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The Promise of Poison: Life in the Field of Pediatric Cancer Treatment

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Author
Wright, Anthony Gerard

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The Promise of Poison: Life in the Field of Pediatric Cancer Treatment

by

Anthony Gerard Wright

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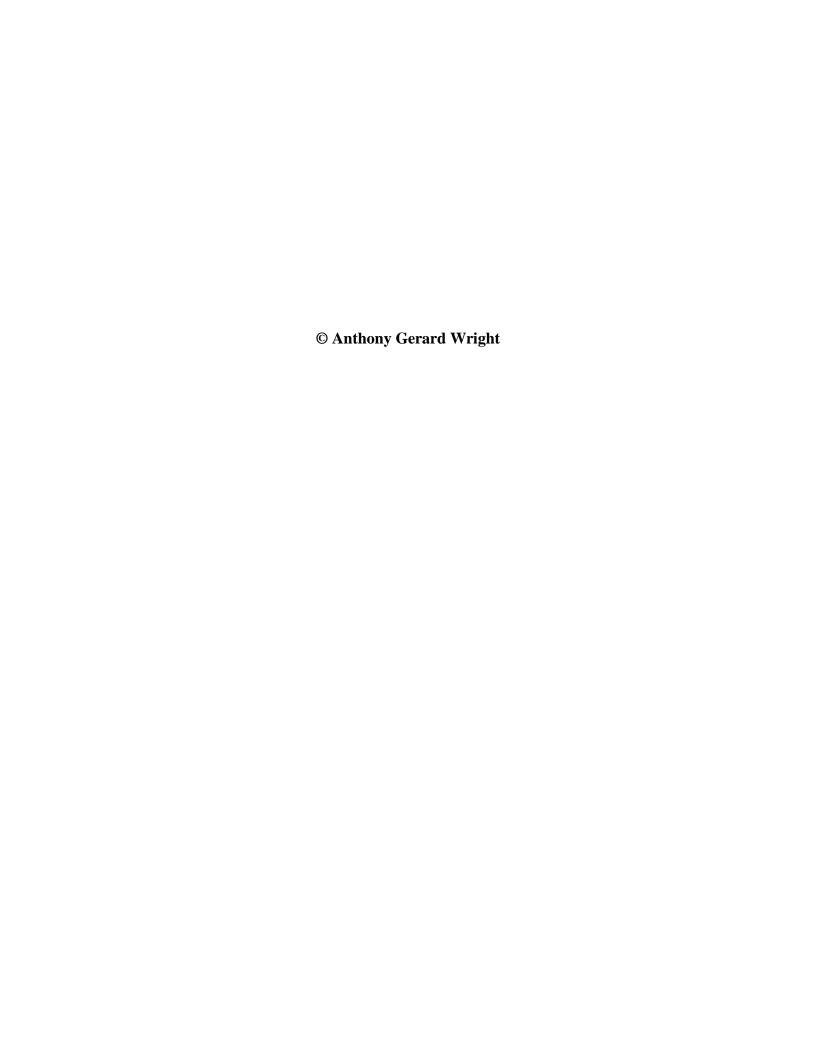Medical Anthropology

in the

Graduate Division

of the

University of California, Berkeley

Committee in Charge

Professor Nancy Scheper-Hughes, Co-chair
Professor Seth Holmes, Co-chair
Professor Charles Briggs
Professor Patricia Baquedano-López

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Abstract

The Promise of Poison: Life in the Field of Pediatric Cancer Treatment

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Joint Doctor of Philosophy in Medical Anthropology

University of California, Berkeley
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The Promise of Poison: Life in the Field of Pediatric Cancer Treatment is an exploration of the ideologically mediated practices through which people are made into different kinds of participants in processes of pediatric cancer treatment. Since the 1950s, the field of pediatric cancer treatment in the United States has become organized around a multidisciplinary model that the oncologist Sidney Farber dubbed "total care." In recognition of the various forms of havoc that cancer diagnosis and treatment wreaks on patients and their intimate networks, Farber's vision calls for multidisciplinary teams of biomedical and psychosocial professionals to provide various caregiving services to both patients and their family members, particularly parents/guardians. Since the time of Farber, many cancer treatment centers throughout the world have adopted some version of his model. In this dissertation, I explore practices of total care at Bay Area Children's Hospital, which is the site of a major pediatric cancer treatment center in the San Francisco Bay Area. In doing so, I show how models of pediatric cancer care intersect with models of communication and youth in ways that can produce multivalent effects that range from therapeutic to iatrogenic. As young people and their families become positioned as participants in the field of pediatric cancer treatment, their lives become spatially, temporally, and ideologically re-arranged around the demands of particular cancer treatment protocols. In the process, they are not only promised the possibility of healing, but they are also warned about the negative, or iatrogenic, effects of treatment. While the negative effects of biomedical cancer treatment practices are commonly recognized, here I show how psychosocial caregiving practices can also produce harmful effects. One common way in which this occurs is via the subjection of individuals who identify as teenagers to habitats, artifacts, standards, and practices that were designed to facilitate care and communication between adults and young children. Such forms of subjection can enact processes of infantilization, alienation, and stigmatization that inhibit therapeutic interactions. As I will show, the processes that constitute total care are also mediated by ideologies of race, class, and gender that inflect models of care, communication, and youth. Patients and families who inhabit non-white and non-bourgeois identities may be particularly likely to experience the negative effects of total care insofar as it reproduces standards that derive from white, Euro-American, bourgeois ideologies that mark them as "inappropriate" people.

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For those who left too soon.

'Tis a fearful thing
to love what death can touch.

A fearful thing
to love, to hope, to dream, to be –

to be,
And oh, to lose.

A thing for fools, this,

And a holy thing,

a holy thing
to love.

For your life has lived in me,
your laugh once lifted me,
your word was gift to me.

To remember this brings painful joy.

'Tis a human thing, love,
a holy thing, to love
what death has touched.

-Yehuda HaLevi

Acknowledgments

Although this dissertation bears my name as the sole author, the stories and voices of many people are stitched into these pages. Above all, I am grateful to the families and young people who allowed me into their lives. Their suffering and loss were immense, but so were their love, compassion, and humor. As in most ethnographic accounts, I had little choice but to cloak real people in pseudonyms. Although some of these people have tragically passed away, the love that others feel for them lives on. I hope that this account conveys the depth of that love.

In addition to the families and patients who I met through this work, I am extremely grateful to the many professionals who opened their workplace up to me, trained me as a hospital volunteer, allowed me to observe their activities, and took time out of their incredibly hectic schedules to participate in interviews. Although I take a critical stance toward certain professional practices and institutional structures, I hope it is clear how greatly I respect many of the individuals who carry out the work of cancer care. In addition to being brilliant people with stunning knowledge of a dreadful disease, I found most professionals to be passionately devoted to their work and to the families they serve.

