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## A Constellation of Caring: The Dynamic and Fluctuating Nature of Pediatric Cancer Care

Anne Friedrich  
Colby College

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# A CONSTELLATION OF CARING: THE DYNAMIC AND FLUCTUATING NATURE OF PEDIATRIC CANCER CARE

Annie Friedrich  
Senior Honors Thesis  
Department of Anthropology  
Colby College  
May 2015

## DEDICATION

I dedicate this thesis to the most caring and inspiring people in my life, my parents. Mom and Dad, thank you for showing me the beauty of care each and every day. I love you both.

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## ACKNOWLEDGMENTS

While writing this thesis, I had the unique opportunity to simultaneously study the anthropology of creativity with Professor Chandra Bhimull, who also happened to be my advisor for this project. In our first class, we explored creativity as gift and interacted with creative thinkers such as Elizabeth Gilbert (2009) and Lewis Hyde (2007). Gilbert, the author of the best-selling book *Eat, Pray, Love*, talked about her creative experience in a Ted Talk called “Your Elusive Creative Genius.” In this talk, Gilbert reflected on ancient artists who claimed to have a genius or *daemon* who bestowed creative gifts. Rather than viewing humans as the locus of creativity, as geniuses in and of themselves, we as creative beings should see creativity as a gift that is on loan to us, a gift that must be passed on. Gilbert says that in her creative process, she is like a pack-mule—she shows up every day to do her job whether or not her genius shows up with her. At the outset of this project, I naïvely envisioned a writing process filled with moments of genius, where phrases align to form the perfect thought. Alas, that was not the case. Each day, I had to show up and work, whether or not my genius decided to join me. Even at the conclusion of this project, I am deeply critical of my creative endeavor, but I know that each word was given to me as a gift and was crafted into something meaningful by many people to whom I owe my thanks.

First, to Professor Chandra Bhimull, my advisor, my creative guide, my ceaseless questioner. You pushed me when I needed to be pushed and encouraged me when I needed to be encouraged. Your questioning, critiquing, and probing brought this project to a level of which I could only dream, and you helped me navigate areas of anthropological inquiry that I never

could (or would) have traveled alone. Chandra, your presence and guidance were true gifts, and I am so thankful.

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My friends and family were incredibly supportive throughout this whole process. My friends listened to my whining and knew when to offer advice. My family tolerated my mood swings as I encountered both highs and lows. To my mom especially, thank you for guiding me through those teary late-night phone calls and for supporting me no matter what.

And lastly, I thank the providers, patients, and families of Children's for opening their world to me. Their kindness, generosity, honesty, bravery, and love transformed this project from a scholarly endeavor to something much deeper, much more personal, and I am truly grateful for that gift. Now to you, reader, I pass on this gift, with the hopes that you will be changed and will continue to pass it on.

## INTRODUCTION

*Lisa, a pediatric nurse practitioner who specializes in solid tumor oncology, walks into one of the exam rooms in the pediatric hematology/oncology clinic at Children's Hospital in Minneapolis, Minnesota, and a three-year-old girl in a hot pink Minnie Mouse velvet track suit turns around from her fruit snacks. Without a word, she offers a handful of fruit snacks to Lisa, who says, "Oh, are these for me? Thank you! How many are there? Can you count them?" Today, this little girl is getting outpatient chemotherapy through her port, a process which usually takes less than one hour. "Where's Susan?" asks the little girl. Susan is the Child Life worker who ensures that children have toys to play with and things to do while at the clinic. Lisa says, "I don't know where Susan is, but should we go get some toys?" The little girl happily responds, "I want the Minnie Mouse boat!" So Lisa, the little girl, and her mother and I all walk down the hallway to the toy closet. Once we are back in the room, the little girl starts to play with her toys while Lisa asks mom how things are going. Suddenly, the little girl starts to whimper and cry. When mom asks what is wrong, she does not answer. Mom picks her up and puts her on her lap. After she has calmed down, Lisa proceeds with the examination. As the little girl sits on mom's lap, Lisa listens to her chest. She stands up to put the stethoscope away, but the little girl interjects, "What about my back?" Lisa and mom chuckle. Even this three-year-old knows the patterning and routine of visits to the clinic. Amidst the play and counting of fruit snacks, this little girl has some illusive ideas of why she is here—because she needs care. Yet that care can take many different forms and can look different in various situations. This thesis explores the myriad ways in which practitioners enact the dynamic, fluctuating, moving ideal of care.*

Children's Hospital in Minnesota first opened in St. Paul in 1924 and began operating with sixteen beds. Throughout its early years and the Depression, it was dedicated to providing free service for poor children and families. In 1973, the Minneapolis Children's Health Center opened on Chicago Avenue, and in 1994 it merged with Children's Hospital of St. Paul to become the largest pediatric health care provider in the Upper Midwest. Throughout the 1990s, Children's opened several specialty clinics in the metro area, and today the organization is known as Children's Hospitals and Clinics of Minnesota. It is the seventh-largest children's health care organization in the United States (Children's 2014a).<sup>1</sup>

My research takes place in the Cancer and Blood Disorders Center of Children's Minneapolis. The cancer and blood disorders program at Children's Minneapolis cares for more than fifty-five percent of children diagnosed with cancer or blood disorders in Minnesota and seventy percent of those diagnosed in the Twin Cities. Each year, nine hundred patients are admitted as inpatients to the Cancer and Blood Disorders Center at Children's (Children's 2014b). The center has sixteen physicians and thirteen nurse practitioners, in addition to staff members such as nurses, social workers, psychologists, physical therapists, interpreters, and chaplains who all make up the collaborative care team at Children's. This language of "team" is used throughout the center and is an important part of care at Children's.<sup>2</sup>

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<sup>1</sup> Children's Hospitals and Clinics of Minnesota emerged in an historical context in which society was beginning to understand the importance of healthcare specifically for children. The first children's hospital in the United States was The Children's Hospital of Philadelphia, founded in 1855 (Stang and Joshi 2006). During the 19<sup>th</sup> century, children's hospitals were charitable enterprises devoted to the care of the urban poor, orphans, and immigrants (Markel 2008). Consequently, children's hospitals sought to reform children morally as well as to heal them physically. Parental visiting hours were restricted because it was considered therapeutic to remove children from harmful home environments (Markel 2008). In the 20<sup>th</sup> century and continuing to the present, advances in hospital architecture and a move towards consumer-based healthcare has shifted the focus of children's hospitals from moral instruction to family-centered care. See chapter two for an analysis of the ways in which the built environment of the hospital as an institution shapes and informs care practices.

<sup>2</sup> Children's implements collaborative team care to ensure that the physical, mental, social, emotional, and spiritual needs of the patient are being met. Each patient has a care team that may include a primary physician, nurse practitioners, several nurses, social workers, physical therapists, massage therapists, Child Life workers,



While the Cancer and Blood Disorders Center is one entity, it is comprised of two distinct spaces: the specialty outpatient clinic and the hospital unit. The specialty clinics of Children's are located on one side of Chicago Avenue, and the hospital is located on the other side (see Image #1 in Appendix). Each building has eight floors, and the clinics and hospital are connected via a skyway on the second floor (see Image #2 in Appendix). The pediatric hematology/oncology clinic is located on the first floor of the specialty clinic building, and the cancer and blood disorders hospital unit is located on the seventh floor of the hospital. These spaces are intricately woven together, yet the differences in the functions that they serve and the ways in which providers navigate the spaces are striking. Children who have clinic appointments are generally healthier than children in the hospital. They come in to the clinic to check blood counts, receive outpatient chemotherapy, get a blood transfusion, or have a routine maintenance check. On average, the clinic sees thirty to forty patients each day. There are twenty-six rooms, six of which are specialty infusion rooms equipped with gas for procedures such as spinal taps. These infusion rooms allow procedures to be done in the clinic that before would require hospitalization. Conversely, children in the hospital are receiving intense chemotherapy that cannot be done outpatient (they must be monitored overnight), have a severe infection, are getting surgery, or are not responding well to treatment. The providers work both in the clinic and on the floor, following their patients as they move between the clinic and the hospital for different phases of treatment.

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radiologists, x-ray technicians, and sometimes interpreters. This team care reveals that there is no single idea of care at Children's but rather that care incorporates all aspects of a child's well being.

Each provider has her<sup>3</sup> own desk in the clinic, and there are separate team offices for the different specialties. For example, the physicians, nurse practitioners, and nurses who work with solid tumor patients all sit in the solid tumor office. Before this separation into specialties four years ago, physicians would sit in one office, nurse practitioners in another office, and nurses in another. Many of the providers appreciate the new distinction into teams because it allows for greater collaboration between all of the different people who care for a certain child. If a nurse has a question, the provider is nearby to answer the question.

In this project, I explore notions of care in pediatric hematology and oncology. I am especially intrigued by the ways in nurse practitioners enact care. Nurse practitioners occupy a unique position within the medical realm because they have been trained with a nursing sensibility to care for the patient as a person while simultaneously being trained to fight illness and disease. In this thesis, I argue that for the medical practitioners whom I shadowed, care is a way of being in the world, a way in which to create meaning for themselves and for their patients in their lived everyday experience. Yet care is a liminal way of being in that providers, especially nurse practitioners, are constantly living and caring “betwixt and between” as they strive to uphold different ideas of what is meaningful.<sup>4</sup> Providers strive to produce healthy bodies that are meaningful to Children’s as an institution while at the same time enacting a more

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<sup>3</sup> The providers that I shadowed were all women. I have chosen to use the female pronoun when referring to medical providers more broadly. While this decision was made for stylistic convenience, it also serves to highlight the gendered dynamics of care, an idea that is explored further in chapter one.

<sup>4</sup> This concept of liminality is developed from Victor Turner in his theory of ritual and drama. According to Turner, liminality is a “state or process which is betwixt-and-between the normal”; liminality is full of “potency and potential,” and it may also be full of “experiment and play” (1979:465). While Turner argues that this state is bounded temporally, that people enter and exit this liminal stage, I argue that this liminality is a way of being for providers because they exist in an “interstructural situation” between ideas of care that are structured by the hospital and ideas of care that are structured by society (Turner 1967:93). However, liminality uniquely brings these two structures together; a liminal way of being is “neither this nor that, and yet is both” (Turner 1967:99). Liminality allows providers to enact myriad forms of care to create meaningful lived experiences.

personal, social, and relational moment of care. This liminality is made visible as providers navigate through the shifting landscapes of care at Children's, what I call *carescapes*.<sup>5</sup> These carescapes highlight the fluctuating, irregular, dynamic nature of care as providers constantly strive toward wholeness for their patients, a wholeness which includes not only physical health but also a meaningful lived experience.<sup>6</sup>

I analyze the ways in which providers, nurse practitioners especially, employ their liminality to create meaningful experiences of care through their care labor. Care labor is an everyday practice, an emotional practice, and an embodied practice. This care labor is made manifest through the carescape of the built environment of the hospital, through the carescape of value that creates socially and materially valuable care, and through the carescape of physical movement. I contribute to broader scholarship on care, gendered labor, and institutional bio-power by critically analyzing the myriad ways in which providers live and enact care, which could take the form of play, teaching, learning, listening, touching, and many other practices. At its core, this thesis is about the ways in which medical practitioners create meaningful lived experiences for themselves and for their patients through the fluctuating and dynamic expressions of care.

