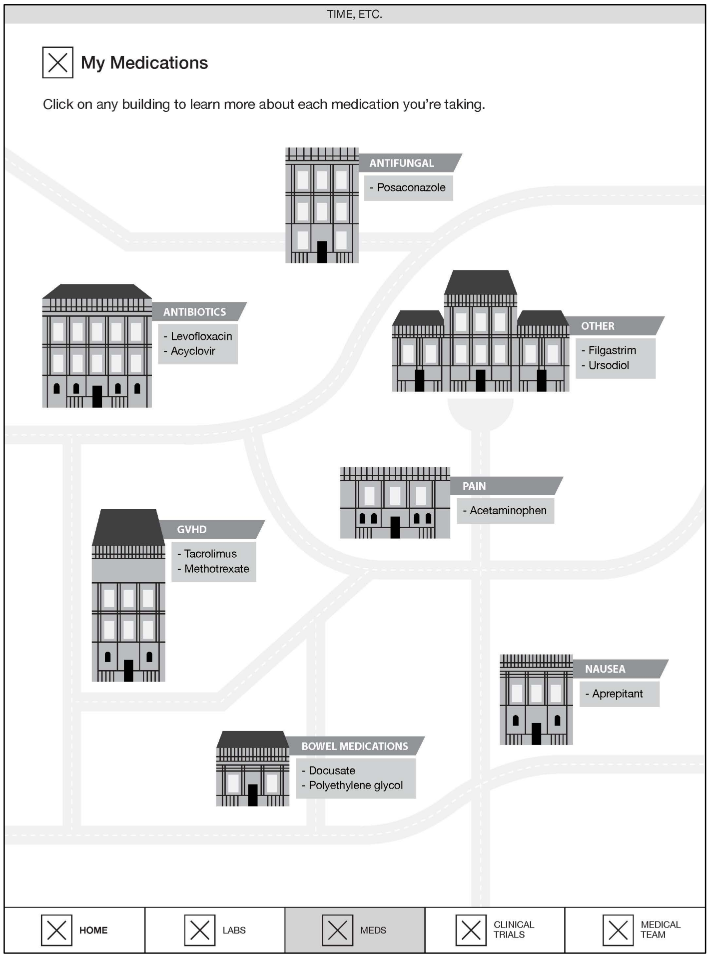
Items Remaining

- Know how to clean your central line catheter
  ● ● ● ○ ALMOST THERE
- Eating real food
  ○ ○ ○ ○ NOT READY
- Can give IV infusion
  ● ● ○ ○ ON MY WAY
- No active infection
- Don't need daily blood transfusions
  ● ● ● ○ ALMOST THERE
- Go to the bathroom on my own
  ○ ○ ○ ○ NOT READY

Items Completed

☒ Taking oral medication
☒ Off IV narcotics

Figure 9: Screenshot of the BMT Roadmap, end of road detail. This prototype was used on an iPad during design workshops with caregivers and patients. Users could interact with prototype through a touch screen. Note the image of the road which ends upon leaving the hospital.



Click on any building to learn more about each medication you're taking.

Figure 10: Screenshot of BMT Roadmap, medications detail. Tapping on a building would bring up screen that provided general medication information.

Sociotechnical Complexities and Simplifications

As detailed throughout this chapter, information for BMT caregivers was never fully clinical. Representing information of bone-and-blood digitally, then, was challenging design work. This was not because the application required particularly advanced software or database solutions, but because of the decisions involved in translating the various materialities of care work (each with important social and emotional facets) into code. I detail a of few examples of the critical complexities and simplifications that arose for caregivers during a design workshop for the BMT Roadmap.

The digital representation of laboratory data was of particular interest to caregivers who discussed the impact of design decisions. The BMT Roadmap had several screens that allowed caregivers to access real-time lab results, including blood counts. The system would also track and display a graph for white blood cell counts (CBC), hemoglobin, platelets, and absolute neutrophil count (ANC). Other lab results included electrolyte tests and the patient's liver panel which showed how the patient's data was trending. This design represented a significant departure from standard clinical practice in the Hemphill BMT unit (and most other pediatric oncology-hematology departments), as the medical community has long argued that patients and their families should only get laboratory results in the presence of a clinician; both to prevent misunderstandings of clinical context, but also to help families process bad news.

White blood cell count: Today's Count: 0.6 — Yesterday's Count: 0.3
Hemoglobin: Today's Count: 7.0 • T — Yesterday's Count: 9.0
Platelets: Today's Count: 11 — Yesterday's Count: 27
ANC: Today's Count: 59.7 — Yesterday's Count: 59.9

Electrolytes (Last 3 days: / Today:)
Sodium: 142
Potassium: 4.2
Chloride: 105
Carbon dioxide: 31
Blood urea nitrogen: 13
Creatinine: 0.85
Glucose: 95
Calcium: 9.7
Magnesium: 2.2
Phosphorus: 3.5

Liver Panel (Last 3 days: / Today:)
Protein: 6.8
Albumin: 3.9
AST: 27
ALT: 26
Alkaline Phosphatase: 97
Bilirubin, total: 0.9

Figure 11: Screenshots of the BMT Roadmap, lab results detail. The lab results page included information visualizations for blood work data. The image on the left shows white blood cell counts over time and the image on the right shows electrolytes and liver lab results.

On examining the lab results screens, one father-caregiver called John noted that while he was very pleased that caregivers would have increased access to patient data in order to "own the disease." Empowerment, for him, included insight into how to interpret the results; and he argued that the application should also show normal, low, and high levels for the blood counts (similar to other tests) so that caregivers could figure out the "norm." Along with helping caregivers understand more of the clinical context, however, John noted several emotional concerns could arise when parents looked at lab data. For instance, blood counts typically rise and fall during the BMT process and John felt the application should also make caregivers aware of these expected fluctuations. He explained:

> "Conditioning, or day after that, your ANC is going to start to fall. Knowing that, that is appropriate. Not just a norm, but what is appropriate. What do the doctors expect? Are you following that trend or not?"

Anxiety about blood counts led John and other caregivers in the workshop to recommend the application show how blood counts were connected to different phases of the BMT process, such as pre-conditioning treatment, a time when children received various chemotherapy and radiation treatments to destroy diseased cells. A mother-caregiver, Kim, for example, discussed how families might need emotional support in seeing the data:

> "There should be something that explains, in the conditioning module, saying, 'Yes, you'll have fevers. That's okay. Your counts will go down. They won't look spot on every time.' Things like that are okay."

As discussed previously in this chapter, blood data was also important to caregivers because they were connected to specific types of treatments which both physically and emotionally impacted children, causing pain or making them feel better. On examining the lab results page, a caregiver maintained that allowing caregivers to digitally make connections between the data and medical treatments like transfusions would be a useful tool for engagement:

> "Transfusion is really important. When you're feeling bad, you're watching those levels; because as you approach them, you can petition the doctors. Like, 'she's [child] feeling really bad, and tomorrow you know she's going to be there. Let's go ahead and do it [transfusion] right now, and let's get her feeling a little better."

Lab data in the BMT Roadmap was depicted from a clinical point of view and this was generally understood as useful (and even potentially empowering). However, workshop participants also expressed interest in generating other representations of that data. Andrew, a 12-year-old boy who had gone through a bone marrow transplant, explained that he would like to see different images, not just numerical representations, that spoke to the experience of getting data from his body. Blood cell counts, for him (and other children), came with painful needle pokes, IVs, and ports. Andrew explained:

> "It would be useful to have a picture in it, to show them [other children] what it is…I've had lots of IVs and a central line. I think a drawing would be more appropriate. A drawing with blood cells going through your skin."

Caregivers also responded to the general aesthetic of the BMT Roadmap design and debated the linear representation of the BMT process as a set number of milestones on a road from hospital to home. While most of the people at the workshop generally liked the road map design motif; the road, for most caregivers, rarely ends neatly at home. Complications like GVHD or a failed engraftment, for instance, could easily send people back to earlier milestones. A mother noted that the road motif troubled her, "I think it would be really depressing to be in the discharge place and then have to go back a little bit." Another mother explained that caregiving, for her, continued on long past the hospital discharge, "Going home doesn't mean you're all done…Things happen when you go home."

Other caregivers, questioned the bright colors and graphics that made the app feel like a game when the BMT journey for them was more of an ongoing confrontation with difficult decisions and numerous setbacks. A father in the workshop explained that going backward (while emotionally difficult) was part of the lived experience of BMT, "You have to remember that it's not a game. This is cute here, but we've lived it. That's real. If you go back, you go back. You still need to know where you're at." This father went on to articulate the challenge of design in the context of critical health situations, arguing that designers needed to understand that BMT "is not a pretty road."

> "What it comes down to is, how do you have a list of the nasty things that can happen and how to deal with them? I think part of it is, you guys, as the programmers of this, have to deal with the fact that this isn't a pretty road. The graphics don't make it a pretty road. That means you have to deal with the fact that you have to communicate some nasties with us, showing us what those nasties are and how to deal with them….But it also means that the information would have to be different than what is currently provided by the docs. I don't think they're so good at communicating until the situation's upon you."

The experiences of caregivers in this chapter demonstrate that “going home” can—depending on the success of engraftment and types of complications—be a moment of celebration, but also, as was found by Buyuktur (2015) in the context of adult BMT, a time of anxiety and despair. A mother and her teenage daughter at the workshop explained that in going through the transplant process, their road was anything but pretty and straight. “You should be off Tacrolimus [a medication] about six months after transplant,” explained the daughter. “I'm two years out, and I am still on stuff.” Her mother concurred, “We set that as a goal, but when it's not achieved, we thought, "What's wrong with her? If this is what they say, and this is what happens to the general population of these patients, why is my kid doing this?" Such caregiver feedback shows how interacting with the digital representations of health data and information (such as blood counts and discharge criteria) requires careful attention to the specific emotional as well as clinical context of users.

Interestingly, while participants in the workshop pointed to important emotional design considerations, a few caregivers argued that the BMT Roadmap should only show information from a clinical point of view. These caregivers felt there was an unavoidable conflict between the care logics of a clinician and parent; and that it would be difficult for a caregiver application to be both a useful source of information for navigating the hospital process and a system that provided personal support and encouragement. For example, a workshop participant argued that the app would never “be fun” for families. “It should just be the medical way of saying it rather than trying to sugar coat it, or ‘let's try to be positive.’ It can't be both. You just want to keep it from being offensive or discouraging.” In this way, clinical information, displayed as scientific facts and numeric probabilities, was preferable to an overly sentimental representation of BMT, which (for some) felt false. Furthermore, for some it was a relief to deal with clinical explanations than emotional experiences. The abstraction of engraftment into a numerical data point was a simplification necessary to for the medical processes care, but also helped caregivers get through the day.

As these examples illustrate, caregivers had diverse opinions on the various meanings of the information, the usefulness of the data and information, and how engaging with the representations of BMT made them feel. Some caregivers saw BMT as more complex (both socially and technically) than the BMT Roadmap portrayed and argued for richer digital representations that better accounted for the lived experience of BMT; and other caregivers recommended designs that focused on the clinical context of data. Such workshop findings suggest that there are moments in the BMT process when both complexity and simplification were desirable in digital representations of care.

In this final section, I discuss the significance of these findings for HCI and points towards design considerations in developing future iterations of the BMT Roadmap and other similar caregiving systems. In so doing, I highlight the sociomaterial tensions and power dynamics involved in designing for care when systems are viewed as a site of engagement.

Caregiving Engagement: Practice and Power in Information Design

Throughout this chapter, families wrestled with the ways information intertwined with practice through the various caregiver materialities of IV pumps, blood bags, and the bruised bodies of children. Digital information, such as included in the BMT Roadmap, also could not escape the material and emotional weight of blood and bone. As a workshop participant somberly remarked: “this data is somebody’s real lab results.” Though design, the representations of the BMT process simplified some of these complex sociomaterialities in ways that were useful (data trends), but also distressing (the end of a road).

In *Malignant*, anthropologist S. Lochlann Jain, narrates the experience of being diagnosed with cancer and going through chemotherapy, writing about cancer as both a personal encounter and cultural project. Evocatively, Jain describes the way information simultaneously embodies, illuminates, and obscures the realities of cancer. “With my pathology report,” Jain writes, “the material of my body (that me and not-me tumor) seemed to be literally lifted out of myself and into data” (Jain, 2013, p.203). Asking the oncologist to explain the meaning of the information on her diagnosis, Jain writes:

> ‘“What does it mean?’ The doctor responded in a way that was both helpful and not helpful, depending on the moment that I recall it: ‘Exactly what it says.’ Banal as a winter day or the color of the ceiling, survival statistics offer a smidgeon of information, but not much to cuddle with. How could something be at once so transparent (*you will live or die*) and so pig-headedly confusing (*will you live or die*)?” (Jain, 2003, p. 27, original emphasis).

Similarly, for BMT caregivers, blood and bone is lifted out of fragile bodies and into lab results.

In caregiving activities, information—described in this chapter as a site of labor, confusion, hope, and despair—is bound to the fragile bodies and future well-being of children. Information for BMT caregivers is not just a structured set of data, a series of facts, or even a thing, but a child on a knife's edge of life or death. Given the materialities of bone-and-blood information, the BMT Roadmap (or any prototype in a risky health context) can never be a fun game, a pretty road, or, as Jain dryly maintains, "much to cuddle with," despite the development team's considerable efforts to engage the participation of caregivers. But then, designing a dark and ominous road is also not desirable, nor is reverting to the clinical starkness of survival statistics. Is there a way for technology design to engage the messy entanglements between caregiving practices and the materialities of information?

Currently, there are no easy technical solutions to address all the complexities of caregiving work with a computational system. Some in HCI/CSCW have argued that this is a fundamental challenge of design; for instance, Ackerman's (2000) concept of a "social-technical gap" argues that the distance between *what should be supported socially* (e.g. situated, fluid and nuanced systems) and what *can support technically* (e.g. rigid, brittle systems with limited social intelligence) cannot be fully bridged with today's technology. Software development requires simplifications; nevertheless, Ackerman and others have maintained that interpretivist and grounded approaches can open up design space for supporting highly contextual phenomenon, like caregiving, within the practical realities of computational systems.

Simple technical designs can still capture social nuance. For example, at the BMT Roadmap design workshop, a 13-year-old boy who went through a transplant, suggested that the development team alter the representation of the BMT road:

> "What about continuing it [the road]? It doesn't stop when you go home. So, continuing the path. You're at home, what do you do now?"

In a new design iteration, the team followed-up on his suggestion so that the system interface depicted an ongoing road that extended off the side of the screen. The final milestone that was previously labeled "leave the hospital" was changed to "continuing the journey." While still very much a simplification of the BMT process, it is a design decision that better reflects the social, emotional, and clinical realities of discharge for families going through the transplant experience.

Hi Demo!

My Characteristics

My Checklist

4/8 Items completed on your list!

Items Remaining

- Know how to clean your central line catheter
  Watch video
  ●●●○ ALMOST THERE
- Eating real food
  ●●○○ ON MY WAY
- Don't need daily blood transfusions
  ●●●○ ALMOST THERE
- Taking oral medication
  ●●●○ ALMOST THERE

Items Complete

☒ Can give IV infusion
☒ No active infection
☒ Go to the bathroom on my own
☒ Off IV narcotics

Figure 12: Final BMT Roadmap design, extended road detail.

While this is an encouraging example of how design can begin to address the sociotechnical complexity of care work, it is important to note that what simplifications that get made (and who gets to make them) is also a question of power. Scholars in HCI and CSCW have long drawn attention power dynamics in design, arguing that design processes reinforce how some things come to count as information, as well as what gets left out and unaccounted for (Dourish, 2018; Bowker and Star, 2000; Star and Strauss, 1999; Suchman, 2006). Design methods, such participatory design, developed in response to traditional top-down design approaches, seeking to incorporate the expertise of a wide range of users beyond that of professional designers or engineers. Participatory design has been especially helpful in medical settings as a means of addressing patient/caregiver perspectives and needs in system design; and the BMT Roadmap design workshops discussed here are an example of this design approach.

While such design methods are important and necessary, they are also limited in addressing the complicated power dynamics at play in developing systems aimed at increasing caregiver 'engagement' and 'empowerment.' Health technologies not only expresses the intent of individual engineers, doctors, and researchers (and caregivers); but, as Dourish argues, "embed assumptions and imaginings of conditions of use, arise in particular institutional conditions, and reflect the needs and values of their sites of production" (Dourish, 2018, p. 206). The ways in which engagement is thus conceptualized in design is not just a question of data ownership and control, but a matter of designing for people's relationship with the medical system.

Writing across the fields of science and technology studies (STS) and medical anthropology, technofeminist scholar Annemarie Mol has theorized about the nature of reality through detailing both the multiplicity of practices (and logics) of biomedicine. While information is not the focus of her empirical investigations, Mol's work points to the wider political import of information design in clinical contexts. For instance, in *The Body Multiple,* Mol argues that the presentation of medical information is inextricably connected to human vulnerabilities, healthcare policies, and the costs of particular technologies:

> "Which facts should be presented…It is not simply a matter of which textbook page to turn into a nicely illustrated, suitable didactic leaflet. It is also a practical issue. Which machine to put to use, with what money to pay for it? Which hurts to evoke and which casualties to risk? Information, presenting some version of reality, does not come after practice. Neither does it precede it. Instead they are intertwined" (Mol, 2002, pp. 170-171)

Following Mol, in this chapter, I have attempted to show the ways information is a negotiated activity tied to particular risks, hurts, and obligations. Information design, in the context of the hospital and BMT unit, is also a matter of contending with clinical power. As digital information cannot be divorced from the types of practices it enables (and limits) through technology, Mol and Jain’s theoretical insights challenge designers and developers to consider the partial realities created by health information systems as necessarily empowering. In this way, caregiver engagement is not a neutral design goal, but should be seen as a practice deeply enmeshed in biomedical processes and clinical authority.

In this chapter, the practices of engagement often varied widely among families. In the BMT unit, some families demanded clinicians communicate all the “nasty” information upfront and so they had a chance to reflect on it in making clinical decisions; other families asked no questions and entered into a tacit agreement with clinicians to be shielded from any information not relevant to immediate care activities. How to translate such subtle encounters into a form of digital interaction?

The BMT Roadmap development team viewed engagement primarily in clinical terms, designing it as a digital tool to support the caregiver’s need for medical knowledge, such as biomedical terms and clinical procedures, as well as to provide access patient data like lab results. Conceived as an inpatient system, the BMT Roadmap application was connected to hospital’s electronic patient record system in order for it to retrieve and display data like lab results. As a part of this larger health information system, the patient data provided in the BMT Roadmap was black boxed, allowing families to view only partial bits of the larger record. Furthermore, it was originally envisioned as a stand-alone application with all other iPad functionality and applications disabled. Importantly, caregiver engagement was designed as clinical compliance; and in promoting the application, the hospital hoped for higher rates of adherence to treatment protocols and better BMT outcomes.

Engagement for caregivers, however, was not only a question of information access and adherence, but also an issue of ownership and advocacy. During design workshops, for instance, participants raised issues around technology cost and control, both in terms of being able to take the iPad device home with them after the hospital in order to access data, but also in regards to using the device and application as they wished. “Will it be locked down?” several caregivers asked the development team. “Can we put other applications on it? Will we be able to go on the Internet?” During the design workshop, one caregiver-mother, who also worked as an information professional, discussed the usefulness of development tools (such as a “slider”) that would allow families to customize the BMT Roadmap based on their information preferences. She explained:

> “It would seem really obvious to have a user/hacker/developer slider at the beginning of it. Individually, if the information's already in the system, the application based on where you have that slider set is going to expose different information. Each of us are very different in how we choose to raise our families, and how we choose to deal with being in the hospital. That would be a way that you could accommodate everyone.”

Here, caregiver engagement is envisioned as the ability to control the display of particular types of data and information (such as future complications, survival statistics, or blood counts) based on individual informational needs; but more importantly, it conceives the BMT Roadmap as a flexible system, one that should accommodate multiple ways of both being in the hospital and of enacting care. In this way, it can be seen as a digital representation of how families currently petition nurses in the middle of the night for lab results, while others protect themselves from emotional pain and information overload. It is a tool for supporting reflection work.

Some families at the design workshop also expressed concern that the system might enable greater clinical surveillance of previous autonomous caregiving practices. For example, this prototype of the BMT Roadmap allowed for families to track dietary information and create personal goals around calorie consumption and exercise, two important caregiving activities after transplant. “I’d be really careful how the doctors utilize that information,” a father-caregiver noted upon seeing that the application would allow for caregivers to create daily goals:

> “There definitely needs to be a separation between what's a medical goal and a personal goal. The last thing I would have needed (and it happened, it just didn't help) was the doctors to get on us about getting my son to get out and walk. You [doctors] don't even understand! You come in here for 30 minutes a day and talk to us. I'm in here all day trying to get the kid to walk! I don't need the iPad hovering over me trying to him to walk. It's nice to have the reminder, but the doctor should be really careful of that data just showing up on the report. ‘I see you didn't get your two laps in yesterday.’ That kind of thing.”

Here caregiver engagement is a framed as protection, a digital support for separating ‘medical’ and ‘personal’ care logics rather than as a way to reinforce compliance to clinical treatment protocols. Such caregiver imaginings of future system uses (and abuses) are important, because they show that while designers, doctors and caregivers both drew on the language of engagement, speaking of empowerment through data; the types of information practices they envisaged through design spoke to different realities of care. Through this chapter, I have shown that while caregiving realities are always partial, they are powerfully grounded in the lives of fragile children and deserve careful attention in system design.

Echoing Dourish, I previously asked: *What does it mean for something to be information in the context of bone marrow transplantation?* Information, in this critical medical setting, is always a material concern and a matter of care. For bodies to become information, children must go through chemotherapy and maybe radiation, get blood draws and biopsies and a transfusion of stem cells. They will need a Port-a-Cath inserted into their chest, a medical technology that connects medications directly to the heart. The lines coming out of their bodies will need to be maintained and kept clean. Children will be dependent on the blood donations while their body may turn on their donor cells. The medications they take might destroy their organs. They might die. Information, for BMT caregivers, represented medical facts and biological complications, but also hope and fear. Furthermore, information was also an everyday practice: a means of engaging medicine and coping mechanism. Collectively, these findings argue for greater attention in HCI to the various meanings and specific materialities of information in various health settings.

This chapter also explored how to support the complexities of care work in information design, asking: *What are the costs of engagement?* For a caregiver reflecting on BMT information in treatment decisions, a parent must weigh the risks of life and death. They need to see their child poked and prodded and crying out in pain. They must sooth when children are lonely and afraid. Coax and entice appetites. Say no to clinicians. They must endure boredom together. They must stay strong. In looking at health information as a site of information work and emotional labor, this chapter ultimately complicates a clinical narrative of caregiver/patient engagement in design as necessarily empowering. Care, located in the information materialities of a child's fragile body, is messy and emotionally fraught experience. There are times a parent's advocacy on behalf of a child's welfare is worth fighting (and dying) over, and moments when it is relief to give up control.

CONCLUSION

In this chapter, I have presented a sociotechnical study of bone marrow transplantation by opening up the clinical concept of caregiver engagement—the various activities involved in managing treatment protocols and making medical decisions—to include a nuanced understanding of the role of information work and emotional labor in care. In doing so, this chapter provides several contributions to HCI/CSCW.

At a theoretical level, I have sought to analytically unpack what we mean by 'care work' in detailing how caregivers manage information, including its various meanings and materialities. Drawing upon Mol's (2002, 2006) writings about the multiplicities of practice and logics of care, I have focused on caregiving as a site of reflection and negotiation. I showed, for example, how the caregiving goals of families and clinical teams were often misaligned, and that information used in treatment-making decisions (such as blood counts) held multiple meanings for caregivers acting as part of a clinical team, but also as concerned parents and advocates for fragile children. My findings demonstrate the considerable amount of effort required by parents to navigate between different care logics, some of which were unknown at first or even conflicting. Seeing care as a continually negotiated activity—involving many types of labor, including reflection work—speaks to the social tensions and emotional burdens that arise in managing a complex healthcare treatment.

This extends Strauss' theories about information work, and details how two important kinds of Straussian micro-interactional work (information and emotional) are related through specific sets of social relationships and material arrangements. Previous HCI/CSCW work has pointed towards the consideration of both information and emotional user needs in health system design (e.g., Mamykina et al., 2008; Mentis et al., 2010; Prilla et al., 2012), but my findings argue for the centrality in understanding the specific ways information work and emotional labor combine in various care settings. For BMT parent-caregivers, information could not be separated from the bodies and lives of their dependent children; rather, information was transformed and embodied in a wide range of physical and digital artifacts that held deep personal import as a coping mechanism, but also as an important part of familial roles and relations. Taking such caregiving materialities seriously complicates a straightforward model of information transfer in health settings and in technology systems, showing the unexpected ways care is enacted through interactions with clinicians and patient records, but also bones and blood counts, Facebook posts and family life.

My findings also offer important implications at a practical design level. A goal of this study was to better understand how to use technology to better support pediatric BMT caregivers, as well as other patient populations who collaborate closely with clinicians. In this chapter, I showed that caregiver engagement with the medical system depends on invisible (and often unaccounted) forms of information work that has significant emotional costs. Designing technology systems that attend to these care complexities in the digital representations of health information, is a difficult (although critical) task, even when developers and doctors carefully consider the needs of users and involve the expertise of patients and their families in the design process.

As healthcare and technology industries increasingly seek to use patient-generated data and health information to support patient-clinician collaborations and everyday personal well-being, HCI needs to call attention to important moments of engagement that don't fit neatly into clinical narratives of adherence to treatment protocols and compliance to biomedical logics. As a critical health setting, BMT highlights the costs—social, emotional, and physical—of turning bone and blood into information, in all of its digital representations and interactive forms. It also suggests new directions for attending to the lived experience of care in technology design, such as supporting reflection work as an important part of caregiver engagement and empowerment.

Chapter 5 Precarious Interventions:
Designing for Ecologies of Care

> "Care…includes everything we do to maintain, continue, and repair our world so that we may live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web."
>
> –Joan Tronto, *Moral Boundaries*

> "The commitment to care can be a speculative effort to think how things could be different…Can we contribute, by carefully staging how things hold together, to more sustainable caring relationalities and life conditions in an aching world? Ultimately, what is perceived as a problem is always situated, a partial intervention."
>
> –Maria Puig de la Bellacasa, *Matters of Care in Technoscience*

INTRODUCTION

Jackson, Michigan—a small, Midwestern city with deep manufacturing roots—is one of many rustbelt communities in the United States whose residents have struggled with the loss of well-paying jobs due to factory closures over the last several decades. There is a long tradition of "making do" among families in Jackson, pulling through difficult times with determination and a deeply held belief in self-reliance; and yet, in recent years the growing number of people facing serious socioeconomic and emotional hardships—long-term unemployment, home foreclosures, a rise in opioid addictions—has seen the need for local behavioral health and social services outstrip the city's capacity to provide care. Common behavioral health conditions like depression, anxiety, and bipolar disorder are often left untreated or poorly managed due to a shortage of psychiatric specialists, confusion or fear of treatment and diagnosis, stigma of social assistance programs and mistrust of the medical system, as well as long, often inflexible work hours for those who are still fortunate to have employment.

Bill's experience looking to get help for depression exemplifies the importance of grappling with the community context of personal health management—how people's needs are inextricably connected to local resources and cultural understandings of care. Born and raised in Jackson, Bill found himself out of a job in his late 40's after working on an assembly line for an automotive parts manufacturer since graduating high school. To make ends meet, Bill found some work as a day-laborer with a roofing contractor. The work was difficult even for a large man over 6 feet tall and used to physical labor. Dealing with chronic lower back pain, he struggled to keep up with a younger construction crew and was among the first laid off when business slowed down during the cold Michigan winter months. Once a steady contributor to a two-paycheck household, Bill struggled to meet mortgage payments and support his three children. His wife, Linda, a manager at a popular local diner took on extra shifts whenever she could, but ultimately, there wasn't enough money to save their family home from the bank. "You don't feel like a man," he said grimly about being unemployed in Jackson.

Facing mounting anxiety, periods of intense anger, and long bouts of insomnia, Bill grew increasingly depressed and his thoughts turned suicidal. At his lowest point, he called the hospital to admit him. "I was just crying there on the phone," Bill recounted, "And they just ask me, are you going to do it now?" Thinking of his family responsibilities, Bill knew that while he desperately needed help, he was determined to fight through his depression at all costs. Feeling like he did the right thing in confronting his fears and admitting he needed assistance, he was shocked that the hospital's response was to deny him admittance and refer him to a local clinic. He would have to get through several weeks on his own before he could see a nurse practitioner and if he wanted to see a physiatrist, the wait time was several months. "Thinking about suicide isn't enough," Bill recalled dryly, "You have to actually kill yourself to get help."

Left on his own, Bill began searching for a way to get through the days and long nights without turning to prescription painkillers to manage the pain. After seeing a cousin overdose on narcotics, he was terrified of even the slightest chance of addiction. Sometimes he drank heavily, but knew it wasn't helping his anger issues. An old work friend recommended Bill look into getting a medical marijuana card. Linda thought they should save up for him to see a chiropractor even if it wasn't covered by insurance, reasoning that he'd be less irritable if they could just fix his back problem. His aunt told him they would pray for him at her church. Eventually, after a of year of navigating insurance policies and rescheduling doctors' appointments, Bill received a formal diagnosis of bipolar disorder and a prescription for lithium he could refill at a neighborhood pharmacy. Things are in balance for the moment, but he feels tomorrow it could all change. They are behind rent on their apartment and their landlord might be forced to evict them if they can't pay up soon. Bill's oldest daughter and her boyfriend are having a second baby and they depend on Bill and Linda to live nearby for childcare. Bill continues to struggle with managing his moods, and the memory of that hospital phone call (of care being denied during his darkest moment) stays with him. Care for Bill, and many in Jackson, is a precarious experience. Indeed, living with chronic mental illness in a community with limited resources means continually engaging with uncertain and fragile systems—medical institutions, one's own body—that are prone to breakdown; a situation that necessitates creating workarounds or finding alternative ways of "making do."

Recognizing that managing behavioral health conditions—like Bill's bipolar disorder—are inextricably connected to wider socioeconomic and environmental conditions, such as poverty, substance abuse, and trauma, there have been a number of research efforts in population-based health domains to more actively involve communities in creating new models of healthcare delivery. These efforts include the patient-centered medical home, a model for family medicine that seeks to better integrate disparate medical and social services for people living with complex conditions, including behavioral health (Baird et al., 2014; Croghan and Brown, 2010; Zeigler et al., 2014).

In an effort to support community-based health initiatives, clinicians and medical informaticists are increasingly developing technical support systems such as community-wide electronic health records and care coordination systems. To date, however, these systems have primarily focused on sharing patient data and improving the clinical work processes rather than on facilitating the everyday needs of people seeking to manage behavioral health conditions (Bates and Bitton, 2010; Krist et al., 2014; U.S. Department of Health and Services, 2016a; U.S. Agency for Healthcare Research and Quality, 2016). They most often do not address complex social issues, such as economic barriers, cultural values, and mistrust of local institutions and resources, and this has limited the usefulness of such systems in communities with significant health disparities (McLoughlin & Wilson, 2012; U.S. Institute of Medicine, 2014; U.S. Department of Health and Human Services, 2016b).

Supporting Behavioral Health Needs in HCI/CSCW

Creating community-health systems that take seriously the needs of diverse patient populations requires design work built on contextually rich understandings of care. HCI/CSCW has long investigated social issues related to healthcare and championed the necessity of understanding lay forms of knowledge and the lived experience of patients, families, and informal caregivers in considering how health is practiced both in and outside of clinical settings (Fitzpatrick & Ellingsen, 2013; Barbarin et al., 2015; Schoroch et al., 2016). Research in HCI, for instance, has explored the use of health technologies in community settings like schools and neighborhoods, particularly around promoting healthy behavior change (Chaudhry et al., 2016; Schaefbauer et al., 2015), as well as tackling systemic social justice issues like health literacy and access to food (Parker & Grinter, 2014).

While HCI/CSCW is well-situated to address some of the pressing sociotechnical challenges involved in developing community health systems, studies to date have primarily examined behavioral health as an individual biomedical or emotional concern, designing applications and using personal data to sense and track moods. For example, a growing literature has investigated the self-management needs of people living with a wide range of behavioral conditions such as depression, anxiety, bipolar disorder and schizophrenia with the goal of providing greater insight into the health condition and/or promote positive behavior change through technological interventions. For instance, Wang et al. (2016) describe a passive sensing system for detecting mood changes in people managing schizophrenia; Bardram et al. (2013) detail the design of a mobile tracking system for supporting individuals living with bipolar disorder; and Matthews & Doherty (2011) discuss providing psychotherapy to teenagers via mobile phones. Recent studies have also aimed to use machine learning techniques to identify behavioral health conditions (such as depression) through the analysis of social media data (Chancellor et al., 2016; De Choudhury et al., 2016), arguing that such technology could be used to provide real-time interventions for people in need.

Research in HCI/CSCW that have examined the social dimensions of behavioral health have primarily focused on clinical settings and the relationship between patient and clinician (Tuli et al., 2016, Mohr et al., 2015), or examined behavioral health in online contexts like online patient forums, with a focus on using technology to provide digital forms of peer-support (Li et al., 2016; O'Leary et al., 2017; Huh et al., 2012). A notable exception here is Yamashita et al. (2013) study on designing to support the caregivers of depressed family members, which notes a range of conflicting social demands experienced in managing behavioral health in the home. While important, studies about digital spaces or domestic settings are unable to fully delve into the wider social issues that impact care in local contexts. There remains a need to better understand the everyday care practices around living with behavioral health, particularly in diverse community settings. I follow Parker et al. (2012) who has articulated the importance for HCI/CSCW researchers to grapple with systemic and political issues related to health, including socioeconomic resources, cultural attitudes, and environment. My study adds to these ongoing efforts by helping better understand the various meanings and situated practices of behavioral health as it is lived in real-world settings.

In this chapter, I present an ethnographic account of people's everyday behavioral health experiences in Jackson, Michigan to explore care work through an infrastructural lens. In detailing people's interactions with various clinical processes, local resources, and diverse social worlds, I highlight several problematic care delivery gaps, as well as the workarounds people depend upon to manage their behavioral health needs in the face of community-level challenges. In doing so, this chapter offers several practical and theoretical contributions to HCI.

One goal of this study is to consider how to design health information systems that help address the social complexities of community-based health. In documenting the infrastructural context of personal health management, my findings provide several key insights: (1) I show how the particular arrangements of care matter on a local level, drawing attention to how people's behavioral health practices are inextricably connected to social relationships, organizational systems, and cultural understandings of health, an understudied area of system design; (2) Importantly, I found people utilizing alternative, informal care systems to circumvent routine breakdowns in local medical and social services and examine this as an opportunity for future system support; (3) As well, I discuss challenges in an ongoing community-led effort to redesign care delivery in Jackson, reflecting on sociotechnical considerations for large-scale design projects in healthcare.

Another overarching aim is to theoretically unpack care as an infrastructural activity and site of intervention. Drawing on symbolic interactionism and STS/feminist theory, (1) I analyze the types of medical tasks, information work, and emotional labor involved to live with infrastructural brokenness as type of care/repair work that involves holding together both fragile health systems and human bodies; (2) Secondly, I argue that care/repair work highlights the need for HCI research and health system design that contends with the vulnerabilities (and costs) of patient engagement on the margins of medicine; (3) Finally, conceptualizing care as a deeply relational activity, I offer a design narrative of *precarious intervention* that reflects on ways of repairing (rather than disrupting) the wider care ecologies people depend upon for managing their everyday health needs.

In the following sections, I first situate my study within the theoretical literature and then turn to outlining my study methods and describe my fieldsite and interlocutors. Next, I present my study findings on people's experiences with behavioral health in Jackson, Michigan, as well as a community-led project to improve behavioral health services through a shared community health record. Finally, I reflect on the important characteristics of care work I observed in Jackson and discuss its implications for HCI/CSCW.

THEORETICAL FRAMINGS

In this chapter, I investigate the lived experience and everyday practices of behavioral health management amongst people and their surroundings by drawing together several theoretical threads of literature across the domains of sociology, science and technology studies (STS), and feminist studies. In this section, I outline the history and use of symbolic interactionism in HCI/CSCW, particularly the scholarship of Strauss, as a means of investigating the relationship between people's activities and social context for system design. I also describe how the study of work (and practices of repair) figures into a growing STS literature on infrastructure studies, focusing on the writings of Susan Leigh Star and Steve Jackson. Finally, I draw on STS/feminist theories of care that provides a language for articulating the arrangements (and ethical considerations) between various human/nonhuman actors as part of wider sociotechnical assemblages.

Investigating Context: Social Worlds and the Practices of Work

HCI/CSCW has long been interested in the ways in information is bound up with highly-situated everyday life activities and concerns. Symbolic interactionism[5], a micro-sociological

---

[5] Symbolic interactionism is also known as social interactionism or the Chicago School; I refer here to the second Chicago School generation that included Anselm Strauss, Herbert Blumer, Howard Becker, and others. A fuller treatment of symbolic interactionism's place in CSCW research can be found in Ackerman & Kaziunas (2017).

tradition rooted in the premise that meaning is derived from people's interaction with others in social settings, has been a useful approach to sociotechnical system design (Ackerman & Kaziunas, 2017). Importantly, in symbolic interactionism, interpretation is fluid and ongoing, and meaning is reconstructed through repeated interaction.

Through varied studies, often of medical settings, Anselm Strauss and colleagues developed a theoretical framework of social worlds to analyze the arrangements and processes of collective action. Unlike formal organizations with clear boundaries and known memberships, social worlds are shaped by "forms of communication, symbolism, discourses" as well as "palpable matters like activities, memberships, sites, technologies" (Strauss, 1993, p. 5). People participate in multiple social worlds both small and large in scale, local and international, as well as visible and hidden. Strauss maintained that social worlds have a primary organizing activity, such as art collecting, medicine, politics, punk music, etc., as well as have particular sites of action and technologies to carry out action. Strauss and colleagues were interested in understanding the conditions where and when social worlds intersect, situations where new types of skills and expertise were needed, and when a process (or later, practice) was made visible when technology was adopted or modified.

While a Strauss' social worlds theory is limited (for instance, there is an analytical fuzziness in what constitutes a social world verses a social arena); it has been theoretically extended and proven particularly useful as a theory/methods package in analyzing how complex micro-interactional activities are bound up with various social groups, organizational settings and technological systems (Clarke & Star, 2008; Charmaz, 2008a; Charmaz, 2008b). Of particular interest for health research in HCI/CSCW is how Strauss and colleagues extended the concept of work to investigate the practices around living with illness, especially chronic illness. For Strauss, and here in this chapter, work is comprised of micro-interactional activities, and is not necessarily conducted in formal workplace settings. This includes, for example, the activities of hospital staff in caring for the chronically ill, such as *comfort work* (associated with tending to physical discomforts), *sentimental work* (associated with psychosocial issues such as trust and composure, now termed emotional labor), and *articulation work* (associated with the collective effort of clinicians, including planning and coordination to operationalize tasks) (Strauss et al., 1982; Wiener et al., 1997).

In this chapter, I refer collectively to the various types of interactional activities that make up everyday behavioral health management as “care work.” This describe the practices of clinicians, but also the practices of lay people and concerned others in their social worlds, such as family, friends, clergy and social workers. Furthermore, it is important to note that some types of everyday care work are visible (e.g. recognized by the formal medical world as “real” work), especially if they duplicate or supplement the work of clinicians (Wiener et al., 1997). For example, this work includes what patients do in managing medications or adhering to clinical protocols. Some types of care work, on the other hand, is invisible—not openly or frequently recognized by clinicians or lay people alike as “work,” such as seeking out alternative treatments, documenting one’s family medical history, or learning how to provide (and ask for) help from others in one’s community. Whether or not these activities are openly recognized as “work” they can influence clinicians’ (and designers’) judgments about how cooperative people are to biomedical treatments and protocols. Star & Strauss’ (1999) sensitizing concept of *invisible work* includes those activities (often types of emotional labor and/or activities associated with traditionally “feminized” occupations) that are not supported by organizational processes or technological systems.

Social worlds can be invisible (but essential) parts of people’s healthcare experiences in a community setting but are currently understudied in literature on designing systems to support health conditions of all sorts. There has also been a renewed interest in HCI/CSCW to articulate more contextually situated understandings of informal care work. In this chapter, I seek to address this gap by further contemplating the relationship between care work and the social worlds in which people live.

Infrastructure Studies

Star, among others, connected the symbolic interactionist perspective with STS (science and technology studies) theory, to examine infrastructure in terms of its sociomaterial practices (Star & Ruhleder, 1996; Star & Bowker, 2002; Clarke, 2005). Star & Ruhleder (1996) for instance, argued that infrastructure is fundamentally relational and becomes visible upon breakdown. Drawing on Star’s foundational work, scholars in HCI/CSCW have studied the social relationships and types of interaction work involved in building and maintaining technical infrastructures like the Internet or large-scale, collaborative scientific research platforms known as cyberinfrastructure or e-infrastructure. For example, in studying the design of organizational information systems, Pipek & Wulf (2009), proposed ‘infrastructuring’ as a methodological approach for investigating various stakeholder activities in information system usage. Likewise, Bietz et al. (2010) looked at cyberinfrastructure to investigate the work of creating infrastructure, proposing the sensitizing concepts of ‘synergizing’ to describe the processes of building and managing relationships between people, organizations, and technologies. In their article, ‘From Artefacts to Infrastructures, Monteiro et al. (2013) also argue for the need to reconceptualize the role and nature of design in light of the unique characteristics of information infrastructures, although their specific concern was with figuring out how to accommodate large-scale, interconnected systems in global organizational contexts.