This dissertation grew out of six years spent as a graduate student in medical anthropology at the University of California, Berkeley and San Francisco, and I am forever grateful to all of the mentors and colleagues I met along the way. I would like to thank my dissertation co-chairs, Nancy Scheper-Hughes and Seth Holmes, for all of their support, encouragement, and wisdom. I am also grateful to Charles Briggs and Patricia Baquedano-López for their thoughtful and constructive engagement with my work. I greatly appreciate the feedback that Clara Mantini-Briggs, Kristina Lyons, Javier Auyero, and Gillian Feeley-Harnik offered on earlier drafts of this work. I also could not have gotten through dissertation writing without the love, support, and stimulating conversations provided by my fellow graduate students: Melina Salvador, Brittany Birberick, Nadia Gaber, Jonathan Wald, Candace Lukasik, Shakthi Nataraj, Héctor Beltrán, Nicole Rosner, Clare Cameron, Fabian Fernandez, Jaleel Plummer, Levi Vonk, Raphael Frankfurter, Vera Chang, Mauricio Najarro, and David Thompson. Finally, I would like to thank the UC Berkeley Institute for the Study Societal Issues Graduate Fellows Program for fostering a collaborative and constructive environment as I carried out this work. I am grateful to Deborah Lustig, Christine Trost, David Minkus, and all of the graduate fellows for their feedback and advice along the way. I could not have done this without them.

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Chapter 1
Pediatric Cancer Treatment in the United States: The Disneyfication of Care

On a sunny St. Patrick's Day in 2018, I went down the street from Bay Area Children's Hospital (BACH) to the BACH Research Institute, where the St. Baldrick's Foundation was holding its annual "Brave the Shave" event to raise money for pediatric cancer research. Each year, the BACH oncology department helps to organize the event, which draws hundreds of people who have been personally affected by pediatric cancer, as well as those who work in proximity to cancer patients and their families—physicians, nurses, psychosocial professionals, researchers, etc. Everyone gets together in one space with food, music, entertainers, and a stage on which several shaving stations are set up and hair stylists stand wielding buzzing clippers that they use to shave each head that passes through their station. Each "shavee" campaigns prior to the event, using their personal and professional networks to generate donations to St. Baldrick's. As shavees take the stage, their friends and family members watch in amusement as locks of their hair tumble to the ground, leaving their scalps exposed.

The event was held in a large, open area at the Research Institute, where bookcases full of medical journals lined the walls. Folding tables were set up with cookies and other refreshments. Loud pop music was playing from several large PA speakers that flanked the stage, and some of the crowd members danced along. There was a man with a microphone acting as an MC, telling jokes, asking audience members questions, and calling up each group of shavees as their time slots approached. Each group went up in regular intervals, and those who had longer hair first had it measured to see if it was long enough to donate to a non-profit organization run by the hair care product company Pantene, which uses the donated hair to make wigs for cancer patients. If it was long enough, the hair stylist would tie the hair off into several ponytails and then chop each one at the base with scissors, after which the ponytails were placed into a Ziploc bag with a piece of paper instructing the shavee how to go about sending the hair to Pantene's Beautiful Lengths program. Of course, as with most practices of corporate charity, there are deep contradictions operating here. Pantene is a company that has made its fortunes selling hair and beauty products that contain a number of toxic chemicals, particularly certain parabens, which some studies have found to be carcinogenic (Pan et al. 2015). In engaging in charitable activity around the problem of cancer treatment, corporations such as Pantene obscure the potential role of their products in producing the disease.

Despite my misgivings about common forms of corporate charity, I decided to participate in the event, which I attended with my friend Malachi. Malachi and I heard about the event several months ago at BACH, where we were both spending a great deal of time—Malachi as the father of a twelve year-old boy being treated for acute myeloid leukemia, and me as a medical anthropologist studying pediatric cancer treatment. Several of the young patients at the hospital, including Malachi's son, Rashad, had encouraged me to raise funds as a shavee, partly because I had long hair at the time, making me a perfect candidate. I agreed that this was a good idea and signed up on the St. Baldrick's website.

About twenty minutes after we arrived, my group was called to the stage. I climbed the stairs up and took my seat at the shaving station. "You want a '1' or a '0'?" the hair stylist asked me, holding up the clippers and a plastic clipper guard. "The '0' is totally bald. The '1' leaves just a little bit of hair." In a moment of cowardice, I opted for the '1.' She tied some ponytails, quickly lopped each one off, and handed me a bag of my hair. Then she proceeded to shave. As the clippers moved across my head, I felt tufts of hair falling down my shoulders. When she was

finished shaving, she removed the cape she had placed around me. I returned to the crowd, and Malachi poked fun at my new look.

At this point, the hair stylists took a break, and a group of actors dressed up in Disney prince and princess costumes arrived. Many of the children's eyes lit up and smiles came across their faces as they recognized the characters. An actor dressed like Princess Merida from the movie *Brave* took a microphone and greeted the crowd in a Scottish accent. "Now who wants to sing a song with me?!" She asked the crowd, eliciting excited responses from many of the children. The song "Touch the Sky," which Princess Merida sings in the movie, began to play over the speakers. As the actor sang the lyrics, many of the children began singing along, and all of the other actors began a choreographed dance. While many of the children happily danced and sang alongside the actors, I couldn't help but notice some of them who exhibited the telltale signs of active treatment were not participating with the same outward enthusiasm as their cancer-free counterparts. I wondered to what extent they were enjoying the event.

After the song and dance break, the head shaving resumed, and we decided to leave. On the way out, we bumped into Dr. Bhandari, one of Malachi's son's oncologists and the physician who had sponsored my study, giving me access to the oncology department. Dr. Bhandari was also there to get his head shaved, which he did every year. We chatted for a bit, and then we parted ways. I walked with Malachi back to BACH, where his son and a number of other patients were still hospitalized as they endured the excruciating rituals of cancer treatment.

Producing Cancer Patienthood via Ideologies of Youth, Care, and Communication

This dissertation explores the production of pediatric cancer treatment as a lived condition that people respond to in different ways depending on the particular social positions they voluntarily and involuntarily inhabit. I build on work in medical and linguistic anthropology, science and technology studies, and childhood/youth studies to explore the productive effects of intersecting ideologies of childhood, communication, and pediatric cancer care in the urban United States in the early twenty-first century. The account that follows is based on eighteen months of fieldwork carried out in 2017 and 2018 among health care professionals, family members, and patients going through cancer treatment at BACH, a "safety net" children's hospital in the San Francisco Bay Area.

As the vignette above demonstrates, what I will refer to as *the field of pediatric cancer treatment*—a notion that I develop in detail in the following chapter—is deeply shaped by ideological models of childhood. As I will describe in what follows, these models exist in tension with models of adolescence that also play a powerful role in the process that Ian Hacking (1986) might refer to as "making up" pediatric cancer patients and caregivers. Here I use the term *ideologies of youth* to encompass ideas of both childhood and adolescence. As many anthropologists, sociologists, and historians have pointed out, neither childhood nor adolescence should be seen as universally and naturally occurring stages of life (Ariès 1965; Fass 2016; James and Prout 1997; Jenks 1996; Lancy 2008; Montgomery 2008; Scheper-Hughes and Sargent 1998; Stephens 1995). Particular forms of childhood and adolescence do not exist independently of the discursive constructions and material relations that enable and constrain their production. As I hope to show in what follows, the manner in which individual young people and their caregivers are made into participants in the field of pediatric cancer treatment is shaped by ideologies of youth that circulate within and beyond the field.