While my project focuses on the ways in which practitioners enact care to make meaning, there are other trajectories of analysis that warrant consideration. In addition to the symbolic

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<sup>5</sup> Working from Arjun Appadurai's notion of *-scapes* (1990), the suffix *-scape* allows me to point to the fluctuating and irregular enactments of care, both the diverse places where care occurs and the flowing ways in which it occurs through one's care labor. Carescapes make the liminality of providers visible by highlighting the frictions created through encounters and interactions of care. The "shifty and unsteady" yet palpable moments of care engendered through liminality are brought to light through carescapes, as carescapes allow me to focus on the edges of lived everyday experiences and the meaning that can be created there (Stewart 2007:3). The idea of *carescapes* also indicates that care does not look the same from every angle but rather is a deeply "perspectival construct" (1990:33).

<sup>6</sup> I understand *meaning* as a concept that is not inherent to the experience of patients and providers but rather as something that is created through care. When children receive a diagnosis of cancer, their world and their families' world is irrevocably altered, so they seek to make sense of this experience by imbuing it with meaning and by incorporating it into the lived narrative of their lives.

world of meaning-making, providers also engage in material, functional aspects of care, or “care for the institution” (Winifred Tate, personal communication, 30 April 2015). Providers operate in a hierarchical structure, wielding power over their patients. Important aspects of care for the institution include avoiding lawsuits and producing as many healthy bodies as possible. Some would argue that this functional, material approach is the “dark side of care” (Maple Rasza, personal communication, 30 April 2015). However, this concept of care silences the small, meaningful gestures that comprise the everyday experiences of providers and their patients. My project pushes the notion of care to highlight textures of humanity, the ways in which providers live and make meaning in both symbolic and material ways. I argue that providers enact their liminality to expand notions of care. In this way, there is no “dark side” of care but rather only lived experiences of care.

### **Cultural Context**

My project focuses on the ways in which providers care and create meaning in the particular cultural context of Children’s Minneapolis. Care practices are culturally defined, and caring looks different cross-culturally. The culture of Children’s is comprised of many different cultures coming together, and each patient and his family brings with him certain cultural expectations of care that may be different from the provider’s expectations of care. I saw Hmong families, Somali families, Hispanic families, working-class families, low-income families, wealthy families, and more. Providers often have to work with interpreters and social workers to ensure that culturally sensitive and appropriate care is provided. In some instances, the culturally appropriate decision is to withhold care. Nancy Scheper-Hughes explores forms of caring (or noncaring) in her article “Culture, Scarcity, and Maternal Thinking: Maternal

Detachment and Infant Survival in a Brazilian Shantytown” (1985).<sup>7</sup> At times, the mothers withheld attention, love, or care practices because they thought it would better serve the wellbeing of their child. It is not that the women did not love their children; rather, maternal detachment was used as a tool both to care for themselves and for their children. In the same way, some families at Children’s may make the decision to stop or withhold treatment for their child. Even though the practitioners may not agree, they work with the family to understand their cultural context and to provide the best care, even if that care is a form of non-care.

### **Theoretical Approaches**

In this project, I engage with several theories, but I draw primarily on Foucault’s theory on power (1979). Foucault argues that the power of the state works in and through institutions such as the hospital to discipline and control bodies through a regime called bio-power. Bio-power works to control the human species and control the human body. Political “technologies” such as hospitals that join knowledge and power come together around the objectification of the body to create “a docile body that may be subjected, used, transformed and improved” (1979:198). Both patients and providers are disciplined by bio-power to act in certain ways.

The body remains a theoretical focus throughout the thesis as I explore the ways in which care is embodied and how providers move their bodies to enact a caring self. Nancy Scheper-Hughes and Margaret Lock call for a “mindful body” and advocate for the deconstruction of the

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<sup>7</sup> Scheper-Hughes studies the women of Alto do Cruzeiro in Brazil, a hillside shantytown of recent rural migrants, and looks at the ways in which maternal detachment and indifference lead to high infant mortality rates. Babies judged to be too weak or too vulnerable to survive shantytown life are left to die without attention, care, or protection (1985:291). Scheper-Hughes argues that these practices are socially produced by the economic situation of the women. There is a link between economic and maternal deprivation, between “material and emotional scarcity” (1985:292). This idea of maternal detachment can also be linked to ideas of care. While it may be difficult to view a child dying of neglect as a form of care, for the women of Alto do Cruzeiro, letting their child die was a form of care. They thought it was better to let them die than to suffer a prolonged death in the shantytown. Thus, noncaring can also be a form of care.

“Cartesian dualism” that separates mind from body, spirit from matter, and real from unreal (1987:6-7). Medical providers enact this mindful body to manifest forms of everyday care and emotional labor. The theory of the everyday, as explored by Michel de Certeau (1984), is a lens through which to analyze the ordinary, everyday practices of people and to see how they make meaning in and through those practices.

A theory of the everyday often focuses on marginalized people, especially women. Because all of the providers that I shadowed were women, I explore the gendered dynamics of care through the theoretical approach of emotional labor. As articulated by Arlie Hochschild (2003), emotional labor is the management of feelings to produce a certain type of emotional commodity. While Hochschild studies flight attendants, I argue that medical providers also engage in this emotional labor to create a certain facial and bodily display of care.

In addition to being understood as an emotional commodity, care undergoes certain transformations as it is exchanged between the patient and the provider, and this exchange creates care that is both socially and materially valuable. I analyze this exchange through the work of Paul Eiss (2002) and Terence Turner (2008) in chapter three. Lastly, I engage with theories of human movement as espoused by Drid Williams (2002) and David Best (1997) in order to understand the ways in which physical movement allows providers to care through their bodies.

## **Methods and Process**

Throughout this project, I have had the privilege of using fieldwork methods not readily available to undergraduate students. I was granted access to the private world of pediatric hematology and oncology, and I was able to engage with medical providers who care and work

in this realm. I did my fieldwork over three separate occasions in November and December of 2014 and February of 2015. I spent two days at Children's in November, three days in December, and I returned to Children's in February for a four-day research trip. Over the course of these nine days I shadowed two female nurse practitioners and one female physician who specialize in solid tumor oncology. Lisa is a registered nurse (RN) and certified nurse practitioner (CNP) who joined Children's as a pediatric nurse practitioner in 2008. Maggie is also a registered nurse and certified nurse practitioner. She worked at Children's on the inpatient hematology/oncology floor as a staff nurse before getting her pediatric nurse practitioner degree and joining the solid tumor team as a nurse practitioner. Nora is a medical doctor (MD) who joined the Children's hematology/oncology program in 2006. She specializes in head and neck cancers. In addition to shadowing these three providers, I also spent time at Children's when I was not shadowing. I sat in the cafeteria and in the atrium, observing the people and space around me. In January, I conducted in-depth ethnographic interviews with two of the providers, and I also communicated with them via email after my February research trip when I had additional questions or points of inquiry.

I shadowed providers both in the clinic and in the hospital. Providers often move between the two spaces throughout the day to follow up with patients as they move through different phases of treatment. If a provider is working in the clinic, she will often go see patients on the floor between clinic appointments. A provider's normal working hours are from 9 a.m. to 5 p.m., but she will often come in early and stay late. When I shadowed providers in the clinic, I would arrive at the clinic around 8:30 a.m., and the practitioner whom I was shadowing would meet me in the lobby. We would then either sit in the back office or in the workroom before seeing the first patient. We would see between four and eight patients each day, and in each

patient room, the provider would introduce me as a student observing their interactions and would ask the family if I could observe. I would then either sit or stand quietly during the visit, which could last between fifteen minutes and forty-five minutes. After the visit was complete, the provider would go directly to see another patient, would go back to the workroom to write notes on the visit, or would follow up on a question raised by the family.

Each day that I spent with providers was full of encounters and interactions rich with information. I walked rounds in the hospital with the oncology team, examined CT scans and PET scans, ate lunch with providers in the staff lounge, and joked with them in the office. I observed spinal tap procedures, played with children, and held babies. I talked with nurses, social workers, and palliative care providers. In order to protect patient and family privacy, I did not talk with patients or their families about my project, nor did I ask them any questions. In order to protect the privacy of both patients and providers, I have used pseudonyms in this project. I do not discuss any of the medical diagnoses in-depth, as I do not want the medical terminology to distract those who may not be familiar with it from my interest in the relational and personal dimensions of care. However, I had to learn this medical terminology quickly during my research. Even after the provider would explain something, I was often left with lingering questions and confusions.

## **Reflexivity**

As I stumbled through my first few days in the field, I was made acutely aware of my lack of medical knowledge. Terms flew by at a frightening speed as I struggled to keep a running list of everything that I needed to look up. I wondered: what is Bactrim, and why is everyone taking this medication? I soon learned that it is used to stop infection. I asked



providers why I had to put on a robe in this room and not in that room. They told me that children with a higher risk of infection require greater precautionary measures against the spread of germs, and putting on a sanitary robe before entering can stop the spread of germs. Before going into a patient's room, the providers would often start explaining the patient's medical condition to me and then would stop and say, "Oh, that's right, I forgot that you don't care about this." It is not as though I did not care, so to speak, but rather I was more interested in what goes into diagnoses or treatment in terms of social, relational, lived everyday experiences than the biological processes occurring within the body.