Perspectives on Repair

Of particular interest in the growing literature around repair studies that have expanded the theoretical lens of infrastructure to investigate a wide range of sociotechnical systems and work practices in non-western settings. Importantly, the writings of Steven Jackson and colleagues have highlighted the wide range of human activity involved in creating and maintaining infrastructures that can often be overlooked in technological-focused disciplines like HCI/CSCW. For instance, Jackson et al. (2012, 2014) have examined the “repair worlds” of Namibia and Bangladesh to investigate how information technology infrastructures are routinely maintained and extended in local contexts. Furthermore, Jack et al. (2017) discussed the logistics of customer service and delivery in Phnom Penh, Cambodia as a type of “creative infrastructural action” which they describe as “the resourceful and imaginative development of a homegrown infrastructure” (ibid., 2017, p. 6519). They show how the activities of buying and selling in the city have long involved a complex ecology of tools, people, and traditions; however, the introduction of digital commerce websites on the Internet have also created new forms of work, such as “making a new tool work within the context of older tools and infrastructures in an environment” (ibid., p. 6513).

Also important here is Rosner & Ames (2014) paper on a computer project and fix-it communities which details the infrastructural processes of breakdown and repair as they emerge from everyday practice. In their paper, they discuss the materialities and practices of repairing broken machines as a type of collective activity they call “negotiated endurance.” They explain:

> “This refers to the process by which different actors—including consumers, community organizers, and others—drive the ongoing use, maintenance, and repair of a given technology through the sociocultural and socioeconomic infrastructures they inhabit and produce. In this framework, breakdown and repair are not simply planned or avoided through design, but instead actively produced and reconfigured through use” (Rosner & Ames, 2014, p. 319).

In their paper, for instance, they discuss the ways in which technological repair is a deeply gendered activity in both Paraguay and parts of the United States in which male expertise is rewarded and female labor is viewed as unskilled and less valuable. While Rosner and Ames’s observations are directly connected to the social worlds of fixing computers and various electronics, their insights on negotiated endurance highlight the dynamics of how infrastructure and practice are interconnected and points to the broader sociological and political stakes in studying and supporting the work of repair in its many forms.

Technofeminist Care Ethics

Finally, there is a growing literature on technofeminist perspectives of care that point to the ways care is both a practice and a politics, and as such, often a site of intervention. ‘Care’ in this scholarship is contextual, relational, and often ambiguous. Scholars like Annemarie Mol, for instance, have theorized about the nature of care through looking at the relations between human and nonhuman actors (Mol et al., 2010), while Puig de la Bellacasa (2011) has investigated care as a site of reflection and active engagement, asking: How do we, as STS scholars, feminists, (and designers) enact in our relations with the world?

In their article, “The politics of care in technoscience,” Martin et al. (2015) outline a larger agenda for studies of care. “In its enactment, care is both necessary for both biological and social existence and notorious for the problems that it raises when it is defined, legislated, measured, and evaluated” (Martin et al., 2015, p. 625). Importantly, in their view, a politics of care extends the scope of technofeminist theory beyond healthcare settings to deepen how we think about work and engagement in other settings, from domestic labor to climate science to markets of technology innovation. Care as a form of feminist engagement here is not necessarily generated by warm feelings of concern or interest, but “propelled by anxiety, injustice, indignation or frustration” of living in a broken world (ibid, p. 630).

Martin et al. (2015) also make note of the common critiques to care, including the risks that come with intervention. In writing about the 'engaged program' in STS, they reflect that, "Some in STS worry that the subtleties of our work are lost, or worse, that work is conscripted as anti-science in facile applications aimed to bolster fringe viewpoints on hot-bed issues like climate change, intelligent design, or the vaccine wars" (ibid, p. 629). And yet, for them, "care does not offer closed and teleological solutions" but "remains open-ended and responsive" (ibid., p. 630). Following their direction, Kerr et al. (2018) point to care as both attention to present suffering, but also as a means of designing more ethical futures:

> 'Vulnerability, or the human capacity to suffer, therefore brings with it certain kinds of moral and political obligations to intervene, innovate, care. This reminds us to consider how innovations, be they technological or social, address vulnerabilities, meet material, bodily and phycological needs; how they prevent exploitation: how they protect us from hazards" (Kerr et al., 2018, p. 25).

I draw on this rich theoretical literature to investigate the wider ecologies of care and make visible important, but often-overlooked forms of labor. I also seek to extend this theoretical work in new directions by looking at the costs of creating and maintaining homegrown systems of care in the face of infrastructural brokenness. In focusing on care as a site of repair and intervention, this chapter further explicates infrastructure's relationship to everyday practice and design by centering its inquiry on the ways care is enacted through clinical processes, technical systems, social worlds and human bodies, and what it means to engage and possibly change those relations.

METHODS AND PARTICIPANTS

This study was part of a larger research project investigating patient and clinician experiences of care in Jackson, Michigan.[6] The data included in this chapter includes 34 semi-structured interviews that I conducted with members of the Jackson community who engaged with the behavioral health system. These semi-structured interviews took place face-to-face at

---

[6] While not used in this chapter, an additional data set of 20 clinician interviews conducted by Mark Ackerman informed my analysis by providing a deeper understanding of Jackson's behavioral health system. A combined data set of patient, stakeholder, and clinician interviews was the result of a collaborative research project on Jackson together with Dr. Michael Klinkman.

various private locations and focused on exploring: (1) People's understanding of "care"; (2) Everyday management practices and strategies; (3) local challenges; and (3) Community health resources/arrangements that people used in various social worlds.

I focus on interview data collected from 22 Jackson residents who spoke to me about their experiences managing one or more behavioral health conditions. These residents included 16 women and 6 men who represented a wide range of ages as well as socioeconomic and educational backgrounds. This included residents with college degrees and those who dropped out of high school; some people had full-time employment and health benefits while others expressed financial difficulties in meeting basic necessities like rent and utilities. A number of residents were currently unemployed and living on disability benefits. Some residents had interacted with the behavioral health system for years while others were new to the system. The majority of people interviewed had lived and worked in Jackson for their entire lives.

The people I spoke with lived with a number of different behavioral health conditions, including: depression, anxiety, bipolar disorder, schizophrenia, post-traumatic stress disorder, schizoaffective disorder, borderline personality disorder, and obsessive-compulsive disorder. People often had more than one health condition and were typically using more than one prescription medication to manage their conditions. While "severity" of health and wellness is subjective, it is important to note that many residents shared a number of activities and (often traumatic) encounters that shaped their care experiences, including: suicidal ideation or attempted suicide, self-harm activities such as cutting, time spent in inpatient psychiatric facilities, violent physical and/or sexual abuse, and personal struggles with substance abuse.

I also use data from an additional 12 interviews I conducted with various community health stakeholders in Jackson that included social workers and therapists, community organizers, pastors, and nonprofit staff, members of the local government and transportation authority, support personnel like health coaches, care managers. These interview data were also informed by over 12 months of ethnographic observations in which I attended Jackson's Behavioral Health Action Team (BHAT) meetings, observed the daily work of local care managers and health coaches, and visited a wide range of Jackson clinics, group homes, and churches. In these settings, I interacted and spoke with a range of clinicians, including nurse practitioners, physiatrists, and primary care physicians. Observational data were recorded as field notes and later transcribed. Additionally, over the course of 12 months, an ongoing analysis of

Jackson-related websites, various health literature such as patient pamphlets and resource lists, news articles, and a wide range of social media, including YouTube videos and Facebook posts added to my understanding of people's experience of living in Jackson and helped triangulate interview and observational data.

IRB approval for data collection was obtained along with participant consent. Interviews were approximately 1-2 hours and were recorded and transcribed. Pictures were taken and included for publication with permission.

Data Analysis

I followed situational analysis as articulated by Adele Clarke which is an updated version of grounded theory. Iterative cycles of data collection and analysis informed one another (Clarke, 2005). After a set of initial interviews were transcribed, I analyzed the data using an open coding method to identify significant themes. Coded interviews were then discussed among entire research team during data analysis sessions. New codes were generated collectively as important concepts were identified, compared, and revised. These subsequent codes were later used as probes in future interviews.

The second stage of data analysis with new transcribed interview data resulted in consistent themes and confirmed our findings. Fieldnotes were read, coded, and analyzed in a similar manner during data analysis sessions. Furthermore, utilizing Clarke's situational analysis mapping methods, I generated an array of situational, discourse, and social worlds/arena maps and analytical memos. These map artifacts and memos were discussed among the research group as theoretical insights emerged from the ongoing data collection and analysis. All data presented here has been anonymized. Some minor edits to quotations have been made for clarity.

CARE WORK IN THE MARGINS

In this section, I detail the ways in which people's everyday health activities such as getting medication or finding a referral to a therapist, were connected to wider ecologies of care that included medical institutions, processes and systems, but also various nonmedical social worlds. As one might expect, the city hospital, family clinics, and neighborhood pharmacies were centers of care activity in Jackson. Clinicians and patients alike struggled with shifting regulations for federal and state programs that impacted local behavioral health delivery on multiple levels. Systemic gaps in care were widely acknowledged by interlocutors throughout the study with the often-repeated phrase: “falling through the cracks.” And yet, what does this mean for people in practice? What might the gaps, cracks, and spaces between social worlds tell us about care, but also the role of design in healthcare systems?

Community behavioral health is such complex issue to study since people are often involved in self-managing conditions over long periods of time, either lacking or eschewing access to formal medical services, thus making local systems of care all the more difficult to observe. Bowker and Star’s (2000) reflection that infrastructure becomes “visible upon breakdown,” however, highlights Jackson’s importance as a fieldsite, in that the social and economic challenges faced by residents cast workarounds to formal medical and social services in high relief. People were often forced to take care into their own hands with little information and few tools. I found they looked for help in social worlds far outside the boundaries of state-recognized healthcare institutions, such as medical cannabis growers and faith-based communities, developing alternative, DIY approaches and even spiritual practices for managing behavioral health conditions.

In the following, I provide a brief background on Jackson, describing some key behavioral health challenges and opportunities faced by the community. Next, I detail the experience of breakdown from the perspective of people living with behavioral health conditions. Finally, I turn to describing the workarounds taking place in their diverse social worlds.

Community Background and the Legacy of Labor

Located 70 miles west of Detroit, Jackson is a city located in the state of Michigan and part of the Midwestern region of the United States. Home to a largely working class, blue-collar community of about 32,000 people, its workforce has been impacted by declining industry in the area, particularly automotive manufacturing. Neighborhood corner bars still dot the city landscape, remnants of when workers would flood out of the factory doors to grab a drink at the end of their shift. It is a community whose identity is deeply rooted in the value of labor and a respect for hard work. Such values were written into Jackson’s origin story which was recounted to us by many locals: in the mid-1800s, the city leaders were tasked by state officials with choosing if they wanted to build a university or prison in their community. Reasoning crime would never go out of business, Jackson became home to the first state prison and several future correctional facilities while the nearby town of Ann Arbor turned into a college town. In those early days, the prisoners were put to work manufacturing goods as a means of redemption for social ills.

People telling this story often held the belief that this historic decision was in part responsible for Jackson's present socioeconomic troubles, which over the years, brought both steady jobs for correctional officers as well as a semi-transient population who came to live near incarcerated family members. Jackson struggled while Ann Arbor flourished. Recent efforts to invest in the city's future—and reframe a civic narrative—have placed a focus on education and creating opportunity for a skilled, but displaced workforce. A city hall project to revitalize the downtown area by demolishing blighted properties has led to the subsequent openings of independent coffee shops, a farmer's market, and even a local makerspace. Nothing is perhaps more emblematic of Jackson's efforts to reclaim its history than the conversion of its historic state prison building, at one time the world's largest walled prison, into a resident arts community. Within the 25-foot stone walls of the Amory, local artists, musicians and designers now live and work. Collectively, such efforts have begun to help shift lingering negative perceptions of Jackson, reconnecting the city with the best parts of its manufacturing past: a place of innovation where people can learn to apply craft honed the factory floor in new directions.

This legacy of work, the historic practices and mythos of labor, is important to consider when trying to understand the current context of healthcare in Jackson. People's experiences of care were very much tied to tolerances for and values around work; for instance, residents often took an active role in the self-management of their chronic illness and often worried if it was reasonable to ask clinicians for help with related medical tasks, such as finding affordable medications. In a city grounded in an ethos of making-do, I found people persisting to care for themselves and others with the resources at hand, managing health in unexpected ways when the medical system became opaque, or at times, seemed to be falling apart.

Breakdowns in Care

In recent years, health and wellness has become a priority for Jackson. Recognized health disparities linked social and environmental factors like income, education, and neighborhood crime are increasingly seen as a community problem, something to tackle with dedication and hard work. One of Jackson's largest employers is a privately-operated health system which owns the city hospital with an inpatient psychiatric unit and also runs a number of specialty clinics in the city, including an emergency drop-in care center and a wide range of outpatient services for behavioral health. Working together across private, public, and nonprofit sectors, the local healthcare leadership have spearheaded a number of initiatives to support innovative community behavioral health programs in Jackson.

Despite such efforts to better connect people to local resources, however, gaps in care remain a problem for many residents who face difficulties getting behavioral health treatment for themselves and their families. Some of these "cracks" in the behavioral healthcare system are well-known systemic challenges, policy breakdowns of a massive scale that have limited government funding. A feeling of widespread frustration was expressed by one mother seeking a therapy for her depressed teenage daughter: "You always know somebody who is struggling to get some mental health services." Along with the strain of waiting for an appointment (sometimes multiple months) due to a scarcity of trained specialists in the area, people also described the anger and hopelessness they went through in not being able to get assistance.

Janine's story illustrates a common lived experience of seeking care and the complex medical and social circumstances that can nudge a person in and out of the formal behavioral healthcare system. A lively 60-year-old woman with a no-nonsense attitude, Janine proudly shared stories of the people she had helped during her 20 plus years as a social worker. As the conversation turned to her own life, however, she struggled to hold back tears in narrating her journey to unemployment and disability—a situation she never expected to find herself in as someone who "used to be on this side of the table and advocate for other people." Janine's story came in small fragments, a series of traumatic events: she had to take on sole caretaking responsibilities her elderly and increasingly ill mother, a contentious legal battle erupted among her relatives, and then, one night, a stranger's violent assault upon her body left her broken.

In a bad place both physically and emotionally, Janine's family doctor prescribed medication—Xanax and Celexa—for her depression and anxiety. While the prescription drugs helped with stem the frequent nightmares that came after her assault, Janine found she could not recover fast enough to deal with all the responsibilities piling up at work and home. "I was under a lot of stress," Janine recalled. "I was taking care of my mother. My car was breaking down…Everybody just left me hanging. It was constant, constant." Unable to hold down her job, she also lost her health insurance and the ability to afford her medications. Her unemployed and uninsured status left her adrift, months away from qualifying for Medicaid, a federal and state insurance programs for those with disabilities or low income. Unsure of what to do, Janine sought help from the local community mental health clinic but was turned away. She remains uncertain why she was denied in such a vulnerable state,

> "People that need help, they need help…I got turned away and I was at the end of my rope. I come to you, I pour my heart out and you can't help me or you're sending me off someplace else."

The community mental health center is a highly visible and important resource for people seeking behavioral health help in Jackson. Located next to a sprawling parking lot in a busy shopping complex, it is always packed with people making appointments, getting screenings, using private computers to receive remote therapy services online, and attending a wide range of workshops and support groups. A private club space for people living with behavioral health conditions is conveniently located next door, a friendly place where members can stop by to grab a cup of coffee, chat with friends, volunteer, and get help from an assigned case manager or social worker to set up doctor's appointments or manage housing needs. Also within walking distance to the community health center sits a large office space for private network of mental health professionals that offer a range of psychiatric services. The community health center would appear to be an ideal place for someone like Janine—unemployed, depressed, desperately needing help—to get on their feet again. Yet, many residents who come to the center are denied, not because of over-capacity, but by the political processes of classification.

This particular local facility, like many others across the nation, is federally-funded through the Community Mental Health Act. As a designated resource for underserved populations, legislation requires that only people with "the most severe" mental illness or developmental disabilities can be served there. Approximately 70% of people like Janine who show up at Jackson's community mental health center looking for help are referred back to their insurance companies or told to see primary care providers. Marcia, a long-time staff worker at the center, explained why this gap is so problematic for a small community like Jackson with limited care options:

> "There is a law that says, 'There will be in existence a community mental health center to serve the most severely mentally ill and we're going to give a ton of money to do it.' But you can't help people until they are severe..., It's so hard to help a community understand that because all they see is their loved one falling. A lot of people say, 'Who are you to say I'm not severe? How do you know that I'm not? I can't get out of bed every morning!' Or 'My loved one is on the verge of being arrested and you think they're not severe? You are going to refer me back to my primary care physician?' How do you soften that blow?"

People in need of behavioral health resources, even those who are referred by doctors or the court system, often get turned away from the community mental health center. Severity of illness is determined through a standardized screening tool administered by trained staff at the center. A common problem, however, especially for people who are uncomfortable (or unable) to discuss behavioral health issues, is to hold back specific details about their situation and illness from the evaluator. Marcia viewed this as a system breakdown stemming from stigma about mental health issues, but also a lack of transparency about how the behavioral health system works in the community. She maintained:

> "A lot of times what happens is a person will come in and they'll be referred to us from somebody like the schools. And then they're sitting face-to- face with the evaluator, and the evaluator's asking them questions and they're saying their answers, and then the evaluator scores them at the end using an objective tool that we have. And they don't score high enough. And so then the referral source is like, 'Are you kidding? Did they tell you about this, and this, and this?' Well, no. [The client will say:] 'You didn't ask that question. I didn't know you wanted me to tell you that.' And so, then it's like, 'Okay, we can only make a decision based on what we're told."

The standardized screening protocol—viewed as an objective information tool—becomes a barrier for many people seeking care. The evaluation process does not account for people who struggle to vocalize the pain and trauma of illness and classifications of severity are often wrong due to faulty or missing data. Furthermore, with little understanding about how the test is scored it is difficult to challenge the results that come from a “black-boxed” system, even when the severity of illness seems glaringly obvious. Efforts to get better information to evaluators are complicated by needs to protect people’s privacy. For example, referring clinicians and social workers in schools, courts, and clinics often have critical information about people’s behavioral health issues, such as struggles with substance abuse, financial troubles, and family dysfunction, are currently excluded from the evaluation process.

Evaluation breakdowns where people are being denied care is often a matter of life and death. A community health worker described the courage it takes for people she knows to engage behavioral health services:

> “They are scared to death about stepping foot into this building. They have no idea what to expect. And then when they sit through a 45-minute screen and you tell them, ‘Go back to your insurance company’…And then we find them in the ER. That’s what happens; or worse, they could just end their own life.”

After Janine was told she wasn’t eligible for low-cost treatment, she considered various options for self-care. Fearful that the side effects of withdrawing from antidepressants would affect her ability to care for her mother, who by now was completely dependent on her, Janine turned to her friends for help. Amid tears, she recalled:

> “Without my insurance, I ran out of medications and I couldn’t hardly function. You’re supposed to be weaned off. I had friends. I was calling them up, “Do you have any pills?” I’m serious. I had to deal with my mother...I took the pills and cut them up—trying to stretch it out.”

Janine got through several months with borrowed medication, but life soon spiraled further out of control. She went through a grueling court case related to her assault and simultaneously lost her mother. Desperate, Janine sought help from her former family physician who gave her free samples of Xanax to help tie her over till her Medicaid insurance came through. Despite knowing “how to fight the system” from her years as a social worker, she still couldn’t stop her fall between the cracks. Janine’s story highlights how the experience of care is sociotechnically messy, dependent on access to resources, as well as an ability to navigate opaque processes. When the medical system fails to address human complexity—reducing suffering to a numerical score—people turn elsewhere. As a community, maintained Janine, “We can do better.”

The Care/Repair Work of Behavioral Health: On Living with Breakdown(s)

It required a great deal of effort to manage chronic mental illness in the face of routine breakdown; a situation which gave rise to particular forms of information work and emotional labor. Maintaining one’s body in the face of precarious systems can be understood as a type of hybrid care/repair work, one that had significant costs for a number of people living in Jackson.

Jumping Hoops and Repeating Loops

Many people who lived with chronic behavioral health issues spoke about the long-term difficulties in managing their health and accessing care within a fragmented healthcare system. Chuck, managing depression and a neck injury with marginal insurance, noted that he struggles with the uncertainty of the system he finds himself enmeshed in, likening getting care to a game of chance that he can’t stop playing despite not being able to win,

> “It’s like a game of roulette for me right now. Luck of the draw…I’ve been the man under the stick when it comes to the health care system the last 10 years. It has been rough, but I’m pulling through it.”

Pulling through it for Chuck means having nights when he can’t sleep in his bed because he is in so much pain. He resists filling the prescription for pain medication he has been given, fearful of addiction to opioids. Lying on the floor of his trailer he stares at the ceiling and counts through the spasms. His wife tried to find him find him help but finding a local clinician with the appropriate expertise who also takes his insurance is a challenge. After treating him for a few months without success, his family physician recommended he see a behavioral health specialist, yet there is a constant turn-over of psychiatrists. Many doctors have ended up leaving the Jackson area before Chuck even gets close to his appointment date, sometimes made half a year in advance. Much of his time is now spent on the phone, calling offices and waiting for a response. “I have called places for them to give me more numbers to call,” Chuck explained:

> “Here’s a resource, here’s a resource. Then you call them and have to go through these people. Half the time, it’s not even local. You have to relay everything to the person all over again. You get put on hold.”

Chuck talks about care as a series of tangled loops he has struggled with jumping through for the last two years:

> “It’s hard to deal with it, because you can’t get through the system…. It loops. You can’t get through the loops. Loop this, loop that, jump this, jump that. You give up, and then what happens? You’re popping stuff you shouldn’t be. Because you have no choice. You weren’t getting the care you needed. I’m only two years in. Could you imagine the people that have been out there 10, 15 years dealing with this? Can you imagine, because they’re not getting the care they need or the attention. …You should seek help if you need it. But if it’s not there, you don’t know where it is, you don’t know how to [access care]…. what do you do?”

The lived experience of behavioral health for many people is encountering medical services that feel like a black boxed system, one with an impenetrable logic that twists and turns in ways that can’t be figured out or engaged with. Sometimes this makes people frustrated, angry and edgy, but so too, it can wear them down. As Chuck found from the years of going between primary doctors and specialists, he is “right back to where I started.”

Managing chronic behavioral conditions over the course of a lifetime makes navigating jumping hoops and navigating loops all the more difficult. Annie, a 32-year-old single mother, who has received treatment for bipolar disorder since she was 12 years old, knows the ins and outs of managing behavioral health—trying medications, going to therapy—and the sheer amount of work and effort it takes to engage the medical system day in and day out. She described bipolar disorder as “the ever-present,” noting she can only remember a few times in her life when she felt really good. Mostly she is just trying to get through her day and manage her moods:

> “I’ve been dealing with it [depression] for a really long time. I’ve tried almost all the drugs out there that you can imagine. Been through therapy. It seems to help in the short term, but for the long-term picture it’s up and down like roller coaster. It’s really frustrating and defeating. At times you feel hopeless that you’re never going to get better, you’re never going to get better because

> all these medicines that are supposed to be helping you, they don't seem to touch me. It's monotonous and you get on autopilot after a while and the doctor suggests a new medicine. You're like, "Okay, sure."

The complexity of her condition, a series of ups and downs and failed medications, makes managing the uncertainty of the medical system all the more fraught. Sometimes the monotony of maintaining her health year after year emotionally weighs her down and she goes into "autopilot"; other times, Annie tries to engage the healthcare system for her daughter's sake. The desire to be a healthy and strong mom gets her through the dark times. It is difficult to be an engaged patient, however, given how her health situation shifts day-to-day while clinical appointments need to be scheduled up to months in advance. When she is having a bad day, Annie explained that sometimes she is finds herself too depressed to get out of bed and brush her teeth, let alone find a doctor is free to see her and also takes her insurance. If a previously scheduled appointment happens to come around on a good day, she often cancels the appointment. Sometimes this is because it is hard to get off of work and she needs the hours, other times because it doesn't make sense to spend half the day (and money) at the clinic when she is could be spending quality time with her daughter instead. "Your feelings and thoughts change on a day-to-day basis," Annie shared with me:

> "There have been times when I've been severely depressed, and when I finally get there [the clinic], I might have had a good day. I'm thinking, 'I don't need this.' Then, two days later, I'm right back down to the bottom."

Getting the needed medical services at the right time while factoring in the chemical uncertainties of depression is a daunting task. Annie described this as "completing the whole cycle of care":

> "It seems like you have to jump around to all these different doctors. The odds of completing the whole cycle correctly and getting the correct treatments are pretty slim for me. You'll skip the doctor here or you have to reschedule here. You don't get in there. Then they prescribe you something and the pharmacy doesn't have it. You get a generic and then your insurance doesn't cover it. It's one barrier after the next."

In making doctor's appointments, getting new medication, and figuring out her changing insurance policies, Annie describes how her life is intimately entangled within a precarious infrastructure through the management of her illness:

> "This is my life… I feel like I'm trapped going to appointment after appointment after appointment, and most of the time, not figuring anything out…Some days, I can't do it. I can't make myself go. I'm over it. I'm done. I'm not going and a week later, I'm like I need to go now and I'll make an appointment."

In this way, Annie's ability to function physically, but also her work schedule and even role as a parent are interconnected with healthcare system.

The emotional labor and pain of jumping through endless hoops (with not enough to show for one's efforts) wears on many people I spoke with in Jackson. In interviews, people recounted the work that went into trying to figure out their care during the liminal time in-between doctors' appointments and medical services. The experience of navigating a precarious cycle of care with a chronic health condition involves detailed information work to find resources but also a great deal of emotional labor to live with routine breakdowns. One resident of Jackson shared the emotional and physical costs of care/repair work:

> "It really brings you down. It hurts. You cry because you hurt. You're not getting anywhere. It takes so long to get in and it hurts. I'm about ready to cry right now from two years of dealing with the same pain. It takes time, I understand. But when you can't get in to see somebody for months, six months, whatever …Waiting. Feeling worse. Getting down because nobody wants to help you. That's the way you feel. Nobody wants to get you on the right track...Even though you know some doctors do, they are trying, they are fighting, they are doing what they can do. But you don't feel like you're getting it. It's like rush, rush, rush, rush. Then you're on your own again."

A sense of being on one's own was a feeling expressed by many people living with behavioral health conditions in Jackson. In-between appointments, on the edges of medical world, people relied on a wide range of workarounds and self-care practices to "patch up" bodies broken down by chronic depression, pain and anxiety.

Tinkering with Therapies: Experimenting with Medications and Moods

One of the everyday concerns people faced was managing their medications, a complex task given behavioral health conditions that changed over time, interactions between multiple drugs, fears of addiction, and loss of dosage efficacy with long-term use. People often tinkered with their medications, usually with some level of clinical oversight, but many times by themselves or with close friends or family members in order to manage negative side-effects or symptoms of withdraw that occurred in the months that stretched between doctor's appointments.

Taking powerful drugs that alter one's chemistry, mood, and even personality was often frightening, even when holding a prescription was in hand. Common side effects, such as uncontrollable shaking, mood swings, loss of memory, and mental fogginess, all impacted quality of life to such an extent that people regularly took themselves off medications by either going "cold-turkey" or tapering their doses over time by cutting pills in half or quarters. Other people would borrow pills from friends, or up their doses periodically when their medication stopped being as effective, local adaptations to find balance without getting bloodwork from a lab. The majority of these efforts at self-experimentation were a desperate attempt by people to keep their bodies going with daily care/repair work, making do and maintaining till they could get back into a doctor's office. Occasionally, however, the reason for going off medication was grounded in fear. People spoke openly about their anxieties of drug addiction and concerns with social stigma during our fieldwork; furthermore, many residents were also worried about their growing dependence on a medical system that was prone to failure for them. A woman in her late 60's who had been prescribed Xanax for anxiety and panic attacks explained why she took herself off medication: "You have to deal with it and get past it, because once you get off of this antidepressant, you are going to deal with it anyway. I took myself off of it [medication]. I would always wind myself off them." Ultimately, she felt a need to learn how to deal with her depression without reliance on the medical system.

People discovered that common behavioral health conditions like depression and bipolar disorder were easily diagnosed, but as chronic conditions, were also difficult to treat over time. Managing depression for the last 10 years, Margaret, a 46-year-old bus driver and mother of three teenagers, remembered going to her first doctor's visit for depression. She remembered thinking that she would soon be "fixed" and able to move on with her life: "I thought I would go to the doctors, they would know what's wrong with me or figure it out fairly quick, and I'd be good. I never knew that it was going to impact my life this much." As we spoke, Margaret admitted that she can't even remember every medication she's taken for her depression. "There are so many of them," she explained, wearily. "I swear I tried probably 15 of them out of [my family doctor's] office alone."

Margaret recounted her experience of care as an endless cycle of trial and error to find a treatment that enabled her to maintain her many family responsibilities. In the early days after diagnosis, Margaret did her best to be a compliant patient. She followed never forgot to take her medication and followed dosage instructions to the letter. Soon, however, she started having bad side effects from the medication and it scared her. She recalls being on Seroquel:

> "That was the worst medicine ever. If I couldn't devote 10 hours to sleep, I woke up in a rage. I truthfully thought I was going to hurt somebody. I was like, I can't take this... It was a horrible feeling to feel. I didn't even want to be around my kids because I'm like, I don't feel safe. I feel like I will do something."

When she brought up her concerns with her family doctor, he told her that she should keep track her sleep patterns and moods to work out how much rest she would need to maintain a healthy balance. A busy woman who works full-time and keeps up with her children's school activities and sports, Margaret gamely tried figuring out a rhythm for a few months, diligently logging hours of sleep: 8 hours, 9 hours, 8.5 hours, 7 hours, noting that she still felt the rage. The task of tracking her symptoms was difficult to manage on top of her illness and daily life.

> "I tried to track the length of what's going on so that I can give them a better understanding. I'll write it down, or I'll stick it in my phone. I'll send a text to my husband so that I can copy it later onto a piece of paper. I try to keep everything on my calendars…It's stressful and time-consuming."

Eventually, frustrated and exhausted by tracking, Margaret gave up taking Sereoquel. The medication was incompatible with both her job (where she needed to stay both calm and alert) and life as a hands-on parent (being there for her kids every football game and cheerleading practice). "I was like, I can't do this! If I can't devote 10 hours to sleep every single night for this medicine, I can't be on it." After quitting medication without her doctor's knowledge, she's been on the hunt for a treatment that can keep her sharp and focused and still help curb the irritable moods that comes with being chronically depressed. After years of going on and off different medications, she now takes a more active approach to her care.

> "In the beginning, I didn't have a lot of questions. I was like, they're doctors. They'll figure it out. Whatever they say goes. That's not been the case after many medications, [doctors] putting me down many times, and realizing this is not how I want to live. If I'm not comfortable on this drug, I'm not taking it, but it's taken a lot for me to get to that place. I think I'm to the point where I'm beyond irritated and beyond tired. I want the right type of help."

The Burden of the Clinical Encounter: Finding Help Amid Burnout

It was particularly hard to get "the right type of help" to manage behavioral health issues, to find a clinician who had the time, expertise, and personality to tinker with you. People noted that they needed clinicians to listen and help them figure out how medications interacted with their bodies, especially when they experienced negative side-effects. One systemic issue with medical delivery services was an overall lack of time, particularly in regards to impacting information exchange during patient visits. One Jackson resident with depression commented,

> "A lot of these doctors just push pills. I don't feel like they give you a lot of other tips and resources and coping mechanisms to deal with it...They're very brief and short and to the point. You're diagnosed and out the door. They don't really delve into anything."

Short appointment times—sometimes 10 minutes or less—made it difficult for people to share details related to the medications they were taking, such as tolerance or dosing issues.

When people found a "good clinician," namely someone they trusted to help them manage their medications, they tried hard not to lose them. One beloved nurse practitioner, Gina, who worked at a family health clinic was highly regarded for her tireless efforts in helping people find medications that worked with their lives, helping them keep doing what was important to them: hold on to a much-needed job, exercise pets outside, and take care other family members who counted on them to stay functional and strong. The story of Gina and her patient, Kathy, helps explicate the importance of clinicians who understand how medical treatment for behavioral health is interconnected to broader concerns, like domestic violence and substance abuse.

After moving to Jackson almost 15 years ago to be near her incarcerated husband, Kathy struggled to take care of two children on her own. She soon ended up getting a divorce, and a series of boyfriends came into her life who physically and emotionally abusive. Depressed, often to the point of nonfunctioning, Kathy drank heavily and began to use coke with her current partner. Her children were placed in foster care while she struggled to get clean and pull her life together, only to have it unravel again in the drama of dysfunctional personal relationships. Through this personal turmoil, Kathy had been on a number of different medications to manage her depression, including Effexor, Prozac and Zolloft. These prescriptions interacted with one another and at times seemed to exacerbate the symptoms of her illness. Hitting rock bottom, Kathy enrolled in a substance abuse program and started the hard work of "dealing with her demons."

It was at this vulnerable point that Kathy found Gina, a much-needed source of empathy and expertise. Formerly a nurse in a psychiatrists' office, Gina was familiar with the recovery program Kathy was attending and deeply aware of the need to treat trauma along with biochemistry. "I have been to a psychiatrist which I didn't like well," Kathy told us. "You have to mesh with them. You don't want to talk to someone that's very snooty, you can't understand what she's saying, and down to business. I can't open up to that." In contrast, Kathy felt Gina was concerned with her health and emotional well-being. "*She's the best. I can even talk to her about my ex boyfriends,"* Kathy shared. *"She actually cares*." Gina helped Kathy untangle her many prescriptions so that they could figure out what was working. Together they tried a lot of different combinations without success. Everything made Kathy feel "zombie-ish" or as if she didn't have any emotions. "I didn't like the way that I felt," recalled Kathy. "I wanted something that made me feel like I was still me." Eventually, Gina won a fight with the insurance to cover gene-testing for Kathy, which recommended a strong match with Latuda. "I've never felt better in my life," Kathy told us on starting a new treatment plan.

While a seeming triumphant narrative of an empathic clinician helping a traumatized patient, Gina and Kathy's story is more complex and fraught when one pulls back and analyzes the story in terms of the labor it takes to live well in relation to an ever-precarious health system. In the middle of Kathy's recovery, for instance, Gina ended up taking a job opportunity outside of Jackson. While the job didn't work out, for a few months she was gone and there was no one to fill the gap left behind. "She left and I was so broken hearted," acknowledged Kathy. Not feeling the same kinship with the other clinicians in the office, Kathy stopped going to appointments and her depression spiraled. Coming back to the clinic once again in bad shape, she saw Gina had returned as well. “She came back and I was like, “Oh my God! You’re back!” I so happy. She helps me with everything.” In helping a patient find a way through the brokenness of care, however, Gina also took on costly invisible work that was not valued or supported by the medical delivery system. Taking the time to figure out a strategy for managing complex health issues and social problems, she would get behind on appointments, often skipping lunches and working late. While patients like Kathy were deeply appreciative of Gina’s efforts, they were also dependent upon her being available and willing to take on difficult tasks that were not always rewarded by healthcare employers.

It was surprising to me at first how many people were highly attuned to the burdens of their clinicians. While frustrated with their own experience of care, patients were also keenly sympathetic to the nurses and doctors they encountered. In a precarious system, no one seemed to be thriving. One retired man with bipolar disorder, who himself was used to the hardships of line work on the factory floor, astutely observed that the doctors and nurses in his neighborhood clinic “just look overwhelmed.” He elaborated:

> “You can see it whenever you see them. They are beat down. They’re tired. They’ve been working 12, 14 hours straight. That’s when accidents happen. They’re working too long, too hard. Yes, they might want to work like that, but take the burden off because they’re making people fall into these cracks because they can’t spend the time with them."

Too many patients and not enough doctors often leads to Jackson residents dealing with missed messages, mixed-up prescriptions, and too often, a rote, mechanized form of care. It is perhaps less surprising that people expressed concern for their clinicians when one realizes that care work can often look very similar to manufacturing labor. One care delivery solution might be to try adding more “Ginas” into the system; and, in fact, this was an approach taken by the Jackson health leaders who launched an innovative program of care coordination using trained social workers and nurses to help connect people with severe health conditions to local resources. And yet, even with a community-led investment into healthcare infrastructure, it is not easy to replicate the work of Gina on a larger scale. The blend of personal rapport, local understanding, and hands-on clinical knowledge that helped Kathy achieve a moment of stability in life is different for every patient.

Helping people navigate the complex intersections of biomedical and social concerns, so common in behavioral health, is not an area not well understood by most clinicians. In this study, for instance, I found doctors on the front lines of care rarely probed into social issues like trauma and abuse as it related to managing behavioral health issues. This was not only because clinicians were tired, rushed, and quite possibly depressed themselves, but also because it was in these situations that the logic of medicine itself broke down. Without established guidelines and clear treatment protocols, it was uncertain if probing into dark, messy, but also very human stories of abuse and addiction would be any more efficacious for a patient than simply writing out a prescription. Furthermore, screening for trauma felt brutal without having any local and affordable resources in place to assist people in managing those difficult situations. While a health infrastructure dependent on patient care/repair work was clearly broken, purely clinical interventions into complex community issues had the potential to disrupt care in problematic ways. I further explicate what this looked like for Jackson residents in the following section.

Bearing the Cost of Care Work in the Infrastructural Shadows

In the former section, I detailed the myriad of ways that care breaks down in Jackson, including both systemic gaps and small-scale cracks. In documenting lived experience of breakdown, I was struck by the beforementioned quote from one resident:

> "You should seek help if you need it. But if it's not there, and you don't know where it is, or you don't know how to [access care]…What do you do?"

Taking this query as a starting point for further investigation, I broadened the scope of my inquiry to examine a wider ecology of care beyond clinical settings to focus attention on behavioral health workarounds found in a diverse range of social worlds.

I discovered a number of people in Jackson who—for reasons both practical and personal—sought alternative care arrangements outside of the formal medical system. At times, people fell out of the system through the loss of health insurance. Others had a bad experience with doctors or lost the support of family. Outside of formal care, people engaged in a type of DIY (do-it-yourself) mental health management where self-care involved tinkering with bodies, food and herbal supplements, as well as prayer and prescription medications. In this section, then, I discuss findings from two social worlds, namely, medical cannabis users and faith-based communities, that provide an interesting contrast in terms of care practices and logics. In doing so, I also draw attention to the personal costs of performing care/repair work in the infrastructural shadows among social worlds whose understanding of health and wellness does not neatly align with standard biomedical treatments prescribed in formal clinical spaces.

The Moral Weight of Workarounds: Self-Medicating with Cannabis

Riding past a series of identical square, concrete buildings that made up a shopping strip on a busy thoroughfare, the driveway for the family health clinic was almost hidden if you didn't know where to look, sandwiched in-between an ancient-looking Arby's and a discount tire store. Pulling behind the stores to a private parking lot gave view to a neat, new structure with large plate windows and a welcoming sign. Inside, a tidy waiting room was packed even in the middle of a work day, its plastic chairs filled with patients: a sick teenager sitting next to a frazzled-looking parent, an elderly couple with matching walkers, a young, pregnant woman looking like she was ready to deliver at any moment. Beyond the waiting room doors and the reception area, private consultation rooms lined the outside walls while a team of doctors and nurses pooled around central workstation table, swapping folders and perched on stools as they filled out patient charts on computer terminals. A couple of young nurses huddled together sharing a quick laugh before breaking apart and hustling in separate directions to meet with individual patients.

On entering the clinic, one is left with an impression of professional camaraderie and bustling activity: this is a place where work gets done, and done well. The staff works hard to earn the trust of people who walk in the door and let them know they are in good hands, their efforts all the more impressive given that they work with a complex patient population, indeed some of the poorest and sickest in Jackson. Although they have no trained psychiatrists or psychologists on staff, the majority of their patients have at least one health condition like diabetes, kidney disease, hypertension, and chronic pain and are also taking medication to manage behavioral health issues like depression, bipolar disorder, schizophrenia, and anxiety.

Conducting interviews with people in a private office space next to the clinic, it is easy to imagine medical spaces like this one as the epicenter of care activity in Jackson. And while people did rely on clinical services for managing behavioral health issues, we found that neighborhood clinics, hospitals and doctor's offices represented only one of the many social worlds where people sought care. People were sometimes hesitant at first to speak of those worlds, fearing stigma or misunderstanding, but slowly, over the course of a two-hour interview in which moments of anguish were recounted and tissues passed around, people opened up and started sharing about alternative sites of care/repair practices. Care outside of the clinic was spread out over Jackson in chiropractors' offices, corner bars and health food stores. There was a little store downtown that sold crystals and could do acupuncture. A local lady knew about cupping. A friend of a friend could get you weed even if you didn't have a medical marijuana card.

Indeed, many of the people I spoke with were using (or had tried) cannabis to manage behavioral health conditions. At the time of this study, there was one licensed marijuana dispensary in the city of Jackson, although I was told by interlocutors that the city had recently shut down other stores. Residents of the city were legally permitted to have an ounce of marijuana in their homes. While there were a wide variety of reasons for use, many people described it as a self-medicating strategy for chronic conditions that were difficult to treat, even with the best clinical help. Sometimes people used it when they didn't have insurance; others found that it helped them manage their symptoms with fewer side-effects and less risk of addition than prescription medication. Some people took it to sleep through the night, others to calm their anxiety or anger during the day. While cannabis use varied in terms of method, frequency, and reasoning, it was telling that almost no one discussed their usage with clinicians. Information on how cannabis might affect their behavioral health conditions was scarce. People took a DIY-approach, experimenting to see how cannabis might interact with other prescribed medications and finding strategies and advice for dosing at medical marijuana dispensaries, online forums, or among family members and friends.