As the vignette above demonstrates, what Giroux (1999, 1994) refers to as "Disneyfied" ideologies of youth commonly circulate in pediatric spaces. In using this term to describe ideologies of youth, I do not mean to imply that all such models literally draw upon content or ideas produced by the Walt Disney Company. Rather, I follow Giroux in recognizing the undeniable influence that Disney's products and practices have on many different forms of public culture that affect the lives of young people. As Giroux observes:

> If we imagine the Disney Company as a teaching machine whose power and influence can, in part, be measured by the number of people who come in contact with its goods, messages, values, and ideas, it becomes clear that Disney wields enormous influence on the cultural life of the nation, especially with regard to the culture of children (1999, 19).

Obviously, Disney is not the only major company to have an influence on children's culture. As Pauline Hunt and Ronald Frankenberg (1997) point out, while Disney may have pioneered the use of popular characters in selling various child-directed products and forms of entertainment, such practices have now become widespread. As I hope to show in this dissertation, these practices have also had an influence on various forms of pediatric care and communication in the context of cancer treatment. This happens not only at fundraising events, such as "Brave the Shave," but also in various spaces throughout the children's hospital. With features such as brightly painted cartoon murals, playrooms stocked heavily with children's toys and games, and professionals engaged in various forms of "child-directed communication" (Ochs, Solomon, and Sterponi 2005), the hospital is clearly designed with particular ideologies of youth in mind, and theseideologies draw heavily on Disneyfied forms of children's culture. Although many young people respond positively to the environments and practices these designs foster, I argue that these child-directed dynamics can be emotionally harmful and socially constraining to some young cancer patients. In particular, patients who are positioned as adolescents/teenagers may feel infantilized or alienated by caregiving environments and practices designed for young children. In addition to differences along lines of age, there are also race, class, and gender dynamics at play.

In short, many different processes that constitute the field of pediatric cancer treatment are *produced by design,* and these designs draw on existing ideologies. Certain ideologies of youth are made to iterate throughout the space of cancer treatment, producing a spectrum of effects that shape specific cancer treatment trajectories. The Disneyfied forms of children's culture that are now commonly associated with pediatric cancer treatment centers, as well as with other "child-centered" spaces, do not spawn themselves into existence but are brought into circulation by people positioned as professionals and volunteers, who see it as the hospital's role to provide both biomedical and psychosocial care to children and families. As I will explain in the following chapter, the eminent pathologist Sidney Farber originally proposed this multidisciplinary model, which he branded "total care," in the 1950s, and it has since become seen as a global standard of care among pediatric cancer treatment professionals, although it is implemented in a broad range of ways that are affected by shifting processes of biomedicalization (Clarke et al. 2010) and psychologization (Rose 1996), or, as I will refer to it, *psychosocialization*.[1] As new people enter the field in hopes of becoming professionals, they are socialized into this iterating inheritance, taking up positions associated with particular professional roles that are partially constitutive of the project of total care.

Yet, in order for any ideological model—whether of childhood, cancer care, or something else entirely—to circulate, it must be rendered "communicable," as Briggs (2005) puts it. That is, it must be made to pass through various circuits and social positions that are themselves ideologically mediated by models of communication. For instance, in order for the "Brave the Shave" event to be carried out, the organizers first had to take up positions as organizers with a stake in the cause of pediatric cancer research. This would have involved correspondence with people who had taken up positions as non-profit professionals at the St. Baldrick's Foundation. Together, they constructed various ads and other forms of messaging that were designed to circulate across networks that had already been modeled and set up. For example, after hearing about the event from oncologists and seeing a poster for it taped to the wall in the BACH cafeteria (a posting site that requires approval from the hospital administration), I went to the St. Baldrick's website, which offers a platform for shavees to create an account and a webpage that they can circulate for fundraising purposes. The webpage is designed not only to circulate information about the event and the shavee's role in it, but also to collect money from donors and to route it to St. Baldrick's account.

In addition to a fundraising platform, the website provides a number of other resources, including a PDF document titled *Your Ultimate Shavee Guide* (St. Baldrick's 2019), which provides tips about fundraising, as well as some bullet point facts about the gravity of pediatric cancer and St. Baldrick's role in raising money for pediatric cancer research. All of these materials are designed to serve the function of positioning people as shavees, providing them with compelling information and tools to take up that position. Obviously, they also serve the function of generating economic capital for the organization and its mission, which exists in a neoliberalized system of health care and research and thus relies on individuals to mobilize their energy and resources in hopes of generating charitable contributions. In this context, many people perform care for friends and family members by engaging in fundraising work that is intended to further various causes related to pediatric cancer treatment.

"Brave the Shave" and other fundraising events are just one example of how ideological models of childhood, care, and communication intersect and co-construct the field of pediatric cancer treatment. I will raise many other examples in this dissertation, attempting to show the wide variety of ways that individuals who inhabit specific positions within this field are affected by the iterative circulation and hybridization of these models. Of course, given its vastness, I cannot address all of the positions that constitute the field of pediatric cancer treatment, and I therefore restrict my analysis to clinical professionals, patients, and family members (particularly parents/guardians).

My Initial Encounter with the Field of Cancer Treatment

Although this dissertation is based on fieldwork carried out in 2017-2018, my first encounter with cancer treatment took place in 2006. At the time, my older sister had recently gotten married and settled into a new house close to our childhood home in Amarillo, Texas. She and her husband had also recently received the news that they were expecting a child, and my whole family was ecstatic. My parents began helping them renovate their second room into a nursery. Then, about 12 weeks into the pregnancy, my sister began having very intense symptoms, which she initially thought were typical pregnancy symptoms. She went in for a sonogram and found out that she was no longer pregnant. As she recounts it:

I went for my initial sonogram and was told that there was no heartbeat and no baby. I had miscarried. But after several weeks I was feeling very ill and still had all the symptoms of a woman who was pregnant. And so I went back to my doctor, but he was very dismissive and insisted I would be fine. So I went to another doctor…I went back because I kept having all the signs and symptoms of a woman who pregnant, but I had been told that I wasn't pregnant. And there was a small part of me that thought that the first diagnosis of miscarriage was wrong, that they'd missed something. I was positive that something was missed.