At the beginning of the project, I found it hard to situate my positionality within this medical realm.<sup>8</sup> I was not sick, and I was not healing those who were sick, so why was I there? Was I effecting a type of violence by studying this deeply personal, emotional realm, by turning sick children into objects to be studied? At the same time, my project seemed to be met with great enthusiasm by the providers whom I shadowed. In part, my project sparked interest because it was situated outside of the medical realm; a student who did not want to know about the medical aspect was somewhat of an anomaly. Providers were open and willing to have a different type of conversation about care, and one provider said, "Hm, it really makes me think about what I am doing" (Lisa, personal communication, 29 November 2014). While I was only an undergraduate student, I did seem to elicit attention and interest due to the nature of the questions that I was asking, and the attention gave me a kind of power. I was creating space in time for providers to talk about and think about their labor in different ways. While my power

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<sup>8</sup> I was first brought into this project through the story of Grace. Grace, the daughter of a family friend, was a young girl who contracted cytomegalovirus in utero. This virus left her severely handicapped—at age 5, she could not talk, walk, see, hear, or eat on her own. Last spring, her family decided to stop feeding her, and she died several days later. I was struck emotionally and intellectually by this story. What goes into making this kind of decision? Who is involved? On an emotional level, how does a family make this type of difficult decision? These questions of power and decision-making ultimately led me to explore ideas and ideals of care. I will be forever grateful to Grace and her family for sharing their hearts in Christmas cards and for not only spurring this project but also for opening my eyes to the complicated and meaningful realm of bioethics.

can in no way be compared to the power of the providers, I hope that my project opens up new ways of thinking about care in important and meaningful ways for the providers.

### **Organization of Chapters**

My thesis is organized in such a way as to explore care as a liminal way of being in the world and the ways in which that liminality is made visible by carescapes, which are the fluctuating and irregular enactments of care. In chapter one, I explore the doing of care, or care labor. Care is engendered through practices of the everyday, through the body, and through emotional labor. This emotional labor is often a gendered labor, and I analyze the role that gender plays in care at Children's. The subsequent three chapters explore the carescapes in and through which this care labor is enacted and the ways in which these carescapes make visible the liminality of the providers. In chapter two I focus on the built environment of care and analyze the ways in which Children's as an institution disciplines both patients and providers through Foucault's notion of bio-power. However, by using creative forms of care such as art and play, providers enact their liminality to shift and transform notions of what is meaningful and for whom. In chapter three I explore the carescape of value and the ways in which care gains both social and material value through a process of exchange. Lastly, in chapter four I investigate the carescape of physical movement and consider the extent to which movement allows providers to care from their bodies. As providers navigate through these shifting carescapes, they enact their liminality to create meaningful lived experiences for themselves and for their patients.

## ONE

Making the World: The Doing of Care

*On a Wednesday morning before Thanksgiving, Lisa and I enter a hospital room in the cancer and blood disorders unit to visit Lindsey, a twenty-one-year-old girl with Downs syndrome. The curtains are drawn, and the soft glow of the television casts a drowsy light across the room. When we enter the room, Lindsey is not there. Her mom is sitting on the couch and says that she is out walking with the physical therapist. Just then, Lindsey comes back into the room, dressed in fleecy tie-die pants and gripping tightly onto the arm of the physical therapist as she shuffles over to the bed. “You did so great!” exclaims the physical therapist. Lindsey looks up at the television, and then says something quietly to her mom. Lisa asks, “What did she say?” Mom replies, “Oh, her favorite soap opera is on. She likes to watch it.” Then Lisa replies, “I can tell people not to bother you at 11:00 a.m. when your show is on. You are always so polite, just like, ‘Yep, let’s get this done,’ but you need time for yourself.”*

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What is care? And how can it be described? As Annemarie Mol aptly notes (2010), writing about care can be difficult because care is not necessarily verbal. It can be a hand on the arm, a walk through the woods, or a machine monitoring vitals. Care also infiltrates our everyday speech with warnings such as “careful!”, adjectives like “careless” and “care-free,” and flippant phrases like “I don’t care.” What is this “care” that we speak of, experience, do, live, and be? Throughout this thesis I argue that care manifests in different ways as it flows through the carescapes of the built environment, of value, and of physical movement. In this chapter, I

explore the *doing* of care, that which is actually being made manifest in those carescapes. I consider three facets of this *doing* of care: care as upholding the practice of the everyday, care as emotional labor, and care as embodied. Practitioners learn about care through their medical training, as ways in which to address the physical health of the patient, but they also draw on gendered ideas of care as motherly, nurturing, and emotional to inform their care. Nurse practitioners, trained with a nursing sensibility, pay particular attention to forms of care that reach beyond the physical purview.

### Everyday Care

In her book *The Body in Pain: The Making and Unmaking of the World*, literary critic Elaine Scarry argues that “intense pain” is “world-destroying” (1985:31-32). For many patients and families at Children’s, a diagnosis of cancer is world-destroying. The emotional, physical, and mental trauma that can ensue from a cancer diagnosis is severe and significant. Medical providers respond to this world-destroying experience by reconnecting children and their families to everyday things and routines, to what contemporary novelist Marilynne Robinson calls “the dear ordinary” (1980:15). Through daily, accumulating acts of care, medical providers are able to maintain the everyday—the normal—for their patients. This is what Michel de Certeau (1984) calls the *practice* of everyday life.<sup>9</sup> By rooting practice in what Pierre Bourdieu calls “the production of a commonsense world” (1977:80), the care of medical providers poses a critique of medicine’s emphasis on the acute, exceptional moment and instead offers forms of

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<sup>9</sup> In his seminal study on everyday life, de Certeau analyzes the ways in which individuals within a mass culture re-appropriate tradition, language, symbols, and art in everyday settings to subvert the rituals and representations that institutions seek to impose on them. By “poaching” on everyday practices and making them their own, individual “users” are able to create new ways of being in the world, a “*bricolage*” of human experience (1984:xxi, xvi).

physical tending that are “quotidian rather than heroic, ongoing rather than permanent or conclusive” (Davis 2005:7).

By enacting everyday care, medical providers uphold and create stability and normality for both children and their parents in times of great confusion and chaos. Lisa and I go to see Abby, a thirteen-year-old girl with stage-four sarcoma. She is receiving a five-day course of outpatient chemotherapy and radiation, so she has been to the clinic every day this week. Abby is curled up on a leather reclining chair, headphones in her ears and eyes glued to her cell phone screen. Dad is sitting on another chair in the corner, also looking at his phone.<sup>10</sup> Lisa greets Abby and her dad as she sits down at the computer desk to look up Abby’s chart, and neither Abby nor dad look up from their phones. Lisa asks how things are going and receives short one-word answers from Abby, whose eyes remain on her phone. Lisa turns to look at the computer, and dad suddenly asks, “Are either of you Vikings fans?” There is a brief moment of silence, as if Lisa needs to process this unexpected shift in the conversation. Then Lisa turns around from the computer and says, “Yea, my husband is a fan, so I guess by virtue of him I am.” Abby’s dad slips the phone into his pocket and talks about the latest update in the case of Adrian Peterson, a professional football player for the Vikings. The Federal Court has decided to overrule his suspension from the NFL. Lisa and dad talk for a few minutes about this piece of news, and then before Lisa goes, conversation returns to Abby and anything else that she might need. As we leave, dad pulls out his phone again.

In this instance, care moves—it shifts from care of the child to care of the father. Abby seems to disappear as Lisa gives her attention to Abby’s dad. Yet it is in the nature of the

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<sup>10</sup> I will refer to parents as “mom” or “dad” throughout the thesis, as that is how the medical providers addressed them and talked about them with other providers. For example, one provider would say to another, “Dad seemed upset today,” or “Mom is so great.” This absence of names brings the identity of ‘parent’ to the forefront, erasing any individuality or other identities. According to Michel-Rolph Trouillot (1997), this is a form of silencing the past, or silencing the lived experience, of the parent. Only their identity as a parent is upheld in this medical setting.

everyday to be inconsistent, popping up in “pocket-sized moments of attention and repair” (Davis 2005:17). Medical providers move and adjust within this inconsistency to care not only for the child but also for their family members. Nurse and poet Cortney Davis has explored the idea of *care as keeping* (1997a).<sup>11</sup> Lisa, with her background in nursing, employs pocket-sized moments of the everyday to keep the patient and her family in the normal, everyday world of sports and football, news and scandal. Lisa also upholds and keeps dad’s gendered role by discussing football with him. His shift in conversation from cancer to court cases may reveal his discomfort with this world of sickness, so Lisa employs the everyday, situated from her own gendered role as wife, to make the situation more comfortable for him.

One of the values of everyday care is that it provides comfort and reassurance for patients and their families that life goes on, that the world still exists outside of the hospital. In a way, they have made a new normal, a new everyday. For many patients and their families, coming to the clinic three times a week is their reality, their lived experience. When the abnormal becomes normal, the everyday can paradoxically provide an outlet for something different and above the regular (Fumerton 1999). In fact, it is often in the trivial exchanges of the everyday, in talk of football, that children and their families create extra-ordinary meaning.

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<sup>11</sup> Through her poetry, Davis explores the ways in which nurses orient their patients “day after day, thereby holding [them] to life” (1997b:118). This holding can be physical, as nurses connect with their patients “skin to skin, through daily ministrations and intimate contact with the patient’s body” (1997b:114). Yet at other times, caring holds patients in the world by incorporating them into the caregiver’s memory. In her poem “Body Flute” Davis says, “Your last glance, your last/sensation of touch,/your breath/I inhale, incorporating you/into memory./Your body/silvery and still on the bed,/your lips fluttering into blue” (1994:51). In a way, the nurse poet embodies the memory *and* the body of the patient by breathing in her breath. Care as keeping is thus not only deeply embodied but deeply subjective, as well. For an account of subjectivity and touch in a theory of nursing care, see Gadow 1985.

## Care as Emotional Labor

The practice of the everyday tends to focus on certain subjects: the common person, the marginalized, and especially women (Fumerton 1999). While there are varied and often contradictory meanings of the everyday, the everyday is most often associated with women. Interestingly, care work, as Meyer (2000) calls it, has also historically been associated with women. Care work has been defined as women's work, which creates gendered notions of care. These gendered notions of care—as motherly, nurturing, and emotional care—play out at Children's through what Arlie Hochschild calls “emotional labor” (2003:7). According to Hochschild, emotional labor is the “management of feeling to create a publicly observable facial and bodily display” (2003:7). This emotional labor is then sold for a wage and therefore has economic value. Because our culture values gendered notions of care, female medical providers use their gender to enact certain forms of nurturing, motherly care. In addition to this economic and gendered value of care, care labor takes on different meanings and values through a process of exchange, as I discuss in chapter three.