Bill's emotionally fraught experience with trying to get help for depression in a precarious healthcare system, told in the introduction of this paper, is also a story of seeking help in the infrastructural shadows. His narrative illustrates some of the practices around self-medicating with cannabis, but also the moral weight such workarounds held for those living in Jackson. Self-medicating with substances started in his early twenties when Bill was still employed at his good auto manufacturing job. He viewed it as a way of coping with stress of a demanding, but repetitive workplace. For many years, Bill worked a lonely second shift from 4 p.m. to midnight while his family ate dinner together and went to bed without him. "You couldn't really talk to anybody," he mused, describing what it was like to be on the factory floor. He explained the stress of assembly line work for him and many of his friends in Jackson:

> "You either had 11 seconds or 30 seconds to get your job done before the next panel came by. For every second that the line is down, that's $1,000 that [the company] is losing. There were 50, 60 people on my line. I think the pressure to succeed and not to fail… you had the peer pressure of everybody else around you. If you keep screwing up and you're stopping the line, you're going to piss people off. You're creating friction for yourself at breaks."

The stress only increased when workers got loaned out to other lines temporarily, a common situation when one had low seniority. Bill often found himself struggling with anxiety on the job which often led to anger problems at home. "My problem is aggression," admitted Bill. "That and depression. I'm not sure when it started or how it came about. Every ending to the conflict, in my view, was to pound on somebody." Needing to keep it together to hold down his job and his family together, Bill found ways of coping. He'd carry an iPod to listen to music while on the line. Sometimes during his lunch breaks he would take a quick ride down the street from the plant and park his truck in the woods to smoke a bit of reefer to calm himself down the rest of the night. After his shift ended he would often grab drink and play ball with the guys from work to unwind before heading home to his sleeping family. He credited occasional marijuana use with helping him manage the worst of his stress and anxiety. "If I use," explained Bill, "I can plug myself enough to mellow to where my family can deal with me." He continued:

> "It's part of my lifestyle, but when I'm feeling anxious and I don't have anxiety medicine, that's my got-to. I don't have a large quantity or anything…I don't use anything else."

After Bill lost his job at the plant and then injured his lower back, his self-medicating strategies of using cannabis to cope started to fail him. Struggling to live with intense, chronic pain, his depression spiraled and he smoked and drank more. Through it all, however, what he feared most was turning to narcotics like Vicodin seeing old friends from work become addicted. "You keep popping more," Bill said, explaining how people in the community will do pretty much anything to be able to keep on working on the line.

> "I've got a friend that did it, and now he'll take two or three at a time…He's taking the pills like they [doctors] are telling him to. But it shouldn't have to come to popping them just to get through your day…To overtake them because the pain is getting worse, and

> nobody will do anything, so you just pop it. Anything you can do to dull it so you can have a life. You lose everything once you get to the crowning pain."

Determined not to lose anything else important to him—particularly, the close relationships he has with his wife and children—Bill refused to take any pain medication, instead relying on a combination of cannabis and anxiety medication prescribed by his doctors to manage his behavioral health issues. Bill doesn't have a medical cannabis card, instead relying on a local network of friends to help him. "I know people who grow it and I can go help them out and they'll give me a little," explained Bill, "That's how I get mine. I don't have it every day, but I do it." One local grower Bill knows got into marijuana farming after a family member got cancer and wanted an alternative pain treatment. While the grower has plans to do things legally and get licensed to supply a dispensary, right now, he works quietly from his farm just outside the city with only a small circle of trusted family and friends.

People talked about how they relied upon people in the community to figure out strategies of using cannabis to help manage behavioral health issues, sharing information and practices. "I have a friend that's a caregiver," one young woman with depression explained, "and he makes oils and you name it. I can go to him at times…He has helped me out with, 'Use this for this.' Another older man shared how he did research on what to buy: "Years and years it's been out there. My wife was looking into different things. Talking to friends, people are like, 'Yes, CBD oil[7] is really great for this…'People that have been through it." While this social approach served many people well, others mentioned challenges in figuring out if cannabis might interact with other medications, such as herbal supplements or antidepressants. A resident who was interested in using cannabis to manage anxiety worried about causing a "chemical imbalance" if she took it at the same time as her prescription medications, noting:

> "[Cannabis] could have alternate affects, because it is a psychotropic and you're on psychiatric meds. It's probably something I'll be looking into to see if because obviously CBC doesn't have THC in it. It might not affect it as much. I might just lean towards that way."

---

[7] Cannabidiols (CBD) is one of the many cannabinoid compounds identified in cannabis. Importantly, for many patients with behavioral health issues, CBD does not have intoxicating effects commonly caused by tetrahydrocannabinol (THC). THC is the compound associated with people getting "high."

Concerned about possible negative outcomes of THC and smoking on asthma, she followed the advice of a friend and decided to restrict her use to CBC lotions, waters, or medicals while on her prescription medications.

Although a few people mentioned they didn't think cannabis should be regulated by the state, the majority of people I spoke with who used or were interested in using cannabis for managing behavioral health conditions expressed a desire to do it "the legit way" and go through a licensed dispensary and get a medical marijuana card. Clinical information and guidance on cannabis use, however, was often hard to find in Jackson, and people described a number of barriers to doing this type of care/repair work openly with the help of doctors. Amy's experiences help illustrate some of the costs and tensions that come with using medical cannabis in Jackson.

I met with Amy after a visit to her family doctor. While small in stature, Amy was also wiry and fierce. Growing up on a farm outside of Jackson, she talked with pride about working together as a family, learning how to can fruit from her grandmother and raise livestock from her brothers. Even though she has left the farm behind, she still viewed herself as a capable person who can survive hardships and make tough decisions. When our conversation turned to her health, however, her voice wavered. Depression had been a disruptive force in her life over the last several years; and figuring out how to manage her health was difficult, even with hard work and family support.

Amy took a straightforward approach in describing her varied care experiences both in and out of the clinic, including her experiments with using cannabis to manage her fibromyalgia pain and chronic depression. "It's expensive!" she lamented with a wry laugh. A stay-at-home mother of four children, Amy was an expert in stretching her husband's salary to cover food and rent. As a truck driver, he often works irregular hours, and some months are more difficult than others for the family. Her health situation often made her feel guilty because she knows it puts more stress on her partner, who she calls "a really good guy."

Cannabis was one of many treatments Amy had tried over the years in an effort feel better. She explained how she became disenchanted with the various prescription medications she took (and her family had to sacrifice to buy) which were only marginally helpful in controlling her symptoms. One day, Amy's mother, who herself suffers from arthritis, talked about trying cannabis together. "She was on a webpage of a lady and she sold the little chewable, oils and stuff," remembered Amy. "My mom's like, 'I was reading the comments, and all these people are saying it's helpful and it manages knee pain, back pain, and neck pain. Why don't we try it? Order it and see. It can't hurt to try.'" Amy told me it took some convincing, but that her husband encouraged her to investigate medical cannabis as he was concerned about the emotional and physical toll her health problems were having both on her and on the children. Once an energetic whirlwind in managing her household affairs, there were days now when her pain kept her in bed.

Hopeful that cannabis might bring some much-needed relief, Amy persisted in learning about treatment options despite the challenges of trying a therapy that wasn't covered by their health insurance policy. The financial costs quickly added up. First, she needed to spend $125 to have an initial doctor's consultation and then another $75 to be issued an official medical marijuana card. The doctor Amy saw for her medical marijuana card was brusque and not very interested in giving her guidance on how to use cannabis for her health conditions. "He treated me like I was just a pill popper," Amy told me, noting the memory of clinical judgement still rankled. At the local dispensary, she puzzled through the various options on her own and tried to figure out what might be a therapeutic dose. Not comfortable with the idea of smoking with her children in the home, Amy looked into different oils and edibles and recalled being taken aback by the prices, "Three gummies were $20, and you're supposed to take, I don't even remember how many a day." Anxious, she bought a few CBC gummies to try out and took them home to split with her mother.

It was a huge disappointment when the cannabis didn't work as she expected. "I didn't feel any relief, anything," recalled Amy. "When I tried it with the THC in it, it was a horrible feeling...I felt like I couldn't walk right." Her mother, however, fared better and found the gummies useful in taking the edge off her pain. Amy considered trying other cannabis options, such as CBD oils, which a friend told her wouldn't make her high. But shortly after she got her card, her husband's work hours were cut back. Unable to afford additional experiments, Amy didn't go back to the dispensary again and gave the rest of the gummies to her mother.

Despite not using cannabis, she is still registered as having a medical marijuana card on her patient record, a piece of information that all her doctors can see. Amy vehemently maintains that there is a stigma attached with getting the card and has noticed the ways clinicians treat her differently when she goes in for consultations. For example, Amy described how she went to see a local surgeon for an ongoing neck problem (she had been badly injured in a car accident as a teenager) who talked to her as if she was an addict:

> "He found out that I got that [card]. He got really mad at me. He lashed out at me…He said, 'With this medicine and your medical marijuana, you shouldn't be feeling a thing. Three months? Does that sound good to you? You come back in three months and see me.'"

Amy is still angry and upset about the encounter, feeling as if the doctor dismissed her concerns and the complexity of her medical situation. "It shouldn't be like that," she argued, passionately:

> "I don't care if you're a doctor, what your opinion is, you shouldn't push that on the patient. Because you don't like it, I understand. But don't be mean about it. He was [mean]. He was really rude to me."

The injustice of such judgements felt particularly harsh as Amy continued to struggle with depression and pain.

Other people in Jackson echoed Amy's concerns that having a medical marijuana card on your patient record could impact the attention and respect you were given during clinical encounters. A concern about stigma kept many people from getting cards or informing clinicians about their self-medicating practices, even when it might affect how they used prescription medications. People were also anxious about withholding important medical information from clinicians. One resident who uses oils told me that a strategy of evasion, while necessary to keep his doctor happy with him, stresses him out. "The doctor asks, 'Do you smoke marijuana?' No. Technically I would be lying if I said yes, because I'm not getting it from a dispensary. So I'm like, no." While people feared doctors would drop them or be angry if they discovered cannabis use, they also often felt misunderstood in adopting these alternative health practices. Cannabis, for many residents, was a useful way of managing pain and coping with chronic illness. Importantly, for some it was much less frightening than taking pharmaceuticals like antidepressants or prescription pain medication which people viewed as being highly addictive and having negative side-effects.

Given the many breakdowns of the formal medical system, people found strategies and ways of coping with complex behavioral health conditions. This care/repair work required subterfuge—keeping information in the shadows, hidden from the legal authorities, but also medical providers. People in Jackson had to wrestle with the moral weight of their workarounds as those with medical marijuana cards were not seen as engaged patients who were legitimately trying to take care of themselves. Viewed by many clinicians with skepticism or judgement, the costs and labor of self-medicating with cannabis was often invisible, taken on by people who were trying to "make do" in precarious circumstances.

The Multiple Meaning(s) of Care: Brokenness and Hope in Faith-Based Communities

Some of the most visible alternative care practices I discovered in Jackson were centered around the social worlds of churches rather than clinics. Many residents maintained that faith-based communities provided an important source of care for people living with behavioral health conditions, offering places to talk about personal difficulties, but also to get a warm plate of food when they fell upon difficult times. In this section, I use faith-based communities as an alternative site of care/repair activities that take place outside the boundaries of the formal behavioral health system.

There is a wide variety of churches in Jackson. A large, traditional Catholic church sat downtown along with a handful of mainline, Protestant dominations. Some of these faith communities were progressive in politics and theology, and a number of them were contrastingly conservative. For instance, several large, independent evangelical churches were built on the outskirts of Jackson and driving through Jackson you could see small storefront Pentecostal churches around the city center. Faith-based groups offered specific behavioral health programs, including one-on-one counseling with clergy, support groups for depression, grief, and substance abuse, and even at one church, a dedicated center with licensed therapists. Such programs were utilized by church attendees along with their friends and family members, but were also a valued resource for non-religious people in the neighborhood who needed free or low-cost therapy options.

Importantly, faith-based organizations sought to address a number of the wider social issues—such as poverty, loneliness, and trauma—that often impacted behavioral health conditions for people living in Jackson in ways that medical institutions could not. Churches, for instance, ran food pantries and hosted free community dinners. They provided financial assistance for emergency utilities fees and rent payments and offered job training and assistance for a Jackson's large population of parolees. A pastor described the most common types of encounters with her church as "crisis-driven," explaining:

> "Oftentimes people come to us with a financial need first. They look to the church for resources of some sort. Sometimes they are looking for childcare or a mentor for their child…And when people are at that level of asking, they're usually frequently also in some kind of crisis."

In contrast with the tightly regulated world of medicine, clergy members and lay leadership tried to have an open-door policy in meeting with people during times of crisis, moments when a person's deepest needs and vulnerabilities were exposed. People living with chronic behavioral health conditions also found the church a place that could address some of the long-term of care challenges that came with being alone without any close family members to rely upon, including taking people to appointments, checking in on people at home, and providing social support. A clergy member described his church as taking an approach of "embracing and living with" chronic behavioral health conditions.

Renee's story highlights some of these care complexities that faith communities come to address. In her 40's, Renee's grown son overdosed. In the years following his death she went from managing natural feelings of grief to experiencing a full-blown depressive episode that left her unable to cope for months on end. After losing her job, she fell on hard times and routinely visited local churches for free food as well as the company. Although not particularly religious, Renee acknowledged finding relief in talking with the minister about missing her son—something she could not do with either her doctor or social worker. "Last time I talked to my doctor was over a year ago," Renee recalled, continuing:

> "He just wrote out prescriptions and that was it. I didn't share my son with him. He's the one that said I was bipolar and depressed. He said I had a lot of anxiety. He wrote out my prescriptions and left. No talking, just a few questions and that was it...I feel like I need to talk to somebody."

For many people like Renee, empathy and understanding were an important part of care that was missing from medical encounters. Although she takes her medication without fail, she also needs someone who has time to listen.

> "The reverend helps out a lot. He'll take you in the office and talk to you. He doesn't give you the stuff and say bye. He'll talk to you about things, ask, 'How's it going? How's your life going?' and stuff like that. Relieves some of that stress before you leave. I feel good when I walk out of there. I feel relief."

Renee was not alone in looking to the church to seek some relief from her emotional pain. Given the gaps in the formal medical system, clergy were often called upon to perform care work with little support or training. One pastor we spoke with noted wryly: "There is an old joke that a pastor will sometimes hang a sign out front that says, 'Cheapest psychologist in town.'"

The labor involved in caring for a large population of people in crisis is often overwhelming. "There are 40 small groups of people meeting weekly," shared one minister of a large Jackson church with over 300 members, "every one of them dealing with some kind of mental health issue in some way. I could counsel people 24/7." While some of the clergy were licensed counselors, others had little formal training other than a handful of pastoral counseling classes taken in seminary. One rare exception, a pastor with dual graduate degree in psychology, noted that she often draws upon her background. If someone comes to her with a serious behavioral health issue she performs a risk assessment and tries to help people navigate the first few steps of getting medical services.

However, a few pastors discussed how this type of work often puts them in uncertain waters both in terms of sharing medical information, but also morally and legally. "I can talk to you like a pastor, I can't be your counselor," explained one church leader in recounting how he interacts with people who seek care at the church: "That's to protect my own liability, but also to make sure they understand. And I think it's a kind of informed consent." Another pastor described her approach, "I'm not going to be meeting continually with somebody. It's not my area of expertise, so I'm pretty quick to refer to other professionals in the area." While some pastors wanted to offload the heavy responsibilities of behavioral health care; importantly, some clergy saw referrals as a pastoral activity, one where they guided people to a trusted medical resource. A pastor who has lived and worked in Jackson for many years told us about a hand-written resource list he maintained over the years which make note of all the behavioral health specialists in organizations where he had a personal contact or connection. He updates it routinely so he doesn't send desperate people back into an infrastructural gap, but to someone he knows and trusts. At times, however, a specific need arises or the demand is too high, and his go-to list falls short. During those times he turns to his congregation for help: "I'm just simply stumbling upon a resource through someone I know. Often times these pathways are very murky and not clear."

Often people came to churches seeking behavioral health help (even when they had medical insurance or could afford counseling services) because they wanted health advice from someone who shared their faith perspective. While pastors maintain that faith-based resources filled an important need, they also sought to educate people about what to expect in seeking clinical help for behavioral health problems. Rev. Judy, a minster of a small, evangelical congregation in Jackson, observed:

> "I know that the Christian community will perceive mental health issues as deeply connected to their spiritual formation. And then therefore, will be highly selective how they seek help. Mostly because they're just kind of frozen because they don't know what comes next. They might not have an appropriate view of the mental health community."

Rev. Judy shared how she recently counseled a mother whose teenage daughter was struggling with suicidal ideation and the family was caught up in finding a psychiatrist from the same denomination.

> "I can tell you that part of my work is to make sure people understand that they don't always need a Christian counselor, that it is not essential for all things, and that some things are so serious that you ought not be wasting your time trying to find this perfect fit that may not exist. I made it really clear to her that if it was my own daughter, that I'd be looking for somebody who was really good at dealing with depression and suicide before I'd be looking for someone who was specifically Christian."

When people are uncomfortable with the idea of psychiatric care, however, pastors find themselves called upon to perform what Steinhardt and Jackson (2015) in their study of large-scale scientific infrastructure call anticipation work or "the practices that cultivate and channel expectations of the future, design pathways into those imaginations, and maintain those visions in the face of a dynamic world" (ibid, 2015, p.443). In relation to a precarious health infrastructure, anticipation work included guiding and educating people about what types of activities they can expect to encounter in therapy and helping them construct a narrative that connects therapeutic treatment to their religious worldview. Rev. Judy described how this work unfolds:

> "When I am making a recommendation to them about seeking additional counseling, I will often give them sort of like an overview, broad picture of what they might expect, and why it's important to stay with it. I'll tell them, 'If you go through these services, you're probably going to get cognitive behavioral counseling."

For those more comfortable outside the formal health system, alternative care/repair work involves reconciling fears of the unknown and finding paths forward when medical treatment doesn't align with faith traditions.

Care Conflicts and Spiritual Logics

Faith-based leaders in Jackson were upfront about negotiating conflicting viewpoints of behavioral health in their churches. In some conservative congregations, for instance, mental health had been both historically stigmatized and dangerously "spiritualized." A local minister explained:

> "I would say the church as a whole has not done a good job with mental health. That has been an area that was either ignored or stigmatized or people were kind of just told, 'Oh, get over it.' Or, it was honestly, over-spiritualized to where something like depression, which could be chemically induced, there could be lots of external [e.g. spiritual] sources. Someone would say, 'Well, that's a spiritual problem. You just need to keep praying."

Those clergy who sought to maintain the connection between spiritual systems of care and the world of institutionalized medicine found themselves taking on a great deal of care/repair work, negotiating with other faith-based community members and those within their own congregations. Sometimes, however, these care conflicts couldn't easily be patched up.

Sofia, a devout churchgoer who also lived with chronic depression, told us about the tensions between her faith (which helps manage her pain) and the stigma her faith community holds towards clinical behavioral health therapies like antidepressants. "I'm Pentecostal. My three cousins, we all get together, go to church and bible study. It helps." While at church, however, Sofia does not tell her pastor or church leaders about her depression. "They believe in the Pentecostal church that you shouldn't take any medication," she shared. "I believe strongly that God gave man [medical] knowledge." Reflecting on the people she knows in her church, she acknowledged that others probably take medication quietly too without any forms of community support or understanding.

Experiences like Sofia's were deeply troubling to many faith-based leaders we spoke with; in fact, one minister decried strict practices of faith healing as "causing harm" to the Jackson community. However, rather than seeking to reconcile care logics, or keep them artificially separated, I discovered people creating ways of holding disparate systems together. This workaround involved "thinking theologically about therapy and thinking therapeutically about theology, and how those interact," as one pastor articulated his alternative care/repair work. He further explicated his role in community health:

> " I am trying to see people holistically as spiritual, physical, and psychological; my hope would be that then the person [e.g. therapist] I am sending to them would see them in the same way. And that what we're doing is in tandem and in conjunction with each other as opposed to just a silo where, "This is just what I deal with."

In crafting holistic narratives of care, faith-based communities in Jackson are finding creative ways in/around/through the gaps of a broken health infrastructure as well as imagining new futures where medical systems and religious practice might be brought together in helpful ways. While offering hope and comfort to their neighbors in times of crisis, however, the resources of these faith-based organizations were often stretched thin in order to meet growing community behavioral health needs. Furthermore, this type of spiritually-centered care/repair work, while important to many residents in Jackson, was poorly understood and marginalized in medical contexts.

PRECARIOUS INTERVENTIONS: DESIGNING FOR ECOLOGIES OF CARE

Throughout this paper, I analyzed people's everyday behavioral health activities through the lens of infrastructure, looking at breakdowns and workarounds as part of a relational process, a way of living with unruly bodies and unreliable medical systems. For people in Jackson, care—experienced simultaneously as enigmatic science, endless routine, moral reckoning, constant hope and searching, and often disappointment—played out through depression screenings, prescription plans, cannabidiol gummies, denials for insurance coverage, and prayer. I documented how living with infrastructural brokenness was both emotionally difficult and labor intensive for many in Jackson, including clinicians; however, the costs that came with creating workarounds were primarily born by lay people: patients, family members, friends and concerned community members. In managing medications, getting a state-approved medical marijuana card or giving/receiving therapy, people routinely opened themselves up to a number of vulnerabilities: chemical and relational dependencies, judgement from clinicians, legal repercussions and spiritual struggles. In this section, I take a step back to reflect on the significance of such invisible work in the ways HCI identifies and engages breakdown as a site of design intervention and explore some of the implications it has for researchers and designers creating technologies that seek improve healthcare for patients and communities.

First, drawing on two independent, but complementary bodies of STS literature—studies of maintenance and repair and feminist theories of care—I describe an infrastructural design approach of *precarious intervention* that offers a counternarrative to popularized characterizations of design acting as a disruptive force of innovation that can "solve" complex social and medical challenges like behavioral health. In seeing care as a form of repair work, a long-term maintenance not just of the body, but of holding together ill-fitting and cobbled together parts, including critical social relationships, organizational processes, and technological systems, my study findings challenge HCI designers and researchers to take seriously the lived experience of health, the practices of diverse social worlds that (depending on where one stands) may seem questionable or problematic.

Secondly, in crafting a narrative of precarious intervention, I seek to account for the uncertainty and messiness involved in living with (and altering) highly dependent and interconnected systems, while still finding a way to move forward to address pressing human needs. Moving from theory to practice, I discuss an ongoing community-led behavioral health design project in Jackson, Michigan. I highlight challenges and opportunities in trying to include new participants and perspectives in already beleaguered behavioral health system; noting how any intervention, no matter how well-intentioned, will include some groups and leave out others.

Finally, I reflect on the impact of attending to care/repair work for health-related studies in HCI. In looking at the boundaries of social worlds, such as the clinic and church or the pharmacy and dispensary, I saw many moments of generativity in the creative approaches and the local strategies people used to manage pain, find help, and share hope. I also witnessed how participation in wider care ecologies could be a fraught activity. The types of interconnected emotional labor, medical tasks, and information and anticipation work people performed in trying to live well with chronic illnesses like depression and bipolar disorder call attention to the very precariousness of patient engagement when it situated in the infrastructural shadows, viewed as marginal or illegitimate, and unsupported in health systems. I turn now to reflect upon alternative concepts of care found in feminist literature.

Care as a Living Technology: Considerations from Feminist Technoscience

STS scholars have theorized care as a relational activity and politics of engagement that extends beyond formal health contexts to include a wide range of actors, processes, and sites of intervention. In *Moral Boundaries: A Political Argument for an Ethic of Care*, the political science and women's studies scholar, Joan Tronto (1993), wrote that "in the most general sense, care is a species activity that includes everything we do to maintain, continue, and repair our world so that we may live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Tronto, 1993, p.103). This ecological vision of care includes configurations of both human and nonhuman actors that are dependent upon one another and in need constant tending, upkeep, and repair.

Technofeminist scholars, such as Susan Leigh Star, Donna Haraway, Lucy Suchman, and Annemarie Mol, have drawn on and theoretically extended feminist care ethics in their writings, analyzing people's relationships with standards, code, animals, and various machineries as complex sociotechnical assemblages to ask questions around materiality, sustainability and the labor involved in maintaining ecologies of care in an increasingly globalized, neoliberal, and environmentally fragile world (Star, 1991; Haraway 1985/1991; Suchman, 2007; Mol et al., 2010). In examining the specificity of the relations between human/nonhuman actors, this literature also shows how sociotechnical assemblages can reinforce asymmetrical power relations, marginalizing particular actors and devaluing types of work.

In her STS paper on "matters of care," Maria Puig de la Bellacasa (2011) argues that care itself is "a living technology," a way of intervening into political issues and ethical concerns. What does it mean, however, to generate care? Puig de la Bellacasa presents a case for engaging in creating new narratives, writing: "…the commitment to care can be a speculative effort to think how things could be different…Can we contribute, by carefully staging how things hold together, to more sustainable caring relationalities and life conditions in an aching world?" (Puig de la Bellacasa, 2011, p.100) It is my intention with this paper, then, not only to document how things break, but to also take seriously the work and that goes into holding things together.

This precarious nature of care as a form of intervention that excludes some as it also protects others, is important to consider when thinking about the role of design research in HCI. Importantly, while care is viewed as a transformative ethos for Puig de la Bellacasa, it is not taken as a universal good. Care is messy, complex, slippery, and even dangerous. In viewing problems as inextricably situated in ecologies of actors/relations, interventions are always partial and incomplete. "The way in which caring matters is not reassuring," she writes. "Care eschews easy categorization; a way of caring over here could kill over there... We need to ask 'how to care' in each situation." Referencing Puig de la Bellacasa's work, Martin et al. (2015) also point to "care's darker side," noting:

> "Care is a selective mode of attention: it circumscribes and cherishes some things, lives, or phenomena as its objects. In the process, it excludes others. Practices of care are always shot through with asymmetrical power relations: Who has the power to care? Who has the power to define what counts as care and how it should be administered? Care can render a receiver powerless or otherwise limit their power. It can set up conditions of indebtedness or obligation…Care organizes, classifies and disciplines bodies" (Martin et al., 2015, p.627).

In Jackson, I've argue that documenting the particular ways people live intimately with breakdowns and workarounds is a form of care, a reframing of a dominant medical narrative that can see some people who engage their care in unexpected ways as problems to solve.

"Broken World Thinking": Reflections on Maintenance and Repair

While care necessitates repair, as this study of Jackson shows, what can we learn from examining the specifics of repair work? There is a growing body of literature across the fields of media studies, anthropology, STS, and HCI/CSCW which have focused examining diverse repair worlds, including phone repairers in the Global South (Jackson et al., 2012; Jackson et al., 2014), artists appropriating broken technologies in creative projects (Jackson & Kang, 2014), book-binders (Rosner & Taylor, 2011) and “fixer collectives” in Seattle (Houston et al., 2016). The majority of these studies have focused on the materiality of objects and the human infrastructure involved in living with technology beyond the moments of invention and adoption, what scholar Steven Jackson calls “the aftermath.”

In his essay, *Rethinking Repair*, Steven Jackson articulates what he calls “broken world thinking,” an approach to studying (and designing) technology that starts from a perspective of breakdown and decay, rather than growth and progress. Jackson sees this as both an acknowledgment of the many infrastructural cracks experienced by people in their lives, whether it be driving down a highway with potholes, fixing a broken laptop, or accessing social welfare systems; but also, the resilience and work of those who perform ongoing maintenance in our societies. He writes:

> “On one hand, a fractal world, a centrifugal world, an always-almost-falling apart world. On the other, a world in constant process of fixing and reinvention, reconfiguring and reassembling into new combinations and new possibilities—a topic of both hope and concern. It is a world of pain and possibility, creativity and destruction, innovation, and the worst excesses of leftover habit and power. The fulcrum of these two worlds is *repair:* the subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is persevered and extended and the complicated work of fitting to the varied circumstances of organizations, systems, and lives is accomplished” (Jackson, 2014, p.222).

Steven Jackson and colleagues have extended his “broken world thinking” to a range of new contexts and settings; importantly, for my argument, this body of research points a way towards an infrastructure-level approach to design (Rosner & Ames, 2014). In reorienting HCI to consider repair sites and repair actors, Jackson and colleagues complicate neat and linear design narratives where technology moves seamlessly from designer to individual user. It draws attention to who performs the work to maintain fragile sociotechnical assemblages, as well as who has the knowledge and power shift those relations. This is a special concern of repair worlds given technologies are increasingly “black boxed” from people whose livelihoods might depend on tinkering, modifying, and repairing them.

In this study of behavioral health in Jackson, however, it was not only livelihoods, but actually lives at stake. Care/repair work in the context of chronic illnesses like depression, schizophrenia and bipolar disorder further highlights the vulnerabilities and costs that come with maintaining broken infrastructures. Suicide, trauma, and abuse, for instance, were a part of almost every conversation we had with people in Jackson. These stories showed up as a specter in people's family histories—grandparents that took their own lives, cousins that accidentally overdosed—as well the grim present: I heard about wives who drank secretly in the closet, girls who cut their skin to cope with pain, boyfriends that lashed out physically in anger, children as young as 9-years-old who tried to hang themselves in the garage, men who while growing up in deer hunting country were afraid to own a gun because they might use it on themselves.

One woman's story of care/repair became inscribed on her body. Jess, a woman in her late twenties, sat down for an interview with a great deal of wariness. As she shared about her behavioral health experiences, including multiple lengthy inpatient stays at the hospital, she spoke quietly, but eloquently about how she has sought to engage brokenness with creativity. Holding up her arms, she showed two tattoos and told me, "These [tattoos] are here for good reasons. To cover up cut scars." Jess explained how over the years, she has experienced breakdown of the behavioral health system many times.

Once few years ago, she became severely depressed and was worried about the suicidal thoughts she started having. Knowing from experience that she needed to get help quickly, she tried to make an appointment to be taken to the hospital through a special access program.

> "I called on time. I told them a little about my past, that I felt to the point that I was getting low, low, and suicidal. In response, Jess remembers being told by the staff: 'We don't have any transports tonight so unless you can find a ride here.' This is why I'm calling you because I don't have a vehicle right now! I don't have a ride! What do you want me to do, walk and risk getting hurt on the way there? Or hurting myself or somebody else? What qualifies me to get help?"

Another time when she was struggling with depression, Jess walked into her community health center and was turned away. "Unless you actually go in there and you're acting 50 shades of bat crazy or injured yourself," Jess explained, people are often denied care. Through such encounters with the medical system, Jess learned that it wasn't enough to say you were suicidal and came up with a desperate workaround: cutting herself and abusing pain medications.

> "I lashed out and I OD'd on pills and I cut myself to send myself in there. I pretty much showed proof of it. Scars on my arms or anything like that. Some people say it was for attention, but in actuality, I was hoping for the end of all that. I had walked in there [the health center]. Look, it was fresh wounds! If this isn't enough to say I need help, I don't know what is."

Jess acknowledges this was a drastic and risky act, one she regrets most days, but at the time she felt she needed to do something, anything.

> "It's pretty bad. I told myself, at least I'm recognizing this. I'm coming to you to seek the help. You're not coming to me because of some madness at my house because I've bled out. I'm looking for the help. It wasn't even medication. I just needed somebody to talk to.

Now, in a good place in her life, she holds down a part-time job as a nurses' aide in an assisted living facility. She was concerned about people there seeing her cut arms and judging her, so she repaired them by covering her scars over with art. "I drew all mine [tattoos]," Jess described with pride.

> "This one I had "love" carved on my wrist underneath. I did this to my inner demons breaking loose and new beginnings. This was a tribute to my grandfather because he was Native American and it's a good cover up."

Figure 13: Scars as acts of care/repair.

Such acts of care/repair demonstrate the precarious work of intervening for people living in this small, Midwestern city. "Above all, repair occupies and constitutes an *aftermath*," Steven Jackson writes, "growing at the margins, breakpoints, and interstices of complex sociotechnical systems as they creak, flex, and bend their way through time." At the margins, I would add, the care/repair work undertaken by many of my interlocutors is dangerous, desperate and often uncertain. People tremble in the balance, an inextricable part of a sociotechnical system that does not respond to their most pressing needs. In a world where breakdown is routine, interventions—as exemplified in Jess' story—are costly, requiring people's body and blood to repair.

Reflections from a Community Health System Project

Throughout the course of my ethnographic engagement in Jackson, I had the opportunity to be participants and observers of a multi-year community health system project. In attending planning sessions led by the Jackson Behavioral Health Action Team (or BHAT), a local group comprised of volunteers from across the medical system, social services and various community organizations, we gained insight into Jackson's behavioral health system from the perspective of those trying to improve the many gaps detailed in this paper, such as access to services. This group was predominately comprised of knowledgeable professionals—such as concerned clinicians, nonprofit staff, and seasoned social workers—who worked with populations of people struggling with behavioral health needs. In group discussions, an electronic community health record was proposed as a means of sharing relevant patient data amongst currently disparate local organizations, in effect better connecting medical delivery, behavioral health, and social services to improve patient care. There was an optimism expressed during meetings for rethinking models of health to address critical needs. As one attendee, who ran the local makerspace, commented during a BHAT meeting: "We are turning a prison town into innovation town!"

The design of a community health record (and behavioral health more broadly) was envisioned as a collective process involving the entire community of Jackson. As explained by one long-time BHAT member: "I think that we are all just figuring that out that we all play a different role...It's realizing we all have to deal with mental health. It's not just the job of the mental health providers; it's all our job." The BHAT group actively sought to reach out to residents—putting together funding for community listening sessions and running focus groups—to better understand people's experiences of behavioral health and discover unmet needs. My ethnographic work detailed here was a part of this larger design project. Despite a clear concern for community perspectives and a desire to increase patient engagement in BHAT projects, few residents of the community attended these monthly planning sessions. For instance, while faith-based organizations were considered an important resource in Jackson, at the time of this study, they were not yet an active presence at BHAT meetings. The group was only beginning to consider what their connections to the faith community might be, as one member noted, “I think churches are a very under-tapped resource.” Awareness of community governance issues, especially as it related to health information technology infrastructure, were often on the agenda to be discussed: Who are the stakeholders? What voices are missing?

The questions of who gets a say in such design decisions is important, not only for governance or buy-in, but also because technologies are not neutral platforms. As sociotechnical systems, they hold the values (and prejudices) of those who build them (Suchman, 2007). Furthermore, as research has shown, once a system is adopted and embedded into infrastructure, it becomes extremely difficult to change or remove it (Bowker & Star, 2000). Designing an intervention, such as a community health system, then, is also a question of who has power to shape people’s experiences of care. Feminist STS scholar Susan Leigh Star’s query (Star, 1991, p. 43.) “*cui bono?*” helps us question design as a site of care. This is important to consider not only in thinking about who in the community has a seat at the BHAT meetings and has the opportunity to talk about the types of data permissions and privacy protections they want engineers to build into a community health record (although that is important); but also in terms of how the original concept of an electronic community health record itself already reflects supporting the work processes of professional organizations rather than the costly labor of people living with behavioral health problems.

This observation is not intended to be a critique of the BHAT group, who in many ways displayed a deep understanding of and empathy towards the needs of the most marginalized members of their community. Nevertheless, the community health system addressed one problem they felt had a technical solution. This in part a reflection of the limits of technology to address the complexity of social contexts, Ackerman’s (2000) classic paper called the “social-technical gap.” But it is also points to the narrowing of our design imaginations, which tend to frame the limited, partial ways technology can intervene in settings like health from the perspective of those who already have power, e.g. formal medical organizations or the tech-savvy quantified self-movement.

HCI research, when it views health as a clinical activity (albeit one that increasingly values patient engagement) or in terms of generalized wellness practices (that rely on a goal of mind/body optimization) often envisions designing for "care" as a support system for biomedical expertise in which technology can help promote individual behavior change. When this view of care is extended to the design of community health systems is becomes overly limited as the lives of my interlocutors did not neatly map to celebratory experiences of "self-care" nor to patient-centric visions. In Jackson care depended on the expertise, creativity and labor of the entire community. Furthermore, engagement for patients here was as much a desperate activity as a moment of empowerment, and one that could leave people stigmatized or excluded from medical services.

I found behavioral health in Jackson to be comprised of (at times uncomfortable) complexities that called for an alternative conceptualization of care in design, one that sees care as a community activity responding to the realities of infrastructural brokenness interacting with human brokenness. The HCI/CSCW research community has developed a rich legacy of scholarship that addresses questions around social context and "messiness" in system design. I seek to return to this longstanding concern with a narrative of *precarious intervention* that takes medical activities in the margins as a starting point in design, seeks to account for the varied costs of care/repair work, and grapples with the complex concerns that come with infrastructure-level, rather than application-based, health interventions.

Precarious interventions encapsulate the messiness of managing one's health needs across multiple, conflicting social worlds. While seeing care as a part of wider ecology of interconnected human/nonhuman actors, I nevertheless argue for a way forward, seeing intervention (while always partial and incomplete) as necessary in addressing the crises of trauma and suffering that people in Jackson found themselves struggling to manage. How, then, to design a community health system? One direction might be to support people living with behavioral health conditions to have greater agency in the sociotechnical assemblages they find themselves enmeshed, to realign power. Taking the proposed community health record as a starting point, one might create technological tools and educational programs to "open-up" a previously closed technology. This might mean having options not only about what types of data is included and who has access to personal data, but also realigning the boundaries in which data might be shared. A personal health ecology might be shaped to include clinicians, but also, for some Jackson residents who depend on informal networks of care, trusted clergy, neighbors, or friends. In such a design, who benefits? Who bears the costs? My research in Jackson show that there are no pain-free interventions in a complex sociotechnical system like behavioral health, but if one is careless or carefree, ways of caring—especially those encoded into infrastructure—can marginalize people needing help. In a narrative of precarious interventions, I follow Puig de la Bellacasa (2011) who directs: "We need to ask 'how to care' in each situation."

CONCLUSION

Throughout my ethnographic engagement in Jackson people shared many personal moments of loss and pain. There were stories of attempted suicide and overdose, fear of eviction, sexual violence and abuse, hopelessness and death. People described feelings of vulnerability, fear, and anger towards a system had that let them down in their moments of greatest need, time and time again. This is a grim part of the lived experience of behavioral health for many people in the U.S., as well as other parts of the world without robust health services. But it also speaks to the wider human experience of living with flesh-and-blood bodies that are troublesome to maintain in the best of times, and for some, seemingly impossible to repair upon breakdown.

My interlocutors highlighted problematic gaps, but also noted many examples of the generativity that came through forms of care/repair work. Over the course of this study, there were shared moments of tremendous strength, narratives of hope and even joy. People, for example, spoke of victories in getting to appointments on bad days, the peace of receiving prayer, and described local nursing heroes, who although severely understaffed and overworked, tirelessly helped people straighten out problematic prescriptions and get needed referrals to specialists. Care includes all the practices that people do to maintain their health and well-being as parts of sociotechnical assemblages. HCI needs research that engages this wider ecology of care, finding ways to repair, rather than disrupt fragile sociotechnical systems.

The possibilities of design in supporting wider ecologies of care in health has the potential to improve the experiences of people living with a wide range of health conditions, particularly those with conditions that are inextricably tied to social worlds like behavioral health. Designers and researchers, however, must look beyond supporting the organizational practices in formal healthcare institutions to also account for important informal systems of care work in community settings. As an ethnographic study of a community behavioral health system, this chapter offers a more nuanced narrative of care work, one that impacts HCI design writ large. I suggest that *precarious intervention* is a conceptual approach that highlights the relationship between invisible labor and social worlds, and the costs of designing information systems that ignore those in the margins

Chapter 6 Lived Data: Tinkering with Bodies, Code, and Care Work

> "Caring is a question of 'doctoring': of tinkering with bodies, technologies and knowledge—and with people, too."
>
> –Annemarie Mol, *The Logic of Care*

> "The cyborg is our ontology, it gives us our politics as we have become theorized and fabricated hybrids of machine and organism."
>
> –Donna Haraway, *The Cyborg Manifesto*

> "...We need to ask how any object of analysis—human or nonhuman or combination of the two—is called out as separate from the more extended networks of which it is part...
> Our task as analysts is then to expand the frame, to metaphorically zoom out to a wider view that at once acknowledges the magic of the effects created while explicating the hidden labors and unruly contingencies that exceed its bounds."
>
> –Lucy A. Suchman, *Human-Machine Reconfigurations*

INTRODUCTION

A 2014 Wall Street Journal article entitled "Citizen Hackers Tinker with Medical Devices" reported on people living with type 1 diabetes (T1D) who decided they were no longer waiting for medical device companies and the health care system to give them the personal data and the tools they needed to better manage chronic illness (Linebaugh, 2014). Starting as a small, informal group of like-minded technologists in the United States who began to hack a continuous glucose monitor, these ad hoc efforts rapidly expanded into an open source project called Nightscout, a do-it-yourself (DIY) remote-monitoring system for diabetes data with global reach. Nightscout provided open source software code to access, view, and interpret data that commercial continuous glucose meters (CGMs) produced but had always been locked behind a black box, unattainable. Their hashtag #WeAreNotWaiting captured in a single phrase the hope that a DIY approach toward diabetes could be a force of positive change for people frustrated by the regulations and limitations of formal health care systems. A community of users comprising patients and parents of children with T1D grew quickly as Nightscout seemingly shifted control of health care management into the hands of individuals by giving them access to the data they felt was rightly their own. Media attention on Nightscout followed with enthusiastic headlines. More recently, elements of these stories—such as a patient's right to access personal data—have received attention by scholars as an illustrative case of a much broader phenomenon often referred to as "end user innovation" (Torrance & von Hippel, 2015) and model of patient empowerment through data tracking (Neff & Nafus, 2016). At the same time, Nightscout has been discussed with both caution and optimism in the commentaries of medical journals, as clinicians worry both about data privacy and risks associated with patients using their personal data in making dosing decisions (Klonoff, 2015; Walsh et al., 2015) and also see potential for better engaging patients in the design of health technologies (Lee, Hirschfeld, & Wedding, 2016).