Frustrated with her doctor, my sister got a referral from her general practitioner to seek a second opinion from my mother's gynecologist, who agreed to see her promptly. After hearing about her symptoms, he decided to investigate the issue further. He did another sonogram and various blood tests, which confirmed that my sister had a molar pregnancy, a condition that results from a placental abnormality that leads to the development of a tumor. In many molar pregnancies, the resulting tumor does not become cancerous. But after biopsy, it was determined that my sister was not so lucky. She was diagnosed with a malignant form of gestational trophoblastic disease and told that she would require chemotherapy from an oncologist. The good news was that the survival rate for this particular cancer was very high, and the doctor assured her that she would very likely be healthy again. Nevertheless, my family was devastated, and my sister was furious at her first gynecologist for dismissing her concerns and failing to catch the molar pregnancy before it became cancerous.

My sister began treatment very soon after diagnosis, and it transformed her entire life. She had to go on medical leave from her job as an elementary school teacher, and my mother became her primary caregiver as she went through the excruciating process of chemotherapy. My mother, who is a devout Catholic and models herself on the image of Mary as a loving and long-suffering mother, rose to the occasion. Stories of my mother cleaning my sister's chemo port, wiping vomit from her mouth, bathing her when she was too weak to do so herself, and brushing her hair as clumps of it fell out have become a permanent part of our family history.

In addition to having an effect on my family, my sister's diagnosis also cast a dark cloud over her new home and marriage. Her husband, who worked in construction and often had out of town assignments, began spending less and less time at home. My sister felt that her husband's parents, who were avid followers of the fundamentalist Christian self help guru, Joel Olsteen, encouraged their son's distance by suggesting that this wouldn't have happened to my sister if she had more faith in God and worried less. By the end of my sister's treatment process, it came to her to attention that her husband had been seeing another woman almost the entire time she had been in treatment. My sister decided to file for divorce.

Fortunately, my sister is now healthy and has since remarried and had two children. Yet the experience of having been a cancer patient has left permanent marks on her life. Likewise, for myself, the experience of having a sibling who was diagnosed with cancer at a young age had a deep emotional impact on me. Watching my sister and my parents suffer so deeply will always live in my mind as a nightmarish memory. At the same time, I am also very grateful that my sister had health insurance, access to cancer treatment, a mother who had the time and resources to care for her, and a job that allowed her to take significant time off without serious penalty. Although our experience was terrifying, it was nothing close to the fear and uncertainty faced by many other families, who may have fewer resources and/or a loved one with a more aggressive form of cancer.

I share this story not only to demonstrate the personal experiences that led me to the study of cancer, but also because it speaks to issues surrounding the ideological mediation of communication and care that I will raise in this dissertation. Models of communication had a productive effect on my sister's interaction with her first doctor, who exercised his authority in a way that delayed her diagnosis. American health care institutions and insurance policies are often designed around a model of communication that relies on the practice of physician referral. Such models project the general practitioner's office as a patient's first line of communicative contact with the health care system. When a patient's particular issues are seen as beyond the purview of the general practitioner, they will be referred to a specialist, who may refer them to even further specialists. Of course, certain more costly insurance plans are built on models that permit patients to schedule specialist appointments without a referral, but many patients do not have this option.

For most patients, in order to be granted access to a specialist, they must first pass through the office of a general practitioner, who must recognize the patient's condition as warranting the services of a specialist. In my sister's case, she was initially placed into the social position of a pregnant woman, and then a woman who had had a miscarriage, and this led her first gynecologist to mistakenly see her as someone who would recover in due time. There are many reasons why this doctor could have failed to recognize the gravity of this situation, but here I will refrain from attempting to account for what exact factors caused the failure of recognition. Instead, I just want to note how the ideological model of physician referral, which has been institutionalized in the American healthcare system, played a role in creating a point of inertia for patients whose complaints doctors may initially dismiss as "normal" and self-limiting. Anyone who has spent time in the field of cancer treatment knows that such stories abound.

Models of biomedical communication—in this case, a model that projects a process of physician referral in which one physician legitimates the patient's need for the services of another—are deeply intertwined with biomedical models of care. In my sister's case, she was not recognized as a legitimate cancer patient until she had secured a referral to her second gynecologist, who rendered her condition biomedically legible through a series of technologically mediated tests that convinced him that she had cancer and would therefore need the care of an oncologist. Once she was referred to an oncologist, her concerns were taken extremely seriously and she was quickly thrust into the process of cancer treatment.

Beyond professional models of care and communication, patients and family members also deploy models of care and communication that co-produce their relationships as kin. Certain family members (often women are positioned as primary caregivers, and these individuals are also often positioned as communicative intermediaries between the biomedical team and the patient. As I will discuss in the next chapter, this is particularly true in the context of pediatric cancer treatment, as children are viewed as irrational communicators and vulnerable beings who must be protected from the impact of unfortunate information.

In my sister's case, my mother took up the position as primary caregiver, which required her to attend many of my sister's appointments and to absorb a great deal of information about the treatment process and how best to care for my sister throughout it. As my mother took up this position, her actions were not only shaped by biomedical models of care and communication, but also by her own model of motherhood that was tied to her experiences of Catholicism. In performing her role as maternal caregiver, my mother drew deep inspiration from the figure of the Virgin Mary, which has iterated through her life in countless ways—from her experiences as a student at Catholic schools, to the various statues and icons of Mary that decorate her home, to

the cyclical experience of going to mass every weekend and hearing stories about Jesus's birth, life, and death, and all of associated trials that Mary endured with grace. In citing this model of Mary—that is, in using Mary as a kind of metaphor through which to construct herself—my mother found a way to cope with the literal destruction of her daughter's biographical trajectory as she had once envisioned it.

At the same time, my family's Catholic models of care and communication, which acknowledged the inevitably of suffering in life and projected idealized ways of inhabiting that suffering with grace and acts of sacrifice, came up against the Evangelical models of my sister's ex-husband's family, who saw suffering as a failure of faith—a consequence of inadequate efforts to drive Satan's darkness out and invite God's light in. Of course, there are plenty of commonalities between these models, and I do not mean to imply that they do not get hybridized in many different ways. But in this case they were articulated in ways that gave rise to distinct approaches to interpreting and dealing with the suffering of cancer treatment. The collision between these models—one which rendered my sister a legitimate recipient of care from a loving mother, and another which rendered her a religious failure (and, in subtext, a bad wife and daughter-in-law) who had invited her problems upon herself—played a role in producing an impasse that my sister and her ex-husband were unable to overcome.

Moving From Personal Experience to Anthropological Inquiry: The Problem of Suffering

While my own family's entry into the field of cancer treatment has shaped my perspective profoundly, as an anthropologist, my goal is to understand the lives of other people and not to project my own experience onto them in the process. My family's experience provides valuable insight, but to better understand life in the field of cancer treatment requires an analytic orientation that takes into account the complex ways in which diverse ideologies and political economic relations shape situated cancer treatment trajectories. As I've already mentioned, in the context of *pediatric* cancer, this also requires attention to the ideologies of youth that structure how individuals are positioned as patients and caregivers. As I move into an analysis of how other people's lives are shaped by participation in the field of cancer treatment, I will pay close attention to the specific ideologies that people cite as they go through the process of being made into cancer patients and caregivers.