On Friday, Maggie and I go to see Abby, who is on her last day of outpatient chemotherapy. I had seen her the day before with Lisa, so when Maggie introduces me, she says that she remembers who I am.<sup>12</sup> Like Thursday, she is sitting in the reclining chair with her headphones on, watching something on her phone. Mom is with her today, working on her laptop. As we walk in, Maggie notices a box full of Girl Scout cookies. “Oh, are you selling those?” she asks Abby. Abby replies, “Mmhm,” and her mom adds, “and we have more in the car.” Maggie rummages through the box and finds one that she wants. “Ok, I don't have money

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<sup>12</sup> Because Lisa and Maggie are both nurse practitioners who specialize in solid tumors, they do some “job sharing” and often see the same patients. Abby's team includes Lisa, Maggie, Nora (the physician), and numerous other nurses, specialists, and therapists. Even though these providers see the same patient, they each have a different role to play in her care and enact that care in different ways.

right now, but save these for me and I'll bring the money in a bit." Maggie then sits down on the rolling stool and asks how radiation is going. Abby replies, "good," eyes still on the screen. Maggie then grabs the otoscope and moves closer to Abby to examine her mouth and ears. As she leans in, Maggie looks at Abby's phone and asks, "So, what are you watching? Is that Minecraft?" At this question, Abby lifts her eyes from the screen and says excitedly, "Yea, it is Minecraft!" Maggie says, "My kids love that game! And Stampy! Do you know Stampy?" Putting her phone in her lap and sitting up a bit straighter, Abby says, "I love Stampy!"

In a moment, Abby's whole persona had changed from a resigned patient to an engaged teenager. By invoking her gendered role as a mother, Maggie made a connection with Abby that transformed a routine moment of treatment into an affected experience of care. *Something* had happened in this encounter. An ordinary affect, the a-social, pre-social surge before an emotion, the *some* in the *something*, had rushed up (Stewart 2007). When Abby looked up from her phone, there was an intensity shared between Maggie and herself, an intensity that cannot quite be put into language. While this connection may not make the chemotherapy work any better or the nausea go away, there was a surge, a spark that changed the trajectory of the routine visit. Afterwards, Maggie said, "I always try to connect with teenagers somehow." Maggie's emotional labor had created space in time for those true surges of unregulated and unmanaged affect to influence both Abby and Maggie.<sup>13</sup>

Unlike Hochschild, I argue that medical providers can and do experience natural, unmanaged emotions that create meaningful connections between patients and providers. Nora experienced this raw emotion in an encounter with a young Hmong boy. The little boy was lying

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<sup>13</sup> My argument that emotional labor can lead to affect may seem contradictory, as affect is pre-emotion. However, I believe that emotional laborers are often so deeply caught up in the management of their feelings that the feelings themselves cease to be feelings at all. Only a relational spark of affect with another person will bring them back to their unregulated emotions. For power and ordinary affect, see Stewart "The Politics of the Ordinary" and "Power is a Thing of the Sense" (2007:15-16, 84).



on the bed and playing on his iPad when Nora and an interpreter entered the room. Nora sat down on a small stool next to the bed and asked him what he was playing. With the help of the interpreter, the little boy said that he wanted to show Nora some pictures. For the next five minutes, the little boy swiped through all of the pictures on his iPad, all of which were pictures of him and his family. He would smile and then point out something particularly funny to him, like his little brother in a traditional Hmong outfit. During this time of sharing, neither Nora nor anyone else spoke about cancer. Not only was this a moment of everyday care, but it also struck Nora emotionally. After we left the room, she said she loved all of the pictures and videos that he showed her because they were about his family and the love that they share. She placed her hand on her heart and said that she will be devastated when this little boy dies, telling me that his treatment was not going well. Even though he looked like a happy, healthy little boy playing on his iPad, he was sick, and emotional labor alone could not heal him. Nora did not try to regulate her feelings in this moment—she simply took the time to sit with this little boy and share in the memories of his love.

### **Embodied Care**

Everyday care and emotional labor are enacted on, in, and through the body (see Foucault on power 1979). The physicality of care closes the distance between patient and provider that illness can create. As Maggie leans in to look at Abby's phone or as Nora sits down to look at photos, the body is used as a way through which to enact everyday care and emotional labor. As Robert Leigh Davis aptly notes, care is often associated with matter, or with mattering (2005:19). Through touch, physical proximity, and bodily awareness, embodied care “restores the material particularity to people in danger of being seen or treated—or in danger of seeing or treating

themselves—as insubstantial, weightless” (2005:19). It is also through embodied care that practitioners employ Courtney Davis’s idea of care as keeping. She says, “While the doctor shields a patient from disease, the nurse can only stand next to the patient, holding his hand. While the physician hurls weapons of choice at illness and death, the nurse can fight only with touch” (1997b:119). As nurse practitioners, both Maggie and Lisa draw on their nursing sensibilities to keep their patients in the world through touch, by enacting care through their bodies, while also fighting disease.

As medical providers strive to make meaning by enacting everyday care and emotional care through their bodies, they are also being disciplined to produce a certain type of social body. Foucault (1979) argues that the political technologies which organize us into disciplined subjects work ultimately through the body. However, Fiske (1992) argues that the concrete practices of everyday life embody and perform differences. The body enters into distinct, individual relationships with the people and spaces it encounters, relationships that are meaningful because they are distinct and different from the monotony of socially organized relationships. Lisa performed everyday care by talking about football in a way that not any *body* could do. Maggie did emotional labor by connecting her body to her specific experience as a mother. By enacting moments of difference through the body, medical providers push against the disciplining forces of bio-power to open the experience of care to include affect, emotions, and the everyday. In chapter four I discuss how the ways in which providers move their bodies give rise to experiences of care.

## **Conclusion**

Through everyday care, emotional labor, and embodied care, medical providers make the world for patients and their families. In a time of uncertainty and chaos, everyday care keeps children and their families grounded in the world, not to be swept up by the tornado of cancer. Emotional labor creates meaningful connections between medical providers and their patients. Both everyday care and emotional labor contain within them gendered notions of care as feminine, and medical providers often enact these gendered roles to produce socially valued care. Additionally, everyday care and emotional labor are deployed through the body, thus enacting deeply embodied care. The next three chapters explore the various carescapes in and through which these forms of care are enacted.

## Two

Making Space Into Place: Care and the Built Environment

*In the clinic next to the workroom is the medicine room. This room, a veritable warehouse of medical goodies and supplies, is filled with bandages, syringes, and even a lone set of crutches. Everything is neatly organized in drab grey bins and drawers. In addition to the plethora of medical knick-knacks, all of the controlled medications such as chemotherapy and antibiotics are kept in this room. Key cards are required for entry both from the workroom and from the hallway. Lisa and I went to see an eight-year-old boy, and when we entered, the nurse was drawing blood. After she was done, she asked the boy, “Do you want to see the rocket where the blood gets sent?” She was referring to the machine in the medicine room through which providers receive medications and send blood and urine samples for testing. The provider places the blood or urine sample into the tube-like capsule, and the machine sucks the tube up and delivers it to the desired lab in the hospital. The little boy was excited to see the “rocket” and happily followed the nurse into the treasure trove of the medicine room.*

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During the past several decades, anthropologists have become increasingly interested in the built environment and the ways in which spatial and temporal dimensions impact human behavior. In their review of the literature on this field, Lawrence and Low (1990) define the *built environment* as a concept that describes the products of human building activity. It refers in the broadest sense to any physical alteration of the natural environment, such as buildings, plazas, streets, or shrines. Anthropologists are interested in the relationship between society and

culture and the built environment, an interactive relationship in which people both create, and find their behavior influenced by, the built environment (1990:454).

The built environment of the hospital as an institution engenders certain care practices. Through the built environment, forms of bio-power discipline the providers to employ certain practices of care. At the same time, medical providers enact their own agency to manipulate and change the space. In this way, they are acting in a liminal sense. They use their liminality to move and operate “betwixt and between” the disciplining forces of the institution and the possibilities of meaningful patient-provider interactions (Turner 1979:465). Through creative expressions of care such as art and play, medical providers are able to transform the institutional space into a personally meaningful place both for themselves and their patients, which in turn transforms their disciplined practices of care into meaningful social encounters.

### **The Disciplining Power of Children’s**

Children’s Hospital is a public institution that is built, staffed, and equipped for the diagnosis of disease, for the treatment of the sick and injured, and for their housing during this process. As a pediatric hospital, Children’s only treats children, and it is not considered a teaching or a research hospital. Its primary focus is diagnosing and treating childhood disease and injury. While medical providers and family members are concerned with treating the child, the power of the state works in and through this public institution to discipline both medical providers and patients to act in certain ways. In Foucault’s seminal theory on power, he articulates a new regime called bio-power that brings together power and knowledge to control bodies. Bio-power works to control populations and control the body through drills and training of the body, through the standardization of actions over time, and through control of space

(Rabinow 1984:17). This disciplinary technology that joins knowledge and power is especially evident at Children's because the body is central to care at Children's; care is enacted through the body of the medical practitioner onto the ill body of the child. Both the sick child and the medical practitioners are disciplined to form a certain docile body, and the built environment of Children's gives rise to this disciplining. When I was brought into the clinic on my first visit, I noticed that there were two doors that led from the waiting room to the examination rooms: one door for patients, and another door for staff. The staff door was locked and required a numerical code to enter. I was brought through this locked door into a back hallway of administrative and team offices, a staff lounge, a workroom, a medicine room, and a bathroom. Each separate team office was locked and required a code for entry. When I asked Maggie why there were locks on all of the doors, she replied somewhat flippantly, "to keep us safe." Then, after thinking about the question for a minute, she said, "I guess I have never thought of why" (Maggie, personal communication, 27 February 2015). While locked doors are often meant to keep people out, these doors only let certain people in. Only those with medical knowledge and power can have access to this controlled space. These locked doors signify to the providers that they have the power and the knowledge to use and occupy this space.

Locked doors were introduced into the clinic when the clinic was re-designed in 2009. The crime rate of the neighborhood is high compared to other Minneapolis neighborhoods, and because the clinic is the first entrance to the facility and the only entrance on the first floor, the hospital wanted to protect both staff and patients from possible intruders.<sup>14</sup> The main entrance to

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<sup>14</sup> Children's is located in what is known as the Phillips neighborhood, a racially and culturally diverse, urban, and low-income neighborhood. According to U.S. Census data from 2010, the median household income is \$28,669, compared to \$46,682 for Minneapolis as a whole (City-data). With an almost equal percentage of blacks and whites and rising Asian and Hispanic populations, the Phillips neighborhood is known for its diversity as well as its racial conflicts.

the clinic is not locked during normal daytime hours, but the front desk has the ability to lock the door from the inside in the event of a crisis situation. In addition to the lock on the main door, the hospital requires that all areas with private patient records remain locked, so all of the individual team offices with files and computers must remain locked at all times. This “history of the present” (Foucault 1979) reveals the ways in which notions of healing and care have changed over time. While care used to focus on fighting disease, care must now protect against anyone or anything that could infringe on that fight. These locked doors not only cut off patients from the outside world but also keep the outside world out of this specialized medical realm.