The narrative of personal data and diabetes, this chapter sets out to show, is neither just an exciting story of individual empowerment nor simply an issue of managing data privacy. For those engaged in the everyday practices of building and relying upon DIY devices to manage chronic illness, it is both and much more: Nightscout and related DIY diabetes systems mean living with data, which is simultaneously hopeful and dreadful, empowering and isolating, highly individualizing and dependent on the help of others. These modes of being play out in and through data, including new collaborative and intensive forms of care. Indeed, DIY health for my participants was rooted in both medical tasks and technical expertise that depended on emotional labor as well as types of information, coordination, machine, and advocacy work.

Dana Lewis, cofounder of a project called OpenAPS (open source artificial pancreas system), has spoken publicly about these conflicting and multiple realities of living and managing her health as a DIY diabetes expert. In 2015, at a conference that I attended as part of a one-year-long ethnographic engagement with DIY diabetes technologies, Dana Lewis was one of the keynote speakers. Diagnosed with T1D at the age of 14, she told her story of personal health data to an audience of techies, Fortune 500 executives, and academics. "Close your eyes," Dana Lewis directed us, "and imagine you are drifting off to sleep." She waited patiently for the audience to grow silent. With our eyes shut and deprived of the usual PowerPoint visuals, Dana's story began to morph into one that could potentially become our own. "Now imagine the feeling, the fear of not waking up. This is a true reality. It's called 'dead in bed.' Imagine, how horrible that feeling is, that fear of not waking up, even though you do everything right." Dana paused, the room enveloped in silence. As we reopened our eyes, she spoke with added emphasis. "This is behind the 'we are not waiting' movement, so that this fear stops now and people stop dying overnight in their sleep." As she described how the mundane act of going to sleep for someone living with diabetes could be an act of gripping fear, we learned that "dead in bed syndrome" is a phenomenon when someone with T1D goes to bed in good health and dies in their sleep. Although relatively rare, this condition is thought to account for about 6% of cases of all deaths in people with T1D who are younger than 40 (Koltin & Daneman, 2008). Lewis's illustration reminded the audience that for her, and many others with chronic illness, diabetes is a matter of daily survival, one that is pressing and often grim.

"When patients say they are hacking the device," Lewis continued her speech, "I want people to understand why they are doing it. Back in 2012, I did not have a way to get the data off my own medical device and do something with it. So I had this workaround"—she paused with a smile—"you might call it a hack." She then gave us the story that we had been eagerly waiting for, how she created a functional artificial pancreas system when similar commercial prototypes were still in clinical trials and unavailable to consumers. Her inspiration came, she told us, when she lived alone and wanted to create an alarm that would be both loud enough to wake her up and automatically notify her family if her blood glucose levels dropped dangerously low during the night. The technical struggles and eventual success of getting data off of her medical devices opened up new possibilities for care, and her tinkering with technology slowly evolved into a larger project to build an open source, DIY artificial pancreas system, a technology that was entirely self-made, unregulated by the U.S. Food and Drug Administration (FDA), or "hacked" as Dana put it. The PowerPoint resumed, and with each of her slides showing graphs of her diabetes data, we were led through a powerful demonstration of how her DIY hack—the right to use her own data as she saw fit—led to radically improved glucose levels and peace to sleep through the night. We witnessed her system in action by watching her partner (and OpenAPS cocreator) in the audience periodically check Dana's diabetes data in real time with a quick glance down at a smartwatch on his wrist. By the end of the talk we too believed in Dana Lewis and her story of ingenuity, creativity, and hands-on intervention. It felt celebratory worthy.

And yet, Dana Lewis did not end on this note of triumph, but circled back to the beginning of her talk, to the uncomfortable place of fear, anxiety, and strain. She still kept multiple juice boxes by her bedside in case of an emergency, she stressed, and access to data had not taken away the daily care work involved in living with diabetes. “Most people think diabetes is about eating healthy, exercise and insulin; this will give you good blood sugars. In fact, it’s not that easy. There are many variables: Am I sleep deprived? Am I excited? Am I stressed? There are a lot of variables that you can’t measure. How do you deal with all these variables? So, yes, I have insulin; I am fortunate to have access to a CGM, but even if you have the best technology, it’s still a hard chronic and incurable disease. The success of diabetes is not a perfect number,” she concluded, “but is the willpower to get to the next data point.”

Dana Lewis’s story points to a narrative around the intersection of personal data and tinkering with one’s health that is as exciting and empowering as it is complex, messy, and more than a self-made, individualized practice. In my ethnographic engagement with various DIY diabetes projects that formed around people like Dana Lewis, I found the lived experience of diabetes data to be multiple, presenting oftentimes contrasting and contradictory faces. On an intimate, physical level, people described being empowered, but also frightened by the devices in their bodies. Some people like Lewis performed high-risk experiments on themselves, because they believed data could provide a better quality of life; furthermore, as “patients” they often lived with their data in isolation from the professional medical community, marginalized by their own expertise and fluency with information technologies.

In the popular media’s numerous stories of Nightscout, “care” has been conceptualized as a heroic feat taken on by individuals who solder and code their way to health and wellness. In practice, however, the narrative of care was more complicated. Many people who used DIY technologies to manage diabetes still relied upon other people’s expertise to address both daily challenges and critical health situations. Only, in this health context, they often found themselves dependent upon the help of strangers trained as software engineers and goodwill of passionate computer tinkerers, rather than clinicians. Should we, as human–computer interaction (HCI) researchers, view this as “empowerment” or rather point to the ways in which such stories of personal data and DIY/making mask important changes in how care is performed and who is responsible for people’s health and wellness? How might we hold up “DIY” as a legitimate and important type of care work and also critique the social and political forces that increasingly make care such a precarious activity for so many?

This chapter takes the conflicting and multiple aspects of living with/in/through data, or what I call “lived data,” as the starting point of my investigation into DIY health. With “lived data,” I propose a theoretical move from viewing *data as a thing* that exists in some ways external to people’s lived experience and to *data as modality*, that is, seeing data as already an inherently central and relational part of being in the world. From traffic data to professional performance indices like the academic h-index to the numbers of one’s Facebook likes, we increasingly live through data algorithms that make sense of us and in turn shape how we make sense of the world (Chun, 2011; Weiser, 1999). And yet, we often talk about data metaphorically with distance. Sometimes data is seen as a “flow” and a “commodity” that can be accessed, manipulated, and interpreted with the right kind of software skills. Or we view data in binary terms as “personal” data generated and used by individuals and the “big” data of the vast repositories that corporations or other collective entities create, aggregate, own, and use. The underlying goal of this chapter, then, is to open up and analytically unpack the concept of “data” itself.

“Lived data” as an analytical sensibility emphasizes data as integral way of living, collectively produced and engaged with. My research shows that personal data are a multitude of things, sites, and practices at once: bodies, needles, parenting, legal concerns, writing code, hacking devices, making visualizations, and sharing memes. I tease apart these various modalities of data, not to artificially separate them but to illustrate how they play into contemporary sociotechnical shifts as software, algorithms, and data increasingly shape how we care for our bodies, relate to one another, and evaluate what counts as productive work and labor—how we live.

The contribution of the chapter is threefold. First, this work brings into conversation two previously largely separated areas of research: (a) personal data, quantified self, and lived informatics, and (b) DIY making and hacking ideas and practices. DIY making and hacking has rarely been studied in relation to phenomena such as the quantified self, data, and tracking. This is in many ways surprising, given that a foray of recent tracking devices, smart and health wearables were designed by startups, self-identified makers, members of hackerspaces, and incubator programs (Lindtner, Hertz, & Dourish, 2014). Recently, scholars have begun to address the social and technical complexities of this emerging research space (Nafus, 2016; O'Kane, Han, & Arriaga, 2016), and my work here adds to these efforts by highlighting the social context of DIY diabetes technologies. I examine not only how data and tracking devices are used, but how they are made by people working outside the corporate context of R&D labs and how, in their making, what counts as expertise and care work is renegotiated.

Second, this chapter draws from a body of work that has evolved out of feminist technoscience studies, providing a rich empirical and analytical vocabulary for investigating DIY making and personal data practices. Such language is important in how we address the social dimensions and collective practices of data in human-centered design. I argue in this chapter that technology design as an enabler of individual empowerment cannot be divorced from dependencies and uncomfortable alliances of human bodies, machines, and organizations. Although celebrated as liberating individual patients from an often backward and beleaguered health care system, DIY health care creates new, arguably more precarious dependencies that rest on the free labor and goodwill of volunteer workers, patient advocacy groups, software coders, families, and friends.

Third, this chapter investigates the social complexities and emotional consequences of living with health data. Managing diabetes with Nightscout is a deeply relational and (at times) contested activity within families, especially for parent-caregivers whose practices reveal the tensions and vulnerabilities of caregiving work enacted through data. As engagement with personal data becomes an increasingly powerful way people experience life, my findings here call for alternative data narratives that reflect a multiplicity of emotional concerns and social arrangements. In the next section, I outline in more detail how I tie together these various strands of lived informatics, personal data, and DIY making to develop an analytical sensibility of lived data.

LIVED INFORMATICS, PERSONAL DATA, AND DIY MAKING

A central focus in research on personal informatics has been the ways in which data and technologies can "help" people achieve goals, independence, and even joy. Studies looking at personal data in the space of health and wellness, for instance, have examined the varied ways individuals in the Quantified Self movement interact with data using commercial tracking devices like Fitbit and Jawbone to promote behavior change, reflect, and form personal relationships (Choe et al., 2014; Li, Dey, & Forlizzi, 2010; Lupton, 2014). There is also interest in examining the potential of "diagnostic self-tracking" to support people with managing chronic illness with studies of various clinical contexts, including irritable bowel syndrome (Karkar et al., 2015), pain management (Felipe, Singh, Bradley, Williams, & Bianchi- Berthouze, 2015), and patient–provider collaboration (Chung et al., 2016). Of note in the area of quantified health and DIY making is Ananthanarayan et al.'s (2014) work on "crafting health," which seeks to help people create meaningful visualizations of personal health data through the use of digital fabrication technologies. For example, participants in their study collected personal data through a wearable UV tracker and represented that data in the form of an artistic visualization of a cherry blossom design. These authors frame an approach to personal data that is largely celebratory and positions DIY making as a design ethos for both empowering patients and democratizing health technologies.

Recent literature has begun to critically examine tensions in Quantified Self–styled data tracking (Bietz, Hayes, Morris, Paterson, & Stark, 2016). Alongside these explorations, a growing number of HCI scholars have explicitly begun to question overly rationalist, techno-centric, or biomedical framings of personal data in health and wellness (Churchill & Schraefel, 2015; Grinter, Siek, & Grimes, 2010; Kaziunas et al., 2015; Maitland & Chalmers, 2011; Ohlin & Olsson, 2015). In data tracking, this holistic view of health and wellness can be seen in the research and design around "lived informatics" (Elsden, Kirk, Selby, & Speed, 2015; Epstein et al., 2016; Epstein, Ping, Fogarty, & Munson, 2015). First articulated by Rooksby, Rost, Morrison, and Chalmers (2014) in a paper about fitness tracking as part of "a praxis of living," lived informatics originally served as a sensitizing concept, an approach to data tracking that took seriously the social and material context of collecting and sharing data. They proposed several design recommendations from a lived informatics perspective, including (a) "attend to the physicality of tracking"; (b) "consider…the emotionality, the hope and fun people may have"; (c) "reconsider personal tracking as social tracking"; and (d) consider behavior change as something achieved by people across various technologies (Rookby et al., 2014, p. 1172).

My chapter extends each of these design recommendations and puts them into conversation with their ethical, political, and social consequences. This includes: (a) considering how the physicality of tracking extends beyond engagement with technological devices to include tinkering with the human body, (b) accounting for the (often invisible) emotional work and labor of self-tracking and self-care, (c) explicating how personal data are not just about supportive friendships but also—crucially—the site of often extreme dependencies and obligations, and (d) teasing apart the complex assemblages of bodies, machines, and institutions at work.

In my fieldsite, the stories of accessing and owning one's data and the right to hack a commercial product were deeply intertwined. Together, they are indicative of a much larger endorsement of a DIY approach that intervenes in passive consumer culture by providing people with the tools to make their own, rather than purchase devices. A growing body of HCI research has stressed the importance of unpacking how the tools, values, and practices of making and hacking have moved beyond hobbyist pursuits, and how they are deployed across regions by governments, educators, and corporations to "upgrade" industries, education, and work (Ames, Rosner, & Erickson, 2015; Avle & Lindtner 2016; Irani, 2015; Lindtner et al., 2014) and retrain students and workers to develop entrepreneurial thinking and hands-on approach to contemporary societal and economic problems (Chan, 2014; Lindtner, 2015; Neff, 2012). Making is commonly portrayed in popular media as site of individual empowerment; by training people in hacking and tinkering, they can, so the story often goes, intervene in passive consumption and corporate monopoly. In this chapter, I zoom in on how this much broader endorsement of a DIY approach toward work, education, and life plays out in the specifics of health care and tinkering with one's body through data.

I found that it took a great deal of work to both live with and legitimize the DIY maker approach to health care. Making was both the site to live out technological dreams of alternate futures and to deal—in a pragmatic fashion—with the day-to-day struggles of living with a chronic illness. As discussed earlier in my chapter on BMT, I use the term care work to refer to the varied sociomaterial practices that composed the everyday management of chronic illness. Here in this chapter, that involves investigating how people used Nightscout and OpenAPS to live with diabetes. As with BMT, living with T1D involved a wide range of care activities that included a wide range of medical tasks and emotional labor, such as prepping insulin injection sites on the body and managing stress. Care also involved unique combinations of information and machine work, such as reviewing CGM data with family and friends, calibrating devices, tweaking an algorithm to dose insulin, fixing broken rigs, and using data to negotiate with the

FDA. In my fieldwork, I found that moments of empowerment were interspersed with the reality of living with systems that themselves required constant upgrading and attention.

As DIY making and hacking continue to intervene in broader industrial, economic, and social processes, I am interested in how DIY health production draws attention to "making" as new a form of labor that extends beyond current narratives of a hobbyist engagement with innovative materials or industrial entrepreneurship. In so doing, I take seriously the seductive draw that such stories of user empowerment have, all the while accounting for the work and relationships that go into producing, maintaining, and quite literally living those stories. I argue that an approach that neither simply celebrates nor denigrates it (Kling, 1994; Lamb & Kling, 2003; Lindtner, Bardzell, & Bardzell, 2016), but rather engages in a careful and empathetic critique of DIY and data practices, offers insights for how HCI might formulate an ethical yet engaged research program for personal data. I aim for a narrative that accounts for the tensions people experience as both a "parent" and "DIY medical person," as both a "citizen hacker" and "patient."

Navigating between technophilia and dystopia (Dourish & Bell, 2011; Nardi & O'Day, 1999), then, I draw on work by feminist technoscience scholars such as Donna Haraway, Annemarie Mol, Lucy Suchman, and Adele Clarke to articulate an approach toward the study of personal data that draws attention to its multiplicity and livedness. Donna Haraway's (1985/1991) influential and enduring "Manifesto for Cyborgs," for instance, pushes us to consider the multiple sides of data, including the uncomfortable aspects. Haraway's cyborg politics points to a future where people's relationship with technology is both alluring/fascinating and fearful/disturbing. Writing of the cyborg body, she maintained that "late 20th century machines have made thoroughly the difference between natural and artificial, mind and body, self-developing and externally designed and many other distinctions that used to apply to organisms and machines. Our machines are disturbingly lively, and we ourselves frighteningly inert" (ibid, p. 20).

And yet, Haraway argued, "in imagination and in other practice, machines can be prosthetic devices, intimate components, friendly selves" (ibid, p. 144). Haraway's cyborg body articulates the tensions felt by many people in this study, especially those living with an artificial pancreas, whose dependency on the data, algorithms, and machines that dispensed potentially lethal amounts of insulin into their bodies is captured by this notion of "frightening intimacy."

In the final chapter of *Human–Machine Reconfigurations*, Lucy Suchman (2007, p. 266) invoked Haraway's figure of the cyborg, noting that it should not be viewed as a singular heroic, monstrous, or marginalized subject but a "multifaceted subject-object assemblage." A cyborg sociomateriality views personal diabetes data as inextricably connected to a distributed and shifting network of bodies, processes, technologies, and people. Furthermore, Suchman argued that cyborg configurations and their consequences play out in the mundanity of everyday life, writing,

> "Along with the dramatic possibilities of the feminist cyborg, we need to recover the ways in which more familiar bodies and subjectivities are being formed through contemporary interweavings of nature and artifice, for better and worse. Put another way, now that the cyborg figure has done its work of alerting us to the political effects, shifting boundaries, and transformative possibilities in human–machine mixings, it is time to get on with investigation of particular configurations and their consequences" [emphasis added] (pp. 275–276).

Suchman referenced a selection of medical studies (e.g., patient anesthesia, fetal surgery) to illustrate some of these consequences, and her insights, although arguably bound to dated information technologies like novel uses of video communication, are more relevant than ever. Today, DIY hacking and personal data-tracking technologies extend as lived practice the kinds of configurations Suchman observed and theorized. They come with values such as individual empowerment and self-care built into the very purpose of their uses, and the consequences of such human–machine configurations have deep sociopolitical and ethical importance.

Engaging with such theoretical elaborations from feminist technoscience, this chapter offers a situated and multifaceted account of lived data by detailing the arrangements and configurations they entail. It further illustrates how familiar tropes of patient empowerment and user innovation mask social and economic consequences such as the shift in responsibility and expertise from the health care provider to the software coder and eventually to the user. I end the chapter by drawing out a lived data stance for HCI researchers and designers that includes a critical sensibility toward the politics and ethics of care within the shifting terrains of personal data and DIY technologies.

STUDY METHODS

Data Collection

My data include 21 semi-structured interviews with users of open source, DIY diabetes technology, focusing on members of the Nightscout community. Interviews were conducted with 20 participants in the Nightscout community (over the course of the study some participants were interviewed more than once, and some interviews included more than one person). Although participants had varying levels of technical expertise, experience with T1D, and participation in the community, all were currently and/or had used parts of the Nightscout system code either personally or with a family member in daily management of diabetes. Interviews were approximately 1 hour long and were recorded and transcribed; children were recorded with permission from their parents. These semi-structured interviews took place both face-to-face at various diabetes conferences and electronically via Skype. Interviews focused on exploring (a) types of involvement in the Nightscout community and related DIY diabetes projects like OpenAPS, (b) everyday practices around diabetes management using Nightscout and related technologies, (c) impact of DIY diabetes technology on family life and clinical care, and (d) broader views on the ethos and motivation of those who participate in the DIY diabetes projects.

Interviewees were selected to represent a wide range of experiences with Nightscout and included 11 parents with children who have T1D (specifically three mothers and eight fathers) along with eight adults and one teenager all living with T1D. Participants involved in different types of work within the Nightscout community included core developers (nine), Nightscout Foundation board members (seven), Facebook group moderators (two), and active members of the technical support group (two); furthermore, all 20 interview participants were active members of the CGM-in-the-Cloud Facebook group. (These categories are not mutually exclusive, and several participants had multiple roles within the Nightscout community and other DIY diabetes projects.) Participants came from a wide range of ages as well as technical and educational backgrounds, although the majority of participants had advanced degrees. I also note that the core developers I spoke with all had previous training in computer science and/or work experience as software engineers or in the broader tech industry. I acknowledge that such demographic data shapes the experience of diabetes management and note that Nightscout users represent a small, self-selected population of patients and caregivers. Whereas only 11% of T1D patients currently use a CGM, the Nightscout community can be understood as a patient population of early adopters that embrace technology use in diabetes management (Rodbard, 2016).

These interview data were also informed by more than 12 months of ethnographic observations of Nightscout presentations at diabetes conferences and a technology workshop, as well as informal planning conversations held by core developers and foundation board members. Observational data were recorded as field notes and later transcribed, adding to my understanding of the Nightscout project. Additionally, over the course of the study, an ongoing analysis of DIY diabetes technology project-related websites, personal patient blogs, code repositories (e.g., GitHub), various technical documentation, news articles, and a wide range of social media, including Twitter feeds, Instagram accounts, YouTube videos, and Facebook posts, added to my understanding of people's experience using DIY diabetes technologies. In particular, I coded 664 distinct posts from the CGM- in-the-Cloud Facebook group to triangulate interview and observational data.

The data reported in this chapter are a part of larger collaborative research project aimed at understanding the patient-centered technology design and the use of technology to manage T1D (Lee et al., 2016; Kaziunas et. al, 2017a; Kaziunas et al., 2017b). My understanding of Nightscout was also informed by a survey of the CGM-in-the Cloud Facebook group completed by 727 respondents that was a part of this wider project that was coded and analyzed. I report here only from the qualitative data I collected. Institutional Review Board approval for data collection was obtained along with participant consent. All interview and survey data reported here were anonymized and pseudonyms used.

Importantly, the data collected in this chapter reflect FDA policies, commercial diabetes technologies, and DIY systems from between winter 2015-summer 2016. Some key developments have been made since my study data was collected such as the FDA's first approval of a commercial hybrid closed looped system that can be used for children in 2018. Despite such commercial developments and advances in federal regulation, open source technologies have only grown in popularity. People use social media now to document using OpenAPS systems to "loop" with their children who have T1D, and Dana Lewis has become a prominent public figure and well-respected patient advocate, recently winning a Red Hat open source award. She has also spearheaded the creation of an OpenAPS Data Commons for people to anonymously donate their personal data for diabetes research and become a co-PI on several research grants with universities from around the world. Nightscout also remains an active user community despite new commercial options on the market. While technology rapidly changes, this study highlights key health design issues and opportunities that extend beyond specific configurations to address the wider social and emotional impact of data in everyday lives.

Data Analysis

I followed a situational analysis approach as articulated by Adele Clarke (2005), which is an updated version grounded theory. In situational analysis, as with grounded theory, iterative cycles of data collection and analysis inform one another. After a set of initial interviews were transcribed, I analyzed the data using an open-coding method to identify significant themes. Coded interviews were then discussed among the entire research team during data analysis sessions. New codes were generated collectively as important concepts were identified, compared, and revised. These subsequent codes were later used as probes in future interviews. The second stage of data analysis with new transcribed interview data resulted in consistent themes and confirmed findings. Field notes and social media data were read, coded, and analyzed in a similar manner during data analysis sessions. Furthermore, utilizing Clarke's situational analysis mapping methods, I generated an array of situational, discourse, and social worlds/arena maps and analytical memos. These map artifacts and memos were discussed among the research group as theoretical insights emerged from the ongoing data collection and analysis.

THE BEGINNINGS OF #WEARENOTWAITING

T1D is a serious autoimmune disease in which a person's immune system attacks and destroys the insulin-producing cells in the pancreas. The pancreas stops producing insulin, a hormone essential for getting energy from food, and people with T1D are dependent on injected or pumped insulin to live. T1D can occur suddenly to both children and adults at any age, and although its causes are still being investigated, researchers believe that onset is linked to both genetic and environmental factors. As a chronic condition, T1D is currently unpreventable and has no cure.

The daily care management for T1D is challenging, both in regards to the medical care required, which involves the risk of serious health complications, and physically and emotionally in terms of fatigue, anxiety, and frustration. Blood glucose levels are routinely checked throughout the day and night, a process in which drops of blood are traditionally drawn through a special needle or lancet (e.g., “finger pricks”) and measured with a blood glucose meter. Doses of insulin must then be precisely balanced—by multiple daily injections or a continuous infusion through an insulin pump—with everyday activities like eating, exercise, and sleeping. As mentioned, even with vigilant monitoring, people with T1D are constantly at risk for dangerous high or low blood glucose levels, both of which can be life threatening. Uncontrolled blood glucose levels for people with T1D can lead to serious health problems like kidney failure, blindness, and nerve damage and have been shown to reduce life expectancy up to 13 years (Walsh et al., 2015).

Given that less than one third of people with T1D in the United States achieve their target blood glucose control levels, technology has been viewed as an important way to better support T1D management (Rodbard, 2016). CGM systems, for example, are FDA-approved medical devices used to measure and display real-time blood glucose readings, allowing people to view and track fluctuations in their glucose levels. Advancements in the sensor technology in CGMs have given patients access to increasingly accurate blood glucose data; however, at the time this study was conducted in 2016, the FDA had determined that displayed data from CGMs are not safe (i.e., accurate enough) to be used in insulin-dosing decisions. Insulin treatments—such as bolus and basal—used to make corrections in person’s blood glucose levels require the continued use of blood glucose meter readings. At this time, diabetes device manufacturers carefully instructed users that CGM data are intended primarily to aid people in determining blood glucose patterns.

Although a helpful tool to many people managing T1D, as late as 2014 commercially available CGM systems from popular medical device companies like Dexcom had several limitations for patients and their families. Real-time blood glucose data could be displayed only on a designated receiver supplied by the device manufacturer; furthermore, the everyday usefulness of the display was hampered by the receiver having to remain within 20 ft of the CGM sensor (which was embedded in the arm of the person with T1D). A technical solution to these constraints— remote monitoring of CGM data on mobile devices—would allow people in the T1D community, particularly the parents of young school-age children with T1D, to track blood glucose levels from afar and potentially intervene if they observed these levels dangerously rise or fall. Although medical device companies developed such tools, in this situation the FDA approval process for classified medical devices often delays the release of new technology to consumers for years.

Nightscout

In 2013, a time when no commercial solutions for remote monitoring were available, a small group of concerned T1D parents and adults with T1D formed online around the shared goal of intervening in the highly regulated and closed system of T1D data management to better manage patient care. Their efforts became an open source, DIY project to "put their Dexcom CGM in the cloud" and enable the remote monitoring of CGM data through mobile devices like smartphones or Pebble watches. Nightscout, as this project became known, was positioned as an "educational source code for monitoring estimated glucose values from a Dexcom G4 Receiver" (Nightscout, 2016).

Several versions of code exist, but most Nightscout members use the "community build" for monitoring blood sugars, which provides an interface for displaying different types of data. The configuration of devices also varies widely but typically consists of a "rig" (the combination of a smartphone + Dexcom CGM receiver), an Android application that transfers data from the CGM to the cloud, and a web application that displays the blood glucose values stored by the CGM, which can then be displayed as data on a mobile or wearable device such as a smartwatch. Nightscout is always in development, a shifting assemblage of digital tools, social support, and organizational resources that include websites, instructional YouTube videos, an associated 501(c)(3) foundation, memes, Github repository, community certificates and awards, diabetes conference presentations, "install parties," and the thriving Facebook group called CGM-in-the-Cloud.

The project began among a small group of like-minded "diabetes parents" with engineering and technology backgrounds who were interested in better, more livable diabetes management strategies for their children with T1D. A primary goal for these parents was to simply sleep through the night, as many were sleep deprived from years of routinely monitoring their children's blood sugar 24/7. Many parents describe their lives prior to Nightscout as one of sleep deprivation and desperation. As one mother explained, “I think it’s almost innate that you just don’t sleep anymore.” One participant, a father of a teenage boy, noted that he and his wife have not slept a full night since his son was diagnosed. “I just want to sleep! We have been tired for 4 years.” As a system designed for the remote monitoring of BG data, Nightscout allowed parents to create customizable alarms and push notifications to alert them if their child’s glucose levels slipped outside of a prescribed range. This feature was particularly useful at night as it allowed parents to get out of bed for fewer checks during the night. As one father remarked, “It changes your life as a diabetes parent.”

Since its beginning days, Nightscout has grown into a community with a diverse group of users and perspectives on managing diabetes. While the largest user group of Nightscout remains children who have T1D and their parents, but there has always been a smaller and highly active group of adults with Type 1 who are interested in exploring new diabetes technology. A number of subcommunities have also emerged around Nightscout to help support technological development and meet organizational needs. During the course of this study, a group of approximately 10–15 core developers (led by one long-standing and highly active member) worked on releasing new Nightscout software versions, fixing bugs, and designing new applications. The developers are all volunteers, contributing their labor for free and taking on projects as time and interest allow. Many of Nightscout’s current features were originally developed as personal tools by developers to meet their own idiosyncratic diabetes management and treatment strategies (e.g., louder alarms, push notifications, predictive algorithms). As the number of Nightscout users grew, there was an effort among developers to respond to design requests generated from the wider community (although our participants also expressed wariness that unmet requests could lead to tensions within the community and the burnout of developers).

As volunteers, the majority of developers juggled full-time employment and squeezed in a few hours of work on Nightscout late into the evening or on the weekends. To meet the needs of a growing number of nontechnical users, the CGM-in-the-Cloud Facebook group was created in 2014 to facilitate the discussion and sharing of information around diabetes technology. Although this Facebook group includes conversations on a range of technologies and topics, CGM-in-the-Cloud quickly became the default forum for quickly disseminating Nightscout news and information. A volunteer technical support team for Nightscout was organized on CGM-in-the-Cloud to provide 24/7 assistance for installation and rig setup and field questions from a growing number of nontechnical users.

As of April 2016 the CGM-in-the-Cloud group had more than 17,000 members and activities had expanded past routine questions on setup and installation to include sharing expertise on self-management techniques, such as making insulin corrections during a child's growth spurt, conversations about pumps, showcasing DIY projects like designing rigs to fit small children or connecting Hue lights to Nightscout alarms as wake-up systems, and selling or giving away medical equipment like old pumps that are used for testing new software projects. CGM-in-the-Cloud also operates as place of camaraderie and emotional support for patients and caregivers of T1D.

Furthermore, a need to engage with larger governmental organizations like the FDA and medical device companies led to the creation of the Nightscout Foundation as an incorporated 501(c)(3) nonprofit organization. The foundation's mission is "to encourage and support the creation of open source technology projects that enhance the lives of people living with Type 1 Diabetes" (Nightscout Foundation, 2016). The foundation positioned the Nightscout community as both an innovator and advocate in patient-driven technology design and disease management. Nightscout was designed to provide remote glucose monitoring, basically displaying the CGM data in different formats, and the website takes pains to warn that the system is for educational purposes. People who embrace the use of open data in their care management, however, can find themselves in a gray area between "micro-dosing" and "remote bolusing," practices that the FDA has tried to discourage patients from engaging in due to safety concerns. Recently, there have been efforts among members of the Nightscout community to explore partnerships with other diabetes technology DIYers, particularly those involved in making their own artificial pancreas systems. Although there have been small, scattered collaborations of people building artificial pancreas systems, for the most part these have been technically savvy adults living with T1D.

Toward a DIY Artificial Pancreas

#OpenAPS is a growing open source, DIY diabetes project that aims to design a safe and effective basic artificial pancreas system that will automatically adjust an insulin pump's delivery to keep blood glucose within a safe range overnight and between meals. It does this by communicating with an insulin pump to obtain details of all recent insulin dosing (e.g., basal and bolus), instructing the CGM to obtain current and recent blood glucose estimates, and issuing commands to the insulin [pump to adjust temporary basal rates as needed. Even more than Nightscout, which is primarily concerned with data access and visualization, OpenAPS is highly experimental and requires constant monitoring by its users. Their website warns interested patients and caregivers that the system is not intended to be "set and forget" at this point for safety and technological reasons:

> "To maximize safety, #OpenAPS only doses basal insulin (not boluses), so patients still need to bolus for meals as they do today. This is a DIY implementation and it requires constant monitoring and testing to make sure the system is working as expected" (Lewis, 2016).

Although only a handful of people[8] were actively involved in OpenAPS at the time of this study (approximately 34 "loopers" as of January 2016 have created their own closed looped artificial pancreas system), these projects, together with Nightscout, are part of a broader movement that seeks to "liberate" data from proprietary medical devices. Whether actively using the system or not, the DIY projects of Nightscout and OpenAPS are viewed by many supporters in the diabetes online community (or DOC, an amorphous collection of social media, blogs, and websites around living with diabetes; see Hillard et al., 2015) as a mechanism for pushing the FDA and the medical device industry to release commercially available systems to the T1D community faster. The stance of those in OpenAPS and Nightscout using the #WeAreNotWaiting hashtag is rooted in both a pragmatic DIY ethos of making life (even incrementally) better and a critical stance toward the formal health care system.

LIVED DATA: DEPENDENT BODIES AND COLLECTIVE CARE

When parents monitor their children's blood glucose levels through software apps at school and programmers write algorithms to trigger alarms when their glucose levels plummet during the night, DIY health care is neither something done "by yourself" nor easily reduced to an "act of innovation." Rather, I found that people involved in Nightscout and OpenAPS performed continuous care work of holding diverse subjects, objects, bodies, processes, and institutions together. The making of DIY diabetes technology, in other words, unfolded through a

---

[8] The number of "loopers" has grown since data was collected for this study and in 2018 a number of people have begun to actively document using OpenAPS to manage their children's type 1 diabetes on social media.

multitude of sites through which data were lived: from poking needles into the skin and managing the needs of family and friends, all the way to legitimating self-written code with regulatory bodies like the FDA and mobilizing a collective sense of "we" (as in "we are not waiting") among patient groups. In the following sections, I unpack each of these sites and moments of data as lived through family relations, physical bodies, among social worlds, in new types of work arrangements, and across institutional boundaries.

Parenting with Data: Freedom and Peace of Mind

Overwhelmingly, I heard two responses from almost every parent I spoke with: 1) using Nightscout helped give their child and family back their "freedom" to live life more fully, and 2) Nightscout provided parents with greater "peace of mind." Indeed, participants repeatedly described their family's experience with Nightscout as "life changing." Childhood activities like going to school, playing at a friend's house or participating in athletic events can be a challenging event for families managing T1D. Parents worry about their children receiving proper care if they are not around to catch and treat dangerous highs and lows. One Nightscout user described how school became at times a dangerous place, especially for young children who were not yet able to care for themselves:

> "For parents, they lack this peace of mind because they are sending their kids to school with an insulin pump filled with a lethal hormone. And they could kill themselves at any moment. Like there is enough insulin in that pump to kill their kid 30 different times, and that kid has total control of the buttons: like that is ridiculous! And until Nightscout there was no way for a parent to see if your kid's blood sugar was crashing."

Nightscout changed this, allowing parents to view their children's blood glucose data while they sat at a desk in a classroom or played during recess. Parents developed plans with schools to coordinate care based on real-time data, sometimes calling the school nurse to alert them when their child was in danger.

While I found that most people were successful in finding ways to collaborate with teachers and administrators in providing care for their children using the remote monitoring of data, some parents said that they and other families they knew have received pushback from school districts over their use of Nightscout. Schools, for instance, have argued that the responsibilities of monitoring real-time data were a distraction for teachers in the classroom and led to the over-involvement of parents. Discussions on the CGM in the Cloud Facebook group often discussed strategies for educating wary school administrators, and at times parents must take legal measures to ensure their children are able to use Nightscout.

Data tracking through DIY diabetes technologies also shifted the dynamics around parenting and family life in subtle and surprising ways. Nightscout parents were often deeply reflective about how data figured into the different social and emotional aspects of caregiving—seeing their role as both enabling their children to be free from the fear, responsibilities, and daily grind of diabetes management, as well as finding ways of training their children to use data to effectively so as to take care of diabetes themselves. Being able to remotely monitor blood glucose data was often a liberating experience for both parents and children. One mother described how Nightscout gave her 8-year-old son freedom to experience the joys of childhood: "It's been beyond a lifesaver for us, just beyond…just the freedom to let him be a child, to go on play dates, to basically—just be—without an adult all the time." Another parent told me she loved Nightscout because it made her feel comfortable to put her infant son with T1D into daycare and go back to work after maternity leave: "We get peace of mind and we get comfort to know that we can still see what's going on. And he can be a kid and the babysitter can be there and present with him and not be so worried." Being present—living together and experiencing the world with and through data—changed the nature of caregiving work from something that was burdensome to potentially empowering.

In general, while many parents noted their children with T1D are incredibly self-reliant and have learned to manage their diabetes from a young age, many others expressed exasperation or fear that their children wouldn't continue to take as good of care their health without parental involvement. Parents with older children and teenagers acknowledged that Nightscout at times impacted the parent-child relationship in stressful ways. The caregiver experience of feeling freedom through data was often tempered by worry in teaching children how to understand and use diabetes data and DIY technologies independently. I heard stories, for instance, of parents who tracked their high school children's glucose levels as they ran cross-county meets or texted treatment plans to teenagers while at a sleep-over.

Chris, the father of a high school senior with T1D, had given careful consideration to the newly gained freedom his son, Jonah, would shortly experience upon starting college. Chris told me he was actively working on preparing Jonah to take on greater ownership of his diabetes data:

> "He's going to go to college. He is going to get drunk at a party. I get that, I was at college, it happens. When he goes to sleep at night…I will not be there and mom will not be there to deal with the alarms and what's going on."

Such situations are a cause of concern for Chris and his wife who at times feel frustrated at their son's lack of independence. Chris explained:

> "[Jonah] sort of chastised me, "How come you temp basal me [an insulin treatment] instead of giving me a juice box?" And I said, "Well you're welcome to take over that role anytime you want. You can either chastise me or you can do it yourself. I am happy to let you!"

As a Nightscout developer, Chris explained that the knowledge Jonah would soon be leaving home had motivated him to work with his son on customizing new alarms specific for college life such as drinking and partying. Other parents were less prepared and described being at a loss for how they would manage diabetes data as their children grow up. "It terrifies me because I know that someday I'm going to have to hand this [data] over and I don't know how it's going to go," admitted one mother with a 2-year old child who has T1D. "I'm hoping by that time, there will be something [new technology] even better than what we have now."

While Nightscout enabled people to experience short-term freedom from the daily grind of diabetes through the remote data monitoring, long-term use of the system led to concerns about how this freedom would be used. As children matured, care work for parents shifted to learning how to let go of their child's data. This was a difficult and emotional task. Many parents expressed a need for guidance and support in anticipating an uncertain future when their children would increasingly need to take control over their own data and diabetes management. Despite an evident deep appreciation of Nightscout, over the course of this study, parents often reflected about their struggles of fixating on numbers, anxieties about making dosing decisions based on data, and difficulties in taking on the burdens of data tracking—all the while teaching their children to learn how to manage their own diabetes. The varied experiences of Nightscout parents shows how lived data brought new emotional complexities and social tensions to family life.

Data That Hurts: Bodies and the Physicality of Tracking

A myriad of images that show how DIY diabetes systems work have flooded social media platforms like Facebook and Twitter, publicly displaying the various configurations of insulin pumps, open source hardware platforms like Raspberry Pi, batteries, and mobile phones. In these images, technology is arranged on a clean surface, parts and wires neatly and even beautifully arranged (see Figure 1). In many ways reminiscent of a whole genre of "open source hardware" hacks and "DIY maker" projects found online, this imagery demonstrates how the thing is made, giving off a vibe of "you can hack this too" and "this is how you can do it." The images articulate a mode of production we have come to associate with DIY making: open, hackable, modifiable, doable.

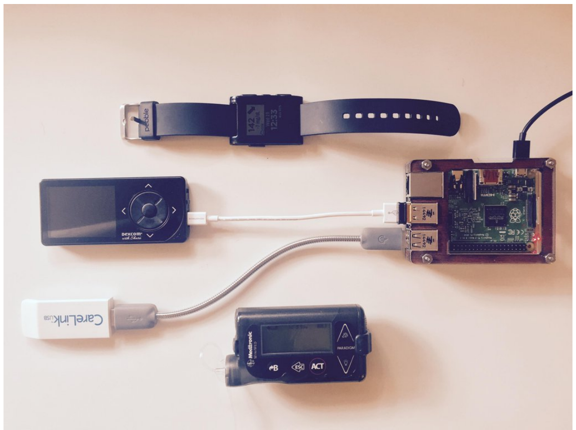


Figure 14: OpenAPS System

Figure 15: Nightscout Pebble watch face

Similarly, popular media articles have largely focused on the celebratory aspects of DIY diabetes technologies. Stories on Nightscout, for instance, often depict people happily holding up their Pebble watches to the camera, their blood glucose data on full display (Costik, 2015; Smith, 2016). In such images (see Figure 2), the Nightscout watch interface shows the person's real-time blood glucose value and an upbeat saying, "Everything Is Awesome" or "Dont WRY be:)[9]" These watch shots are also hugely popular among Nightscout users who post them regularly on Facebook, Twitter, and Instagram, garnering numerous likes and comments of encouragement.

---

[9] An abbreviation for the phrase, "Don't worry be happy" so as to fit on the small screen of a smartwatch.

People document their blood sugar data in relation to everyday experiences like eating pizza at a sleepovers and shopping at the mall, along with more extreme activities like bungee jumping and getting married. Diabetes data have also generated humorous memes on the CGM-in-the-Cloud Facebook group, exemplified by an air force pilot showing the Nightscout system working at 4,000 ft, who became known as “Commander of the CloudForce” (see Figure 3).

Together these images present a powerful testimony—both intimate and public—documenting how data and DIY medical technologies have empowered people to reclaim parts of their lives often stolen by diabetes. This public narrative of triumphant technology is only one aspect of lived data. Take, for instance, the photo (see Figure 4), which I took during a dinner with two developers centrally involved in Nightscout and OpenAPS. An everyday cyborg configuration sprawled across the table in a tangle of wires, pumps, gummy bears, smartwatches, beer glasses, and an old receiver held together with a rubber band. I watched as the developers checked their watches and phones, monitoring blood glucose numbers all the while dinner was unfolding. Haraway and Suchman’s socio-materiality calls for engaging this kind of “mess.” What became so visible at the dinner, amidst of wires, drinks, and Pebble watches, was how DIY innovation, no matter how creative or elegant, does not offer people a quick fix to chronic illness but instead requires constant work to manage the messiness of these configurations.