In writing about how people engage with the difficulties of pediatric cancer treatment in the following pages, I will inevitably portray moments of intense suffering. Medical anthropologists have long written about suffering, and they have described this practice in a range of ways. Some anthropologists use the term "witnessing" to make sense of the task of writing about suffering. To "witness" another's suffering is seen as a political and ethical act—a way of recognizing the pain and violence endured by those whose suffering is usually rendered invisible or naturalized as inevitable (Farmer 2003; Scheper-Hughes 1995).

In recent years, medical anthropology's methods of witnessing and writing about suffering have come under scrutiny. Joel Robbins (2013) suggests that anthropologists have responded to the loss of the organizing framework of "radical otherness" by replacing it with an attention to suffering. In place of the "savage slot" (Trouillot 1991) to which studies of culture gave rise, Robbins claims that anthropologists have produced what he calls "suffering slot anthropology." He describes this project as "a way of writing ethnography in which we do not primarily provide cultural context so as to offer lessons in how lives are lived differently elsewhere, but in which we offer accounts of trauma that make us and our readers feel in our

bones the vulnerability we as human beings all share" (2013, 455). Alongside this work, Robbins (2013) suggests that another framework is forming that can be summed up under "the anthropology of the good." Robbins describes this project as follows:

> The point of this kind of work is not to define what might universally count as good, and its practitioners are neither so panglossian as to claim that any given society has in fact achieved the capital G Good, nor so Pollyannaish as to imagine that societies might achieve it on a regular basis if only we could identify what it is. Their more modest aim is to explore the different ways people organize their personal and collective lives in order to foster what they think of as good, and to study what it is like to live at least some of the time in light of such a project (2013, 457).

Robbins (2013) is not proposing an anthropology of the good as a replacement for suffering slot anthropology. Rather, he suggests that it can be seen as a supplementary project. The purpose of the anthropology of the good from Robbins's perspective is "to help realize in a distinctively anthropological way the promise suffering slot anthropology always at least implicitly makes: that there must be better ways to live than the ones it documents" (2013, 458).

While this strikes me as a worthwhile project, I also have certain reservations, at least in the context of pediatric cancer. Let me try to explain. Pediatric cancer treatment is clearly the site of a tremendous amount of suffering for patients and their family members. As one professor put it to me when I told him my dissertation research was on pediatric cancer: "If I was a religious person, having a child diagnosed with cancer would totally destroy my faith." I, who am also not a religious person, can't help but feel the same, but I know that this is not how everyone reacts. As my mother and many other parents I met throughout my fieldwork might retort, only a non-religious person would say such a thing. For my mother and many other Christian parents, faith is one of the few things that sustained them through such a dark phase of life. By holding onto faith and/or some form of ritual practice, many religious parents are able to convince themselves that the good is still possible despite the tragedy that has befallen them.

Religious practice is only one way that parents and patients maintain hope in the good in the context of cancer treatment. There are many other ways—by spending time with loved ones, by attending cancer advocacy events, by starting non-profit organizations dedicated to helping patients, etc. Despite all of these ways of holding onto the good, the reason I am hesitant to fully embrace Robbins' project in this context is that, for some people, at least for some period of time, cancer diagnosis and treatment actually do obliterate their faith in the good, and I believe it is important not to inadvertently sanitize the depth of suffering that can exist in the field of pediatric cancer treatment by focusing only on people who are actively pursuing a vision of the good. In this account, I certainly portray such people. But I also portray people who are terrified, hopeless, and in intense existential and physical pain. In my mind, to refrain from doing so would be to do a disservice to these people, whose reactions, I think, deserve to be recognized and legitimized.

Life on Planet Cancer: Metaphorical and Literal Descriptions of Illness

> Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we

all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

-Susan Sontag 1978, 3

We note the significance of Rimbaud's intuition that metaphor can change the world.

-Claude Lévi-Strauss 1979, 325

In attempting to convey the spectrum of hope and suffering that exists in the field of pediatric cancer treatment, I pay close attention to the ideological models upon which participants draw in describing their own lives. Throughout my fieldwork, which I will describe in more detail in chapter three, I met many people who described the experience of cancer treatment by using a number of common metaphors: battles, journeys, monsters, foreign kingdoms, and separate planets are a few of the most widely circulating. This is unsurprising, as such metaphors also commonly circulate in print and audiovisual media. To take a prominent example, after enduring treatment for breast cancer, Susan Sontag wrote the book *Illness as Metaphor,* in which she described two "kingdoms"—the kingdom of the well and the kingdom of the sick. Citizenship in both kingdoms, Sontag argued, was a universal human inheritance: "Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (Sontag 1978, 3).

Playing with the metaphor of the kingdom, the oncologist Siddhartha Mukherjee titled his biography of cancer *The Emperor of All Maladies* (2010). In his formulation, our attention is drawn to the force of the disease and to the tireless efforts of scientists and physicians who have dedicated their lives to understanding and curing it. In Mukherjee's account, cancer is metaphorically represented as biomedicine's most powerful and cunning adversary—an adversary that constantly defies even the most scientifically advanced attempts to contain it. In constructing the story in this way, Mukherjee reflects and reinforces the profound fear of cancer that circulates throughout the world today: If one has to enter the kingdom of the sick, one hopes that it will not be under the rule of this tyrant.

Drawing on a similar metaphor, Heidi Schultz Adams, who is a cancer survivor, founded an organization called *Planet Cancer* in 2006. Like "the kingdom of the ill," the name Planet Cancer metaphorically evokes an image of cancer diagnosis and treatment as a process of entry into a shocking new world—a totally foreign and terrifying planet. As Adams and Schultz describe in their book, *Planet Cancer: The Frequently Bizarre Yet Always Informative Experiences and Thoughts of Your Fellow Natives* (2010), while one may frequently feel alone throughout cancer treatment, Planet Cancer is nevertheless populated by many experienced "guides" who have already established fluency in the discourses and practices of oncology, the biomedical specialty charged with the treatment of cancer.

All of these metaphors point to the terrifying experience of cancer diagnosis and treatment. They use morally charged imagery to evoke the shock, disorientation, and sheer terror that cancer patients and their families often experience. In metaphorically evoking the experience of cancer, they provide powerful tools for cancer patients to engage in what Paul Rabinow

(1996) has referred to as biosociality. For example, by developing and circulating the metaphor of Planet Cancer in a popular patient resource, Heidi Schulz Adams and her collaborators have created a model through which patients and families can relate to each other as inhabiting a foreign space that very few other people will understand.

While the metaphors that survivors and their loved ones use to describe the experience of cancer can serve as powerful resources, there are also potentially damaging ways in which cancer and its metaphors interact. For example, although Susan Sontag ultimately developed a metaphor by putting forward the notion of "the two kingdoms," she also argued that metaphoric representation is harmful to cancer patients. As Sontag points out, many of the ways in which cancer is represented metaphorically are incredibly abusive, stigmatizing, and dehumanizing for disease sufferers. For example, militaristic metaphors of battle that cast cancer patients as "warriors" may place undue emotional pressure on suffering people to "keep a stiff upper lip" as they face the possibility of death. Sontag ultimately argues that the metaphoric representation of illness places a burden on the ill, relegating them to a disempowered and abject zone of existence.