Other features of the controlled space also discipline medical providers. In the center of the clinic is a provider workroom where providers can sit or stand between seeing patients. A wrap-around desk on three sides surrounds a large center island, and both the island and the desk have computers so that providers can write notes about their patients and order medications. Some providers sit in their individual team offices between patients, but Maggie says that she likes to sit in the workroom so that nurses can find her if they have questions. All providers carry pagers with them so that they can be paged at any time if someone needs to see them. A large computer monitor mounted on the wall in the workroom shows the location of each provider based on where her pager is located. Even if no one is in the workroom, the provider must control her movements and her actions as if someone was watching her.<sup>15</sup>

The providers also regulate each other’s behavior as they sit in the workroom together. This disciplining is a way in which providers are made into objects. In this space, only their

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<sup>15</sup> In a way, this workroom functions like the panopticon. Foucault selects Jeremy Bentham’s panopticon as the paradigm of disciplinary technology (1979). The panopticon consists of a large courtyard, with a tower in the center, surrounded by a series of buildings. Each cell has a window through which the guard in the tower can observe the inmate. However, the person in the cell cannot see the guard in the tower, so he must act as though he were under surveillance at all times. Likewise, providers must act as though someone always knows where they are because they do not know if anyone is in the workroom watching their location on the computer monitor.

identity as provider is recognized. According to Foucault's notion of "dividing practices," providers create for themselves a socially acceptable identity by combining their knowledge with exclusion. They are excluded spatially in the workroom, and they are in some ways excluded in society because they cannot discuss their identity as provider with those who may not understand (see Foucault on modes of objectification 1979). In this space of exclusion, providers ask questions about patients, seek advice from their colleagues, and talk about work-related issues. While they also discuss their families or personal lives, the conversation comes back to clinical issues. The disciplinary technology of the built environment brings together control of medical knowledge and control of bodies to enact depersonalized, disciplined medical care. In a way, this type of care is *meaningful* to the hospital as an institution because it engenders standardized modes of care that can be copied and reproduced to generate healthy bodies. *Meaningful* for the hospital means fulfilling and accomplishing institutional priorities of fighting illness. However, this type of meaning is different from the meaning that patients and providers seek to create in their encounters. While patients and providers also strive to fight illness, *meaningful* for the patients and providers means creating social, relational, and personal connections in the midst of treatment.

### **Making Meaning Betwixt and Between**

Providers seek to uphold both the notion of meaningful as fulfilling institutional priorities and as intimate personal connections by enacting a form of liminality. Victor Turner employs the concept of liminality in his theory of ritual and drama (1979). According to Turner, liminality is "a state or process which is betwixt-and-between the normal, day-to-day cultural and social states and processes of getting and spending, preserving law and order, and registering



structural status” (1979:465). Medical providers are situated betwixt and between the different notions of meaning being experienced. By enacting their liminality through experiment and play, providers are able to create moments of care that are both institutionally meaningful and personally meaningful, yet also something more, as their liminality allows them to create something “neither this nor that, and yet both” (Turner 1967:99).

This liminality also allows providers to transform space into place. Anthropologists often use the terms space and place, sometimes interchangeably, to talk about the environment in which they conduct their research. At Children’s, however, these terms are not interchangeable. Children’s is a space that people have made into a place. According to Tim Cresswell, the most basic definition of place is a meaningful location (2004:7). The political geographer John Agnew (1987) has outlined three fundamental aspects of place as a ‘meaningful location’: location, locale, and sense of place. By location, Agnew means that a place is located; it has a ‘where.’ By locale Agnew is referring to the material setting of social relations, the actual structure of the place. By sense of place Agnew means the subjective and emotional attachment people have to place. Children’s is a special place because of the ways in which it is transformed from a space to a place. As a political institution in the Foucauldian sense, Children’s is a meaningful *space* that creates meaning by fulfilling institutional priorities as it disciplines both patients and providers to create docile bodies. However, medical providers enact their liminality to create a meaningful *place* through forms of social care such as art and play.

## **Creative Care**

Even as the built environment disciplines the medical providers into enacting certain forms of care, it is also designed in such a way as to allow providers opportunities to transform

space into place through creative care.<sup>16</sup> In the spacious atrium of Children's, a bright orange wall with "welcome" written in four languages greets guests (see Image #3 in Appendix). The four languages—English, Spanish, Hmong, and Somali—represent the most commonly spoken languages at the hospital. Three large television monitors are located on a purple wall next to the welcome desk, each advertising the hospital's slogan "Wash 'em proud," which promotes good hand-washing practices to prevent the spread of germs. As I walked toward the welcome desk, something on the floor caught my attention. Looking down through a glass tile, I saw a family of mice sitting in a whimsical house. For a moment, I was transported to another world, a world of play. I watched several children stop to admire the mice, a lightness in the otherwise heavy world of the hospital. Spaces of play can also be found in the hematology/oncology unit. A play area is located at the front of the unit. This play space has a small table, brightly colored building blocks, a children's toy kitchenette, and a child-size clinic station with a toy stethoscope and blood pressure gauge. This toy clinic station allows both patients and their siblings to engage with their disease through play. By playing doctor, patients can exert control over the type of care they receive. In this area of play, they can control their world and can have a voice in their treatment.

Play is not only for children.<sup>17</sup> A series of "I Spy" artwork is located along the walls of the hospital unit. In each piece, there are two photographs that at first glance appear to be the same. However, the plaque next to the photograph tells the spy to find the differences between the two images. This artwork, mounted high on the wall where children might not be able to see it, is for family members roaming the hall. The corridor, with its shiny sterile floor tiles and too-

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<sup>16</sup> By creative care, I mean the ways in which providers use art and play to form meaningful relational connections with their patients.

<sup>17</sup> See Schwartzman (1978) for an interesting analysis of children's play in relation to anthropological fieldwork.

bright fluorescent lights, disciplines family members into acting in certain ways. The corridor is a space of limbo, of waiting. One does not spend much time in the corridor, only to talk briefly with a provider or to leave the room if a nurse is doing a certain kind of procedure. The corridor is often a space of worry and of anxiety because family members do not want to show those emotions in the child's room, yet the "I Spy" artwork allows family members to manipulate that space. By enacting their agency, family members can create personal meaning in a space of institutional meaning.

In its efforts to improve patient care, Children's conducted the *Delivering Next Generation Care Campaign* in 2013. This campaign, which raised nearly \$170 million, was conducted to renovate and expand facilities to improve patient care. As part of the redevelopment, Children's launched its *Arts & Healing and Urban Renewal Project* with the vision of creating healing spaces by combining architecture, landscaping, science, and art (Children's 2012). Hundreds of new sculptures, paintings, and other pieces of art were commissioned and installed at Children's. The urban renewal component focuses on creating a healing outdoor space that also positively influences the urban landscape of Minneapolis. The "Healing Embrace Plaza" is comprised of a twenty-four thousand square foot healing garden and aspen grove. The garden also features walking paths, benches, and original granite sculptures. This financial and ideological commitment to the arts highlights the importance of art and the physical space in care.

Artwork and gardens are valued as part of the healing process by the Children's administration as well as by patients and their families. In the Starz Café, a café located on the first floor next to the atrium, the back wall features several large pictures of children doing artwork. Large purple letters above the photos read "Children's Gallery" with the subtitle "Art

Making is a Healing Experience” (see Image #4 in Appendix). At the back of Starz Café, a special gallery called Children’s Sculpture Gallery showcases two- and three-dimensional works done by children. Art therapy has been studied as a way through which patients can deal with the emotional and mental stress of hospitalization and prolonged illness (Rode 1994). Art therapists also often work closely with Child Life specialists, who strive to promote optimum development of children and families, to maintain normal living patterns, and to minimize psychological trauma (Association for the Care of Children’s Health 1979).

Art making and play are healing activities, but they are also caring activities. By incorporating art therapists and Child Life specialists into treatment plans, providers are able enact “whole person” care rather than just focusing on treating the disease (Davies 2002). Medical providers also encourage other forms of creative care, such as acupuncture, aromatherapy, and massage. I asked Lisa if medical providers voiced any concern with these alternative forms of medicine, as alternative medicine is usually looked down upon by physicians. She said that she would try anything that could help the patient, yet she also thinks that the patient has to believe in the treatment to make it work (Lisa, personal communication, 26 December 2014). In addition to these creative treatment options, providers at Children’s often incorporate play into their interactions with the children. In the opening vignette in the Introduction, we met a girl with her Minnie Mouse boat. Before Lisa continued with the examination, she knelt down beside the little girl and played with her. “What’s her name?” she asked as she held up a toy princess. “Is this Sophia the First? My daughter loves Sophia the First. Should we put her on the boat?” Lisa and the other providers show a willingness to perform creative care through play, art, and alternative treatment options. This creative care

allows practitioners to manipulate the institutional priorities operating in and through the medical space to enact meaningful social connections that transform space into place.

The fairy-tale mice, the “I Spy” photos, and the Children’s Sculpture Gallery all allow for moments of pause in the hectic environment of the hospital. Cultural geographer Yi Fu Tuan has likened space to movement and place to pause (1977). As practitioners move through the space of the hospital, pauses of art and play create places where meaningful relationships are formed. However, the ideas of space and place require each other for definition. The openness and freedom of space gives way to the security and stability of place. Only by existing betwixt and between space and place, by constantly moving and pausing and being on the threshold of enacting both institutionally meaningful care and personally meaningful care can providers create a meaningful lived experience that transcends the bounded notions of what can be considered meaningful.

## **Conclusion**

The carescape of the built environment is not merely a static structure in which life happens but rather is an inextricable part of patient and provider experiences. As a political institution, the hospital disciplines providers and patients to act in certain ways and to be certain kinds of docile bodies. The space is thus meaningful to the institution in that it upholds institutional priorities of standardization and treatment of disease. At the same time, medical providers enact their sense of liminality through creative care to transform space into place for their patients and for themselves. In the next chapter, I analyze the ways in which notions of what type of care is valuable also undergo transformation as care flows in and through Children’s.