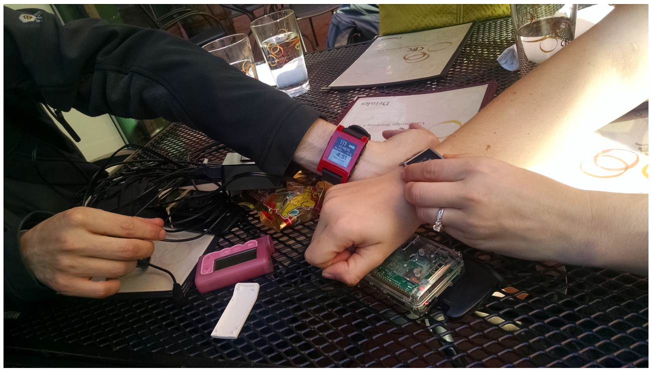


Figure 16: CGM in the Cloud Nightscout meme. **Figure 17:** Lived data at dinner.

Side-by-side the imagery of empowering watches shots across social media is another type of photograph, one that documents a more visceral side of diabetes data where the physicality of tracking is represented by a sensor sticking out of a person’s arm (see Figure 5). This insertion site, the place where the tracking of blood glucose data begins, is rarely pretty. Skin around the sensor can break down, a condition known as dermatitis caused by the constant application of various adhesives like Tagaderm and SkinTac used to keep the sensor attached to the body (see Figure 6). Some people in the Nightscout community try to make the sensor site itself more attractive, using tape and materials to decorate or camouflage the area; yet this aspect of data tracking, of technology being embedded in the body, is intimate and often distressing.

Figure 18: Parent wearing a CGM sensor.

Figure 19: Dermatitis from CGM sensor adhesive.

In DIY diabetes technologies, the physicality of tracking, both hopeful and hurtful, makes visible its sociomaterial complexity and its consequences through the skin. Jose, a self-described "maker," spoke about how the costs of data tracking are not well understood by those who see data as external to the body. Diagnosed with T1D as an adult, Jose explained how within weeks he was frustrated with the daily grind of diabetes care and felt like he was doing a poor job of keeping his blood glucose levels stable with his CGM. After a few close calls in which he didn't catch his blood glucose levels dropping in time, he began typing search terms into Google, everything from "diabetes pump hacks" to "data tracking." His search eventually led him to a Quantified Self meetup where he hoped to pick up some ideas on how to better understand his blood glucose data. Jose described striking up a conversation with one of the regular QS attendees:

> "I met a woman … and she was doing lots of experiments with her body regarding step counting and exercise counting and blood pressure. And I asked her, "Yeah, like this sounds incredible, you got all this information that tells you about what's happening in your body like around the day. But have you tried anything with measuring your blood glucose?" And she was like, "Oh no, that hurts a lot! I would never do that!" So, I was like, "Yeah, of course, it hurts!" That is what is difficult about this!"

The pain and discomfort of tracking that extracting data can actually hurt and are not typically discussed in studies of personal informatics or in the Quantified Self movement, where people use commercial wearables like Fitbits and Fuelbands. When needles poke bodies to get data, the story of empowerment comes at high cost. If one has diabetes, sensors need to be physically inserted into the body. Insertion sites—especially on the small and skinny bodies of young children—can easily become sore and need to be rotated from upper arm to lower back. People living with T1D know that data tracking hurts, and no matter how valuable, the high cost of getting data from the body needs to be carefully weighed. One mother of a small child with T1D described the physicality and pain of tracking: “A lot of this stuff is invasive stuff for your child. I mean, you’re putting something under their arm and it stays there for two weeks. So, there is a trade-off here and it’s worth it for us, but it’s not for everybody.” For another parent, tracking her son’s glucose with a CGM was a decision that took careful consideration: “The reason it took us so long to get a CGM for [my son] is because he was already on the OmniPod [type of insulin pump], so its stuck on you. It’s something that’s on your body all the time. And I was unsure how he would feel about having something else stuck on him.”

The invasive nature of data tracking—having something “stuck on you”—is important to understand, because the physicality of tracking not only is in the materiality of devices but also is as much about data’s relationship to flesh and blood, skin and muscles. In my fieldsites, people maintained the body so that it could accommodate sensors without damaging the skin and considered the human form in strategically placing the device so that a person could move about throughout the day without getting snagged on doorways or clothes. They gauged if/when it is possible to let the mind and body rest from the constant demands of data tracking. Indeed, some people took routine breaks from Nightscout altogether, despite the benefits of the system, because the physical, emotional, and social costs were too high.

A number of parents tried out Nightscout on themselves. Most parents I spoke with wore the CGM sensor and smart watch for a few days to monitor their own blood sugar levels; however, some even went so far as to inject themselves with saline using an insulin pump. They did this for a number of practical reasons, including learning how the system functioned, but also to discover what the experience was like for their children both physically and emotionally. On taking the step to insert the CGM sensor into their arm, a father explained, “I really wanted to experience what [my son] did—if it hurt." He acknowledged ruefully, "I am much more careful about where I place sensor since trying it myself."

Another T1D father, also a software designer of diabetes data applications, explained his reasoning for using the Nightscout for a few months in a blog post:

> "I wear a Dexcom [CGM] so I can always demo the technology, and for a while I was also using an insulin pump and injecting myself with saline. The first time I did it though was to better understand what it really meant to manage Type 1. I did it for nine months and did everything my daughter did (except of course, I never went low or high). She was 12 at the time, and she'd ask me, "Where are your low supplies, Dad?" [referring to checking current levels of insulin stored in pump]. And a lot of times I'd have to say, "I know, I blew it." It really established this camaraderie between us" (Boise, 2016).

Another parent noted that she decided to wear her daughters' CGM when her child decided to "take a break" from the system. In doing so she learned better how the pancreases functioned in response to eating particular foods, but also enlightened her on the intimacy of living with the data.

> "I figured I would take the opportunity to feel what she experiences in some small way. It's been good for her too! She likes to keep the [Nightscout] receiver and check the phone! [the phone displays real time BG data] She likes to tell me when I'm going up or how what I have eaten is affecting me. It's given her a way to voice her feelings in a way I wasn't able to hear prior to wearing it."

This intimate sharing of biometric data between parents and their children can bring them together in the experience of diabetes—allowing them gain a different care perspective. At the same time, however, the experience of data tracking also becomes a source of uneasiness. After using Nightscout herself, a mother reflected, "I think it has given me the realization that it is strange to have people have access to seeing what your body is doing."

Having your body monitored, sometimes 24/7 is a strange (and often unsettling) experience for many children, especially teenagers. Parents, for instance, described how their children told them Nightscout sometimes felt "invasive" and like "being under a microscope." Fluctuations in stress and hormones, for instance, can impact blood glucose numbers and lead to an awkward over-sharing between parent and child through data. One father explained how he could see his 16-year-old son's blood glucose numbers fluctuate during a school dance, a time of socializing with peers as well as adolescent romance. His father admitted feeling he unintentionally invaded his son's privacy with Nightscout at such times. Another parent on CGM in the Cloud explained that emotional boundaries between parent/child and caregiver/patient are in constant negotiation in such data-centric care work:

> "For our T1 kids, every sip, every morsel eaten can be seen. We see when their site [the CGM sensor embedded in the child's body] is petering out, when they played on the trampoline, when they study for a big test or play video games. I know so much from seeing the Dexcom [type of CGM] data. My son complains that no one else in the family is under that kind of scrutiny and it makes him feel defensive, like he has to explain even the ordinary."

He noted that using Nightscout himself gave him empathy for his son's diabetes experience. Despite anxieties about glucose levels, together their family had a conversation and agreed that better care—in this case their son's mental and emotional wellbeing—demanded they limit data tracking activities to night and only lows that could get dangerous.

And yet others in the OpenAPS and Nightscout communities continuously used their diabetes data devices 24/7, 365 days a year—the merging of machine–body data becoming how they lived and who they were. One of my interlocutors who used a DIY artificial pancreas system described how using these systems shaped his ontology:

> "I'm a cyborg absolutely…It's a cybernetic technology; it's an appendage…I have needs in my body and they give me information. Some of them give information about my body, some of them change the chemical makeup of my body. So that makes us all cyborgs to some degree, me more so than most."

The Cyborg—to employ Haraway's figurative use of the term—is monstrous, is frightening, and gives pleasure at the same time. The cyborgian experience of diabetes data exemplified here entices as much as it repels:

> "I have a love/hate relationship with the pump. Because on the one hand, it's like when you go low, there are times I just want to rip it off and throw it against the wall or I'm afraid of it. Like, "Holy cow, I have a computer attached to me that is killing me" in a very palpable way. Like when you're 30 [a low blood glucose value], it is a very real feeling. Like, "This is killing me." So that can be difficult. But when you're 300 and you feel the insulin kicking in

> and it goes, “Woosh!” and you’re back at 100. You’re like, “Wow, that is amazing!” So it’s very difficult to resolve that tension.”

The biomedical effects of blood sugar fluctuations and the emotional response to subsequent insulin corrections can be heightened with technology interventions. The tension between fear and amazement—of wanting to simultaneously rip the machine off and out of your body while your life depends on its silent stream of data—is a darker, visceral counterpart to the current narratives around personal data found in HCI literature. As wearables become smaller and increasingly embedded in the body itself, and as data are increasingly part and parcel to how many people learn, exercise, eat, are being evaluated, rate others, and so on, we need to consider such lived realities in designing for human/nonhuman relationships. There is real work, both physical and emotional, in navigating the tensions of living so intimately, physically with data. Nightscout and OpenAPS highlight the physical cost of getting data and push personal informatics research to engage stories of despair, pain, and messiness, as well as stories about individual empowerment, as they are mutually constituting one another.

DIY and its Dependencies

The physicality of tracking diabetes data, although deeply personal, is also social. The work it takes to live well with one’s machines is difficult to perform alone and managing diabetes through data often requires the support and guidance from others. Through the act of living data that is both celebratory and painful, people who use DIY diabetes technologies navigate the tensions of chronic illness together, leaving their relationships marked by dependencies and obligations that often sit in stark contrast to the more public stories of individual empowerment and self-care.

In successfully hacking a CGM to “liberate” their diabetes data, people were left with the difficult (and sometimes dangerous) challenge of interpreting those data to make appropriate therapeutic decisions. Access to personal data was perceived as a means to increase understanding of one’s body and open up new possibilities for diabetes management, but the benefits of data tracking also required people to engage in types of work that caused anxieties and concerns. Diabetes care, here, required expertise not only in the body’s biochemistry but also in writing and debugging software. Many people were excluded from the inner workings of their machines as they relied upon the help of others to make sense of their data as well as to help manage software labor. A version of the Nightscout interface for the Pebble watch face and website shows the wide range of data used to monitor, predict, and (with the addition of OpenAPS) control diabetes (see Figure 7).

Figure 20: Data display on Nightscout Pebble watch face.

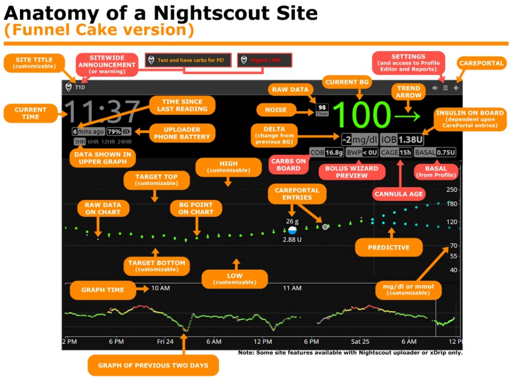


Figure 21: Types of data on a Nightscout website.

Small screens are jammed with information from real-time blood glucose readings to predictive graphs to noise levels. In Figure 8, the small slice of personal data on display is the outcome of the collaborative work of many people—multiple developers, users, and their families—and doesn't even account for the contextual data that don't fit on the screen. As a result of such complexities, many people turn to the CGM-in-the-Cloud Facebook group for help to interpret personal data. An active and passionate group of Nightscout volunteers, for instance, offers technical support through the Facebook group 24/7. This team is staffed with people who have the technical skills needed to address questions involving installing and managing the DIY system, such as connecting the rig, updating software, troubleshooting coding errors, dealing with bugs, and creating a database. This technical support was critical for many parents without engineering or computing backgrounds. Upon learning about Nightscout while researching diabetes technology online or through social media, many parents were determined to try out an unregulated, DIY medical system even though they are not 'techies.' One father, for instance, described to us the experience of learning to code as sleep-deprived caregiver: "It was very technical. You have to do a lot of work yourself because the developers wanted to make sure that you were aware that this was DIY. You literally were compiling code…And the whole community comes into this sleep deprived. You're not coming into this well-rested, having had a good meal, and the only thing you have to do today is set up Nightscout. You are literally having to add this to the crushing burden of what you are currently going through." For these parents, having free and accessible technical support and expertise available was often the only way they could set up and use DIY technologies.

Many individuals also use CGM-in-the-Cloud to share insights on diabetes management and collectively arrive at best practices. Scrolling through the group's Facebook feed shows how people help interpret one another's data. For example, a confused parent posting a screenshot depicting the graph of their child's blood glucose levels after dinner will elicit comments such as, "My kid's graph looked like that when they were having a growth spurt" or "Did you happen to eat pizza?" (a notoriously tricky food for balancing blood sugars). It is in these moments of advice sharing and collective sense making of data that it becomes visible just how much DIY diabetes systems were enacted through mutual dependencies and collective support structures.

Shared and widely adopted by members of the DIY diabetes community, many of these informal data practices have influenced the design of software. Developers connected to Nightscout and OpenAPS, for instance, have begun to create a wide range of open source data visualization and analysis tools such as Tidepool's Nutshell and Perceptus's GlucoDyn in order to assist people in this interpretive information work. Real-time and predictive data applications are considered crucial, as they make data actionable. As one of my participants explained, diabetes data interpretation is a dynamic process of understanding the balance between one's body, social and environmental contexts, and various insulin treatments:

> "Looking at historical data from my CGM isn't helpful. It's what can I do to change the situation? And it wasn't that my basals were messed up. I knew how to do things, but [a bad number] happened. I ran across the street; I got excited; I got adrenalin. All that stuff changes what your numbers are, what the outcomes are. So that's me figuring out how my body reacts to that…It's not data you can really track using any historical system."

A developer of GlucoDyn noted that this type of data work is extremely difficult and most people need help to understand "what's really going on with themselves or with their children."

Data brought increased insight for treating a critical health condition; yet, the more detailed and complex data visualizations and treatment strategies became, personal diabetes data also became a source of tension among family members and friends. With real-time data at their fingertips, parents described feeling negligent if they did not keep their child's blood sugars level and worried about becoming oppressive in their hypervigilance. For example, there were many passionate debates on CGM-in-the-Cloud about "helicopter parents"[10] and making children with T1D feel judged for not maintaining perfect numbers. While Nightscout was adopted by many parents so they could finally sleep through the night; in fact, the system often kept parents up at night as they felt compelled to examine and use the data 24 hours a day. Nightscout gave parents the ability to carefully monitor and control their child's BG levels to minimize highs or lows. As one father, a software engineer, explained that his family now monitors and tracks his 8 year-old-son's BG data in order to devise care strategies for keeping it within normal range as he sleeps: "We can basically micro-correct with insulin or glucose…We'll break glucose tabs into quarters and give it to him just to keep him really smooth…He'll eat glucose tabs in his sleep."

These efforts to tinker and tweak based on real-time blood glucose data during the night often lead to a constant state of sleep deprivation for parents. A number of participants described feeling more secure with Nightscout's alarms and push notifications, but also acknowledged that for them, the routines of night checks have become "what we do" as T1D parents. One mother explained to us that she now looks at her Pebble watch at her child's BG numbers instead of sleeping: "We don't sleep through the night…maybe 2 or 3 nights out of a month the numbers are flat and stable all the time and you do sleep through the night. If that happens, that's great, but it doesn't mean I'm not still tapping my watch…and looking at it. I'll wake up, just because that's what we do. We're used to it…I won't say we sleep through the night, but we certainly have a better idea of what's going on in the night because of Nightscout."

While Nightscout provided parents more accurate data and a greater sense of control in managing their child's T1D, it did not necessarily always bring a sounder sleep or eliminate the stress of care work. DIY data monitoring devices were designed to keep children safe and help parent sleep; and yet, many parents in this study found that the increased access to diabetes data kept them awake long into the night, actively engaged in trying to control diabetes better. Achieving peace of mind through data often remained an elusive goal for parent-caregivers.

---

[10] In early days, the caregiving practices of Nightscout developers and families became a matter of controversy and debate within the diabetes online community after an interview with an executive of a major medical device manufacturer was uploaded to YouTube in which he called DIY diabetes users "rouge cowboy programmers" and "helicopter parents" (see Healthcare Channel, 2014). His negative remarks exemplified the stigma and suspicion faced by open source diabetes technology advocates in the first few years after collectively organizing. Nightscout and OpenAPS users have since come to reclaim these contested terms on social media through memes and posts.

In providing parents with an endless stream of data— Nightscout assuages the panic of the unknown, but also demands the constant attention of caregivers. For many parents the ability to take action upon data through insulin corrections can make it easy to fixate on the numbers. Parents articulated constantly trying to find the right balance between doing too much or too little in regards to their child's blood glucose levels. "This is such an emotional disease," explained a mother whose daughter had been diagnosed at 3 years of age, "It's like so personal, you almost take it personal when some things go wrong with [her child] because we're responsible for the settings."

As managing and interpreting data became central to care, many parents felt inadequate to protect their child's body and wellbeing. A developer noted:

> "We see people looking at their kid's data and we have this widget that shows what percent of the day you were above range, in range, and below range. And these kids are above range 85% of the day. And you look at their mother's face or their father's face, they just feel like failures. They're like, "I'm f-cking this up. I'm destroying my child."

Data-induced guilt brought on by remote monitoring led some parents to try "beating the disease" through data. Sharing his observations of Nightscout parents, a developer noted: "I know some people who are overdoing things. They've got 15 basal patterns [instructions for dispensing types of insulin treatments via the insulin pump] set up and they're jiggering them every night." One father admitted he and his wife struggle with the temptation to constantly tweak his 13-year-old daughter's corrections: "We're on her like a hawk. We measure every piece of food she eats…We change basal rates and bolus rates [used in insulin treatments] and sensitivities. We try to do the best we can." While steady glucose levels can lead to improved long-term health outcomes, the pursuit of 'good numbers' can sometimes conflict with 'good care.' Later in the same interview, this father wryly acknowledged to us that his teenage daughter "didn't love" her parent's obsession with her data:

> "We were checking her too much…And she wants to shoot me sometimes, and my wife as well sometimes, because we are always on her about her diabetes…I've got to watch that, because I'm on her too much…There's definitely a quality of life thing to this…I know I don't have the right mix."

Finding the balance of caring through data can take time. Jamie shared an experience of when she first began using Nightscout with her son to manage T1D diabetes, explaining that it was easy at times to lose perspective—and one's humanity—in the stream of data. "When I first started monitoring him using a spare receiver, I was forever worrying about meal spikes and asking what he ate and if he bolused." Jamie explained, noting that in her impatience to see immediate changes in the data, she would nag her son even though he was taking care of his insulin treatments. Insulin, however, takes time to impact the human body and her son felt judged by her attention to the data. "We just want the best care and outcome for our kids," reflected Jamie, "but sometimes their spirit suffers the more we concentrate on the numbers."

Adults also struggled through living with data together: A 40-year-old woman with T1D told me that she has a few close family members and friends with T1D who have access to her Nightscout data. Whereas her Nightscout friends check her data freely, her husband often feels uncomfortable looking at her real-time diabetes data for fear of invading her privacy. To mediate the role that data play in their personal life, they set up a variety of alarms to alert him only in case of an emergency. To navigate such tensions required routine emotional labor for both the person living with T1D and the family and friends. It was a complex system of dependencies that unfolded through these collective practices of sensemaking, frequent checking in, and legitimizing one's approach with others.

Such practices, people stressed, often reduced the psychosocial burden of tracking when a person's life was on the line. The sharing of source code, photographs of rigs and watches and insertion sites, and even the raw data from people's Nightscout applications happens openly on social media, GitHub, and blogs. The public nature of this data sharing was considered a radical step. Health data are typically viewed as something to be privately guarded, to be shared only with professional health care providers and perhaps close friends and family. Despite warnings from medical data security experts that open source health applications like Nightscout could lead to increased risks in privacy and medical device security (Klonoff, 2015), the people I spoke with were often relieved to no longer be alone with their data.

Outcomes of freely sharing diabetes data were in crowdsourcing some of the information work but also in managing the emotional labor that comes with chronic illness. One of interlocutors explained,

> "Diabetes is such a lonely disease. You don't hang out with a bunch of other people with diabetes because there's just not enough of us…The data and the ability to share the data brings us together and gives us the opportunity to learn from one another."

This sentiment, echoed by many, points to how care work, when performed "by yourself," was isolating. Sharing personal data and experiences online through social media provided people with a glimpse into how one could potentially better manage diabetes, all the while making visible the work that goes into living with a chronic illness. Furthermore, data itself were perceived as deeply relational. "Nightscout has more blood sugar data than the world has ever produced in one spot," a Nightscout foundation board member told me. Generating such a significant "body" of data connected members of the community intimately to one another. One developer described creating a data visualization from all the Nightscout user data that allowed people to view their own personal data as part of a collective diabetes experience.

> "I set up an aggregator that shows everyone's blood sugar that enrolled at the same time. And one of the side effects of that is that the kids and parents are looking at this saying, "Oh, it's not just me. I am not at fault. I am not a terrible parent just because I'm having some readings, because look, everyone gets those readings."

Data, here, are both intensely personal and collective, as people donated bits of themselves, through pokes and pricks to the skin, into shared repositories. It also compellingly points toward a way of engaging the multiplicity of lived data in design: Through making the costs of tracking chronic illness visible, personal pain is not erased but becomes an experience of shared empathy rather than individual isolation.

Providing good care for diabetes has always been a difficult undertaking and counter to the aforementioned narratives of freedom and empowerment having access to an endless stream of blood glucose data does not necessarily make it less challenging. Software and data analytics, although often assumed to increase objectivity and efficiency, required not only constant work to maintain and write code but also adds emotional labor to navigate these new forms of mutual dependencies and obligations. Personal data offered people greater insight and types of control over their bodies than found in the traditionally passive role of the patient; and yet, DIY health care creates new, and arguably more precarious, dependencies that rest not only on fragile bodies but also on the free labor and goodwill of volunteer workers, software coders, families, and friends. Data tracking can bring about a radical empathy between parent and child, for instance, but control is often elusive and the abstraction of diabetes through numbers can at times obscure the person altogether. Stories of data as individual empowerment and problem solver warrant critical reflection by the HCI and CSCW community. Datafication of diabetes is shifting the idea of care itself and this has emotional and social consequences for designing collaborative systems to support health and wellness.

Technical Labor and Care Work

Importantly, shared data gave those involved in open source diabetes projects a newfound power as the owners/custodians of a valuable commodity. Everyone from medical device companies, government agencies, and institutions of higher education (myself included) has expressed interest in “working with” groups like Nightscout and OpenAPS. The sociopolitical stakes of personal data were especially visible in the technical work of developers who both collaborated to create open source tools and experimented together with data, often pushing at the boundaries of human–machine relations and legal, regulatory infrastructures. A number of activities in Nightscout involved advanced programming knowledge or technical skill sets, such as building and designing software and hardware, database management, coding, and calibration, and these activities were done by a small group of developers. Those with experience in software and hardware engineering, for instance, noted that they spent time investigating calibration issues with the Dexcom, assisting others in building and configuring xDrips, providing hardware support, contributing to the Nightscout repo (e.g., Github), and configuring Nightscout databases and web setups. Nightscout code is currently available for anyone to download, and although new builds are still being developed and released, the core developers tended to view remote monitoring of diabetes data as a problem solved and had moved on to explore a number of experimental projects, which included building their own artificial pancreas systems. In the creation of algorithms that dispensed insulin and experiments with bodies, coding itself became an expertise of care work. And yet, developers, in becoming experts in DIY health, also had to increasingly shoulder the burden of risk and responsibility. In what follows, I illustrate tensions in the work of writing software code for managing chronic illness.

Soldering Care and Negotiating Risks

Those who designed DIY diabetes systems formed a small-knit community of open source advocates and software developers who worked closely together in improving and maintaining the various software packages. Many of them were driven by the desire to design a system that managed to "close the loop"—and build the world's first DIY artificial pancreas system. This technical work did not take place on the CGM-in-the-Cloud Facebook group; rather, the developers communicated privately through e-mail, IRC, Twitter, and Skype. Part of the reason for this was a concern over the liability in sharing code with people "who wouldn't know what to do with it." Data sharing, here, was a secretive, risky, and ethically fraught activity, especially when dealing with algorithms and technology that involved insulin dosing. Openness, in other words, was anything but a straightforward approach to simply adopt, but required careful negotiation of what was considered safe or risky to share. This is in stark contrast to avocations of open innovation and radical openness as solution to and intervention into corporate control and monopoly.

"What if something went wrong?" was a concern for developers while experimenting on themselves; however, it was something altogether different when sharing personal code on Github. As one developer put it,

> "I've been doing all these tests and all of the developments around how my body reacts to insulin and to carbohydrates and exercise and whatever. So like putting my code up there…I feel that someone could get harmed with it, and I don't want that to happen. I don't want to have that on my head."

Although people used FDA-approved pumps and sensors in their DIY systems, tinkering with algorithms for dosing could easily have lethal consequences. "I don't want my algorithm to dose the crap out of some kid and kill him … so we're in a grey area here." Deciding when to share data in this technical and ethical gray area was risky. Yet developers strongly argued for the importance of sharing despite the uncertainty, in part because they considered the improvements in people's daily life with T1D was worth the risk that came with open data sharing. The developer of a popular DIY diabetes device voiced his reasoning for putting his code on Github despite wariness about the FDA and possible legal repercussions: "I think I'm not doing anything that's terribly wrong. I think I have warned people: 'Hey, if you are soldering something together yourself, you may know that this is not the same as a store-bought medical device.'"

These may appear as harsh words at first, but developers, who themselves were living with T1D or were parents of diabetic children, understand the desperation that underlies open data sharing and participation in DIY projects all too well. I was told a story of one grandmother whom a developer had taught to use a soldering iron so she could assemble an xDrip for her grandchild with T1D. Although on one hand a celebratory ode to open source and open data, this story exemplifies a harsh reality: DIY health is precarious and risky, and it means to literally solder care together. Care, here, is not only mediated by technology. The ability to code, solder, and debug software itself becomes an expertise of care.

Coding the Cyborg Body

Among the developers, there was a sense of excitement in being at the forefront of science and technology and revolutionizing a broken health care system. The processes of self-experimentation were central to this experience:

> "We're just like doing and trying out different things. And we're experimenting with our bodies. … I'm a little bit more open to risk, to try new stuff. I develop my own protocols for testing, but in the end, I go on and test it and see what happens."

To date, people have tinkered with just about every commercially available diabetes medical technology except for the actual sensor that measures interstitial fluid (used to determine blood glucose values) and, at least so far, the actual insulin pump. "The only thing that has not been touched is building an open source pump," a looper shared in an interview. "I've seen people modifying transmitters, I've seen people modifying receivers, I've seen people modifying everything around that, but not the actual pump." When asked to speculate on why the pump hasn't been modified, he further reflected, "I think there is something in our heads that tells us that we shouldn't mess with those little motors…Right now we can modify stuff that gives information, but not the thing that delivers the medicine." Fear of messing around too much with the machine suggests that in DIY experimentation there is an ever-present careful calibration about just how far one should go in manipulating the boundaries between data, bodies, and technologies.

Self-experimenting was also seen as a social good. When people were engaged in testing devices and trying out new algorithms, the #WeAreNotWaiting movement and the coding of one's body became one and the same thing. Much of the earlier hacking and coding in Nightscout had evolved around the information visualization problems, but moved—especially as developers got to know each other better—into pushing at the boundaries of controlling the body through data. Others, who followed the innovative projects of such developers but were less familiar with software coding themselves, volunteered to "donate their bodies" to aid the cause. One such devoted DIY heath advocate described how he hung out with people building DIY artificial pancreas systems:

> "I said, "Sign me up. When you build it, I'm your test subject." … I didn't have the skill set to do that, but other people do and I think it's fantastic. It's really freaking dangerous, but when the people building it happen to be two of your closest friends, like fair enough. They are like, "We're going to hook you up to it and then you go to sleep. And we're going to stay up right next to you all night and make sure you're okay." And that was like the level of discussion we had, where it gets kind of scary."

Thad, diagnosed with T1D in his early 30s, got involved in designing his own artificial pancreas system to learn about how diabetes impacted his body. Recalling the early, stressful days of managing the disease, he noted,

> "During that point in time, I did not understand what was going on. As far as me taking care of myself as a diabetic, I really had no idea what I'm doing. I had very little idea of how what I was eating was impacting me and how I was taking way too much insulin."

After Thad connected with the DIY diabetes developer community, he started "playing with the data," finding inspiration on Twitter and sites like Hackaday, a blog dedicated to open source hardware and tinkering. He eventually began developing his own artificial pancreas system, explaining,

> "I started working around doing code with the Raspberry Pi and the simulation stuff myself. And I started analyzing how my blood glucose curves would change with different types of carbohydrates…So I was doing all types of crazy experiments like eating stuff for the science."

On using his own DIY artificial pancreas system, he admitted to being both exhilarated and afraid:

> "Trying this thing on myself like for the first time was like a big thing…I spent like two whole days just watching the system give me recommendations and I just was manually bolusing [an insulin treatment]…And afterwards, I decided to put it into live mode. Wearing it for the first time, I was like super nervous for the first whole week. I was watching all the time what the system was doing."

Although he now "trusts it 150%," Thad admits that at times it is still scary to know his artificial pancreas system is dosing him with enough insulin such that if the algorithm was off, it could be fatal. "This little machine is doing the work for me," he told me, 'It's weird to see a machine doing that with entering amounts of insulin in your body that could actually kill you."

Some adults involved in OpenAPS told me that while they trusted their self-made machines, they would never use them on their child and viewed DIY data monitoring tools like Nightscout as a safer option to customize care. Even Nightscout itself has been the subject of a few critical commentaries from the academic medical community warning of potential risks from data privacy to dosing (Klonoff, 2015). All of the people I met with who used various arrangements of the DIY diabetes technologies, however, were well educated about these risks, taking them in stride. A Nightscout Foundation board member explained that those participating in this collective experiment, including those people with T1D, their families, and caregivers, grew adept at balancing the risk between data, diabetes, and bodies. "They're the ones who are saying, I'm willing to accept the state of this code because the alternative of not having it is so much worse," he maintained. "I'd rather have 6 hours of visibility overnight of my child's blood glucose than zero hours of it." In fact, managing the risks of DIY technology was minor compared to the acute and long-term risks of diabetes, itself:

> "The notion that a tool has to be perfect, or a tool has to be risk-free, I think is a misguided notion. Diabetes is a huge risk. We guess all the time with every single insulin dose…And the reality is we all suck at it, it's just terrible. … I would much rather have an imperfect system today, acknowledging that there is some risk that it could kill somebody. I totally get that, but people are dying today without it."

This all makes visible, in a very deeply felt way, what is at stake with the expansion of quantification and self-tracking more broadly. The act of volunteering to be a test subject while your friends watch over you at night to make sure you stay alive is a new data story, one that draws on the popular rhetoric of DIY making, personal informatics, and patient empowerment while undoing them. My participants were forced to make nuanced distinctions between watching data (Nightscout) and acting on it (artificial pancreas dosing). Many walked a blurry line, experiencing the dangerous/fantastic/mundane practices of data every day. The gap between what people were afraid to touch (e.g., those little motors that deliver medicine) and the types of technology, data, and bodily functions they felt free to tinker, modify, and experiment with argues for a complex understanding of personal data and what it means to interpret them, hack them, and live both the opportunities and risks.

Troubleshooting Diabetes: The Role of Clinical Care in DIY Health

Despite the complexity and risk involved in merging technical labor and care work, people indicated they rarely consulted physicians about using Nightscout, OpenAPS, and other DIY diabetes technologies. This response was partly pragmatic, as doctors were viewed as unable to provide the needed expertise in fixing either code or faulty hardware. “That’s not the doctor’s job,” explained one Nightscout user. “My doctor, he could spend an extra hour with me discussing technology or something; but that actually doesn’t help. Because he’s not a technologist, what is he going to do?” The absence of clinical care was also rooted in a misalignment between professional workflows and the dynamics of personal data. Physicians typically relied upon standardized clinical practices for engaging with patient data such as paper templates for charting blood sugars, food journals, and faxed printouts of CGM data. Such systems, however, were rarely helpful to people needing assistance interpreting blood glucose data in real time. Although clinicians continued to be regularly consulted for traditional diabetes management activities (e.g., ordering A1C labs, prescribing insulin), many of the people we met deliberately chose not to disclose their use of DIY diabetes technologies to their doctors. One man with T1D confessed he has no plans to tell his endocrinologist he uses a DIY artificial pancreas system:

> “I have this [OpenAPS] automatically adjusting my insulin levels and I just need somebody to write me lab orders…At this point, I think [my doctor] doesn’t need to know how I manage my diabetes on a day-to-day basis. He is there to troubleshoot any relations if I get seriously ill.”

Others, however, felt strongly that clinicians needed to better understand technical types of care work. Those who brought their use of DIY diabetes technologies to the attention of clinicians received mixed responses. I heard positive stories of people being invited to share their experiences and demonstrate how Nightscout or OpenAPS worked at their local diabetes clinic. More often, however, clinicians didn't feel responsible for understanding the details of people's diabetes data practices. One woman described how a doctor dismissed the specificities of her DIY artificial pancreas system being irrelevant to clinical practice:

> "I took OpenAPS [to my endocrinologist] when I first started using it. In the second month I was already seeing a huge difference, like my blood sugar was already dropping and my A1C dropped. And [my doctor] was kind of like, "Oh, how did you do this?" "Well, I built this tool, it pushes alerts..." And he started talking over me, "Oh okay, but do you have less lows?" I'm like, "Yeah." And he was like, "Okay, that's all I need to know." And he went back to his computer typed something and said, "Here's your prescription."'

She confessed that this lack of interest in understanding the technology is frustrating, because the software she writes directly impacts her treatment strategies: "I'm annoyed when I try to talk to my doctor about OpenAPS, because it's important for me to explain to him why I don't see any improvements [in blood sugar levels], he kind of brushed it off."

Negative or dismissive clinical attitudes were frustrating to those who relied on systems like Nightscout and OpenAPS to manage their diabetes but also expected. Living intimately with technology gave people insight into the nuances of diabetes data that fell outside the expertise of most clinicians. "I spend more time looking at my data than anybody else," explained a Nightscout developer. "My doctor knows less about diabetes than I do, let alone my diabetes." Such experiences suggest the emergence of new types of care work—those activities undertaken to manage a person's health and wellness—centered around data practices and technical expertise. It should be emphasized that this was a hard-won expertise for users. For others, however, the management of diabetes required facility in both technical work and clinical medicine, and I found that clinicians who engaged with Nightscout and OpenAPS were highly valued in these DIY communities. Another Nightscout developer explained how better care required creating collaborative data practices between the DIY diabetes community and healthcare professionals

> "There's an attitude today that each community solves needs for themselves. So the clinicians, doctors solve their own needs and the patients solve their own needs…As we start to get clinicians that are actually interested in solving the issues that patients have with providing better service, better treatment, better care, they could adopt some of these same sort of practices to take the data that the patients already have."

The tensions between clinical expertise and the role of technical labor is troublingly absent in popular narratives of personal data and the democratization of health technologies, as it is patients who must troubleshoot diabetes when bodies depend on the maintenance of data machineries. Care work, here, required expertise in computing, as well as access to equipment and a level of daring, something not everyone can easily afford to do. DIY technologies like Nightscout and OpenAPS, dependent on coding and data analytics skills, in turn shaped how care was practiced and who was able to perform it. Although considered experts, open source developers largely performed this work unpaid, at high personal risk, all the while carrying tremendous emotional weight and responsibility for wider patient communities.

Advocating for/with Personal Data

In the previous sections, I have explored #WeAreNotWaiting as a DIY/ making culture centered around personal diabetes data in terms of its social arrangements and techno-material designs; however, it is also, important to note, a patient-led advocacy movement. As a slogan and rallying cry, "We are not waiting" calls attention to broader sociopolitical issues of data ownership and access: What is the role of regulation in personal diabetes data? When should data-tracking devices count as a medical technology? Whose responsibility it is to address the needs of people living with T1D and their families, and how should they be held accountable? This study points to the ways in which people's use of data in open source projects like Nightscout and OpenAPS should be read not only as a utilitarian work-around but also as a collective political and ethical stance. People weighed the costs of using personal data, not just to their bodies but also legally and ethically both as individuals and as collectives. Working with and living data meant negotiating directly with the FDA and working through the processes of classification, but it was also visible in the everyday ways people enacted care together, such as educating other T1D families about Nightscout, showing them their rigs and blood glucose results, and in people's fights with local school boards to allow their children to use unregulated medical technologies. Taken together, the impact of people's participation in Nightscout and OpenAPS was more than a work-around; it was also a form of collective activism that was possible only because individuals "donated" their code as free labor and their bodies as sites of experimentation. In this section, I "expand the frame," as urged by Suchman (2007) and Clarke (2005), to include in our analysis the relationship between diabetes data/ bodies/technologies to political institutions and biomedical corporations.

A Nightscout father summed up the situation facing both his family and the broader U.S. healthcare regulatory system: "Does the patient own their own data, and can they do whatever they want with it?" People we spoke with described numerous challenges in using commercial products as medical device companies "black boxed" data through proprietary algorithms to gain market advantage. "In order for me to get my own data," explained one programmer with T1D, "I had to hack my devices. And, you know, most people don't really have the wherewithal to do that." Along with the desired access to raw data, people were motivated by the fact that many commercial diabetes devices and data analytics tools were so complicated that they were unusable by most people. People felt ethically compelled to hack devices and create data tools for themselves and others, as one Nightscout father articulated:

> "The software that comes with those devices, what you're supposed to use with those devices, it's like crawling through broken glass in order to get it up and running. Like, I'm a smart guy. I run software teams for a living. I could not get CareLink [a type of commercial diabetes data software] up and running even when I had all the requirements they said I needed…It was way too hard. And it became clear very quickly that we could do way better. It's not rocket science to build well-designed software that just works…So I decided I wanted to do something in this crazy diabetes world."

For my participants, the data complexity that comes with living in "this crazy diabetes world" is not just a biological phenomenon or technical problem but, as Jain (2013, p. 14) argued, "a politics with which to engage and struggle." I saw this struggle play out in the various kinds of advocacy work people performed, both in the effort involved for parents to enable their child to use an unregulated medical device at a local school and in the collective labor needed to challenge the regulatory bodies that defined the categories of "medical device." During my ethnographic engagement, I witnessed Nightscout foundation board members in the process of negotiating with the FDA about whether Nightscout should be classified as a Class II medical device like a continuous glucose monitor. An FDA release of new guidelines on medical display systems, unleashed a flurry of political work as people wrote system documentation, puzzled over and analyzed past discussions with federal agents, and brainstormed their best legal options. A Nightscout parent mused, "The FDA, right now, I don't think they're really sure how to handle a bunch of do-it-yourself medical people. I really don't. I think it is kind of uncharted territory for them." The lines between data and device are often blurry for all parties involved. One developer reflected,

> "I wrote some code and put it online and it doesn't necessarily do anything until you compile it and put it on something. At what point is it like, "Okay, you crossed this line, this is now too much, you made a medical device?"

At the time this study occurred, it was still unclear if the real-time display of data or only retrospective data would be acceptable to the FDA. Furthermore, as there were no agency guidelines on using diabetes data for treatment decisions, people who built and used their own artificial pancreas systems were seen as operating far outside the bounds of the FDA. "Basically, it's just that the FDA will not allow remote bolusing," explained one participant, referring to an automated injection of insulin to the body (controlled through custom algorithms based on real-time diabetes data) taken to cover an expected rise in blood glucose. Some who use DIY artificial pancreases seemed confident about finding ways around regulation, whereas others expressed wariness of their personal liberties. "I'm concerned that companies or the FDA might limit us…As long as I'm doing it for myself, to my body, I don't think this should be a problem. I should have that freedom."

The relationship between Nightscout and other open source DIY diabetes projects also caused concerns about the FDA confusing how data were being used by differently by each system, and therefore leading to stricter regulation, even though in practice these devices often exist as shifting assemblages. One developer of DIY hardware for diabetes explained the situation:

> "At one point some people said that what I was doing was going to be hurting Nightscout and holding them back more. They were worried about me going too far outside the FDA and upsetting people…If someone confuses like what xDrip [a DIY device] is

> doing and what Nightscout is doing and lumps them both together, someone may think, "Oh Nightscout is dangerous, it does all these things with custom algorithms," when it doesn't. It just displays the same data…whereas xDrip has its own algorithm entirely."

Concerns about the FDA impacted data-sharing practices, especially around designs for DIY artificial pancreas systems. For example, some people exchange ideas but never code for fear that the FDA would "punish" people doing open source experiments with diabetes data. Some of our participants mentioned that the impetus for creating the Nightscout Foundation, a 501(c)(3) nonprofit organization, was in part a response to protect the core developers from legal and regulatory threats. The data and devices they are willing to openly share and not share was subject to careful boundary work (Gieryn, 1983). Although some members of the community began partnering with the FDA, these relationships were continuously maneuvered and negotiated. Not all data were the same, and data artifacts differed based on how they might hold individuals accountable for actions potentially considered illegal.