Sontag seems to imply that cancer patients, caregivers, and experts would do well to strip their discourse of all metaphor and to adopt what linguistic anthropologists would call a literalist language ideology. While the term literalism in the United States is most often applied to the Constitution and the Bible, it could be used to describe any ideology of language that refuses to grant legitimacy to interpretations or representations that rely on metaphor or allegory.[2] In theory, a literalist account of cancer would be presented in only the most straightforward language that does not run the risk of confusing actuality with metaphoric representations—for example, confusing a terrified, dying person for a warrior, or casting what are actually billions of wildly proliferating cells as the emperor of a kingdom.

Writing in response to Sontag's call for literalism, Scheper-Hughes and Lock (1986) express sympathy with her anger at the violence of common ways of representing disease. But their sympathy comes with critique:

> It is altogether ironic, however, that Sontag, literary artist and cancer victim, would argue for a de-poeticization and de-metaphorization of disease (or of any powerful human experience, for that matter). She would have us—patients all on one level—retreat into the safe haven of radical materialism offered in scientific biomedicine. She asks that diseases be stripped of their symbolic content, their cultural meanings, and be understood for *what they* (presumably) *are*: biological entities *alone*, things-in-themselves. She would have us desocialize disease so that we might come to see suffering, illness, and death as plain events, bad things that sometimes happen to good people. Hers is, in short, an argument for the reification and medicalization of human misery, a stance very much at odds with the critical, existential anthropology of illness that we and many of our colleagues in medical anthropology are trying to develop (1986, 138).

From Scheper-Hughes and Lock's perspective, the answer to the suffering, stigma, and dehumanization is not de-metaphorization. To abandon the poetic, metaphoric function of human thought, language, and practice in the realm of disease would be to strip humans of a crucial healing and coping resource. Metaphoric discourses are not only used in stigmatizing or distorting ways, but also in ways that can produce positive effects in the bodies and lifeworlds of sufferers. While the most rationalized domains of biomedicine would reduce such effects to the

delegitimizing category of the "placebo effect," Scheper-Hughes and Lock suggest that we would do well to take the effects of metaphoric discourse seriously. Besides being undesirable, it is unlikely that it would ever be possible to purge all health related discourses of metaphoric representations. As Lakoff and Johnson (1980) point out, we all "live by" metaphors that shape the ways in which we communicate, think, and act.

In addition to Scheper-Hughes and Lock, a number of other anthropologists have written about the central role of metaphoric representation in illness experience. Becker describes the uses of metaphor among people struggling with infertility in the United States, showing how it functions as "one mediator of disruption that enables individuals to recreate a sense of continuity and to reconnect themselves to the social and cultural order after a disruption" (1994, 404). Taking a slightly different tack, Van der Geest and Whyte (1989) show how pharmaceuticals act as vehicles of metaphoric association. They argue that the physicality of pharmaceuticals—their "thingness"—aids in rendering the inchoate experience of illness more tangible.

In "The Effectiveness of Symbols," Lévi-Strauss offers a particularly influential account of the relationship between metaphor, illness, and healing. He analyzes a song that Cuna shamans use to facilitate difficult childbirth, showing how "specific psychological representations are invoked to combat equally specific physiological disturbances" (1979, 186). Through narrating a journey along *Mu-Igala* (the path to the abode of *Muu*, who is the spirit thought to be responsible for the adverse circumstances), the shaman helps the patient to delineate the emotional content of her physiological disturbance.

In attempting to identify the mechanisms through which shamanic therapeutic methods obtain their efficacy, Lévi-Strauss is hesitant to reduce successful outcomes to what many biomedical professionals would call the "placebo effect." From Lévi-Strauss's perspective, the claim that shamanic curing is "psychological" in nature is meaningless unless we can explain how the invocation of psychological representations can produce physiological effects. In this case, the shaman psychologically prepares the patient to experience mythical narration as a recreation of the physical experience of vaginal penetration and the pains of labor. It is important to note here that, for the Cuna, the *Mu-Igala* and the abode of *Muu* that feature in the shaman's song represent "the vagina and uterus of the pregnant woman" (1963, 183). In singing his song in a ritual context, the shaman effectively connects the metaphorical, the psychological, and the physiological, making inexpressible sensations legible and accessible to the patient's consciousness.

In short, despite Sontag's call to strip illness of metaphorical representation, many anthropologists provide evidence that metaphors are a critical aspect of illness experience insofar as they function as embodied tools for coping, healing, and sense making. Metaphors help patients and their loved ones to render their condition legible and manageable by relating it to images and symbols with which they are familiar and morally and affectively attached. This process enables the construction of linkages across phenomena that many analysts typically treat as separate—for example, ideas and symbols become viewed as tools for inducing physiological effects. In this way, anthropologists suggest that metaphors must be taken seriously not only for their symbolic content, but also for their ability to literally change the material world.

Back on Planet Earth

At the same time, metaphors can lead to confusion. One evening in 2018, I was at a retreat with a group of medical anthropologists and two physicians to discuss our respective

work in various health-related fields. As I was describing my work, I made the comment that part of my goal was to analyze the processes through which professionals usher patients and families into the foreign, confusing, and terrifying world of cancer treatment. Most of the anthropologists at the table nodded, which seemed to indicate that this struck them as a reasonable approach. One of the physicians, however, looked at me perplexed. "I'm just a little confused by the way you describe it… They're actually *not* in another world, but in the same world as the rest of us." I replied that I meant something more like "lifeworld," or a phenomenological world, not world as in "planet." Of course, the prominent "Planet Cancer" metaphor notwithstanding, cancer treatment obviously takes place on the planet that most English speakers would call Earth.

Despite the physician's attempt to pull me back down to the cold, hard ground, it is tempting to appropriate "separate world" metaphors for my purposes. Among anthropologists, these metaphors may evoke both nostalgia and discomfort. The nostalgia comes from a disciplinary history that casts anthropologists as wanderers who enter foreign worlds in hopes of coming away with an improved understanding of the beings and ways of life that exist within those worlds. The most romanticized images of the anthropologist-as-explorer have no doubt drawn many young students toward the discipline, especially prior to the 1980s, when criticism of the discipline's involvement in facilitating colonial and imperial order became a common feature of anthropological writing. Precisely because of this criticism and the violent histories it renders legible, the image of the field as a "separate world" may be off-putting to anthropologists, as it hearkens back to a time when our disciplinary forebears failed to resist the pull of exoticism and its racist implications.