## THREE

Making Money and More: The Value of Care

*On a busy Monday afternoon in the clinic, Maggie and I go to see Tasha, an eight-year-old girl who has just finished treatment. When we enter, Tasha is wearing a bright purple bob wig and is playing with a flying Tinker Bell toy as she sits on the examination table. Her mom and older brother are sitting in the two chairs beside the computer desk. Susan, the Child Life specialist who works to keep children comfortable during their clinic visit, is talking with Tasha and asks if there is anything she can do to make the day go smoothly. Tasha, with eyes still on Tinker Bell, says she would like to play on the iPad while her port is being accessed, so Susan leaves to go get the iPad. Maggie sits down on the rolling stool next to mom and asks how things are going. She asks Tasha if she has been eating and pooping okay, and she says yes. Mom adds, “She takes Miralax [a non-prescription medication for constipation] usually twice a day, but she did not take it this morning because we were out of orange juice, and she only takes it when it is mixed with orange juice.” Then she exclaims, “Orange juice is expensive! Five dollars a gallon!” Maggie suggests, “You could buy the canned orange juice and just add water. That is what I do for my kids and they still like it.” Mom replies, “Yea, that is a good idea.”*

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Defining what type of care is valuable is difficult because ‘value’ takes on different meanings in the context of Children’s. Care constantly undergoes transformations and gains social value as well as material value through a process of exchange. I define socially valuable

care as the type of care that our society values: as self-less, as a giving of oneself, and as a gift. Practitioners often strive to enact this socially valuable care. However, through the time-work discipline, the labor of social care is transformed into work that produces material value. By material value I mean the monetary, tangible, financial results of care labor. Even while practitioners feel a tension between care as social value and care as material value, they enact their liminality to bring about both types of care by conceptualizing social value as care and material value as work. By using their liminality to move and shift between socially valuable care and materially valuable care, medical providers bring these two values together to create something wholly new. The frictions created between these two types of value engender care that is meaningful because it is neither just social care nor material care but rather a unique combination and synthesis of the two.

### **Social Value of Care**

Providers at Children's conceptualize their labor as either care or work. While they do not use the term 'value' to define care or work, their distinction between these two forms of labor reveals what they consider valuable. In our society, value can mean many different things. In the context of Children's, value can be defined in a social sense, as a conception of what is good, proper, or desirable in human life. Value can also be defined in the material sense, as the degree to which objects are desired, measured by how much people are materially willing to give up to get them (Graeber 2001).

Providers often define care as valuable in the social sense and work as valuable in the material sense. I asked Nora, the oncology physician, what care meant to her, and she said it was "addressing the medical, psychosocial, spiritual, and emotional needs of a patient" (Nora,

personal communication, 24 February 2015). She paused after saying “medical,” indicating that for her, addressing the medical needs of the patient was the most important aspect of care. When I asked Lisa what care meant to her, she said, “How do you define it without using it? I think for me it means being there for someone else to help them feel better, doing it in a way that you show support and empathy for the patient and family” (Lisa, personal communication, 30 January 2015). Maggie defined care as “putting the needs of others before your own” (Maggie, personal communication, 3 February 2015). All of these understandings imply some sort of connection and interaction with the patient, yet there is no sole definition of care. While the medical aspect of care is the most valuable for Nora, physical presence and emotional support is important to Lisa. Each individual provider is able to enact care that is meaningful and valuable to her. As Graeber aptly notes, “Value is the way actions become meaningful to the actors by being placed in some larger social whole, real or imaginary” (2001:254). Even though each practitioner enacts care that looks different, it becomes valuable to her and to others by being placed within the greater ideal of care. This greater ideal of care also incorporates notions of care that are materially valuable.

### **Material Value of Care**

In the Atrium of Children’s, a large purple wall display caught my attention. This large display, titled “Children’s Constellation of Caring,” was comprised of smooth, frosted glass panes with large multi-colored stars surrounding the glass. I was immediately interested by this title as this display would supposedly tell me what “care” meant at Children’s. As I moved closer to read the display, I found that this constellation of caring was a list of major private and corporate investors to Children’s. Donors’ names were listed next to the monetary amount



donated, and different titles were given to groups of donors depending on how much they had donated. For example, the title of Rising Stars was given to those who had donated between \$1,000 and \$9,999. One board, the Guardian Circle, was specifically dedicated to people who had made Children's a part of their estate.

At first, I was confused by this display. This wasn't how I conceptualized care.<sup>18</sup> Where were the practitioners, the patients? You could not have care without them! However, I came to realize that the material value of care, by which I mean monetary, financial value, is just as important to the ideal of care as the social value of care. Without these donors, providers would not be able to fight disease, nor would they be able to engage with and form relationships with their patients because Children's as a public corporation would not have the money needed to pay them. Even though this material value creates a hierarchical patient-provider relationship, there would be no relationship at all without material flows. The social value of care at Children's is contingent on the material value of care. In a way, this constellation of caring also serves as an advertisement for the consumers of care at Children's. Care at Children's is materially valuable and desirable because families are willing to give up a lot to receive treatment here, whether that means traveling from far away or spending a lot of money. Families can feel confident in their decision to bring their children here because of the strong material value of care that will lead to strong socially valuable care. Rather than understanding care in a binary as either socially valuable or materially valuable, the ways in which care labor brings these ideas of value together reveals the ways in which care is part and parcel of both social and material flows.

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<sup>18</sup> When I embarked on this project, my ideas of care were centered on the emotional, social aspects. For me, care was about hugs, tears, and motherly love. It was not until I began to analyze care as an analytical category that I saw the myriad forms that care could take at Children's. This project pushed the boundaries of my notion of care and made me realize that there is no sole understanding of care.

## Exchange of Care

Care is not inherently valuable. It gains value, or a “social life,” as Appadurai claims, through a process of exchange (1986:3). As evidenced by the providers’ understandings of care, care gains social value through a process of exchange as providers form meaningful relationships with patients and their families. These meaningful relationships are often formed through the exchange of material goods, as material objects foreground the experience of care for patients. This materiality highlights the ways in which the market economy is part and parcel of the social value of care. When children come in to the clinic, they must put on a wristband, the type of wristband that would be worn at an amusement park. The children can choose from a variety of different wristbands, from zebra print to Hello Kitty to frogs. The front desk nurse then scans the wristband to check them in, as if scanning a commodity at the grocery store. Once in the exam room, the nurse scans the wristband and the medication being administered to ensure that a detailed record of treatment is kept. These material steps of care are not often conceptualized as care by providers, highlighting the ways in which the social value of care silences and often overshadows the material value of care. When children are done with their appointment, they are given a “token.” This token can be used to get a prize from the machine in the lobby. As Maggie said, “Every kid loves to twist the knob and get a prize. It’s like a little reward” (Maggie, personal communication, 27 February 2015). The children are rewarded for their bravery and cooperation during the visit. The cooperation and sacrifice of the parents is also recognized with a prize—the clinic offers parking vouchers. Because families have to come into the clinic so frequently (sometimes five times per week), paying for parking can pose a significant financial burden over the course of several years of treatment. This materiality of care, however, does not become valuable until it is exchanged. A token is simply a token until it

is given to the child and redeemed for a sticker. A parking voucher is simply a piece of paper until it is given to the parent and redeemed for a moment free of financial worry. Yet both the token and the parking voucher, as elements of a market economy, gain value through exchange. It is not only social value that is gained, but material value as well.

Care is able to gain both material and social value because it is dynamic, always on the move, transforming. Care is not stagnant but rather it is constantly in flux as it moves through the different carescapes and changes depending on what the situation needs. In his article “Hunting for the Virgin: Meat, Money, and Memory in Tetiz, Yucatán” (2002), Paul Eiss explores the ways in which a coin, through the process of exchange and circulation, can come to mean so much more than a coin. It can embody histories of “deer, persons, and pueblos” (2002:295). John and Jean Comaroff disagree with this idea and argue that the coin “does not have the same capacity as the cow, symbolic or substantial, to embody a biography, let alone to bear within it an entire grammar of social relations” (1992:151). Like Eiss, I argue that care can embody histories of patients, providers, and disease. It can bear within it a grammar of social and economic relations. To conceptualize care as just socially valuable or just materially valuable would be to limit its potential to enact meaningful change in the lives of patients and providers.

In the medical realm, care exchange may seem unequal. As medical providers give restored health to their patients, what do the patients give the medical providers in return? According to Marcel Mauss in his pivotal work *The Gift* (1990), an exchange is never free. There is no such thing as a free gift. In a system of “total services,” one realizes that she must give something back to the giver. To give a gift is to give part of one’s nature, one’s substance. When accepting a gift, you are accepting part of one’s soul (1990:12). Yet what can the patients

give back to their medical providers? According to Gadow, patients give their providers the gift of trust (1985:42). Without trust, the patient could not offer herself up for care. Once trust has been established, both medical providers and patients give of themselves by upholding their roles under bio-power. Medical practitioners are trained to find a cure, to fight disease and death, while patients are told to listen to their providers, to be submissive, to be sickly. Thus, in a way, both parties are upholding their end of the exchange by acting in ways appropriately controlled by bio-power. They each give of themselves what is required in this care exchange.

### **Care as Job, Care as Purpose**

As medical providers strive to enact socially valuable care, they are simultaneously being acted on by bio-power to produce materially valuable care. Their care labor becomes work through the discipline of time, yet providers still think of care as distinct from work and talk about care and work in different ways. Lisa was talking with a clinic administrator about the recently high number of relapses, or the reoccurrence of cancer in patients who were in remission. She said, “relapses are a lot of work. They don’t count in the numbers for new diagnoses, but they are just as much work.” In this interaction, “work” signifies a serious commitment of time because relapses require a lot of additional paperwork. Providers feel that time doing paperwork would be more valuably spent with patients. As time-sense developed during the maturation of industrial society, workers experienced a distinction between their employer’s time and their own time. Time became a currency that was spent (Thomson 1967). For medical providers, there is a dichotomy between time passed with patients and time spent on administrative duties. Care-time transcends the boundaries of work-time through coded language even while providers are firmly entrenched in the regulating and disciplining of labor

by time. At the end of each clinic day, providers have to chart and take notes on all of the patients they saw that day. They would often say, “Oh, I just have to finish up some work before I go home.” It was work that took time, not care. When asked what care looks like, Maggie said, “If I have to go into a patient’s room five hundred times to answer the same question, I will do it. Even if it will take me another two and a half hours to do my work, I will go back to see the patient” (Maggie, personal communication, 3 February 2015). Maggie conceptualizes the “work” done at her desk as distinct from the care she enacts in patient exam rooms. By situating care outside of the disciplining of work time, providers are able to conceptualize a form of care that is not influenced by the harsh forces of the market economy. Even though economic processes do indeed influence care, this conceptual distinction allows providers to enact care that they think of as pure, wholesome, and relational.