Rooted in the pragmatism of chronic illness as well as a countercultural ethos that many inherently associate with DIY hacking and making (Coleman, 2012; Turner, 2006), the stakes of #WeAreNotWaiting are both intensely personal and political. In my conversations and interactions, people described their data activities as being grounded in pressing life-and-death concerns, as a legitimate work-around for people who did not have better options for the management of diabetes. A father who used a DIY artificial pancreas system with his teenager, for instance, discussed how he wanted the FDA to understand that even an imperfect data system improved daily life for his son in critical ways:

> "You've got the FDA saying, "Wait a minute, it's got to be super-easy to use, it's got to be perfect. You can have no risk and it's got to be used by the lowest common denominator." … I can't give you a closed-loop algorithm that [can] go off and run and be perfect because my sensor data is not perfect… So we're in this what I call a horrible waiting game. It's right there. I can make it better. I can at least make it incrementally better…It's how do we get it through the FDA?"

A number of people were also quite passionate about pointing out how open source projects like Nightscout and OpenAPS were challenging the status quo of health care, helping move product release dates forward as well as influencing the design of commercial medical devices. "I know that the Nightscout community has completely changed the future of type 1 diabetes community, of type 1 diabetes care," shared one of my participants, a programmer who also had T1D.

> "The FDA has changed largely as a result of Nightscout. Dexcom has accelerated its pathway largely because of Nightscout. Medtronic has completely changed directions largely because of Nightscout… These people are really, really, really influential. And I think that when we talk about hackers…I get a bit defensive… When we look back on history, the people who influenced change, we don't refer to them as hackers, right? We think of them as game changers…The folks at Nightscout…are more game changers than they are hackers."

Changing the game through creating a movement around DIY health technologies is not without significant costs. The collective contribution of countless hours of coding, inventing new algorithms and protocols, testing, calibrating, and documenting was brought about by a community's creativity and expertise, but also daily desperation and, quite literally, people's flesh and blood. There are financial costs as well. One core developer of Nightscout lived off of his personal savings in order to work on Nightscout full-time, devoting himself to getting new, safe versions of Nightscout released to the community and helping people set up and use the system. The costs, from his perspective, were not simply monetary but also ethical:

> "To be honest, I get a little frustrated sometimes because the feedback that I get is often very encouraging and people often say, "Oh yeah, you're doing such valuable work." But at the same time, I've worked pro-bono for a year, so if it's so valuable to the industry then why am I paying the cost for it?"

Other developers also personally took on the wider responsibility of care for an entire community, a difficult and weighty work to sustain. Also, one that feels (at times) frustrating when medical device companies are monetizing people's personal data, but also benefiting from the labors of the DIY diabetes groups who through their systems have contributed to people becoming devoted users and customers of specific corporate CGM models. A goal of this chapter, then, has been to highlight the varied practices and arrangements of care, but also the costs—social, physical, emotional, financial, legal—taken on by those in the DIY diabetes technology community experience. This is not to in any way diminish the inherent value of patient expertise or the innovative systems they have designed, which are indeed impressive, but in order to highlight the precarity experienced by people whose health activities do not align with the guidelines of formal medical institutions or processes of governing bodies. Outside of the clinic, but not in the shadows, those in the open source, DIY diabetes community can be seen as part of a social movement engaging in public dissent though data. This has consequences for how we understand patient engagement, but also for how we in HCI/CSCW seek to design for care.

LIVED DATA AND ITS CONSEQUENCES

I began this chapter by taking Suchman's (2007) directive, drawn from Haraway, as the starting point of my analysis: "Now that the cyborg figure has done its work of alerting us to the political effects, shifting boundaries, and transformative possibilities in human-machine mixings, it is time to get on with investigation of particular configurations and their consequences" (pp. 275–276). This chapter offered one such investigation of particular configurations and their consequences in detailing the sociotechnical configurations of DIY/open source diabetes projects. In the remainder of this chapter, my task is to explicate the consequences of these findings about personal data for HCI/CSCW. In particular, I see my work here as adding to the efforts of those engaged in the research area of lived informatics through an explication of data as both a mode of being and an ethics of design.

By exploring the livedness of data in one of its most extreme contemporary forms, I found that data were a visceral and intellectual experience, a daily grind and a movement for social change, a matter of life and death, inspiring stories of both hope and despair. Data were very much a mode of being, both a dwelling-within and way of interacting in/with the world. We need ways of accounting for the multiplicity of modes (physically, mentally, emotionally, socio-politically) in which data come to have meaning, not as the contextualization of a number or a feeling or the abstraction of a goal but as a way of experiencing life. In HCI/CSCW, lived informatics argues for seeing personal informatics as being done "over a range of lived activities" (Rooksby et al., 2014, p. 1171). I agree, but my findings also illustrate ways in which data become the medium and means of living within an unpredictable body. In lived data, I propose thinking of *data as modality* along with *data as thing*. In viewing data as a modality, the dynamics of this livedness become important to understand. Data, in our study, were simultaneously a way of being a parent, controlling one's body, negotiating with one's government, and empathizing with a community. Designing for people's experiences of/with/in personal data in health contexts and other areas of life calls for better understanding these new modes of being, but also for a moment of pause to consider the ethics of engineering and design.

In *The Logic of Care*, Annemarie Mol (2008) argued that the practices of managing diabetes—the tinkering with bodies, technologies, knowledge, and people—are both a site of innovation and a moral act. The history of diabetes shows how new drugs, technologies, and techniques have repeatedly changed the daily practices of those living with this illness.

> "Insulin, itself, has changed the moral landscape. As result of manufacturing insulin, "not injecting" has become a lethal act, and hence a moral activity. It is what technologies do. They shift both the practical and the moral framework. Do they do so in a good way?" (p. 90).

Personal data technologies are again shifting the practices and ethics of care. Insulin can now be administered remotely through a DIY device or fabricated at home in one's kitchen: To inject or not to inject? In Mol's world clinicians are part of the care team helping people navigate such decisions, but the collaborative care work I discuss in this chapter happened outside of the clinic on social media. People tinkered with their bodies through code, algorithms, and making things together using exclusive skill sets. Data were lived as means of exploration and mode of tinkering together, creating new sets of relationships and obligations.

Adele Clarke et al. (2010) used "biomedicalization" to describe the ways information technologies have made "to know and take care thyself" the moral responsibility of individuals as well as clinicians. This shift in care work has blurred numerous boundaries (public/private, expert/lay, patient/consumer) and is "unleashing new and sometimes unpredictable forms of agency, empowerment, confusion, resistance, responsibility, docility, subjugation, citizenship, subjectivity and morality" (pp. 184–185). In my findings, these new modes of being play out in and through data, including the collaborative, intensive care work. DIY health was rooted in both medical and information work that depended on emotional labor, coordination work, technical machine work, and advocacy work. In everyday practice, data bound together these activities, generating new relationships and forms of labor to maintain this growing care network of data, bodies, technologies, and people.

I argue that technology researchers and designers must attend to the hidden work involved in lived data. To live data is effortful, and despite the hype and stories of empowerment, it comes at a personal cost. People gave up life savings, weekends, and precious sleep to keep the Nightscout project going. They coped with daily stress both through memes and technical support teams. Some gave up their bodies for science, and others struggled with managing new legal anxieties related to personal data. This labor points to how, to a much larger degree, the promotion of self-empowerment and DIY making brings with it the demand to take on the work that used to be performed by the state and health care system. Framed only as a story of a resistance movement of individual empowerment against corporate control makes invisible this exact work. I have shown in this chapter how as software development becomes an important part of care work, individual coders, parents, and children carry the risks and responsibilities of living with data. The story of individual empowerment masks all too quickly the challenging complexities of managing, working, and experimenting with bodies and the data they produce.

Lived data engages the specific practices and politics of care work in the Nightscout and DIY artificial pancreas projects, as they are all necessarily entangled together. Popular narratives of the intersection between DIY making and personal data dwell enthusiastically on "the magic of the effects." Many of the systems, designs, and hacks that I examined in this study were inventive and inspiring; for participants, these projects were often explicitly described as "life-changing." This excitement, however, can obscure the consequences of health care as it is transformed through utopian ideals of self-management and self-care. The story of the empowered patient (or parent) who takes matters into her own hand masks how the work of DIY health care—as I have shown in this chapter—is all but accomplished alone. Rather, DIY health care unfolds through a myriad of dependencies and relations, for example, children on their parents, people on their devices, devices on their developers, developers on the FDA and regulatory system, the future of health care on the productive work of citizens turned makers, and so on.

Projects like Nightscout and OpenAPS provide a unique lens into a much broader sociopolitical phenomenon of shifting responsibilities in governance, employment, discipline, and healthcare from the state onto the individual. Nightscout, on first glance, appears like many other stories about DIY making, a success story of people who took matters into their own hands rather than wait for established institutions, professionals, and corporations to take action (we are not waiting!); and as such, it is celebrated as a unique case for patient-centered/patient-based design and open innovation. And yet, I am wary of such quick, and arguably utopian, renderings of what is at stake when data tracking extends beyond fitness and sleep patterns and into the shaping of bodies, health care, and regulatory regimes. The individual and collective cost of DIY design work using personal health data needs to be wrestled with as a sociopolitical and ethical problem: How are cost and benefit weighted in determining the release dates and design of new medical devices? Who should pay for inevitable coding errors? Who suffers from the unintended consequences of institutional blind spots in healthcare? These are the questions that inspire innovation and keep my participants up at night with anxiety.

The fields of HCI and CSCW have rich histories of unpacking the nuanced relationships people have with technology, of exposing the politics of artifacts, and of seeing design work as an ethical project. We need to remember these insights (exemplified in the work of Kling, Dourish, Star, Bodker, Sengers, Suchman, and others) in this time of excitement and enthusiasm around the possibilities of personal data and DIY/making in health and wellness. In a world where data tracking is adopted by a wide range of people and transformed in new contexts, the boundaries of personal informatics and our understanding of the nature of data itself needs to deepen and become more complex.

This chapter shows the ways in which the uses and meanings of personal data around the management of T1D complicate conventional narratives of data tracking as necessarily "helpful" and DIY as "empowering." My work is set in a realm of personal informatics that can look both similar and far removed from the activities of Fitbit enthusiasts and Quantified Selfers. Nightscout and OpenAPS—analyzed here as extended networks of people, data, bodies, politics, technologies—demonstrate shifting relations around technology use and production. Exactly because of its many extremes, from personal self-experimentation to parents and children to negotiations between DIY hackers and the FDA, my site makes visible how the analytical concept of user empowerment falls short in accounting for the sociopolitical processes and cyborg politics reported in this chapter. My findings highlight how the concept of data itself abstracted out of these various sociomaterial relations can obscure the various meanings and ways of relating through data as lived.

As a design-based discipline, the HCI/CSCW community is interested in learning how we can appropriate personal data to make it personally useful or helpful, as well as investigate how personal data systems can enhance human capabilities (Churchill et al., 2017). This chapter has shown that technology design as enabler of individual empowerment cannot be divorced from dependencies and uncomfortable alliances of human bodies, technologies, institutions, and personal relationships. With empowerment comes dependency, with appropriation and ownership comes risk and vulnerability—from the software coders who risked working at the border of legality to people who risked their lives when living with data machineries.

In speaking of "lived data" I seek to account for this instability and multiplicity of data and technologies as they are lived. Put differently, rather than designing systems that "reduce dependencies," I suggest making dependencies, which I argue necessarily occur, visible and the site of legitimate care work. I have shown in this chapter how much of the human care work, as well as the machine work (writing and updating and maintaining code), remains largely invisible (Star & Strauss, 1999), with those who perform this work receiving little to no compensation. Rather than refusing human–machine dependencies, I follow Haraway in acknowledging that the human and machine in an age of datafication can no longer be separated. Although we cannot un-design dependencies, we can remake them from within so that they are humane, start from a place of empathy, and value the work of care, a typically feminized and undervalued form of labor.

In conclusion, I draw out some reflections for HCI to consider when researching and designing for personal data and/or data/technology DIY empowerment from a technofeminist perspective of care. Following Parker et al. (2012), I believe that the response of technology researchers and designers needs to go beyond design solutions that offer "help" and "support" to thoughtfully engage with larger systemic sociopolitical issues and historical contexts. This chapter urges HCI researchers and practitioners to consider what we lose if we merely stop at the moment of excitement that DIY health and ignore complex data-tracking practices and types of care like the ones I have detailed here. We overshadow the ambivalence that arises from lived cyborg realities with stories of success, we mistake dependencies for collaboration, and stories of individual empowerment mask the spread of neoliberal governance and its rhetoric. I have further shown that visions of technological futures have the capacity to shift legal and institutional arrangements, as in this case partnerships between DIY hackers and the FDA illustrate, as well as how people live and work and how care can be construed and valued. How can we move forward? I argue it requires acknowledging the consequences of narratives and questioning visions of a technological future, no matter be it a future of data or DIY making, as inherently improved and better.

The problem, I argue, lies in part in HCI's tendencies to approach DIY health as yet another site of human-centered design—a story of user participation that can be further extended by HCI design intervention. An immediate design implication that one could have drawn from this work is to argue for the need to design systems that support the users of Nightscout and OpenAPS in their efforts to get access to their data, share their data, and collectively interpret it. Is this good care? Or I could suggest an intervention is needed to bring clinicians and the DIY community together to interpret their data. Numerous studies on health in HCI have found that the interpretation of complex health data is a collaborative process that requires both the expertise of the patient and professional insights of the health care practitioner. The dynamics of lived data, however, no longer make it clear how and when clinical expertise is needed. The types of data I saw being produced were for personal use and not the health-care practitioner. Will collaboration necessarily shift care in a good way given the realities of the current U.S. health care, insurance, and regulatory systems? In many ways, the expertise of the physician has been replaced with the expertise of a system admin. And yet, these findings have made clear that the act of designing with data is a matter of life (and sometimes death). Whether or not this is "good" care is a question for HCI to consider and weigh as DIY devices are now part of the ecology of artifacts that people use to manage their chronic illness.

Ultimately, this chapter argues for understanding the social complexity of care enacted through the practices around DIY data technologies; as well as the importance of proposing an analytic sensibility of *lived data* that provide a necessary counter-balance to the predominant view of data-tracking as inherently beneficial to people's health and wellness. In designing personal health technologies for people living with diabetes or other types of chronic illness, to promote health and wellness, or as part of a wider range of contexts altogether, we need to better understand the multiplicity of modes (physically, mentally, emotionally, socio-politically) through which data are lived.

Chapter 7 Living with Shadows, Designing for Care: Crafting Narratives for Health Technology

> "When you are simplified by the powers that be, you are severed from history and from your own body…At times it feels to me that complexity and the respect that seeing people as complex means, are vulnerable to simplicity…I have also found hope in looking more deeply into how the discarded complex is formed, lives, and carries the shadows as a living entity."
>
> –Susan Leigh Star, *Envoi: When Shadows Become Complex*

INTRODUCTION

Narratives have played a powerful role in the history of technology design. In *Divining a Digital Future*, Dourish and Bell (2011) document how early computing researchers like Alan Kay and Mark Weiser created foundational stories that drove an era of personal and ubiquitous computing development. As a means of designing futures, these "technomyths" (hybrid technological and imaginative efforts) "shaped the kinds of technologies that have been made and also made possible" (p. 3). In this age of rapid health datafication and biomedicalization, what design stories do we tell about care? What themes drive our sociotechnical imaginations in shaping narratives of illness and wellness, and how do those get translated to technology? And importantly, given the fieldsites discussed in this thesis, what stories of care are not being told?

In her 1926 essay, "On Being Ill," the British novelist, Virginia Woolf, reflects on the striking absence of illness as a prominent literary theme within the classical and contemporary canon. In considering this scarcity, she draws attention to how literature (for her, both writers and critics) elevate concerns of mind, rather than of the body. She pens:

> "Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to light...it

> becomes strange indeed that illness has not taken its place with love, battle, and jealousy among the prime themes of literature. Novels, one would have thought, would have been devoted to influenza; epic poems to typhoid; odes to pneumonia; lyrics to toothache. But no; ... literature does its best to maintain that its concern is with the mind; that the body is a sheet of plain glass through which the soul looks straight and clear" (Woolf, 1926, p.23).

Woolf, however, disrupts this dominant narrative of her era, describing the unwieldy (and uncomfortable) relationship between mind and body. “On the contrary, the very opposite is true,” she writes. “All day, all night the body intervenes; blunts or sharpens, colours or discolours, turns to wax in the warmth of June, hardens to allow in the murk of February.” Accordingly, the whole of human experience can be found in the mundane, but momentous interventions of ache and discomfort, hunger and thirst, sweat and shiver that sends a person from health into sickness. “But of all this daily drama of the body,” remarks Woolf, “there is no record” (ibid., p. 33).

While parts of Woolf’s essay are clearly tongue-in-cheek (‘odes to pneumonia’); it is also a thoughtful reckoning of the illness experience through narrative, particularly the linguistic boundaries people find themselves bumping up against amid trying to describe the specificities of sickness and suffering. Importantly, for Woolf, a “poverty of language” limits both our future imaginings and practical forms of support for those who are ill. In her essay, she describes the need for new language—"primitive, subtle, sensual, obscene”—that shifts the literary hierarchy from the mind to body; but she also explores how language connects to the very practices of care. Her portrayal of an invalid being stuck in bed, for instance, captures the way illness inscribes itself not only on the body, but also comes to shape one’s social life and the even the physical environment by both contracting and expanding personal boundaries.

> “ ‘I am in bed with influenza’—but what does that convey of the great experience; how the world has changed its shape; the tools of business grown remote; the sounds of festival become romantic like a merry-go-round heard across far fields; and friends have changed…while the whole landscape of life lies remote and fair, like the shore seen from a ship far out at sea….” (ibid., p.34).

Woolf’s artful prose makes an argument for the illness experience as material worthy of literary (scholarly) attention, an argument made all the more compelling when also read as the testimony of someone who lived and died with chronic illness: a struggle with depression ultimately ended with Woolf's suicide in 1941. Importantly, *On Being Ill* can be studied as the masterly crafting of a narrative that centers and gives form to absence by creating a vocabulary for unspoken silences and a record of the daily drama of the body.

Woolf's writing pushes those of us in the health design space to examine our own disciplinary narratives and the absences within. There are many genres of health technologies being designed today, each with a different design narrative. The medical informatics community; for instance, has largely focused on the development of large-scale health systems, such as electronic health records and patient portal systems widely used by hospitals and other healthcare providers. These technologies are conceptualized through the language and concerns of biomedicine (e.g. adherence, compliance, and even patient engagement) and are grounded in the organizational context of clinical institutions. Increasingly there has been widespread interest ranging from fitness conglomerates to fashion companies to medical device manufacturers in the development of personal health technologies, such as mobile wellness apps and wearable devices. I would argue that the design of such technologies is increasingly framed by a narrative of self-care that draws on the language of individual control and choice (e.g. consumer health, optimization, and empowerment). Recently, a data-centric narrative of precision medicine has captured the popular imagination and draws upon the language of artificial intelligence and machine learning to offer personalized care through data analysis and intervention as prescribed by algorithms. Large technology companies like Google, Microsoft, Apple, and IBM are investing in these health technologies and information infrastructures designed around these themes.

As a young field, at least compared to that of literature, HCI/CSCW is still defining its primary concerns in how humans relate with technology and technology's role the world. In the health design space, HCI/CSCW researchers draw inspiration from these dominant design narratives, but are also involved in actively challenging them by developing new technology genres of their own. Many of the novel health prototypes discussed in HCI/CSCW, for instance, are concerned with supporting the social and emotional dimensions of health; and in so doing, are helping to create a design language that takes seriously people's need for peer-support, collaboration, encouragement, personal reflection, and sense-making (see Jacobs et al., 2014; Kientz, Arriaga, & Abowd, 2009; Mamykina, Mynatt, Davidson, & Greenblatt, 2008; Tuli et al., 2016; Kaziunas, & Ackerman, 2015; Huh, & Ackerman, 2012). Researchers in our field have also has begun to contend with the difficulties of translating systemic health concerns such as literacy, poverty, and injustice into systems that address the socioeconomic nuances found in communities and social worlds (Parker et al., 2012; Parker & Grinter, 2014). Importantly, there have been numerous calls in the HCI/CSCW community to extend health technology design in new directions, to contend with the expanding role of data in health management (Bossen et al., 2016; Elsden et al., 2015; Chamberlain et al., 2015), create systems that address experiences of wellness along with illness (Churchill, & schraefel, 2015; Grinter, Siek, & Grimes, 2010; Storni, 2014), and highlight new forms of human-machine interactions in healthcare (O'Kane et al., 2016a; Karkar et al., 2015; Nunes et al., 2015; Grönvall, & Verdezoto, 2013). As well, our community has started to take important steps in articulating holistic health design narratives (Huh, Patel, & Pratt, 2010) that take concerns of the body into account (Eschler, Bhattacharya, & Pratt., 2018). As of yet, however, these efforts have primarily been ad hoc studies and design projects, and few have developed into a theoretical stance or gained traction as a wider analytic concern.

While HCI/CSCW has a deep and nuanced lexicon to describe users, interfaces, interactions, and infrastructures, we have few design terms or sensitizing concepts that address the raw human experiences that Woolf's writing on illness speaks to. There are some noteworthy parallels between Woolf's critique of literature at the beginning of the twentieth century and our current situation as designers and developers: In many ways, a poverty of language limits both our future imaginings and daily forms of support. Care in technology design is often understood as a form of medical (technical) expertise or a type of emotional closeness; but in viewing information/data technologies primarily as a concern of the mind (a design space of rational, computational solutions to disease) or as social sentiment (a design space of positive, uplifting encouragement in difficult times) do we problematically separate technology design from the messy materialities of the body and the concerns of diverse social worlds? Do we also cast illness—with its troubling relationship to unruly bodies, unspoken pain, and weighty life/death considerations—into the shadows?

While it is still very much an open question as to what types of practices and logics will be included (or left out) of health technologies as they become more widely adopted in society, I argue that these early days of design make it all the more important to consider alternative narratives. We need to more fully reckon with the complexities of care as experienced through information and data before particular ways of caring (such as biomedical, consumer, algorithmic etc.) become encoded into our technologies and embedded into our infrastructures. As Star (1991) cautions, "technology freezes inscriptions, knowledge, information, alliances, and actions inside black boxes, where they become invisible, transportable, and powerful in hitherto unknown ways as part of socio-technical networks" (p. 268). In particular, we need to expand our analytical framings to include diverse and emerging forms of care work.

In this chapter, I take inspiration from Woolf's invocation to craft a design story around care, data, and information technologies that I call *lived health.* This is not an attempt to formally adapt sociomateriality and practice theories for healthcare design processes (see Bjørn & Østerlund, 2014) nor provide an alternative model of lived informatics (see Rooksby, Rost, Morrison, & Chalmers, 2014); instead, I draw together the various narrative threads of care running through this thesis to explicate several sensitizing concepts that engage the everyday complexities of managing health needs. These analytic contributions, I argue, offer important (albeit incomplete) pointers towards developing a richer design language for health technologies.

In the following sections, then, I first situate lived health within a literature of critical, technofeminist discourse that draws attention to shifting relationships and uncertain realities in living intimately with information technology. Next, I discuss what I have learned about care work and share several vignettes from my field work that illustrate the significance of various sociotechnical bodies in how we conceptualize care. Here I analyze experiences of care that didn't fit neatly into the narrative arcs of my individual chapters, but which, powerful in their silences, offer us important insights into the nature of lived health. A minor collection of situated stories rather than a grand technomyth, these lived health narratives are grounded in the everyday care complexities that arose when gathered around the hospital bed, when giving voice to trauma, or when participating in online social movements to combat injustice. In the final section of this chapter, I describe several opportunities and challenges in designing systems for supporting chronic illness, as well as offer considerations in designing futures for care work.

TECHNOFEMINIST NARRATIVES: ON FUSIONS, TENSIONS, & NEGOCIATIONS

Counter-narratives are an important part in feminist scholarship across the fields of the humanities and social sciences, including technology-oriented disciplines such as communication, science and technology studies, and information science, among others. There has generally been a suspicion of “grand narratives” which have historically excluded women and other minorities, and there is a lively legacy of both feminist academics and activists alike finding inspiration in alternative modes of expression—such as art, poetry, and indigenous forms of storytelling—to give voice to those experiences that have been silenced or marginalized. Often, such stories are fragmented narratives; and the theme of literary absence evoked by Woolf is theoretically significant in feminist scholarship across a wide range of disciplines. In the science and technology field, for instance, recent critical investigations have sought to reclaim the technical accomplishments and contributions of women and other minorities who were written out of traditional histories on computing (Hicks, 2018), along with calling attention to the systemic injustices that information technology reinforces among populations living in the socioeconomic margins (Eubanks, 2017) or for racial minorities (Noble, 2018).

This is not just a matter of setting the historical record straight or calling present day developers and engineers to account for their harmful data practices and design decisions; it is also about imagining and designing different futures. Lucy Suchman (2008) argues that a technofeminist critique of popular information metaphors has wider social and material significance:

> “With respect to information technologies more widely, feminist scholars have pointed out the need for a genealogy that traces and locates now widely accepted metaphors (e.g., that of “surfing” or the electronic “frontier”) within their very particular cultural and historical origins. The point of doing this is not simply as a matter of historical accuracy but also because the repetition of these metaphors and their associated imaginaries have social and material effects, not least in the form of systematic inclusions and exclusions built in to the narratives that they invoke” (p. 149).

In seeing information metaphors, design imaginaries, and built technology systems and artifacts as interconnected, narrative becomes as important a site of design intervention as the development of new systems (Dourish, 2006).

In my research on health information technologies, I also found myself in search of new narratives as the experiences of my interlocutors did not easily map to celebratory design framings nor to patient-centric visions. Instead, I found health to be comprised of (at times uncomfortable) complexities that called for new conceptualizations of personal health and wellness. In this thesis, then, I have repeatedly drawn upon the work of feminist technoscience scholars as a means of reframing the way we understand the complex relationship between people and information technology. Collectively, these writings have pointed to: (1) the ways both humans and various nonhuman actors are inextricably connected in everyday care activities, (2) the blurred boundaries between physical and digital materialities, especially in relation to concerns of the body, and (3) the way multiple meanings (logics) are bound up in health practices and negotiated through artifacts. In this final chapter, I draw once more upon this technofeminist literature by looking at the powerful way narratives have functioned as both a theoretical provocation and methodological tool. Here, I focus on stories of sociotechnical "bodies" including Donna Haraway's influential figure of the cyborg as well as Ellen Balka and Susan Leigh Star's concept of shadow bodies. These writings offer an alternative technomyth as well as an analytical language for examining the shifting relationship between humans and information technology a site of political power and social complexity.

Sociotechnical Fusions: The Mythos of the Cyborg Body

As discussed previously in the last chapter, Donna Haraway (1985/1991) rewrites the science fiction trope of the cyborg as an "ironic political myth" (p. 117). We are all cyborgs, Haraway argues, "a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction" (p. 117). Myth-making does important cultural work, an observation that Haraway explicitly calls attention to in outlining her overarching political goal: "One important route for reconstructing socialist-feminist politics is through theory and practice addressed to the social relations of science and technology, including crucially the systems of myth and meanings structuring our imaginations." In maintaining that myth and tool are mutually constitutive, narrative is seen as an instrument for enforcing new meanings and a means of intervening in knowledge systems, social interactions, and even bodies (pg. 130). Haraway's narrative thus is a means of enacting the shifting relations between organisms (natural) and machines (artificial), confusion among traditional hierarchies and categories (mind and body; physical and digital), and politics of challenging how we create and maintain boundaries in society.

There are generative possibilities in a cyborg myth for attending to sociotechnical complexities in various health settings. In discussing Haraway's wider impact on feminist STS, Lucy Suchman (2008) notes that 1990s gave rise to a literature of "cyborg anthropology" and "cyberfeminism," which in relation to the biomedical sciences, "explore[d] possibilities for figuring the body as other than either a medicalized or aestheticized object" (p.149). In the field of technology and computing, specifically, Suchman argues that Haraway's theoretical project can be understood as "materialized refiguration":

> "Figuration recognizes the intimate connections of available cultural imaginaries within the possibilities materialized in technologies….The moves that Haraway encourages, toward recognition of the material consequences of the figural and the figural grounds of the material, and toward a different kind of positioning for the researcher/observer, mark the spirit of feminist STS" (Suchman, 2008, p.153).

Of relevance to my own theoretical interests and design concerns in Haraway's material refiguration of the body is the way in which humans are not sacred or given a special, protective status, but are viewed (at least on a physical level) as a configurable set of 'biotic components.'

> "In a sense, organisms have ceased to exist as objects of knowledge, giving way to biotic components, i.e., special kinds of information-processing devices…In relation to objects like biotic components, on must not think in terms of essential properties, but in terms of design, boundary constraints, rates of flows, systems logics, costs of lowering constraints" (Haraway, 1985/1991 p. 129).

Biology can be likened to an information system which is designed through applying engineering principles. Importantly, bodies, here, are not at the mercy of machines, they are interoperable with them. In my fieldsites, I have seen the power this analytic move offers through examining the ways data and information have provided people increased control over their blood cells and pancreases. Bodies can be "hacked" by biomedical technologies and reconfigured in ways that are personally empowering and also save lives. But my findings have also show the ways this myth of the cyborg body is complicated in the lived experience, creating new dependencies and unaccounted forms of labor. The individual figure of the cyborg as metaphor for political change or sociotechnical relations can also breaks down in the mundanity of everyday life, leaving many types of human experience and meaning unaccounted for, such as the case of community behavioral health.

Suchman (2007), in a perceptive analysis of Haraway and STS theory writ large, notes the contribution, but also the limitations in a strict symmetrical analysis between the agency of humans and machines for technology design. She argues that while social science and the humanities have rightfully attempted to re-center nonhuman actors (such as technology) as important objects of social inquiry, engineering and computing fields face the opposite challenge. “Far from being excluded, “the technical” in regimes of research and development are centered whereas “the social” is separated out and relegated to the margins,” maintains Suchman. “It is the privileged machine in this context that creates its marginalized human others” (Suchman, 2007, p. 270).

Fields like HCI/CSCW, with an emphasis on user needs and human-centered computing, have sought to strike a pragmatic and theoretical balance in understanding and designing for human-machine relations, drawing attention to the processes and politics of design in shaping those relations. Suchman (2007) also argues for the importance in seeing designers as actors in various sociotechnical assemblages across wider academic domains:

> “I want to suggest that the persistent presence of designers-users in technoscientific discourse is more than a recalcitrant residue of humanism: that it reflects a durable dissymmetry among human and nonhuman actors…we need a story that can tie humans and nonhumans together without erasing the culturally and historically constituted differences among them” (p. 270).

Following Suchman, my findings in this thesis argue for new sociotechnical stories that reckon with metaphor as well as how meaning gets translated into lines of code and negotiated through information artifacts. In this age of datafication and biomedicalization, we need to account for the erasure of human vulnerabilities and social complexities through technology design.

Sociotechnical Tensions and Negotiations: Living with Shadows

While Haraway argues for the generative possibilities in new human-machine relations, technofeminist scholar Susan Leigh Star points to the everyday tensions and negotiations involved in living with information technology as part of distributed sociotechnical assemblages. In her writings, Star provides an analytical lens for investigating absence in relation to system design through sensitizing concepts that make visible sites of human complexity that fall into the shadows.

Through their study on ‘invisible work,’ for instance, Star and Strauss (1999) investigated how when complicated activities are abstracted in relation to the design of system design, important aspects of this work are often rendered invisible and unsupported. In a workplace study of nurses in a hospital, for instance, they documented how medical record systems often did not attend to the varied activities of nursing, such as the emotional labor involved to treat patients. Importantly, Star and Strauss argue that when entire domains of gendered and marginalized activity—such as domestic labor or caregiving—remain invisible to system design this ultimately leads to labor displacement and a distortion of the representations of that work. “Work,” argue Star and Strauss, “does not disappear with a technological aid.

> Rather, it is displaced – sometimes onto the machine, as often, onto other workers. To the extent that some people’s work is ignored as they are perceived as non-persons, more “shadow work” or invisible work is generated, as well as the (sometimes) obvious social justice and inequity issues. In the creation of large-scale networked systems, this process may cascade” (Star & Strauss, 1999, p. 20).

Star and Strass (1999) also highlight the effort and tradeoffs involved in bringing invisible work out of the shadows and seen as legitimized form of labor, noting that visibility leads to increased surveillance, standardization, and additional forms of invisible work. “The specification of tasks,” write Star and Strauss, “requires a light hand if one is not to risk mindless Taylorism and the eradication of discretion from skilled workers.” They further note:

> “Nurses struggle to be visible, but simultaneously to hold areas of ambiguity and of discretion. It is one thing to note that one has given counseling to a dying patient; quite another to specify the words one would say to that patient” (Star & Strauss, 1999, p. 21).

Such insights show that the human-machine relations that Haraway mythologized need to be not only actively negotiated and advocated for through design as well as political processes, but also are routinely maintained through human labor. Relevant in relation to the questions raised in this thesis, design intervention in everyday healthcare settings needs to attend not only to invisible work, but also consider the unintended costs and consequences of making that same care work visible.

While the concept of invisible labor speaks to types of shadow activity, Star also drew upon shadow metaphors to discuss the way information systems shape our identities and impact our lives through the absence of data. Star (2015) writes about the power of residual categories—what she calls the 'not elsewhere classified' or the 'discarded complex'—in a world which increasingly seeks to quantify all aspects of human behavior. While the amount of personal data and information being tracked and collected about people has come under increased scrutiny given recent revelations about Facebook's loose data brokerage policies with companies like Cambridge Analytica, Star points out that it is not only what data is gathered, but what is missing that matters. People intentionally leave out all types of data from user profiles and personal records distributed across the myriad information systems that increasingly mediate our daily experience of finance, education, politics, and health for a number of reasons. This discarded personal data comprises what Star calls our 'shadow selves.'

> "The reasons for why people become not elsewhere classified, none of the above, may be for reasons of keeping secrets, of silence, or perhaps of trying to pass as some kind of person while feeling like another. Sometimes one's own experience is unspeakable and there are no words for it…I think that the…discarded complex, is full of promise and aesthetic surprises. Over time, the discarded knowing comes to comprise our shadow selves (both individual and collective). And the nature of that shadow knowledge is layered, complex, and interactional. We go on living with that which escapes standardized testing, quantification of our behavior" (pp. 492-493).

Star argues for such absences to be seen in technology and design disciplines as important sites of human multiplicity and creativity. Extending and developing this earlier work in their concept of 'shadow bodies,' Star and colleague Ellen Balka (2015) conceptualize giving shape/substance to what is left out of the formal medical record. They write:

> "Shadow bodies are constituted of data that fall from view because they are inconsistent with established understandings of bodies, don't fit into existing classification systems (other than "not elsewhere classified," yet somehow persist, precisely because they are rooted in lived experiences…Our lived experiences exist in the shadows, sometimes visible, sometimes not, depending upon how the light falls, and whether or not the richness of the "not otherwise classified" categories has been unpacked, made visible to others" (Balka & Star, 2015, pp. 425-429).

Shadow bodies offer HCI/CSCW researchers a powerful lens for understanding the ways personal information and data are shaping the lived experiences of health. As explored in this thesis, managing chronic illness increasingly involves living with and through data, but in practice, this involves a range of strategies, perspectives, nondisclosures, or even subtle forms of what Bruton and Nissenbaum (2016) call obfuscation: “the deliberate addition of ambiguous, confusing, or misleading information to interfere with surveillance and data collection” (p.1). For example, people who used Nightscout and OpenAPS to share blood glucose data openly on social media, often chose not to disclose that same data to clinicians, insurers, or medical device manufacturers for fear of disapproval, lawsuits, or voiding a warrantee. Or my participants in Jackson who were hesitant about providing information on alternative care practices to clinicians or social workers, as they felt judged for using medical cannabis or might hide self-medicating activities if they are using substances illegally.

Star’s work suggests that design can be problematic when it reduces information or interactions in ways that don’t respect the nuances of context or limits the ability of people to intervene in systems that they view as critical for maintaining their well-being. My interviews and observations, for instance, uncovered numerous challenges people face in taking care of their health even when given exceptional access to medical resources and health information, such as in pediatric BMT. One can see the informal care processes, DIY technologies, and multiple care logics that operate alongside/against/in the shadows of visible, institutionalized healthcare systems as ways of negotiating the discarded complex. A goal of lived health, then, is to make visible these varied experiences of health—the everyday practices around coping with trauma and despair, as well as the labor involved in generating hope—that do not exist in medical records and have not yet been classified in a technology system.

Collectively Haraway and Star’s writings suggests new ways of theorizing the body through information and technology. While Haraway envisions a radical reality of human-machine fusions in which human needs are no longer paramount in a world of various nonhuman actors, Star insists upon the necessity to respect and protect human complexities in the face of technological change. I see both technofeminist narratives as useful in understanding the lived experience of health; particularly, in thinking about the systems we build in a time when health is increasingly experienced in and through personal data. We need to hold generative new possibilities in tension with human concerns, particularly the material and economic costs as well as the social and emotional consequences of depending on information technologies to survive. Chronic illness—with all its messy metaphors and everyday entanglements—requires grounded design narratives that see sociotechnical bodies as inextricably connected to ways of caring. In the next section, I turn to reflecting on the stories of lived health from my fieldwork that made visible unexpected networks of care and important forms of care work, but also obscured others from view

LIVED HEALTH AND THE WORK OF MANAGING CHRONIC ILLNESS

In this thesis, I have shown how the experience of chronic illness took place in hospital rooms and doctors' offices, on social media, and among churches as everyday care practices cut across medical, domestic, and online spaces, as well as across social worlds. Similar to lived religion (Orsi, 2000; Hall, 1997), where scholars have documented the way formal religious teachings and traditions are transformed through the creation of street festivals and urban shrines, lived health seeks to design for care in a way that acknowledges the interplay between clinical medicine and the contributions of various lay populations. While this can lead to generative possibilities and exciting opportunities for design, my thesis has also shown that managing health is a deeply relational and (at times) contested activity for people, and the practices I highlight from my field sites reveal the tensions and vulnerabilities of care enacted alongside/in the shadows/and outside of formal medical institutions.

In Chapter 4, the experiences of BMT parent-caregivers demonstrated the importance of the various materialities and meanings of health information and data in a clinical environment. Even with round the clock medical attention and the resources of a large medical team, caregiving was far from a seamless experience. Some challenges I have documented were due to the high-risk nature of the treatment and the severity of a child's underlying health conditions; but others were a result of being a parent trapped inside a biomedical world. People had to find new ways of coping and caring for vulnerable children when their agency was limited by specialized knowledge and technical skill-sets. The lives of people managing behavioral health in Jackson in Chapter 5 showed the way people manage, adapt, and expand clinical information in a local community context where institutional forms of medical care often broke down or were missing. Care, here, involved forms of repair and holding fragile systems and bodies together in the infrastructural shadows. These findings point to important culturally-bound and alternative ways of caring when biomedicine falls short in helping people live well. Finally, the experiences of those involved in the Nightscout and OpenAPS projects demonstrated types of health practices far outside of the formal medical settings in showing the varied ways care can be enacted through data. Care, here, was full of tensions: fear and freedom, peace of mind and never-ending vigilance, an enigmatic mystery and a puzzle to be solved like an engineering problem, alienation and familial togetherness.

Importantly, in documenting the various micro-interactional activities around chronic illness these chapters highlight to the ways care played out in people's lives as real *work*. While Strauss and other Symbolic Interactionist colleagues theorized on types of medical activities, they did not focus on the labor of patients and caregivers, nor did they contend with how these practices were a part of creating and maintaining sociotechnical assemblages of human bodies, data, and technologies as later advocated by Clarke (Clark, 2005). My thesis uncovers the ways everyday care involved hybrid forms of information/machine/emotional/medical labor that people performed in order to manage the needs of themselves and their family members. A form of routine maintenance, the weighing of life and death, a means of parental protection, a clever hack, and a radical site of repair: care work was difficult, unpaid, and thus often invisible, but it was also generative, leading to new types of expertise and social relations. Importantly, all these different configurations of care work had personal as well as political costs.

Indeed, care work was often uncomfortable and stressful. It was the site of critical dependencies, a form of negotiation and dissent, as well as creative action. Care work involved learning how to leave nurses and doctors who were like family and collaborating with clinicians who were busy and stressed. It required contending with the limits of medicine and the risks of intervention, listening to the silences of trauma, and protesting forms of stigma. It required long hours coding, debugging, and designing new relationships between people and machines. Care work recorded and made visible the daily dramas of the body in all its minor sufferings and major triumphs through spreadsheets, blood bags, databases, and tweets.

The types of care work described in my thesis shows how the boundaries between patient and clinician, hospital and home, body and technology are not only increasingly blurry, but explicate the role of data and information in transforming those relations. Even in the most traditional and hierarchical of clinical spaces—the hospital—I have shown that care is more complex than an issue of information transfer or health literacy. In the pediatric bone marrow transplant unit, for instance, parents were provided with personalized health information and 24/7 clinical support—and yet, they still struggled, at times in quite similar ways, to people with behavioral health needs who were making do with marginal or no resources: looking for remedies, researching options, and trying to situate biomedical protocols in relation to the social and emotional costs of living with chronic illness. Even those who celebrated using DIY diabetes technologies found technology helped manage, but could not fix all of the challenges of care work.