While my goal is certainly not to banish metaphoric discourse from this study, perhaps my physician colleague was right to ask me to deal with the ambiguities of describing cancer treatment as a "world" of its own. Given anthropology's violent disciplinary histories and the ways in which they endure in the present, it is important to be cognizant of the poetics I use to describe the lives I encountered through fieldwork, and I will therefore refrain from using "separate world" metaphors to make sense of cancer treatment, although I will not sanitize such metaphors from study participants' discourse. Metaphors such as "Planet Cancer," and "The Kingdom of the Ill" may provide powerful technologies of biosociality, but it is important to point out, at the risk of following Sontag and my physician colleague in seeming too literal-minded, that these are in fact metaphors. "Planet Cancer" and the "Kingdom of the Ill" offer powerful ways of describing the experiences of people who were all born on the *same* planet, which is no longer predominately carved up into kingdoms, but rather into nation-states that produce and govern racialized, gendered, and classed populations.

To put it tersely, there is no actual Planet Cancer or Kingdom of the Ill where all "natives" share a single culture or mode of identification. Instead, there are multiple biomedical facilities with oncological treatment centers that are embedded within particular national healthcare systems. These facilities are populated with various technologies and socially and physiologically heterogeneous groups of bodies and persons that bear diverse relationships to the colonial, imperial, and patriarchal processes that have shaped human co-existence on Planet Earth. For this reason, here I will rely on a different metaphor that anthropologists and sociologists have developed to make sense of social life: *the field*. I conceptualize pediatric cancer treatment as taking place not within separate planets or kingdoms, but rather within *the field of pediatric cancer treatment*.

In using the term field, I draw primarily on Pierre Bourdieu's praxeology, although I modify it by placing it in conversation with other theoretical frameworks. Bourdieu uses the term

"field" to describe a set of social positions that are hierarchically arranged and endowed with different levels of capital. While fields are products of the embodied activities of specific people, they also play a role in producing those people by compelling them to engage in various acts of position-taking, which I suggest are crucial to the processes that Ian Hacking (1986) calls "making up people." Fields are constituted through physical and social relations that involve historically produced forms of capital and schemes of "vision and division" that structure the embodied practices and perceptions of specific individuals and groups of people, all of whom inhabit historically specific positions in social space. For example, as Bourdieu and Passeron (1977) show in the case of the French educational field, students who are born into upper class families are predisposed to be recognized as exhibiting characteristics associated with intelligence and academic success. Through their own experiences in the educational field and elsewhere, teachers develop a habitus that leads them to almost automatically recognize certain of their students' characteristics as indicative of academic talent. But the rub of the argument is that these characteristics have often been selected and upheld by conventions that are rooted in arbitrary forms power and domination, despite the fact that they present themselves as truthful and rational.

Like all fields, the field of pediatric oncology constitutes and is constituted by human participants who were born into physical and social spaces that they did not invent wholesale, but which they play a role in (re)producing. This is a crucial point, because it also explains how fields are maintained and changed over time. It isn't as if all participants enter into a field, internalize its carbon-copied structures, and then go about reproducing those structures with perfect fidelity. Entering into a particular field as a participant involves a dynamic process of "becoming" (Biehl and Locke 2017), as new practices are taken up, new technologies are encountered, and new social and physical relations are formed. This process of becoming refers not only to the (re)production of embodied humans, but of the field itself, the maintenance of which vitally requires the activity of co-existing participants. In this way, people have the capacity to transform fields by consciously and unconsciously introducing mutations of particular elements.

Given the association of cancer with high mortality, this may strike readers as an odd way to describe the field of pediatric cancer treatment—as a space of *becoming*. In emphasizing becoming as an aspect of the field of pediatric oncology, I do not mean to deny or romanticize the tragedy and loss that too often accompany cancer treatment. But "becoming" need not refer to some romantic process of flourishing or teleological unfolding. In this study, I use the term becoming to emphasize the motions and transformations of individual and collective lives, which of course also entail losses and deaths. As I hope will become clearer in what follows, the notion of the field of pediatric oncology helps to better understand the relationship between individual and collective transformations that constitute lives affected by pediatric cancer, whether as patients, family members, friends, or professionals.

The Layout of this Dissertation

In summary, this dissertation draws on eighteen months of anthropological fieldwork among patients, families and professionals engaged in the process of cancer treatment at BACH. Drawing on interviews and participant observation, the rest of this dissertation will explore the following questions:

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1. How do ideologies of childhood, communication, and care circulate, interact, and become hybridized in relation to the problem of pediatric cancer treatment?
2. How do processes of ideological circulation and mediation produce and shape the hierarchically arranged social positions that constitute the field of pediatric cancer treatment, and how do individuals participate in these processes?
3. How do differently positioned participants interpret and recognize the effects of pediatric cancer treatment and care, and in what ways might dominant patterns of recognition conspire to hide the production of various forms of iatrogenesis, or medically induced harm?

Before diving into more of the material I collected during fieldwork, I will begin by more thoroughly developing the conceptual framework that guides the study. The following chapter draws on an analysis of historical accounts of pediatric cancer treatment in the United States in order to explicate the conceptual ensemble I use to make sense of the field of pediatric cancer treatment. Drawing on the work of Pierre Bourdieu, I show how the positions that make up the field of pediatric cancer treatment exist in productive tension with specific bodies, habituses, and forms of capital. Juxtaposing the biography of the prominent pathologist Sidney Farber with the history of multidisciplinary cancer care, I show how individuals and groups take up positions in ways that have transformative effects upon fields. By developing a model of "total care" and aggressively promoting it using every form of capital at their disposal, Sidney Farber and the advocacy group who called themselves "the Laskerites" completely transformed the field of pediatric cancer treatment. Their work ushered in the widespread use of chemotherapy, as well as a greater attention to psychosocial care through the inclusion of new professionals on the care team and through what I will describe, following Giroux (1999, 1994) as the "Disneyfication" of the children's hospital environment.

As I hope to show through these historical examples, all fields are dynamic spaces of embodied social activity that rely on the construction and circulation of intersecting ideological models that people use to position themselves and each other into the particular statuses and roles that make shared ways of life possible. Of course, as models circulate, they do not remain unchanged. Through various acts of citation, or iteration, ideological models can be altered, whether unwittingly or intentionally. But a very important caveat is in order here: the circulation of ideological models is itself ideologically modeled and controlled. As I will describe in the next chapter, no form of discourse circulates spontaneously or freely, and certain individuals and groups have much greater ability to construct and control the circuits and logics that render the widespread circulation and institutionalization of ideological models possible. This is as true in the field of pediatric cancer treatment as in any other field.

After setting up the conceptual framework, I will move in chapter three to a discussion of my field site and methods. I begin by describing BACH and situating it as a "safety net" hospital within the political economy of the San Francisco Bay Area, which is one of the wealthiest regions in the world with one of the highest levels of inequality. I then describe the general structure of BACH's oncology program, which, as an iteration of the ideological model of total care, is staffed by a large, multidisciplinary team of professionals who are divided into two groups—the biomedical and the psychosocial. I describe the professional positions and roles associated with each group, as well as the forms of capital that produce hierarchies within and across groups. I then describe how I gained access to BACH and the ideologically modeled process of IRB review that rendered me formally eligible to conduct research at the institution.