While practitioners strive to provide unadulterated, socially desirable care, they experience tensions as their relational care-labor is transformed into work-labor through relationships of exploitation in the market economy. Within the last six months, the pediatric hematology/oncology unit has received an influx of new patients, with over ninety new oncology patients since September. Each provider is only allowed to see ten patients per day, but in the last few months that have been seeing eleven to twelve patients per day with double-booked appointments. Maggie said, “Just a few months ago we were only seeing three to four patients per day. We could all go out to lunch as a group, get to know our co-workers, take a moment to breathe” (Maggie, personal communication, 27 February 2015). Within the context of a hospital, this statement is quite shocking. If Maggie cannot breathe in a hospital, a space designed to bring about health and healing, the hospital as an institution would be failing dramatically. However, this need to create time in space reveals a broader issue in the culture of work in the

United States. Those who control the means of production are solely focused on extracting a surplus in the form of value at the emotional and physical expense of the laborers. Terence Turner, working from Karl Marx, sees modes of production as linked to relationships of exploitation because the group who controls production can use that control to extract a surplus, and thus value, from the laborers (2008:45). In a way, laborers in the United States are sick, unable to breathe under the oppressive time-work discipline.<sup>19</sup> If medical providers cannot breathe, cannot care for themselves, how can they care for their patients? In order to protect themselves and their patients from the suffocating effects of the disciplining of labor by time, medical providers conceptualize care as distinct from work. Time with patients is not work because the relationships that are formed are more meaningful and socially valuable to the patients and the providers than the material value gained from the encounter. In chapter four, I discuss the ways in which time regulates the physical movement of the providers and how providers use their moving bodies to make meaning.

Even though providers think of care and work as separate, they cannot have one without the other because providers cannot give personal, relational care without the material flows that make that relational care possible. Conversely, care cannot be materially valued without the social value. From a financial standpoint, the increase in productivity makes the clinic more valuable. The group who controls the production of healthy bodies, the clinic administration, is exploiting the laborers to extract a surplus. However, the laborers—the medical providers—feel burnt out. Many providers say that they have reached their “breaking point,” that they cannot

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<sup>19</sup> Unfortunately, many labor practices in the United States are actually causing physical harm to laborers. Barry Estabrook’s exposé *Tomatoland* (2011) reveals the dangerous effects of Florida tomato farming for the laborers, most of whom are Hispanic. The time-work discipline regulates the laborers as the fruit must be picked within a certain amount of time, yet the constant contact with harsh chemicals causes physical deformities and life-threatening illnesses. While not all labor practices are physically harmful, the mental and emotional effects of the disciplining of time can also be serious for laborers in the United States.

effectively care for their patients. Thus, you cannot have materially valued care without socially valued care, and vice versa. The material value is part and parcel of the social value of care.

Nora, an oncology physician, said, “I do not see care as work, but rather as my purpose” (Nora, personal communication, 24 February 2015). Yet Maggie notes, “Not everyone can do this job” (Maggie, personal communication, 3 February 2015). These comments reveal that care can be both one’s purpose and one’s job, both labor and work. By conceptualizing care as her purpose, Nora transcends the time-work discipline and brings together the tensions of providing socially valuable and materially valuable care in a way that makes sense to her. Care is not something that she *does* but rather some that she *lives* every day. To care is her way of being in the world, her purpose. Providers use this liminal way of being in the world to navigate between the structures of social value and material value and to find meaning in that in-between-ness.

## **Conclusion**

As care moves through Children’s, it can come to embody many values in a way that reveals the fluid, dynamic, and always changing nature of care. Through a process of exchange, care gains both social and material value. Even though providers are firmly entrenched in both social and material flows of care, they are able to make their actions meaningful by conceptualizing the labor of care as distinct from the labor of work, which allows them to provide personal, social, and relational care not only as their job, but as their purpose. In the next chapter, I discuss the ways in which the carescape of physical movement allows providers to enact their liminality by caring from their bodies.

## FOUR

Making Meaning: The Movement of Care

*Nora and I go to see our third patient of the day, a nine-month-old boy with a tumor in his kidney. The baby boy is lying on the examination table, held by his mom and a nurse. Nora walks over and grabs the little boy's toes between her thumb and forefinger. As she wiggles his toes, he smiles up at her. After chatting with mom for a bit about how things are going, Nora wants to examine the boy's bottom to check for rash or reaction to medication. As she unfastens the diaper, she says to mom, "Uh oh, do you have a diaper?" Mom replies, "Oh, I can do it." Nora says, "I don't mind, I have an eighteen-month-old at home." So Nora checks the boy's bottom for signs of a reaction as she deftly wipes his bottom, snugly fastens on another diaper, and tosses the soiled one into the trash.*

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Physical movement is an important part of our human lived experience, yet it is often overlooked or treated as a given. However, physical movement engenders care in particular ways, and providers are able to navigate the often shifty, unsteady carescapes by enacting their liminality and caring from their bodies through physical movement. I experienced this care from the body one day in the clinic. Lisa and I went to see a nine-month-old Somali girl with Downs syndrome. When we entered the room, she was asleep, slumped up against dad's chest. Lisa talked with dad for a few minutes and then reviewed her counts. Things did not look good; she would have to be admitted to the hospital that day. Dad had a feeling it would be today, but he asked Lisa if they could be admitted tomorrow morning instead so that he could go home and get



a bag ready. Lisa said that she would go make some calls to see if that was a possibility. When we came back into the room, the baby girl was awake and wiggling on the exam table, held by the nurse and dad. Lisa sat down at the computer to order medications. After the nurse had accessed the little girl's port, she asked dad, "do you have her?" to make sure that she would not fall off of the table. A few minutes later, while Lisa was still at the computer, dad looked at me, standing in the corner, and asked, "could you watch her while I get her bottle?" I was shocked, stunned.<sup>20</sup> I didn't know what to do. Was I allowed to touch her? Had I remembered to wash my hands properly? Should I ask Lisa for permission? Especially through the tradition of fieldwork, we have been taught to "stand aside from the action, take up a point of view and ask endless questions" (Jackson 1989:135). I was confident in my role as a stationary, observant student, but once that role involved moving my body, the stakes became much higher. Caring from the body is a deeply personal and often fragile practice, as providers can truly hold life in their hands. All of these thoughts flashed through my mind in a millisecond before I confidently answered, "Sure!" and stepped over to the table without hesitation.

In this medical realm, I wanted to play the part of observant student yet capable caretaker in order to create an experience for the patient and her family. In a way, I also wanted to prove to the provider as well as to myself that I could belong in this world. If the dad wanted me to help, I would offer my help to the best of my abilities, not thinking about the consequences. In that one step, I moved from the comfortable corner of quiet observation to the pulsing and exhilarating bodily enactment of care. My mind and body became singularly focused on ensuring that this wriggly and squirmy little girl stayed on the table. It was not difficult—I

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<sup>20</sup> This type of watching was very different from the watching that I was used to through observation because I had to be physically responsible for another person, even if only for a brief moment. As an anthropologist, I need to be responsible to my informants by portraying them honestly and with regard to their safety, but this particular moment of watching required a deeper responsibility. I had to move my body to ensure that no physical harm befell this little girl.

barely had to touch her, and dad was standing less than a foot away, but I could sense the importance of my actions, an importance that words could not express. I had transformed from observant anthropologist to confident giver of care. Even though observing can also be a form of care, enacting the body through movement creates a deeply embodied moment of care in ways that observation alone cannot. In his study of Kuranko social life, it was not until anthropologist Michael Jackson participated in the movement of everyday skills and dancing that he was able to gain valuable insights because physical movement reveals lived experience in ways that words cannot.

Throughout each day, providers perform many regulated and standard motions, such as listening to a heartbeat or looking into a patient's ears. These regulated motions become meaningful interactions of care through the physical movement of the provider. As the provider moves in space, time, and in relation to other objects and people, her liminality becomes visible through her body as she transforms the performed and regulated motions into embodied care by personalizing the motion for each patient in order to connect with them both physically and emotionally. This intentional, embodied movement allows practitioners to care from and through their bodies. Thus, as the providers move, care moves with them.

### **Enacting a Caring Self**

The daily lives of medical practitioners are filled with performed and regulated motions, motions that are taught as the basics of healthcare. Providers find a patient's heartbeat, listen to her chest, and feel her neck for swollen lymph nodes. These motions are all regulated and controlled by bio-power working in and through the hospital institution. According to Erving Goffman (1959), these motions are also performed as providers learn to play a part in the drama

of social life. It is not to say that these performed motions are fake but rather that “reality is being performed” in an examination room (1959:101). However, this controlled and performed motion is different from movement. Movement, a “culturally driven way to change position,” as Chandra Bhimull suggests (in press), differs from absolute motion in that movement carries with it intentionality, a purposeful and cultural desire to effect a change. The provider’s motion of placing her hands on the patient’s neck is different from the intentional movement of feeling her lymph nodes for traces of cancer to change treatment, if necessary. This touch is much more personal and relational, a form of care as keeping (see Davis 1997a). While anthropological literature has shown a renewed interest in the body (see Lock 1993 and Scheper-Hughes and Lock 1997), this body is still a static, unmoving body; accounts of people enacting the body are missing. Farnell (1994) offers three modes of conceptualizing the body that gives agency to the person rather than to just the mind or just the body. A person can talk *about* her or anyone else’s body; a person can feel and talk *of* her bodily experiences; and a person can enact the body (i.e. move) and can talk *from* her body. These three positions ensure person as agent: bodies do not move and minds do not think—people do. I argue that rather than talk from their bodies, providers care from their bodies. Through this embodied care, they enact a caring self (Williams 2002 and Best 1997).

Just as Farnell offers three modes of conceptualizing the body, I offer three modes of conceptualizing care. Medical providers strive to care for, care about, and take care of their patients. ‘To care for’ and ‘to care about’ have a different connotation than ‘to take care of.’ While ‘to care for’ and ‘to care about’ imply an emotional, social, and personal engagement, ‘to take care of’ implies an action, a doing. The word ‘take’ implies physicality, yet it also indicates a kind of ownership that the provider has over her patients, revealing the unequal ways in which

power operates in this medical setting. However, by embodying motions, providers transform these controlled and performed acts of treatment into intentional movements of caring for, caring about, and taking care of, enacted by a caring self through a body that moves in space, in time, and in relation to other objects.