Increasingly, I have come to see care work in chronic illness—the collective information work, emotional labor, machine labor, and medical tasks people perform to manage their health—as the ongoing negotiation of people with various sociotechnical systems. The assemblages of human/nonhuman actors that Haraway evokes and Star and Suchman describe also need to be built, lived with, and repaired when broken. This is daunting work when people must simultaneously depend on these various sociotechnical systems to stay alive. Care work, in my thesis, shows the human costs of reconfiguring the sociomaterial assemblage, of building and maintaining the cyborg body, of negotiating between social worlds, of holding together broken infrastructures and hiding partly among the shadows. The sensitizing concepts and analytic sensibilities of *reflection work*, *precarious intervention, and lived data* proposed in this thesis speak to how these negotiations involve real labor and various social, emotional, and physical costs.

Being responsible for another person's welfare in a high-risk clinical setting, such as in the case of BMT caregivers, highlighted the intense emotional dimensions of information work. While others have noted that information work and emotional are closely intertwined in health contexts, I argue that these activities are better understood within the lived experience of various competing logics and caregiving materialities. With the sensitizing concept of *reflection work*, I hone in on the labor involved in living with the multiplicity of meanings and materialities that information holds in health contexts. This extends beyond what we in information science typically think of as sense-making activities to include how people navigate (and negotiate) care through different logics, such as biomedical science, alternative therapies, machine code, ritual coping, and parental instinct etc. Care, I have shown in this thesis, is never solely clinical; rather, it is grounded in moments of life and death, sleepless nights, bruised bodies, and home remedies. While personal health technology is often designed to promote adherence to clinical protocols, we need to acknowledge the significance of these competing logics operating alongside, against, and with the logic of biomedicine.

In Jackson, I showed how managing chronic illness through routine infrastructural breakdown gave rise to particular forms of information work and emotional labor. *Care/repair* *work* highlights the long-term efforts and effects of maintaining one's health—living with breakdowns and generating workarounds—in the face of an unreliable medical system, invisible labor that had significant costs for an entire community. The types of interconnected emotional labor, medical tasks, and information work people performed in trying to live well with chronic illnesses call attention to the very precariousness of patient engagement when it situated in the infrastructural shadows, viewed as marginal or illegitimate, and unsupported in health systems. Furthermore, *precarious intervention* suggests an infrastructural design approach for community health centered on the uncertainty and messiness involved in living with (and altering) highly dependent and interconnected systems, while still finding a way to move forward to address pressing human needs. Attending to care/repair work involves looking at the boundaries of social worlds across clinical and community contexts to highlight problematic gaps, but also important moments of generativity that could be seen in the creative and collective acts of care/repair. The possibilities of design in supporting wider ecologies of care has the potential to improve the experiences of people living with a wide range of health conditions, particularly those with health conditions that are inextricably tied to social worlds.

Lived data as an analytical sensibility emphasizes data as an integral way of living. Data, in my study of DIY, open source diabetes projects, were very much a mode of being, both a dwelling-within and way of interacting in/with the world. In health technology design, we need ways of accounting for the multiplicity of modes (physically, mentally, emotionally, socio-politically) in which data come to have meaning, not as the contextualization of a lab result, the representation of a mood, or the abstraction of a medical goal, but as a way of experiencing life. In viewing data as a modality, the dynamics of this livedness becomes all the more critical to understand for system design. In this thesis, data were way of being a parent, controlling one's body, negotiating with one's government, and empathizing with a community. Designing for people's experiences of/with/in personal data in health contexts, and other areas of life, calls for better understanding these new modes of being.

While looking at the everyday practices of chronic illness across different fieldsites, I have also made specific agential "cuts" through the assemblage (Suchman, 2007). The experience of BMT extends beyond the hospital and home to include wider infrastructural issues like insurance coverage, medical debt, as well as the scientific and political processes that govern clinical trials and international transplant donor databases. My writing on Jackson meanwhile could easily as focused in on the role of the hospital's emergency room and psychiatric inpatient needs or highlighted other shadow systems of care and the advocacy work of patient groups. As well, there are also larger arenas and discourses that touch on my chapter on Nightscout and OpenAPS, including the rising costs of insulin in the United States. In focusing on specific types of interactional activities, each chapter also leaves some important types of care work unexplored. Next, I take inspiration from the tradition of feminist theory-building around critical absences to highlight moments from my fieldwork that didn't quite fit within the structure of a formal chapter, but which complicated my thinking and research on care work in important ways.

CARE IN THE SHADOWS: STORIES OF THE DISCARDED COMPLEX

By necessity, many ethnographic fragments get left on the cutting room floor; and yet, these are not superfluous stories, but when woven together offer insights into the discarded complex of my own thesis project. In telling these lived health stories, I more openly acknowledge my experience as a researcher and designer, a role that in the rest of this thesis has remained slightly off stage. I am doing this as a deliberate reflexive move and an attempt to account for Suchman's (2007) reflections on the "durable dissymmetry" of the designer both within sociotechnical assemblages and in wider technoscientific discourse.

This section should be read as an exploratory effort to slip more deeply into the shadows of chronic illness. The shadows, Star and others have shown, are sites of complexity and generativity. In my research, I see shadows as comprising important parts of the wider human experience—including different understandings of health and quality of life based on one's personal preferences, but also the dynamics of illness, family arrangements, social worlds, and economic realities—that aren't typically accounted for in health technology design. Shadows, importantly, also make visible important aspects of care. According to the Oxford English Dictionary a shadow is an "image cast by a body intercepting light" or "comparative darkness." In its more archaic usage, however, *to shadow* is also a verb meaning to protect or shelter both people and things from the sun, or more generally:

> "To be a security or protection to; to take under one's protection or patronage; to screen from blame or punishment, or from wrong. Also, to put (oneself, one's rights, etc.) under the protection of another" (OED, 2018)

In this way the act of shadowing is to obscure, but also actively protect and intervene. Seeing shadows as generative spaces, but also places of care is useful in thinking about how to design with for the lived experience of health data and information. What does it mean to be an engaged patient/caregiver in an age of information and the datafication of healthcare? To answer this question, we must first consider what it means to share our personal data (and parts of our lives) with medical providers, insurance providers, device manufactures, regulatory bodies, social services, insurance companies, researchers, and information technology companies, among other parties. We need to design in ways that value the discarded complex, but also protects it. A lived health design space needs to wrestle with such tensions in pondering the role of care in various technological futures. In the following, I share several stories of care in the shadows to draw attention to these important sociotechnical complexities.

The PICU Baby

While my chapter on bone marrow transplant shows the intimate dynamics between parent, child, and clinical information, not every pediatric patient has family who can leave jobs and dependents at home to take on a formal caregiver role. Some children are part of families who have been struggling long before a child's illness even enters into the picture, but I didn't have the opportunity to speak with these families in the BMT unit because they weren't there. Without a formally designated caregiver and an approved home plan by the hospital, these fragile children are not eligible for a BMT procedure.

On rounds, however, I got to see how care easily breakdown and slip into the shadows. The pediatric BMT nurse practitioner, Alisha was devoted to visiting her "boo," a fourteen-week-old infant boy who hadn't left the hospital since he was born. A genetic condition made him a potential candidate for a BMT, but his parents were often absent for days at a time. Each day on rounds I followed Alisha from the hospital's BMT floor up a back flight of stairs to the pediatric intensive care unit (PICU) to check on the PICU baby as the last stop on rounds. We had to put on face masks, robes, and even hair covers to enter the room. All covered up, we looked down at his small, unmoving body lying in the middle of a large hospital bed. The room was dark and quiet except for the soft whirl of medical machineries surrounding her bed. He didn't cry, but occasionally would give a soft gasp for air.

A PICU nurse would usually stop by to chat with Alisha and other members of the BMT team and give them an update on the infant's fragile condition and the family's own precarious situation. "It's a tough case," the nurse tells the team. "The mom has three kids at home. And they are not that educated and able to engage. When the mom comes in at all, she sits by the window and plays with her cell phone." The nurse noted that a social worker was considering whether social services needed to be involved in the case, especially if BMT looked like a viable option. Dr. Garcia was angry, "It is sad, so sad. A fourteen-month-old is all alone in the ICU unit for two days! She could die anytime and there are no caregivers here. The mom has three children under the age of six. I get it is hard, but this is just…just a baby by itself. This isn't right."

Alisha felt strongly, however, that this was the wrong way of looking at things. Care work for the PICU baby might be more complicated, but the family needed to be supported through their struggles. "The mom is trying her best in a bad situation," Alisha reasoned, noting that this mother was pumping breast milk and bringing it in. But along with a very sick child in the hospital, the mother also had other caregiving responsibilities that didn't go away. The baby's father, for instance, had cognitive problems and couldn't watch her other children so that she could come to the hospital overnight. There was a question of post-partum depression and a sense from the hospital staff that she hadn't yet bonded with her baby. "I don't think they have anyone," Alisha argued in thinking about how we understand care services. "The hospital should be trying to get her resources for childcare, not reporting her to the authorities."

The sight of a vulnerable infant alone the hospital is disturbing, but it is important to also see the mother, children, and father as actors in this sociotechnical system of BMT that need care as well. Our health systems and interventions need to be designed for those who struggle with being a caregiver as well as those who follow protocol to the T. Care in the shadows complicates how we understand and design for medical concepts like 'compliance' and 'engagement' by forcing us to engage human vulnerabilities and broader sets of relations.

"I've never told a doctor this before"

I always carried tissues with me to hand out during my fieldwork in Jackson. After a tear-filled interview with a woman who shared a long history of domestic abuse, she gratefully dabbed her eyes with a Kleenex and asked me: "Are you studying to be a doctor? I'm talking to you like you're my counselor. This has really helped." I always made it clear before interviews that I was a PhD student in Information Science and was not studying to be that kind of doctor, but it didn't seem to matter to most of my participants. I was there listening and asking questions with people who had never received therapy before. As a researcher it was gratifying to have people tell me that their interviews were cathartic; but it was also humbling (and frightening) to know that I was as close to a psychiatrist as some people might ever get.

Trauma—unspoken, untreated, and unacknowledged—popped up in moments throughout most of my interviews. Large families networks were important sites of care in Jackson, but I also heard of family members estranged from one another even while living in the same neighborhood. A man told me shared his history of growing up in Jackson as part of an abusive family and connected it to his behavioral health history:

> "I don't speak to my father at all. Not since I've been a teenager. He lives within a mile of me. You stay your way, I'll stay mine. The last time I talked to him, I told him to forget he ever had me. When we were growing up, we'd 'get corrected.' But you would call it abuse today and that's what it was… I would act out as a kid too. I would tear things up. I've questioned my own sanity at times. Am I losing it? Is this where I start to go down? I don't want too."

Most often, though, these stories of trauma were shared by women. Once when I was asking another participant about when she started taking medications for depression, she turned to me and said:

> "It happened four years ago. My mom was murdered and I still have dreams about that, and I still see her laying there…that bothers me every day. First my dad died of stroke and then my mom was murdered. I can't get over it. A man broke into the home we were raised in and he beat her to death. He kicked her severely in the head, took her telephone and beat her in the head. She never regained consciousness. I saw my doctor and he just said, "Well you're going through a depressing stage and bipolar." That was it. He prescribed the medicines. I don't sleep. Maybe three or four hours. That's all I get a night. I feel like I need to talk to somebody."

The only person she had to talk to that day was me. Her experience with trauma and behavioral health issues, while graphic it its particular violence, was unfortunately not unique. I listened to the lived experience of rape, domestic abuse, and fear. I sat across from a small, middle-aged woman, who as a single mother told me with pride about raising two boys. We spoke of her last doctors' appointment when violence suddenly intervened into the interview. "My father raped me," she told me quickly.

> "I left home when I was 19. I went to an abusive guy. He was beautiful, but he kicked me around. He was a bad boy? Kicked me in the head, kicked me in the ribs. Beat me. I got bad injuries because of him kicking me with his boots every day. That's why I didn't have a husband to live with me because I was afraid he was going to abuse my kids. I was a protector. I go, "No one is going to abuse or rape my kids because I will kill them!"

She never told her doctor about her abuse. Many told me their stories often for the first time. Once I ran from a clinic where I was conducting an interview to a nearby CVS once to buy a USB drive so that I could give a woman a copy of her interview to take with her. She wasn't sure she could talk about her behavioral health history again, but she felt it was important to have it. I talked to lonely people, sad people, people who lived a lot of life and also lost a lot. Discerning doctors might rightly guess parts of their patient's difficult lives, but these experiences often remained absent from clinical encounter and lost to the patient record. Some people didn't know how to talk about these experiences or worried they would be seen as inappropriate to the clinician. At times, these silences were carefully preserved to protect people from judgement or stigma in the doctor's office and wider community.

I also spoke with people whose words often failed them. There was Christie, a woman with learning disabilities, who told me about having schizoaffective disorder and post-traumatic stress disorder. She didn't know what these conditions meant, and she didn't feel comfortable asking her doctor. But she knew why she had them: She was sexually abused in a group home and went to a hospital only to experience more abuse at the hands of hospital staff. And then there was John, an elderly man who lived with schizophrenia who I met at a group home. His speech was often badly slurred and while his thoughts tangled in telling his story, in certain moments his comments were sharp and penetrating. In the following, I deliberately rearrange the interview texts[11], restructuring a narrative of care work out of fragments:

---

[11] I draw inspiration in this effort from playwright Emily Mann's "Still Life" which took selected quotations from different interviews to create a play. Her use of personal testimonies shows the power of fragments woven together to create new forms and meanings as part of a larger narrative (Mann, 1997).

John: The VA gave me my prescription.
Mine said schizophrenic.
It's not that bad. It used to be though.
Sometimes you get repetitive thoughts and that's…repeat, repeat, repeat.
I thought I was schizophrenic, cause of three…
All that is, is having so many things going at once,
and people…I don't think they play games, but something else.
I've been in the hospital one time, five times. When I went through that experience,
five times in the hospital,
I learned so many coping skills.
I've been in there forever.
Whatever age I am,
that's about…
A lot.

Christie: I have schizoaffective disorder and I'm not sure what that is exactly.
I don't want to overstep my boundaries and ask the doctor and he not know.
Maybe he does know…
I don't feel comfortable enough to ask my doctor about it.

John: But I had jobs!
I worked for Ford for 20 years or more. It's mostly engineering and running the place.
Henry's either my grandpa or…he's family anyway.
I went through the military.
I went so far back into the war, I was born in war pretty much.
Never had a choice.
But I knew, if you want your voice in things, you keep to democracy and you keep it protected.
I've been wounded so many times in war, it's beyond belief I'm here.

Christie: I have post-traumatic stress disorder.
I know that a lot of people in the war and stuff have it.
I'd like to know what it is.

John: I was in Vietnam.
I had my share of war and I had enough of that,
so I retired.
Doesn't seem like it sometimes,
because we got so bad, they hypnotize us to forget it.
That's done by time and strength.

Christie: I've been in special ed my whole life through school.
I was in a group home.
I had some problems with a man that lived there.
He was a big man and he tried to touch me…
in places that weren't appropriate.
In the past, I had never told anybody some things that had happened to me.

I was scared.
He was threatening to kill me and stuff…
and I wasn't safe there.

John: [holding up hands] I even got steel hands, these are prosthetics.
I've been operating on people forever.
Artificial heart and everything.
I'm not sure whether you knew there was, but there is.

Christie: I tried to commit suicide,
and they sent me to the hospital. They tried to get my medications stabilized for me.
After I went to the hospital,
they sent me to the crisis home,
and I was raped there.
It happened to me and it happened to another girl. It was a staff member.
He worked third shift
by himself.
She pressed charges and he is serving a life sentence.
I'm afraid to go to the hospital now,
they would put me in a crisis home
and it would not be pretty.

John: I belong to the church. Community Church of Christ.
I helped build it years ago.
I love the people. I am supposed to call them on the phone today.
I've been there all my life. Because they'd be honest, and they're never going to lie,
and you need to know the truth if you're doing something wrong.
I've got manners and everything…
but people forget they're human.

Christie: Some of the stuff that goes through my head,
I don't even exactly know how to put it into words.

John: Doctors tend to go off on script.
They sign their name in shorthand.
I don't need as much as what they thought…
Hope this doctor is qualified to tell me the truth.
They seem nice, but they sure want to run your life.

Christie: [holding up photograph before gastric bypass surgery] I brought a picture so you could see what I look like.
This is me,
that's my mom
and that's my sister and her daughter.
I brought the picture in because I wanted you to see
what a difference!

I want people to see that…[points to herself in picture]
and then see me.

John: I've taught a lot of them.
I've been a professor. I'm a doctor myself in psychiatry,
but sometimes it's just nice to talk to people like you and know what I sit through.
Certain medications…now that will be for life.
Risperidone[12]
I hope it's not a blood thinner. But it might be…
I don't dare get off that. The VA ordered it, not my thing, so I called them off.

I have an awful lot of pills and people.

Christie: [she points to photograph] This person is totally different
[she then points to herself] from this person,
even though I'm the same person.
Because this person was depressed,
suicidal,
didn't care about life,
didn't want to live,
tried to commit suicide several times,
wasn't successful.
But this person is alive and wants to live and make a difference.

John: I was working ever since I've been born.

Although difficult to analyze as part of a cohesive "dataset," it also feels wrong to silence their words from this study. Christie and John's interviews can be seen a testimony as they bear witness to costs of chronic illness and the life-long work of care. They spoke here about being in battle, of work and wounds, of hospitals and living with a cyborg body. They live in a town where Henry Ford is family and how through the long years of taking pills and seeing doctors, a patient becomes a professor of psychiatry. It is a story of survival in Jackson when one is ill, where the system is broken, and when language of illness is illusive. Through these fragments, however, one sees that care is about living with hope as with despair. There is no technological fix for chronic illness, no easy solutions for treating trauma.

---

[12] An antipsychotic used to treat schizophrenia and bipolar disorder.

#Insulin4All

During my research into opensource, DIY type 1 diabetes technology projects, the online call #WeAreNotWaiting was increasingly joined by the hashtag #Insulin4All. While ‘we are not waiting’ can be seen as a social movement centered around freeing personal health data from corporate control, ‘insulin for all’ describes the ongoing advocacy work of people with diabetes who can’t afford the rising costs of their medications. Insulin costs have risen sharply in the United States in recent years, nearly tripling between 2002 and 2013 (Cefalu et al., 2018). Increasingly, access to insulin is viewed as a human rights concern. This year the American Medical Association called for a federal investigation into the costs of insulin products from the three pharmaceutical manufacturers who provide insulin (Gibson, 2018).

First developed in Canada in 1921, insulin is an almost 100-years-old technology, and yet no generic version exists. It was patented and sold to the University of Toronto for only $3 ($1 for each scientist listed on the patent form) as an attempt to make sure people would always have affordable access to the drug (Rutty, 2008). When the original insulin patent expired, however, pharmaceutical companies made incremental improvements to the formula which generated new patents and billions of dollars in profits (Johnson, 2016). While the cost of insulin is typically offset by insurance, people often fall through the gaps with limited health coverage or can come up short when they accidentally break or simply lose a vial (Johnson, 2016).

The success of groups like Nightscout and OpenAPS can mask a more fundamental problem: that many people with diabetes struggle to get access to insulin, let alone continuous glucose monitors or personal data. When I started my PhD program one of the first research projects I started on looked at chronic illness experiences in Flint, Michigan. There I met people with diabetes who bartered tests trips, stretched out insulin doses, or chose to buy food over a hormone they desperately needed only to be later viewed as a ‘noncompliant patient.’ Many other people have gone online to document the effects of skipping insulin, sharing supplies, and hording specific brands of insulin in case they lose their insurance coverage. Without access to insulin, the information technologies described in this thesis—even if widely adopted—would still be limited to confronting the complexities of managing T1D in this country and in many parts of the world. There are ongoing efforts in the DIYbio community to manufacture open source insulin, such as the Open Insulin Project in the Bay Area and Oakland. Such efforts point to the broader absences, systemic silences, and social injustices of care in the shadows.

These lived heath stories argue for expanding the design space of personal health beyond individualistic framings and biomedical narratives to address wider ontological concerns in the configurations of various sociotechnical bodies and the shadows they cast. In seeing chronic illness as a problem to manage or a type of behavior to change, for instance, we make decisions about what types of human and nonhuman relations to support or silence, which social worlds and logics to center or marginalize, and what policies to challenge or enforce. How might we, instead, use technology to care for people where they are at, to support diverse ways of being? I would argue that to design for care we as designers and researchers need to first contend with what it means to live with shadows. We need to really *see people* not only as patients and caregivers, users, or parts of a sociomaterial assemblage, but as those who bear witness to the aftermath: People who are laboring, struggling, and bearing the costs of living in a broken world.

DESIGNING FOR CARE

In this section, I reflect on designing for health technology in light of lived health concerns. The experiences of chronic illness described in this thesis argue for seeing health as a negotiated set of activities responding to the concerns of diverse social worlds, infrastructural and human brokenness, and the intimate encounters of living with personal data. Better understanding the complexities of care work in diverse health contexts, then, is an important initial step towards developing technology that supports a more holistic and ecological approach to health. To conclude this thesis, I discuss several immediate design opportunities and challenges for HCI/CSCW community in supporting care work in chronic illness management across clinical and community settings. I also account for the limitations of this thesis project and discuss how I would extend and develop a narrative of lived health in future research. Specifically, I argue for the need to grapple with the social impact and design processes of health datafication and suggest that the project of designing futures of care work might be conceptualized as a process of *caring-through-data*. This approach emphasizes design as form of ontological engagement: a way of being in the world that does not seek to “fix” or “design away” vulnerabilities or uncertainties; but rather, help people negotiate such tensions as an essential part of living in a precarious and interconnected world.

Opportunities and Challenges for Supporting Care Work

There are a number of design implications from my thesis findings that offer insight into creating more useful caregiving, community health, and personal health informatics systems. My study on pediatric BMT, for instance, provides insights for how design can help support informal caregiver needs in a hospital setting. Inpatient caregiving systems should not be viewed simply as educational tools, but as sites of costly reflection work. Participants needed help in weighing medical risks, but also human costs like quality of life. My findings on the materialities and meanings of information in bone marrow transplant also suggest that information design should consider not only where information comes from, but also the various emotional costs of engaging patient data. Caregiver systems that provide clinical information should also consider how people might also use that information to cope. Providing customizable settings and tools, for instance, could allow people to engage health information in different ways. People sensitive to clinical data could restrict the types of information being displayed by the system to what they can emotionally handle. Others might want tools to make graphs as a form of therapeutic charting or be allowed to download data so that it can be saved, shared, or reconfigured into new, personalized information artifacts. Other findings from my work suggests that caregiving systems would benefit from social features, allowing families to connect and learn from one another in the hospital when they are alone and isolated.

My study on Jackson provides evidence of unmet patient needs in behavioral health management and points towards several possibilities for supporting wider ecologies of care. For instance, community-based health records systems that share patient data across disparate organizations, such as medical delivery, behavioral health, and social services, have potential to bridge many system 'gaps,' documented in my field site, such as access to services. While these technological systems have been primarily aimed at supporting professional workflows and organizational processes, my findings also show the importance of informal care work performed by people who rely on alternative community care sites. Sharing behavioral health data within a "patient-centric community network," for example, might include a person's clinicians and social workers, but also trusted friends and clergy. Designing for ways to include information from a wider care team (e.g. referring clinicians, social workers, Big Brothers/Big Sisters, court system, and faith-based leadership etc.) could help fill in critical missing data that people leave out of screenings due to stigma/fear/lack of knowledge. Understanding local social worlds that operate as alternative sites of care becomes a critical design need. The development of future health systems and models of delivery also call for a careful consideration of populations in the infrastructural shadows who can easily be excluded from design processes and further marginalized.

Finally, my research on Nightscout and OpenAPS provided evidence for design opportunities in developing systems that engage collaborative and collectivist forms of care work. For instance, one might image systems that help connect clinicians to patient communities to do research with patient-generated data together. It also suggests helping families better manage the emotional and social role of data in personal relationships. For example, the last chapter discussed how families experienced Nightscout simultaneously as sites of gaining and losing control through data. And yet, parents and children had little control over control, i.e. the system, designed to monitor and display data, did not afford ways for parents to quickly relinquish control when needed (e.g. when teenagers felt surveilled at school). We could design, instead, for a different type of control—one that allowed for a variety of care options, e.g. to pull closer to a friend or family member when there was an urgent need for physical help or emotional support, and at other times to maintain important social and emotional boundaries. Additionally, my findings suggest a need for building technological tools and systems that help people engage in wider systemic health challenges, such as advocating against prohibitive insulin costs or restrictive regulatory guidelines.

While my fieldsites suggest many exciting possibilities for improving patient experiences and the lives of caregivers managing chronic illness, I stress that design cannot fully bridge the all sociotechnical 'gaps' I have described in these chapters. Health support at a single moment in time belies the dynamic nature of health needs and social worlds. Insurance benefits shift, hospital systems are bought and sold, new technologies are developed, and slowly the societal views of illness shift. As medicine becomes increasingly specialized and opens up new treatment possibilities, clinicians will need to find ways of to help people reflect on the balance between risk and quality of life, as well as find new ways of coping. As communities move to change people's views of behavioral health, new types of coordination will be needed to address complex issues like trauma. As patient groups intervene in the medical device and pharmaceutical industries, new types of patient expertise and collective forms of engagement will have to be reckoned with. Any system incorporating relationships among an extended ecology of fragile bodies, families, formal institutions, online spaces and shadow health systems will need to be adaptable and dynamic. This will be a critical, but incredibly difficult, design challenge.

Furthermore, an information system that merely ties together formal and informal care systems in coordination unthinkingly will likely fail or do damage. My findings argue that along with better situating technology to healthcare contexts, we must also attend to the multiplicity of care logics. Importantly, the various care work I observed in my fieldsites was grounded in differing worldviews that extended beyond that of medicalized roles of patient or caregiver. People referred to themselves as warriors, concerned citizens, workers, hackers, cyborgs, innovators, advocates, and parents. My participants often expressed a view that care work helped them manage the complexities of living with chronic health conditions that did not reduce them or their family members to an “illness” or “disease.” To give a concrete example from my fieldwork, many Jackson faith-based leaders expressed a need for increased access to information on specific behavioral health conditions and local clinical resources, but they also wanted to share that data in ways that was aligned with their primary role as spiritual teachers and mentors. Several pastors, for instance, were interested in a community health referral system that helped them to better find medical professionals who would understand their values. Being attentive to alternative viewpoints and personhoods enacted within the shadows is critical for effective and useful health system designs.

In lived health, there are many such social worlds and shadowy spaces where important care work happens, including the factory line, school system, Facebook group, neighborhood bar, church, and code repository etc. These alternative sites of care at times provide a necessary safety net for those with limited resources, but also provide places that allowed people to live meaningfully with their health concerns. Such care work is unacknowledged in the design of patient-centered technologies like patient portals and personal health records, as well as consumer-based health and wellness technologies. My findings in this thesis, however, show that an awareness of such care arrangements is essential for supporting people’s health needs across clinical and communities settings.

LIMITATIONS

As an interpretivist study of chronic illness, my thesis has focused on documenting "stories about what happens to complexity in practice" (Law, & Mol, 2002) specifically in relation to everyday care work and the role of information technologies. While ethnographically-based studies are limited to particular sites, and therefore generalization in the empiricist sense is not possible, I believe that my findings are theoretically generalize to a wider range of chronic illnesses, communities, and health situations.

In concerning myself with thick description and documenting the specificities of my fieldsites, I have examined chronic illness experiences primarily in the United States and the American Midwest. The lived experience of chronic illness would in many ways be different in other parts of the United States, and would most certainly vary widely throughout the world. While my study of open source, DIY diabetes technologies looked at an online community that was global in scale, I focused on the U.S. experience of type 1diabetes management as the majority of participants were living in the United States. New studies might compare care work across a wider range of health concerns or consider the ways in which care work is situated among different configurations of clinical institutions, community concerns, treatments and technologies, and policy.

This ethnographic research is also temporally bound from 2015-2017. The data I collected represents only small slices of people's lives as I was not able to follow participants through their illness journey for any significant period of time. The experience of illness often change over time (Charmaz, 1991) as people encounter new physical setbacks, personal circumstances shift, or additional contextual factors come into play. My data in this thesis, then, speaks to care work in particular moments of time and place. This is also true for the types of technology and healthcare processes I discuss. In the U.S. healthcare context, for instance, new governmental policies and corporate healthcare initiatives can often radically alter insurance coverage and impact access to medical services and medications.

Furthermore, my research in this thesis draws heavily upon the theoretical and methodological sociological tradition of symbolic interactionism (SI) that facilitates a focus on micro-interactional activities. This has been found to be useful theoretical framework for identifying health practices that might be supported by system design. Nevertheless, SI and social worlds theory has a number of theoretical limitations as well, particularly in accounting for how practices relate to wider cultural and political discourses. It also fails to address the complex relations between human/nonhuman actors. To address these limitations, I have drawn upon situational analysis (Clarke, 2005) which updates the SI theory/method package to account for interactional activities across social worlds, arenas, and discourses. In this thesis, however, my chapters do not yet bridge all these analytic spaces and I see this as an opportunity for additional theoretical work.

Finally, my thesis has been focused by my disciplinary interest in the design of personal health technologies. Within the fields of HCI/CSCW, interpretivist studies have traditionally served as a means of outlining specific system design implications and identifying system requirements. Although such a narrow view of ethnographic contributions to the field has been challenged (Dourish, 2006), that this thesis offers few concrete design implications may frustrate some who seek clearer recommendations for building better health technology. My work intentionally, however, offers a theoretical contribution to the HCI/CSCW health domain, but also has relevance for those concerned with the social impact of technology more broadly. I argue that the sensitizing concepts and theoretical stance developed around care in this thesis transcend the specifics of my fieldsites to speak to other types of health conditions, labor arrangements, and social situations where people are negotiating what it means to be human in a world of ever increasing sociotechnical complexity.

FUTURE WORK: THE SOCIAL IMPACT OF HEALTH DATAFICATION

As data and technologies come to mediate an increasingly wide range of everyday activities, it is essential to grapple with the wider impact of computing on human bodies, family life, and local communities. Healthcare—with its highly visible sociomaterial entanglements and critical dependencies—becomes an important site to study the unfolding processes of datafication on society. The rise of people actively engaged in managing their health through patient-centered applications and self-care technologies, along with systemic barriers to clinical care, makes creating health systems that support diverse needs and viewpoints not only a vital matter of design, but an ethical imperative for HCI/CSCW and the wider medical community. Designing for a future of care work demands closer attention to the social complexities and emotional consequences of living with health data and information technologies. My future work will examine how health data is situated in new forms of interactional work including reflection work and in community and infrastructural contexts of care. We need diverse analytic approaches to examine the multiplicity of emotional concerns and sociotechnical arrangements enacted through data. Drawing inspiration from the fields of medical ethics and philosophy, I propose the analytic sensibility of *caring-through-data* as an approach to make visible the consequences of taking an overly simplified approach to supporting care work through data and information technologies.

From "data-as-care" to "caring-through-data"

This thesis accounted for different approaches towards care. I saw people managing care through blood work and spreadsheets, cannabis and antidepressants, as well as prayer. This was all done with the best of intentions and often out of desperate need to both protect loved ones from harm as well as a desire to live well in the face of brokenness. In my last chapter, I have also shown how a group of parents, many of whom have a background in engineering and software development, 'coded' care as a problem that can be solved by data granularity and management. Many people across my field sites believed that access health information and the ability to use data and technologies to manage health needs saved lives. This was especially true for Nightscout and OpenAPS users who relied on real-time blood glucose data to manage their chronic illness. This approach of *data-as-care*, i.e. care as experienced and managed through data, has already become a powerful intervention. Members of Nightscout, for instance, have engaged political and regulatory bodies like the FDA to legalize (at least parts of) the system, all the while Dexcom (a medical device manufacturer) has released its own version of a remote data monitoring app for the Apple Watch. The kind of data-as-care reported in this thesis, then, is already partially legitimized and institutionalized.

Good care is often associated with technical competence and expertise in modern medical practices. However, as a historical practice and philosophical idea, care has long embodied multiple meanings. In the field of medical ethics, Reich (1995) has discussed the conceptualization of care from Socrates to Heidegger, noting that 'care' has long had two fundamental, but at times conflicting meanings: to live with the worries, troubles, and anxieties of being human, but also to actively provide for the welfare of another person. "The struggle between opposing meanings of care," Reich argues regarding the experience of lament/hope, "is part of the radical importance of care to being human" (ibid, p.6). More recently, Mol (2003,

2008) has pointed to the ways in which health care—as an assemblage of practices and people, data and discourses—is not just dualistic in nature, but inherently experienced as multiple. My findings in this thesis suggest that we should aim to support a greater multiplicity of care experiences in the design of information technologies. Looking closely at Nightscout parents, for instance, showed that being attentive to the needs of their T1D children encompasses navigating many fundamental tensions—care is (and has always been) many things simultaneously: a human struggle between control and freedom; of seeking peace of mind and giving into anxiety; and of empowerment and taking on the burden of another.

Given the impact of datafication upon health and wellness in our society (Clarke et al., 2010), I believe that much can be gained from a designerly intervention (Bijker, 1995) that shapes how the underlying approach of data-as-care proliferates beyond this immediate case. Nightscout in its current implementation codifies care through an engineering ethos that motivates much of contemporary IT culture from large software companies like Google all the way to DIY maker culture: the ideal that technology can lead to individual empowerment and help people (re)gain control over various aspects of their lives (Coleman, 2012; Lindtner et al., 2016).

In the case of Nightscout, this ethos of empowerment and self-actualization is applied to chronic illness, whereas diabetes is rendered as a puzzle that can be solved through the right kind of technology. This approach promises to turn anxiety, pain, and suffering into freedom, control, and empowerment. In this thesis, I have shown how these aspirations break down on numerous occasions, and how one form of suffering is often replaced with yet another. For example, parents adopting data monitoring to calm fears that their child may not wake up one morning find monitoring brings with it the emotional weight and responsibility of paying attention to every data point. Research in CSCW and STS has long shown the limitations of any such technologically deterministic view. And yet, technosolutionism, (i.e. the idea that technologies provide solutions to complex societal problems like health and wellness), still drives contemporary system design and implementation (Lindtner et al., 2016).

What I propose here in this final chapter is an intervention into this trope of technosolutionism. What this requires is acknowledging that care is both a set of practices and narratives (e.g. ideas about what constitutes ‘good’ care and how data help make care better). Recognizing that the narratives of BMT, Jackson, and Nightscout represents only a few of many possible types of care allows us envision alternatives and how it can still be otherwise (Suchman, 2007). Moving away from data-as-care, I start instead from an approach of *caring-through-data*, where the relationship between care and data is multiple, and both care and data can mean many different things depending on the particulars of family, social contexts, life stages, etc.

With caring-through-data I attempt to shift the lens from the technosolutionism of data, as enticing as it may be, back to the practices of caregiving. In doing so, I found glimpses of people maneuvering information and data in ways to promote empathy, relational intimacy, and compassion. Families posting blood work numbers, people sharing local strategies in their communities, parents wearing a continuous glucose monitor in solidarity with their T1D children all points to unexpected ways in which people are using information and data technologies to share the experiences of chronic illness together as an intimate 'we.' Caring-through-data is a design narrative that engages a wider range of human experiences between people, data, and information technologies. Our conception of care in the age of datafication should be flexible enough to make space for new ways of being with/in/through data, such as this kind of radical empathy that seeks to be present with others through data-sharing or collective forms of health management.

As HCI and CSCW increasingly designs systems that use personal data, we need to scrutinize not only how data impacts the 'self'—how and why people maneuver data-tracking tools and information technologies to mitigate feelings like guilt, obsession, friction, alienation—but also the collective 'us'. Examining the ways in which interacting with data impacts the most intimate of human experiences—how people care for one another—we in HCI/CSCW can design for a wider range of interactions with data. If we continue to draw only from data-as-care narratives (whereas data becomes the technical solution to diseases of the body) without understanding or addressing caring-though-data (whereas data is a means of fostering empathy and togetherness), we impoverish not only the design of health technologies, but care itself. As a way of enriching our understanding of the possibilities data can play in everyday life, we need to create counter narratives that account for caring-through-data. This chapter is one such effort to open up the conception of 'personal health' and 'personal data' towards this multiplicity.

CONCLUSION

This thesis ultimately argues for the importance of theories of care in health technology design. Through highlighting the sociotechnical complexities of care work in people's everyday lives, my thesis shows how care goes beyond collaboration and coordination, and the design that may support it, to include ways of being with someone in and through illness. The multiplicity of (often conflicting) meanings that care work embodies—the burden of control and the anxiety of freedom—are made visible in the practices around providing for the welfare of another. Neither emotional labor or information work accounts for all the meanings and materialities of blood-and-bone information, the alternative forms (and responsibilities) of care/repair work that defines health for many people, nor does it fully describe the complex anxious-togetherness of Nightscout parents and their children or OpenAPS developers and their little machines. In this thesis, then, I offer HCI/CSCW a re-conceptualization of "care work" to account for the experience lived health as multiple (and often messy), dependent on the shifting relations between policies and people, knowledge and technologies, and dependent bodies.

This thesis seeks to help clinicians, researchers and designers better understand how (and why it is important) to support a wider range of social contexts and emotional needs with information technology. My fieldsites—pediatric bone marrow transplant, community behavioral health, and opensource, DIY diabetes projects—offer insight on emerging (and often contested) forms of information/data and labor, particularly at the boundaries of formal medical systems and informal communities of patients and caregivers. To that end, my work offers several contributions to HCI/CSCW:

1) Documenting the Complexities of Care Work

In examining the lived experience of chronic illness, my thesis unpacks the relationship of care work to wider sociotechnical systems. This is especially important to understand as people's relationships with formal medical institutions are shifting with access to and ability to use health information and personal data. In Chapter 3, I have described information of blood-and-bone to investigate the materialities and meanings of information in bone marrow transplant. These findings suggest that information design should consider not only where information comes from, but also the various emotional costs of engaging patient data. Furthermore, in Chapter 4, I examined community behavioral health, I have shown that care work is often precarious, and that for some communities what counts as information and data are deeply contested. Engaging health without any tools or expertise is a fraught process, and attention needs to be paid to contexts where care work is also a form of infrastructural repair. Finally, in Chapter 5, I have studied early adopters of automated health technologies, such as Nightscout and OpenAPS, who are using patient-generated data to hack and make personalized health technologies. In my ethnographic studies of DIY health, I have sought show the types of control, privacy practices, forms of patient expertise, and human-machine relationships that are important (and problematic) to people who are actively using data and algorithms to manage their everyday health needs.

2) Directions Toward Designing for Lived Health

An interest in applying technologies to “disrupt” and “fix” healthcare has received widespread attention both in the medical community and the popular media. Such narratives have helped fuel investments in health and wellness technologies, but are often centered around clinical work practices, and when patient-facing are rooted in logics of ‘adherence’ and ‘compliance.’ As a data-as-care design approach is increasingly seen as a model for “good medicine,” my thesis offers a starting place to begin critically examining such popular narratives of care, calling attention to who benefits and what voices are marginalized. Designing for *lived health* offers a deeper, more nuanced perspective on care work rooted in concerns of the body, social worlds, precarious systems, and shadowy spaces that are important to consider given the advancement of technology into medicine and many other facets of our lives. My thesis seeks to challenge our “sociotechnical imaginations” by offering an alternative narrative of what it means to create and share, negotiate with, and live through information, data, and technologies that extends beyond utopian or dystopian visions.

Bibliography

Aarhus, R., & Ballegaard, S.A.. 2010. Negotiating boundaries: Managing disease at home. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10). ACM, New York, NY, USA, 1223-1232.

Ackerman, M. (2000). The intellectual challenge of CSCW: The gap between social requirements and technical feasibility. *Human Computer Interaction*. 15, 2, 179-203.

Ackerman, M., & Kaziunas, E. (2017). A new generation of CSCW: Reinvigorating CSCW field- based Research through a theory-inspired reboot. In *Proceedings of 15th European Conference on Computer-Supported Cooperative Work - Exploratory Papers, Reports of the European Society for Socially Embedded Technologies (ECSCW '17).*

Ames, M.G., Rosner, D.K., & Erickson, I. (2015). Worship, faith, and evangelism: Religion as an ideological lens for engineering worlds. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (CSCW '15). ACM, New York, NY, USA, 69-81.

Ananthanarayan, S., Lapinski, N., Siek, K., and Eisenberg, M. (2014). Towards the crafting of personal health technologies. In *Proceedings of the 2014 Conference on Designing Interactive Systems (DIS '14).* ACM, New York, NY, USA, 587-596.

Anspach, R.R. (1997). Deciding who lives: Fateful choices in the intensive-care nursery. Berkeley/LA: University of California Press.

Avle, S. and Lindtner, S. 2016. Design(ing) 'here' and 'there': Tech Entrepreneurs, Global Markets, and Reflexivity in Design Processes. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16). ACM, New York, NY, USA, 2233-2245.

Ballegaard, S.A., Hansen, T.R. & Kyng, M. 2008. Healthcare in everyday life: Designing healthcare services for daily life. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '08). ACM, New York, NY, USA, 1807-1816.

Bansler, J.P., & Kensing, F. (2010). Information infrastructures for health care: Connecting practices across institutional and professional boundaries, *Computer Supported Cooperative Work*. 19,6, 519-520.

Barbarin, A., Veinot, T.C., & Klasnja, P. (2015). Taking our time: Chronic illness and time-based objects in families. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15).* ACM, New York, NY, USA, 288-301.

Bardram, J.E., Frost, M., Szántó, K., Faurholt-Jepsen, M., Vinberg, M., & Vedel Kessing, L. (2013). Designing mobile health technology for bipolar disorder: A field trial of the monarca system. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13).* ACM, New York, NY, USA, 2627-2636.