### *Movement in Space*

Providers enact a caring self by moving to occupy the same physical space as the child. When I asked Lisa what care looked like, she said, “I try to get down to their [the child’s] level” (Lisa, personal communication, 30 January 2015). One of the first things that Lisa does when she enters an exam room in the clinic is greet the child. If the child is sitting at the small kid’s table, Lisa will kneel down next to the table. If the child is sitting on mom or dad’s lap, Lisa will bend over, folding slightly at the waist, in order to look more directly at the child. These small bodily movements of kneeling down, bending over, or walking closer to a patient situate Lisa within a caring space of proximity with the child. This caring space is also maintained throughout the physical examination. The examination consists of: using a stethoscope to listen to breathing and heartbeat, using an otoscope to look in ears and throat, feeling the stomach and lymph nodes, and checking strength and motor function by asking the child to push his feet against Lisa’s hand. As Lisa checks the patient’s neck for swollen lymph nodes, she gently runs her hands up and down the neck, lifting her fingers and then applying pressure again as if playing the piano on the child’s neck. In order to keep the child comfortable, Lisa always asks the child where she wants to do the exam; she does not have to sit on the examination table. Some children sit next to their parent, others sit on a parent’s lap, and some sit at the kid’s table. One active little toddler was crawling around as Lisa tried to examine him. He snuck behind the kid’s

table, and Lisa followed, crouching down into a duck walk. He was not scared—he was playing with a toy car, but Lisa did not interrupt his play. By shifting in space, Lisa enacted a caring self through her body by both caring *about* and caring *for* this child. She cared *about* this child's happiness and mental wellbeing by upholding his play while simultaneously caring *for* this child's bodily health by examining his physical body.

Occupying the same physical space, or “setting,” as Goffman says (1959), is an important aspect of care for providers. If they cannot see the child, feel her stomach, or check her complexion, a gap in care appears. This gap is most felt by providers when they are on-call. All providers in the hematology/oncology unit are required to work an overnight on-call shift at least once a month. If nurses on the floor have questions in the middle of the night, they are instructed to call the on-call provider. One morning in the clinic, Maggie was talking with some nurses about her night on-call. She said that someone had called with a question about medications, and she was not sure that she had given the right prescription. She decided to follow-up with the pharmacist to make sure that she had given the right dosage. She said, “When I’m not there, it’s hard to know.” Medical providers must operate within a certain setting in order to perform and enact a caring self.

### *Movement in Time*

Just as the setting controls and regulates the motions of providers, time also regulates motion and the ways in which that motion can be embodied and transformed into movements of care.<sup>21</sup> In a standard clinic day, providers would see all of their patients in the clinic and would move and operate within the confined space of the clinic. However, this confined movement

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<sup>21</sup> See chapter two on the built environment.

was often not the case. Providers would frequently go to see patients on the floor if they were working in the clinic, and providers working on the floor would often go down to the clinic to talk with co-workers or get something from their desks. When I asked providers about this move or transition from one space to another, they said that they have done it so many times that they do not even think about it. They exit the clinic, walk up one flight of stairs, walk through the skyway, enter the elevator, and ride up to the seventh floor without thinking about this as movement. Even the distinct spaces of the clinic and hospital become bound by this ebb and flow of practitioners. While practitioners seem unconcerned with the movement between clinic and hospital (or rather see it as something normal, ordinary, not worth dwelling on), the time constraints of the working day weigh heavily on the providers and can influence their movements. Providers would often say, “I wonder if I have time to run up to the floor,” or “I think I have time to go grab something from the clinic.” They walk across the skyway at a rapid clip, singularly focused on their next destination, their next patient. It is as though they realize that they must be physically present with the patient, enacting care through their bodies, for care to occur, and they do not want to waste even one second when that care could be enacted. As they move, care moves with them. In a way, providers equate moving with caring. For whenever a provider is sitting down at her desk, she is working, not caring.<sup>22</sup> One provider even has a treadmill at her desk instead of a chair in order to walk as she charts, and I analyze this treadmill as a way in which the provider gives herself the impression that she is *doing* something, taking care of someone with her physical movement, her walking.

Because time is always moving, so also must providers move to fight against this enemy. Yet no matter how fast they walk or how constantly they move, providers still feel as though

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<sup>22</sup> See chapter three on value.

they are running out of time to enact care. Providers continually say things such as, “I wish I had more time” or “I just don’t have time today.” This speed, or acceleration of care, is brought about by the forces of bio-power working in and through the providers. There is never enough time to heal another body, to fight another illness. Providers walk rapidly across the skyway to get to their next patient as quickly as possible. Yet with this acceleration comes a deceleration as providers slow down when they are with patients. They pause to talk about football or play with Minnie Mouse boats. The providers’ liminal way of being allows them to accelerate and decelerate, to pause and to move, and to create meaning in those moments of liminality, those in-between moments where life happens.

### *Movement of Things*

As providers move through space in time, they often come in contact with material objects that have specific, regulated purposes, yet providers can transform these regulated objects into toys, teaching tools, and vehicles of care through embodied movement. Take for example the medical practitioner’s routine act of looking with an otoscope into the mouth of a patient. Each exam room is equipped with its own otoscope and stethoscope. The otoscope is connected to the wall with an extendable curly cord that can stretch all the way across the room. The light on the otoscope is automatically activated when removed from the wall. This device and the ways in which practitioners move to interact with this device could be described in many ways: the practitioner grabs a lighted object from the wall and pulls the cord taught; the practitioner chooses a tool to fix a problem; the practitioner gives the child a slinky toy connected to the wall with which to play. Yet these motions have a certain meaning within the context of the clinic environment. They must be analyzed based on the provider’s meaningful intent to effect a

change for the patient. For example, mouth sores are a common side effect of chemotherapy, so medical providers frequently look into the mouth with an otoscope to ensure that mouth sores are not forming. Thus, the motion of grabbing a tool from a wall becomes an embodied movement of care when the motion's intent to effect change is taken into account.

While the otoscope may not necessarily be a slinky toy connected to the wall, Maggie did find a way to incorporate it into a moment of play. After looking into a child's mouth, she uses the otoscope to look into the child's ears, but she must fix a small cap onto the otoscope first. She lets the child take the cap and twist it onto the otoscope. One little girl said, "do I get to put the hat on?" She had done this before and even had her own term for the otoscope cap. Through play, Maggie transformed the routine motion of looking into the mouth into an intentional bodily movement of a caring self.

## **Conclusion**

Each day, providers perform routine motions of treatment, like placing a stethoscope on the chest of a patient. These motions become intentional movements of care through the body of the provider. By caring from their bodies, medical providers enact a caring self that allows them to care for, care about, and take care of their patients. As providers move through space, in time, and with objects, their care moves with them, revealing the fluid, flowing, fluctuating, on-the-go-ness of care, care that never seems to be moving fast enough. Even as bio-power disciplines providers to move faster, to do more, providers enact their liminality through their bodies to create meaning in the in-between-ness, in the frictions between moments of movement and moments of pause.



## THE STORIES CONTINUE...

As I sit down to conclude this project, I find it hard to stop writing because I feel like so many stories are still ongoing. While my story at Children's may be over, the stories of these children are still being written, and I want to be a part of that. I want to be a part of the amazing ways in which medical practitioners care for these kids every day. And I want to see the hope return to seemingly hopeless situations. During my time at Children's, the Cancer and Blood Disorders Center was experiencing a record number of deaths and relapses. From September to February, the center had twenty-five relapses and nineteen deaths. With a sigh, Maggie said, "the human heart and mind can only take so much grief" (Maggie, personal communication, 20 February 2015). Many practitioners said that they were at their "breaking point." For one week during my fieldwork, colorful star-shaped balloons lined the back hallway of the clinic. Providers could write their frustrations, worries, concerns, or names of patients on these balloons, or they could punch them as they walked by if they needed to release emotions. The hospital chaplain organized this activity as a way for the providers to express their emotions, especially their grief. The emotional force acting on the providers compels them to cry and to punch balloons as they express the anger that they feel in grief, anger that their care could not save the child. Yet despite the often overwhelming feelings of anger in grief, they channel that anger into fighting disease and creating meaning in the midst of grief (see Rosaldo on emotional force 2014).

Despite the grief, frustrations, anger, and sadness, the providers show up every day to care and work for their patients. Care is more than just a job for the providers whom I shadowed—it is a way of being in the world, a way to make meaning in the midst of sadness and sickness, in the midst of much that does not make sense. Yet care is a liminal way of being in

the world of Children's in that providers live and operate "betwixt and between" institutional meaning and social meaning as they strive to bring both of these ideas of meaning together through care. Providers strive to produce healthy, institutionally meaningful bodies while at the same time creating a more personal, social, and relational moment of care. Liminality allows providers to dwell in this in-between-ness, to enact care that is neither one nor the other, yet both.

As providers navigate this complex world of care, carescapes make their liminality visible. Carescapes are the enactments of care, both the diverse places where care occurs and the flowing ways in which it occurs through one's care labor. In chapter one, I explored this care labor as an everyday practice, an emotional labor, and as an embodied practice. In chapter two, I analyzed the ways in which that care labor is enacted in the carescape of the built environment. The built environment disciplines both patients and providers through bio-power, but providers enact their liminality through art and play to transform ideas of what is meaningful and for whom. In chapter three, I discussed the carescape of value and argued that care gains both social and material value through a process of exchange. Providers conceptualize care as socially valuable and work as materially valuable in order to bring these two understanding of value together through their care labor to create meaning for themselves and for their patients. Lastly, in chapter four I argued that the carescape of physical movement allows providers to enact their liminality through their bodies and thus care from their bodies. These carescapes allow us to see the frictions and tensions in care and the meaning that can be created in those encounters and interactions.

While some would argue that the dark side of care still exists, my project offers a new way of conceptualizing care—a way to bring together the institutional priorities and the deeply

personal, emotional, and social experiences of patients and providers that I encountered. I think the beauty of this project is that it allows me to push the notion of what is care, to explore the rich textures of humanity, and to make visible the small meaningful gestures that make up the patient's and provider's lived experience. Medical providers negotiate the institution and maneuver through carescapes in often invisible ways, but I offer this project with the hopes that it may bring the fluctuating, dynamic, and wonderful possibilities of care out from the shadows and into the star-studded light of a constellation of caring.

## APPENDIX



*Image #1.* Children's Hospitals and Clinics in Minneapolis, Minnesota. The specialty clinics are located on the left, and the hospital is located on the right.



*Image #2.* Skyway connecting specialty clinics to hospital



*Image #3.* Atrium of Children's Hospitals and Clinics in Minneapolis, Minnesota





*Image #4. Starz Café and the Children's Gallery*



*Image #5. Children's Constellation of Caring*



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