Balka, E., & Star, S.L. (2015). Mapping the body across diverse information systems: Shadow bodies and how they make us human. In Bowker et al. (Eds.) *Boundary Objects and Beyond: Working with Leigh Star*. (pp.417-434). Cambridge: MIT Press.

Bardzell, S. (2010). Feminist HCI: Taking stock and outlining an agenda for design. In P*roceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10).* ACM, New York, NY, USA, 1301-1310.

Bates, D.W., & Bitton, A. (2010). The future of health information technology in the patient-centered medical home. *Health Affair*s, 29, 4, 614-621.

Bauchspeis, W.K., & Puig de la Bellacasa, M. (2009). Feminist science and technology studies: A patchwork of moving subjectivities. An interview with Geoffrey Bowker, Sandra Harding, Anne Marie Mol, Susan Leigh Star and Banu Subramaniam. *Subjectivity*. 28, 334-344.

Bellini, R., Strohmayer, A., Alabdulqader, E., Ahmed, A.A., Spiel, K., Bardzell, S. & Balaam, M. (2018). Feminist HCI: Taking stock, moving Forward, and engaging community. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems (CHI EA '18)*. ACM, New York, NY, USA, Paper SIG02, 4 pages.

Berg, M. (1999). Patient care information systems and health care work: A sociotechnical approach. *International Journal of Medical Informatics*. 55, 87–101.

Berg, M., & Harterink, P. (2004). Embodying the patient: Records and bodies in early 20th century US medical practice. *Body and Society*, 10, 13–41.

Bernadina, L., Bosch, J., & Kanis, M. (2016). Design opportunities for supporting informal caregivers. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16).* ACM, New York, NY, USA, 2790-2797.

Bietz, M.J., Baumer, E.P.S., & Lee, C.P. (2010). Synergizing in cyberinfrastructure development. *Computer Supported Cooperative Work*. 20, 245-281.

Bietz, M., Hayes, G.R., Morris, M.E., Paterson, H., & Stark, L. (2016). Creating meaning in a world of quantified selves. *IEEE Pervasive Computing.* 15, 2, 82-85.

Bijker, W.E. (1995). *Of bicycles, bakelites, and bulbs*: *Toward a theory of sociotechnical change*. Cambridge: MIT Press.

Bjørn, P. & C. Østerlund, C. (2014). *Sociomaterial-design: Bounding Technologies in Practice*. CSCW series edited by Richard Harper, Springer.

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. University of California Press.

Bødker, S. (2006). When second wave HCI meets third wave challenges. In *Proceedings of the 4th Nordic Conference on Human-computer Interaction* (NordiCHI '06), Anders Mørch, Konrad Morgan, Tone Bratteteig, Gautam Ghosh, and Dag Svanaes (Eds.). ACM, New York, NY, USA, 1-8.

Boehner, K., Vertesi, J., Sengers, P., & Dourish, P. (2007). How HCI interprets the probes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '07).* ACM, New York, NY, USA, 1077-1086.

Boise, M. (2016). Tide pool—a comprehensive platform for diabetes management. Retrieved 3.7.2016 from http://beyondtype1.org/tidepool-a-comprehensive-platform-for-diabetes-management/

Bossen, C., Pine, K., Ellllingsen, G. & Cabitza, F. (2016). Data-work in healthcare: The new work ecologies of healthcare infrastructures. In *Proceedings of the 19th ACM Conference on Computer Supported Cooperative Work and Social Computing Companion* (CSCW '16 Companion). ACM, New York, NY, USA, 509-514.

Bowker, G.C., & Star, S.L. (2000). *Sorting things out: Classification and its consequences*. Cambridge: MIT Press.

Bowker, G.C., Timmermans, S., Clarke, A.E. & Balka, E. (Eds.) (2015). *Boundary objects and beyond: Working with Leigh Star*. Cambridge/London: MIT Press.

boyd, d. & Crawford, K. (2012). Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon*. Information, Communication & Society*. 15, 5, 662-679.

Brunton, F., & Nissenbaum, H. (2016). *Obfuscation: A user's guide for privacy and protest*. Cambridge: MIT Press.

Büyüktür, A.G., & Ackerman, M.S. (2014). Issues and opportunities in transitions from specialty care: A field study of bone marrow transplant. *Behavior & Information Technology*, 34, 6, 566-584.

Buyuktur, A. G. (2015). *Temporality and Information Work in Bone Marrow Transplant.* (Doctoral dissertation). Retrieved from https://deepblue.lib.umich.edu/bitstream/handle/2027.42/111491/abuyuktu_1.pdf?sequence=1&isAllowed=y

Büyüktür, A.G., & Ackerman, M.S. (2017). Information work in bone marrow transplant: Reducing misalignment of perspectives. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*. ACM, New York, NY, USA, 1740-1752.

Caoilfhionn. (2014). Love her so much. Instagram post. (17 September, 2014). Retrieved May 26, 2016 from https://www.instagram.com/p/tDJKvBtLFm/

Chamberlain, A., schraefel, m.c., Poole, E., Munson, S., Danis, C., & Churchill, E. (2015). Moving beyond e-Health and the quantified self: The role of CSCW in collaboration, community and practice for technologically-supported proactive health and wellbeing. In *Proceedings of the 18th ACM Conference Companion on Computer Supported Cooperative Work & Social Computing (CSCW '15 Companion).* ACM, New York, NY, USA, 273-276.

Chancellor, S., Lin, Z., Goodman, E.L., Zerwas, S., & De Choudhury, M. (2016). Quantifying and predicting mental illness severity in online pro-eating disorder communities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16).* ACM, New York, NY, USA, 1171-1184.

Chaudhry, B.M., Schaefbauer, C., Jelen, B., Siek, K.A., & Connelly, K. (2016). Evaluation of a food portion size estimation interface for a varying literacy population. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* ACM, New York, NY, USA, 5645-5657.

Charmaz, K. (1991). *Good days, bad days: The self and chronic illness in time*. Rutgers, New Brunswick, NJ.

Chen, Y. (2011). Health use in chronic care cycles. In *Proceedings of the 2011 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '11).* ACM, New York, NY, USA,485-488.

Chen, Y., Ngo, V., & Park, S.Y. (2013). Caring for caregivers: Designing for integrality. In *Proceedings of the 2013 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '13).* ACM, New York, NY, USA, 91-102.

Chen, Y., Cheng, K., Tang, C., Siek, K.A., & Bardram, J.E. (2014). The invisible work of health providers. *Interactions*. 21, 5, 74-77.

Choe, E.K., Lee, N.B., Lee, B., Pratt, W. and Julie Kientz. 2014. Understanding quantifed-selfers' practices in collecting and exploring personal data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI'14).* ACM, New York, NY, USA, 1143-1152.

Churchill, E.F., & m.c. schraefel. (2015). mHealth + proactive well-being = Wellth creation. *Interactions*. 22, 1, 60-63.

Chun, W. (2011). *Programmed visions: Software and memory*. MA: MIT Press.

Chung, C.F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J.A., & Munson, S.A. (2016). Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (CSCW '16). ACM, New York, NY, USA, 770-786.

Clarke, A.E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. CA: Sage Publications, Inc.

Clarke, A.E., Shim, J.K., Mamo, L., Fosket, J.R., & Fishman, J.R. (2010). Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine. In Clarke et al. (Eds.) *Biomedicalization. Technoscience, Health, and Illness in the U.S.* (pp.47-87). Durham: Duke University Press.

Coleman, G. 2012. *Coding freedom: The ethics and aesthetics of hacking*. NJ: Princeton University Press.

Corbin, J. & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology.* 8, 3, 224-247.

Corbin, J.M., & Strauss, A.C. (1998). *Basics of qualitative research*. Sage Publications, Inc.

Costik. J. (2015). DIY diabetes remote monitoring. *IEEE Spectrum*. 52, 6, 21-22.

De Choudhury, M., Kiciman, E, Dredze, M., Coppersmith, G., & Kumar, M. (2016). Discovering shifts to suicidal ideation from mental health content in social media. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* ACM, New York, NY, USA, 2098-2110.

Danholt, P. (2008). Interacting bodies: Posthuman enactments of the problem of diabetes: Relating science, technology and society-studies, user-centered design and diabetes practices (Datalogiske Skrifter; No.120). Roskilde: Roskilde Universitet.

Denzin, N. K. (2001). *Interpretive interactionism.* 2nd ed. Thousand Oaks, Calif.: Sage Publications.

Dourish, P. (2006). Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06).* ACM, New York, NY, USA, 541-550.

Dourish, P., & Bell, G. (2011). *Divining a digital future: Mess and mythology in ubiquitous computing*. MA: MIT Press.

Dourish, P. (2018). T*he stuff of bits: An essay on the materialities of information*. MA: MIT Press.

Eiser, A. R. (2014). *The ethos of medicine in postmodern America: Philosophical, cultural, and social considerations.* Lanham, Maryland: Lexington Books.

Ellingsen, G., & Røed, K. (2010). The role of integration in health-based information infrastructures, *Computer Supported Cooperative Work*. 19,6, 57-584.

Elsden, C., Kirk, D., Selby, M., & Speed, C. (2015). Beyond personal informatics: Designing for experiences with data. In *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems* (CHI EA '15). ACM, New York, NY, USA, 2341-2344.

Epstein, D.A., Ping, A., Fogarty, J., & Munson, S.A. (2015). A lived informatics model of personal informatics. *In Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '15).* ACM, New York, NY, USA, 731-742.

Epstein, D.A., Caraway, M., Johnston, C., Ping, A., Fogarty, J., & Munson, S.A. (2016). Beyond Abandonment to Next Steps: Understanding and Designing for Life after Personal Informatics Tool Use. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16). ACM, New York, NY, USA, 1109-1113.

Eschler, J., Bhattacharya, A., & Pratt, W. (2018). Designing a reclamation of body and health: Cancer survivor tattoos as coping ritual." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI), April 21-26.*

Eubanks, V. (2017). *Automating inequality: How high-tech tools profile, police, and punish the poor.* New York: St. Martin's Press.

Fadlon, J. (2005). *Negotiating the holistic turn: The domestication of alternative medicine.* Albany, NY: State University of New York Press.

Farnham, S., Cheng, L., Stone, L., Zaner-Godsey, M., & Hibbeln, C. (2002). HutchWorld: Clinical study of computer-mediated social support for cancer patients and their caregivers. In *Proceedings of the 2002 CHI Conference on Human Factors in Computing Systems (CHI '02).* ACM, New York, NY, USA, 375-382.

Felipe, S., Singh, S., Bradley, B., Williams, A., & Bianchi-Berthouze, N. (2015). Roles for personal informatics in chronic pain. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth '15). ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), ICST, Brussels, Belgium, Belgium, 161-168.

Fitzpatrick, G., & Ellingsen, G. (2013). A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. *Computer Supported Cooperative Work*, 22, 4-6, 609-665.

Foucault., M. (1978/2008). *The Birth of biopolitics. Lectures at the college de France, 1978-1979*. NY: Springer.

Gemmill, R., Cooke, L., Williams, A.C., & Grant, M. (2011). Informal caregivers of hematopoietic cell transplant patients: A review and recommendations for interventions and research. *Cancer Nursing*. 34, 6, E13-E21.

Gieryn, T. F. (1983). Boundary-work and the demarcation of science from non-science: strains and interests in professional ideologies of scientists. *American Sociological Review,* 48(6): 781–795.

Glaser, B. G., & Strauss, A.L. (1965). *Awareness of dying*. Chicago, IL: Aldine.

Glaser, B. G., & Strauss, A.L. (1968). *Time for dying*. Chicago, IL: Aldine.

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory*. Aldine, Hawthorne, NY.

Ghosh, A.K., Aljallad, Z., Badillo-Urquiola, K., & Wisniewski, P. (2018). Carebit: A privacy-preserving “step" toward remote informal caregiving. In *Proceedings of the 2018 ACM Conference on Supporting Groupwork (GROUP '18).* ACM, New York, NY, USA, 154-157.

Gregg, M. (2011). *Work’s intimacy*. Cambridge, UK: Polity.

Grimes, A., Landry, B., & Grinter, R.E. (2010). Characteristics of shared health reflections in a local community. *In Proceedings of the 2010 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '10).* ACM, New York, NY, USA, 435-444.

Grinter, R.E., Siek, K.A., & Grimes, A. (2010). Wellness informatics: Towards a definition and grand challenges. *In CHI ’10 Extended Abstracts on Human Factors in Computing Systems (CHI ’10).* ACM, New York, NY, USA, 4505-4508.

Grönvall, E., & Verdezoto, N. (2013). Beyond self-monitoring: Understanding non-functional aspects of home-based healthcare technology. In *Proceedings of the 2013 ACM international joint Conference on Pervasive and Ubiquitous Computing (UbiComp ’13)*. ACM, New York, NY, USA, 587-596.

Güldenpfennig, G., Nunes, F., & Fitzpatrick, G. (2015). ProxyCare: Integrating informal care into formal settings. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '15).* ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), ICST, Brussels, Belgium, Belgium, 141-144.

Hall, D. (1997). Introduction. In D. D. Hall (Ed.), *Lived religion in America: Toward a history of practice*. Princeton: Princeton University Press.

Haraway, D. (1985/1991). Manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s. In *Simians, Cyborgs, and Women: The reinvention of nature*. NY: Routledge. (originally published in *Socialist Review* (1985) 80, 65-108.

Hayes, B. M. (2010). *Health informatics: A patient-centered approach to diabetes.* Cambridge, Mass.: MIT Press.

Healthcare Channel. (2014). Dexcom’s CEO Gregg discusses the G4 SHARE with Jay Skyler, MD. Video. (30 October 2014). Retrieved August 02, 2016 from https://www.youtube.com/watch?v=WUT5QszkNXM

Hibbard, J.H., Mahoney, E.R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research*. 42, 4, 1443-1463.

Hicks, M. (2018). *How Britain discarded women technologists and lost its edge in computing.* Cambridge: MIT Press.

Hilliard, M.E., Sparling, K.M., Hitchcock, J., Oser, T.K., & Hood, K.K. (2015). The emerging diabetes online community. *Current Diabetes Reviews*. 1, 4, 261–72.

Hochschild, A. R. (2012). *The managed heart: Commercialization of human feeling, third edition.* Berkeley and LA: University of California Press.

Hong, M.K., Wilcox, L. Machado, D., Olson, T.A., & Simoneaux, S.F. (2016). Care partnerships: Toward technology to support teens' participation in their health care. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* ACM, New York, NY, USA, 5337-5349.

Houston, L., Jackson, S.J., Rosner, D.K., Ahmed, S.I., & Young, M. (2016). Values in repair. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16).* ACM, New York, NY, USA, 1403-1414.

Huh, J., & Ackerman, M.S. (2012). Collaborative help in chronic disease management: Supporting individualized problems. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work (CSCW ’12).* ACM, New York, NY, USA, 853-862.

Huh, J., Liu, L.S., Neogi, T., Inkpen, K., & Pratt, W. (2014). Health Vlogs as Social Support for Chronic Illness Management. *ACM Trans. Computer-Human Interaction*. 21, 4, Article 23 (August 2014), 31 pages.

Huh, J., Patel, R., & Pratt., W. (2010). Tackling dilemmas in supporting 'the whole person' in online patient communities. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12).* ACM, New York, NY, USA, 923-926.

Irani, L. (2015). Hackathons and the making of entrepreneurial citizenship. *Science, Technology & Human Values*. 40, 5, 799-824.

Jack, M., Chen, J., & Jackson, S.J. (2017). Infrastructure as creative action: Online buying, selling and delivery in Phnom Penh. In *Proceedings of the 2017 SIGCHI Conference on Human Factors in Computing Systems CHI Conference, (CHI '17*). ACM, New York, NY, USA, 6511-6522.

Jackson, S. J. (2014). Rethinking repair. In *Media Technologies: Essays on Communication, Materiality and Society*, edited by Gillespie, Tarleton, Boczkowski, Pablo, Foot, Kirsten, 221–40. Cambridge, MA: MIT Press.

Jackson, S.J., Pompe, A., & Krieshok, G. (2012). Repair worlds: Maintenance, repair, and ICT for development in rural Namibia. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work* (CSCW '12). ACM, New York, NY, USA, 107-116.

Jackson, S.J., Ahmed, S.I., & Rifat, M.R. (2014). Learning, innovation, and sustainability among mobile phone repairers in Dhaka, Bangladesh. In *Proceedings of the 2014 conference on Designing interactive systems* (DIS '14). ACM, New York, NY, USA, 905-914.

Jackson, S.J., & Kang, L. (2014). Breakdown, obsolescence and reuse: HCI and the art of repair. n *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14).* ACM, New York, NY, USA,449-458.

Jacobs, M.L., Clawson, J., & Mynatt, E.D. (2014). My journey compass: A preliminary investigation of a mobile tool for cancer patients. In *Proceedings of the 2014 SIGCHI Conference on Human Factors in Computing Systems CHI Conference, (CHI '14*). ACM, New York, NY, USA, 663-672.

Jain, S.L. (2013). *Malignant: How cancer becomes us*. CA: University of California Press.

Karkar, R., Fogarty, J., Kientz, J.A., Munson, S.A., Vilardaga, R., & Zia, J. (2015). Opportunities and challenges for self-experimentation in self-tracking. In *Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers* (UbiComp/ISWC'15 Adjunct). ACM, New York, NY, USA, 991-996.

Kaziunas, E., & Ackerman, M.S. (2015). Designing for lived health: A practice-based approach for person-centered health information technologies. In V. Wulf, K. Schmidt and D. Randall (Eds). *Designing Socially Embedded Technologies in the Real-World*. London: Springer, 357-382.

Kaziunas, E., Ackerman, M.S., & Veinot, T.C.E. (2013). Localizing chronic disease management: Information work and health translations. In *Proceedings of the 76th ASIS&T Annual Meeting: Beyond the Cloud: Rethinking Information Boundaries (ASIST '13)*, Andrew

Grove (Ed.). American Society for Information Science, Silver Springs, MD, USA, Article 11, 10 pages.

Kaziunas, E., Buyuktur, A.G., Jones, J., Choi, S.W., Hanauer, D.A., & Ackerman, M.S. (2015). Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15).* ACM, New York, NY, USA, 1763-1774.

Kaziunas, E., Ackerman, M.S., Lindtner, S., & Lee, J.M. (2017). Caring through data: Attending to the social and emotional experiences of health datafication. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17).* ACM, New York, NY, USA, 2260-2272.

Kerr, A., Hill, R., & Till, C. (2018). The limits of responsible innovation: Exploring care, vulnerability and precision medicine. *Technology in Society*. 52, 24-31.

Kientz., J.A. (2010). Understanding parent-pediatrician interactions for the design of health technologies. In *Proceedings of the 1st ACM International Health Informatics Symposium (IHI '10)*, Tiffany Veinot (Ed.). ACM, New York, NY, USA, 230-239.

Kientz, J.A., Arriaga, R.I., & Abowd, G.D. (2009). Baby steps: Evaluation of a system to support record-keeping for parents of young children. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '09).* ACM, New York, NY, USA, 1713-1722.

Kitchin, R. (2014). Big data, new epistemologies and paradigm shifts. *Big Data & Society*. Jun 2014, 1(1) http://dx.doi.org/10.1177/2053951714528481

Klasnja, P., Hurtle, A., Powell, C., Phan, G., Pratt, W. (2010). HealthWeaver Mobile: Designing a mobile tool for managing personal health information during cancer care. In *AMIA Annual Symp. Proceedings,* 392-6.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition,* New York: Basic Books.

Kleinman, A. (1980). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine and psychiatry.* Berkeley: University of California Press.

Kling, R. (1994). Reading “all about” computerization: How genre conventions shape nonfiction social analysis. *The Information Society*, 10, 3, 147-172.

Klonoff, D.C. (2015). Cybersecurity for connected diabetes devices. *Journal of Diabetes Science and Technology.* 9, 5, 1143-7.

Koltin, D., & Daneman, D. (2008). Dead-in-bed syndrome: A diabetes nightmare. *Pediatric Diabetes*. 9, 504–507.

Krist, A.H., Beasley, J.W., Crosson, J.C., Kibbe, D.C., Klinkman, M.S., Lehmann, C.U., Fox, C.H., Mitchell, J.M., Mold, J.W., Pace, W.D., Peterson, K.A., Phillips, R.L., Post, R., Puro, J., Raddock, M., Simkus, R., & Waldren, S.E., (2014). Electronic health record functionality needed to better support primary care, *Journal of the American Medical Informatics Association*. 21, 5, 1, 764–771.

Lamb, R. & Kling, R. (2003). Reconceptualizing users as social actors in information systems research," *MIS Quarterly*, (27: 2).

Law, J., & Mol, A. (Eds). (2002). *Complexities: Social studies of knowledge*. Durham and London: Duke University Press.

Lee, J.M., Hirschfeld, E., & Wedding, J. (2016). A patient-designed do-it-yourself mobile technology system for diabetes: Promise and challenges for a new era in medicine. *JAMA*. 315, 14, 1447-1448.

Lewis, D. (2016). #OpenAPS Winter 2015 update. https://openaps.org/openaps-winter-2015-update//. Last accessed March 13, 2016.

Li, G., Zhou, X., Lu, T., Yang, J., & Gu, N. (2016). SunForum: Understanding depression in a Chinese online community. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16).* ACM, New York, NY, USA, 515-526.

Li, I., Dey, A., & Forlizzi, J. (2010). A stage-based model of personal informatics systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '10). ACM, New York, NY, USA, 557-566.

Lindtner, S. (2015). The promises of the maker movement against China's manufacturing culture. *Science, Technology & Human Values*. 40, 5, 854-879.

Lindtner, S., Bardzell, & JBardzell, J. (2016). Reconstituting the utopian vision of making: HCI after technosolutionism. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 1390-1402.

Lindtner, S., Hertz, G.D., & Dourish, P. (2014). Emerging sites of HCI innovation: Hackerspaces, hardware startups & incubators. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI'14).* ACM, New York, NY, USA, 439-448.

Linebaugh, K. (2014). Citizen hackers tinker with medical devices. *Wall Street Journal*. http://www.wsj.com/articles/citizen-hackers-concoct-upgrades-for-medical-devices-1411762843.Last accessed January 2, 2016.

Liu, L.S., Huh, J., Neogi, T., Inkpen, K., & Pratt, W. (2013). Health vlogger-viewed interaction in chronic illness management. In *Proceedings of the 2013 CHI Conference on Human Factors in Computing Systems (CHI '13).* ACM, New York, NY, USA, 49-58.

Liu, L.S., Hirano, S.H., Tentori, M., Cheng, K.G., George, S., Young Park, S.Y., & Hayes, G.R. (2011). Improving communication and social support for caregivers of high-risk infants through mobile technologies. In *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work (CSCW '11)*. ACM, New York, NY, USA, 475-484.

Lock, M. M., Nguyen, V. (2010). *An anthropology of biomedicine.* Chichester, West Sussex: Wiley-Blackwell.

Lorraine. (2014). Nightscout: Getting Started. Retrieved from https://thisiscaleb.com/2014/09/08/nightscout-getting-started-wearenotwaiting-cgminthecloud/

Lupton, D. (2014). Self-tracking cultures: Towards a sociology of personal informatics. In *Proceedings of the 26th Australian Computer-Human Interaction Conference on Designing Futures: the Future of Design* (OzCHI '14). ACM, New York, NY, USA, 77-86.

Maher, M., Hanauer, D.A., Kaziunas, E., Ackerman, M.S., Derry, H., Forringer, R., Miller, K., O'Reilly, D., An, L., Tewari. M., & Choi. S.W. (2015). A novel health information technology communication system to increase caregiver activation in the context of hospital-based pediatric hematopoietic cell transplantation: A pilot study. *JMIR Research Protocols*. 4,4, e119.

Maher, M., Kaziunas, E., Ackerman, M., Derry, H., Forringer, R., Miller, K., O'Reilly, D., An, L.C., Tewari, M., Hanauer, D.A., & Choi, S.W. (2016). User-centered design groups to engage patients and caregivers with a personalized health IT tool. *Biology of Blood and Marrow Transplantation*. 22, 2, 349-35.

Maitland, J., & Chalmers, C. (2011). Designing for peer involvement in weight management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '11). ACM, New York, NY, USA, 315-324.

Mamykina, L., Mynatt, E.D., & Kaufman, D.R. (2006). Investigating health management practices of individuals with diabetes. In Proceedings *of the SIGCHI Conference on Human Factors in Computing Systems (CHI '06).* ACM, New York, NY, USA, 927-936.

Mamykina, L., Mynatt, E., Davidson, P.R., & Greenblatt, D. (2008). MAHI: Investigation of social scaffolding for reflection thinking in diabetes management. In *Proceedings of the 2008 CHI Conference on Human Factors in Computing Systems (CHI '08).* ACM, New York, NY, USA, 477-486.

Mankoff, J., Kuksenok, K., Kiesler, S., Rode, J.A., & Waldman, K. (2011). Competing online viewpoints and models of chronic illness. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11).* ACM, New York, NY, USA, 589-598.
Martin, A., Myers, N., & Viseu, A. (2015). The politics of care in technoscience. *Social Studies of Science.* 45, 5, 625-641.

Mann, E. (1997). *Testimonies: Four Plays.* New York, NY: Theatre Communications Group, Inc.

Matthews, M., & Doherty, G. (2011). In the mood: Engaging teenagers in psychotherapy using mobile phones. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11).* ACM, New York, NY, USA, 2947- 2956.

McLoughlin, I., & Wilson, R. (2012). *Digital government@work,* Oxford: Oxford University Press.

Mead, N., and Bower, P. (2000). Patient-centerdness: A conceptual framework and review of the empirical literature. *Social Science and Medicine.* 51,7, 1087-1110.

Mentis, H., Reddy, M., & Rosson, M.B. (2010). Invisible emotion: Information and interaction in an emergency room. In *Proceedings of the 2010 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '10).* ACM, New York, NY, USA, 311-320.

Miller, A. D., Mishra, S. R., Kendall, L., Haldar, S., Pollack, A. H., & Pratt, W. (2016a). Partners in care: Design considerations for caregivers and patients during a hospital stay. In *Proceedings of the Conference on Computer-Supported Cooperative Work (CSCW '16)*, ACM, New York, NY, USA, 756–769.

Miller, A. D., Pollack, A. H., & Pratt, W. (2016b). Bursting the information bubble: Identifying opportunities for pediatric patient-centered technology. *AMIA Annual Symposium Proceedings 2016 (AMIA '16)*, 894–903.

Mishra, S. R., Haldar, S., Pollack, A. H., Kendall, L., Miller, A. D., Khelifi, M., & Pratt, W. (2016). “Not just a receiver”: Understanding patient behavior in the hospital environment. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems CHI Conference, (CHI ’16*). ACM, New York, NY, USA,3103–3114.

Mishra, S.R., Miller, A.D., Haldar, S.H., Khelifi, M., Eschler, J., Elera, R.G., Pollack, A.H., & Pratt, W. (2018). Supporting collaborative health tracking in the hospital: Patients' perspectives. In P*roceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*. ACM, New York, NY, USA. Paper 650, 14 pages.

Mohr, D.C., Montague, E., Stiles-Shields, C., Kaiser, S.M., Brenner, C., Carty-Fickes, E., Palac, H., & Duffecy, J. (2015). MedLink: A mobile intervention to address failure points in the treatment of depression in general medicine. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '15)*. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), ICST, Brussels, Belgium, Belgium, 100-107.

Mol, A. (2003). *The body multiple: Ontology in medical practice*. Durham: Duke University Press.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. NY: Routledge.

Mol, A., Moser, I., & Pols, J. (2010). Putting practice into theory. In Mol, A., Moser, I., & Pols, J. (eds). *Care in practice: On tinkering in clinics, homes and farms*. Bielefeld: Transcript Verlag, 7-25.

Murphy, M. (2012). *Seizing the means of reproduction: Entanglements of feminism, health, and technoscience.* Durham: Duke University Press.

Nafus, D. (ed). (2016). *Quantified: Biosensing technologies in everyday life*. Cambridge: MIT Press.

Nardi, B., & O'Day, V.L. (1999). *Information ecologies: Using technology with heart*. MA: MIT Press.

Neff, G. (2012). *Venture labor: Work and the burden of risk in innovative industries*. Cambridge: MIT Press.

Neff, G., & Nafus, D. (2016). *Self-tracking*. Cambridge: MIT Press.

Nightscout. (2016). What is the Nightscout project? http://www.nightscout.info/. Last accessed August 21, 2015.

Nightscout Foundation. *Mission.* (2016). http://www.nightscoutfoundation.org/about/. Last accessed April 22, 2016.

Noble, S.U. (2018). *Algorithms of oppression: How search engines reinforce racism.* New York: New York University Press.

Nunes, F., Verdezoto, V., Fitzpatrick, G., Kyng, M., Grönvall, E., & Storni, C. (2015). Self-care technologies in HCI: Trends, tensions, and opportunities. ACM *Trans. Computer-Human Interaction.* 22, 6, Article 33, 45 pages.

O'Leary, K. Bhattacharya, A., Munson, S.A., Wobbrock, J.O., & Pratt, W. (2017). Design opportunities for mental health peer support technologies. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17).* ACM, New York, NY, USA, 1470-1484.

O'Kane, A.A., Rogers, Y., & Blandford, A. (2015). Concealing or revealing mobile medical devices? Designing for onstage and offstage presentation. *In Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems (CHI'15*), 1689-1698.

O'Kane, A.A., Hurst, A., Niezen, G., Marquardt, N., Bird, J., & Abowd, G. (2016a). Advances in DIY health and wellbeing. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems* (CHI EA '16). ACM, New York, NY, USA, 3453-3460.

O'Kane, A.A., Han, Y., & Arriaga, R. (2016). Varied and bespoke needs of caregivers: Organizing and communicating diabetes care for children in era of DIY. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth '16). ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), ICST, Brussels, Belgium, Belgium, 9-12.

Ohlin, F., & Olsson, C.M. (2015). Beyond a utility view of personal informatics: A postphenomenological framework. In *Adjunct Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers* (UbiComp/ISWC'15 Adjunct). ACM, New York, NY, USA, 1087-1092.

Ong, A., & Collier, S.J. (eds.). (2004). *Global assemblages: Technology, politics, and ethics as anthropological problems*. MA: Wiley-Blackwell.

Orlikowski,W.J. (2000). Using technology and constituting structures: A practice lens for studying technology in organizations. *Organization Science*. 11, 4, 404-428.

Orsi, R. (2002). T*he Madonna of 115th street: Faith and community in Italian Harlem, 1880–1950*. New Haven: Yale University Press.

Park, S.Y. (2014). Supporting collaborative care in an emergency department (ED) through patient awareness. In *Proceedings of the companion publication of the 17th ACM conference on Computer supported cooperative work & social computing (CSCW Companion '14)*. ACM, New York, NY, USA, 81-84.

Parker, A., Kantroo, V., Lee, H.R., Osornio, M., Sharma, M., & Grinter, R. (2012). Health promotion as activism: Building community capacity to effect social change. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12).* ACM, New York, NY, USA, 99-108.

Parker, A.G., & Grinter, R.E. (2014). Collectivistic health promotion tools: Accounting for the relationship between culture, food and nutrition. *International Journal of Human-Computer Studies.* 72, 2 (February 2014), 185-206.

Paul, S.A., & Reddy., M.C. (2010). Understanding together: Sensemaking in collaborative information seeking. In *Proceedings of the 2010 ACM Conference on Computer Supported Cooperative Work (CSCW '10)*. ACM, New York, NY, USA, 321-330.

Phipps, S., Dunavant, M., Lensing, S., & Rai, S. (2004). Patterns of distress in parents of children undergoing stem cell transplantation. *Pediatric Blood & Cancer*. 43, 3, 267-274.

Pina, L.R., Sien, S.W., Ward, T., Yip, J.C., Munson, S.A., Fogarty, J., & Kientz, J.A. (2017). From personal informatics to family informatics: Understanding family practices around health monitoring. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17*). ACM, New York, NY, USA, 2300-2315.

Pine, K.H. & Mazmanian, M. (2014). Institutional logics of the EMR and the problem of 'perfect' but inaccurate accounts. *In Proceedings of the 17th ACM conference on Computer supported cooperative work & social computing (CSCW '14).* ACM, New York, NY, USA, 283-294.

Pipek, V., & Wulf, V. (2009). Infrastructuring: Toward an integrated perspective on the design and use of information technology. *Journal of the Association for Information Systems*. 10, 447-473.

Pollack, A.H., Backonja, U., Miller, A.D., Mishra, S.R., Khelifi, M., Kendall, L., & Pratt, W. (2016). Closing the gap: Supporting patients' transition to self-management after hospitalization.

In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 5324-5336.

Pratt, W., Reddy, M.C., McDonald, D.W., Tarczy-Hornoch, P., & Gennari, J.H. (2004). Incorporating ideas from computer-supported cooperative work. *Journal Biomedical Informatics*. 37, 2, 127-137.

Pratt, W., Unruh, K., Civan, A., & Skeels, M.M. (2006). Personal health information management. *Communications of the ACM*. 49, 1, 51-55.

Prilla, M., Degeling, M., & Herrmann, T. (2012). Collaborative reflection at work: Supporting informal learning at a healthcare workplace. In *Proceedings of the 17th ACM International Conference on Supporting Group Work (GROUP '12*). ACM, New York, NY, USA, 55-64.

Puig de la Bellacasa, M. (2010). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science*. 41,1, 85–106.

Steinhardt, S.B., & Jackson, S.J. (2015). Anticipation work: Cultivating vision in collective practice. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (CSCW '15). ACM, New York, NY, USA, 443-453.

Rehm, R.S. (2013). Nursing's contribution to research about parenting children with complex chronic conditions: An integrative review, 2002 to 2012. *Nursing Outlook*. 61, 5, 266-290.

Reich, W.T. (1995). Care: I. History of the notion of care & Care: II. Historical dimensions of an ethic of care in health care. In Warren Thomas Reich, *Encyclopedia of Bioethics, 2d Edition.* Simon & Schuster Macmillan, 319-336.

Rodbard, D. (2016). Continuous glucose monitoring: A review of successes, challenges, and opportunities. *Diabetes Technology and Therapeutics*. 18, 2, 2-13.

Rooksby, J., Rost, M., Morrison, A., & Chalmers, M. (2014). Personal tracking as lived informatics. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '14). ACM, New York, NY, USA, 1163-1172.

Rosner, D.K., & Ames, M.G. (2014). Designing for repair?: Infrastructures and materialities of breakdown. In *Proceedings of the ACM Conference on Computer-Supported Cooperative Work & Social Computing(CSCW'14).* ACM, New York, NY, USA, 319-331.

Sawyer, S. & Jarrahi, M.H. (2014). Sociotechnical approaches to the study of information systems. In *Computing Handbook, Third Edition*. 5-1 p. 5-27. Chapman and Hall.

Schaefbauer, C.L., Khan, D. U., Le, A., Sczechowski, G., & Siek, K.A. (2015). Snack buddy: supporting healthy snacking in low socioeconomic status families. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (CSCW '15). ACM, New York, NY, USA, 1045-1057.

Schorch, M., Wan, L., Randall, D.W., & Wulf, V.(2016). Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing(CSCW'16).* ACM, New York, NY, USA, 787-799.

Shannon, C. & Weaver, W. (1949). *The mathematical theory of communication.* Urbana: University of Illinois Press.

Siek, K.A. (2011). What are our responsibilities when designing sociotechnical health interventions? *Interactions* 18, 5, 20-23.

Smith, P.A. (2016). A do-it-yourself revolution in diabetes care. *New York Times*. Retrieved March 14, 2016 from http://nyti.ms/1LCuPAw.

Star, S. L. (1991). Power, technologies and the phenomenology of conventions: On being allergic to onions. In Law, J. (ed.) *A sociology of monsters: Essays on power, technology, and domination*. London: Routledge, 26-56.

Star, S.L. (2015) Envoi: When shadows become complex: Weaving the Nanmarra. In Bowker et al. (Eds.) *Boundary Objects and Beyond: Working with Leigh Star*. (pp. 489-497). Cambridge: MIT Press.

Star, S. L., & Ruhleder, K. (1996). Steps toward an ecology of infrastructure: Design and access for large information spaces. *Information Systems Research.* 7, 1, 111–34.

Star, S.L., & Strauss, A. (1999). Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer Supported Cooperative Work.* 8, 1-2 ,9-30.

Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1982a). Sentimental work in the technologized hospital. *Sociology of Health and Illness*, 4, 3, 255-278.

Strauss, A.L., Fagerhaugh, F., Suczek, B., & Wiener, C. (1982b). The work of hospitalized patients. *Social science & Medicine.* 16, 9, 977-986.

Strauss, A. (1993). *Continual permutations of action*. Chicago, IL: Aldine Transaction.

Storni, C. (2014). Design challenges for ubiquitous and personal computing in chronic disease care and patient empowerment: A case study rethinking diabetes self-monitoring. *Personal and Ubiquitous Computing.* 1 8, 5, 1277-1290.

Subramaniam, B. (2009). Moored metamorphoses: A retrospective essay on feminist science studies. *Signs*. 34, 4, pp. 951-980.

Suchman, L. A. (2007). *Human-machine reconfigurations. Plans and situated actions. 2nd ed.* NY: Cambridge University Press.

Suchman, L. (2008). Feminist STS and the sciences of the artificial. In: Hackett, E.J., Amsterdamska, O., Lynch, M., & Watchman, J. (eds.) *The handbook of science and technology studies, 3rd ed.* Cambridge, MA: The MIT Press, 139-163.

Sullivan-Bolyai, S., Knafl, K., Tamborlane, W., & Grey, M. (2004). Parents' reflections on managing their children's diabetes with insulin pumps. *Journal of Nursing Scholarship* 36, 4, 316-323.

Tixier, M., Gaglio, G., & Lewkowicz, M. (2009). Translating social support practices into online services for family caregivers. In *Proceedings of the ACM 2009 international conference on Supporting group work (GROUP '09).* ACM, New York, NY, USA, 71-80.

Tixier, M., & Lewkowicz, M. (2016). "Counting on the group": Reconciling online and offline social support among older informal caregivers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '16). ACM, New York, NY, USA, 3545-3558.

Torrance, A.W., & von Hippel, E. (2015). The right to innovate. *Michigan State Law Review*. 793-829.

Toscos, T., Connelly, K., & Rogers, Y. (2012). Best intentions: Health monitoring technology and children. In *Proceedings of the 2012 CHI Conference on Human Factors in Computing Systems (CHI '12).* ACM, New York, NY, USA, 1431-1440.

Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.

Tuli, A. Singh, P., Sood, M.,Deb, K.S., Jain, S., Jain, A., Wason, M., Chadda, R., & Verma, R. (2016). Harmony: Close knitted mhealth assistance for patients, caregivers and doctors for managing SMIs. In *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct (UbiComp '16).* ACM, New York, NY, USA, 1144-1152.

Turner, V. (2006). *From counterculture to cyberculture: Stewart brand, the whole earth catalogue, and the rise of digital utopianism*. Chicago: University of Chicago Press.

U. S. Agency for Healthcare Research and Quality. (2016). *Connecting those at risk to care*. AHRQ Publication No. 15(16)-0070-1-EF, January.

U.S. Department of Health and Human Services. (2016a). *Advancing community-level core measurement: A progress report and workshop summary*. Report, February.

U.S. Department of Health and Human Services. (2016b). *Environmental scan of existing domains and indicators to inform development of a new measurement framework for assessing the health and vitality of communities*. Report, June.

U.S. Institute of Medicine. (2014). *Capturing social and behavioral domains and measures in electronic health records, phase 2.* National Academies Press.

Veatch, R. M. (2009). *Patient, heal thyself: How the new medicine puts the patient in charge.* Oxford: Oxford University Press.

Wiener, C., Fagerhaugh, S., Suczek, B. & Strauss, A. (1997). *Social organization of medical work.* Transaction Publishers.

Walsh, J., Roberts, R., Morris, R., & Heinemann, L. (2015). Device connectivity: The next big wave in diabetes. *Journal of Diabetes Science and Technology*. 1-5.

Wang, R., Aung, M.S.H., Abdullah, S., Brian, R., Campbell, A.T., Choudhury, T., Hauser, M., Kane, J., Merrill, M., Scherer, E.A., Tseng, V.W.S., & Ben-Zeev, D. (2016). CrossCheck: Toward passive sensing and detection of mental health changes in people with schizophrenia. In *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '16).* ACM, New York, NY, USA, 886-897.

Weiser, M. (2002). The computer for the 21st century. *IEEE Pervasive Computing*. 1, 1, 19-25.

Williams, K. (2015). An anxious alliance. In *Proceedings of the Fifth Decennial Aarhus Conference on Critical Alternatives (AA '15)*. Aarhus University Press, 121-131.

Yamashita, N., Kuzuoka, H., Hirata, K., & Kudo, T. (2013). Understanding the conflicting demands of family caregivers caring for depressed family members. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems(CHI '13).* ACM, New York, NY, USA, 2637-2646.

Yu, S.H., Wang, L.S., Chu, H.H., Chen, S.H., Chen, C.C.H., You, C.W., & Huang, P. (2011). A mobile mediation tool for improving interaction between depressed individuals and caregivers *Pers Ubiquit Comput.* 15, 695–706.

Zeigler, B. P., Redding, S. A., Leath, B. A., & Carter, E. L. (2014). Pathways community HUB: A model for coordination of community health care. *Population Health Management*. 14, 4, 199-201.

Zhou, X., Ackerman, M.S., & Zheng, K. (2010). Doctors and psychosocial information: Records and reuse in inpatient care. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems(CHI '10).* ACM, New York, NY, USA, 1767-1776.