This process shaped the manner in which I was able to take up a position within the field and thus how I was able to engage with professionals, patients, and family members. In addition to the productive effects of ideological models that were institutionalized into the hospital's organizational practices, my own models of communication and care, which in part derive from my disciplinary training in anthropology, also played a productive role throughout the process of inquiry. Drawing on anthropological discussions of interviews and ethnographic writing, I describe how this work is the product of a series of ideologically modeled acts of professional transformation through which I converted embodied practices of observation, social interaction, documentation, and analysis into *a text*—a polyvalent monograph that can be decontextualized and recontextualized. I have done so in hopes of informing specific publics—particularly medical researchers and health care professionals—and compelling them to address a number of issues that arise in the field of pediatric cancer treatment.

In chapter four, I discuss how patients' and family members' enter and take up positions in the field of pediatric cancer treatment. This chapter draws on a mix of interviews and participant observation to reconstruct the cancer treatment trajectories of three patients—Rachel, Jun, and Jared. Building on the work of Lochlann Jain (2013), I note how cancer diagnosis enacts a "collision in modes of time," or a violent experience of disjuncture between the temporalities of cancer treatment and the normative time of various institutions that shape life trajectories. I show how the process of treatment involves a re-temporalization of patients' lives around the temporal projections of the treatment protocol. This is done in hopes of healing patients' bodies and thus repairing the rupture between their biographical trajectories and dominant modes of institutional time, but it often requires painful phases of separation from fields and positions into which patients were previously habituated.

While the temporalized models of care projected in cancer treatment protocols are intended to make treatment into an orderly process, their iterative deployment is nevertheless characterized by a tremendous amount of uncertainty that patients and families must endure. As previous anthropological research has emphasized, physicians view it as their role to help patients and families maintain optimism throughout this process. One way they do this is by attempting to limit discussion of uncertainty and bad news, particularly in the presence of patients (Bluebond-Langner 1978; Clemente 2015). However, sometimes patients are unable to ignore the uncertain efficacy of treatment, and they become overwhelmed by the fear that their life will never be routed back onto the tracks of institutional time. In such situations, the psychosocial arm of the care team is deployed with extra force, and these patients are also often prescribed psychiatric medications to help cope with negative emotions. In recounting and analyzing these issues, I draw on anthropological discussions of time in order question the binary opposition between being and becoming that is so commonly deployed in childhood studies.

Chapter five also relies on a mix of participant observation and interviews, focusing on the ways in which professional ideologies of care and communication intersect with ideologies of childhood. Pediatric professionals tend to espouse ideologies of childhood that emphasize young people's vulnerability and need for protection from influences that can harm physical and psychosocial health. These ideologies draw on bourgeois, white, Euro-American ideas that scholars in childhood studies and the anthropology of childhood have thoroughly questioned, and I draw on these lines of questioning for guidance (Lancy 2008; Montgomery 2008; Scheper-Hughes and Sargent 1998; Stearns 2016; Stephens 1995; Ariès 1965). Such child-directed ideologies not only shape social interactions between professionals, family members, and patients, but they are also built into the hospital environment in various ways. Although many

patients take pleasure in child-directed interactions and environments, I argue that they can also have *morally iatrogenic* effects—by which I mean professionally-induced effects that devalue, delegitimize, and/or stigmatize the patients' sense of personhood and the various ideologies, relations, and practices that constitute it as a site of value. Drawing on a range of examples from music therapy, and other psychosocial care activities, I show how ideologies of childhood become hybridized with models of care and communication in ways that can result in feelings of infantilization, stigmatization, and censorship among specific young people.

In emphasizing how the citation of child-centered models of care and communication produces moral iatrogenesis, I build on the work of (bio)medicalization theorists and medical anthropologists who study various forms of violence (Illich 1982; Farmer 2004; Holmes 2013; Scheper-Hughes and Bourgois 2004). I show how moral iatrogenesis is entangled with other forms of iatrogenesis that are much more commonly recognized in the field of cancer treatment. For example, it is often recognized that chemotherapy and radiation can be intensely harmful to patients. However, iatrogenesis is much less commonly viewed as a possibility in psychosocial care. In pointing out moral iatrogenesis, I do not mean to draw an equivalence with more commonly recognized forms of iatrogenesis, but rather to consider the relationship between biomedically and psychosocially inflicted forms that affect cancer patients, as well as their loved ones, particularly parents. Insofar as ideologies of childhood are connected to ideologies of parenthood, professionals may draw on these ideologies to judge parents for making decisions that are viewed as not in the patient's best interest. In the most extreme cases, this can result in professionals reporting parents to Child Protective Services, although this does not happen very frequently.

In the conclusion, I review the key points of the dissertation, followed by a discussion of study limitations and future directions for research. Like most anthropologists, in the end, I offer no final, exhaustive answers to the questions and problems posed in this dissertation. Still, I hope that the reflections I offer here will broaden our understanding of how young people, particularly critically ill young people, make themselves and are made through the hybridization of multiple ideologies, which function as models for living.

End Notes

[1] Economic disparities across national healthcare systems certainly prevent the model's thorough implementation in many of the world's cancer treatment centers. For example, Julie Livingston (2012) describes how Botswana's only designated cancer ward is forced to "improvise care" in the face of an emerging cancer epidemic. Of course, healthcare inequities do not only exist between national systems, but also within them. Although BACH is designed as a "safety net" children's hospital in one of the wealthiest economies in the world, and one might therefore expect it to be well taken care of in terms of funding, it operates at a chronic deficit, and professionals are required to find creative ways to patch together various streams of volunteer labor and charitable funding in order to keep certain programs going, particularly those related to psychosocial hospital care. Still, through the creativity and labor of many people, the hospital manages to offer various forms of psychosocial care to all patients and family members who walk through their doors. This is certainly not the case in all American hospitals, particularly private institutions that turn away uninsured or underinsured patients.

[2] I will review work on language ideologies in chapter three. On literalism as a general phenomenon in the United States, see Crapanzano (2000).

Chapter 2
The Field of Pediatric Cancer Treatment

> A field consists of a set of objective, historical relations between positions anchored in certain forms of power (or capital), while habitus consists of a set of historical relations "deposited" within individual bodies in the form of mental and corporeal schemata of perception, appreciation, and action.
>
> -Bourdieu and Wacquant 1992, 16

Anthropologist Myra Bluebond-Langner (1978), who carried out a study of how children dying of leukemia make sense of their worlds, describes the children's hospital where she carried out her work as a "physical plant" that consists of various facilities—e.g., the cancer ward, clinics, conference rooms, laboratories, the surgical unit, etc.—equipped with a variety of technologies—e.g., televisions, x-ray scanners, surgical instruments, etc. Although I too carried out fieldwork within the "physical plant" of a children's hospital, I will not limit my analysis to what goes on inside hospital walls. Rather, I will speak of the *field of pediatric cancer treatment* and the various positions it makes available to agents who enter it. Neither the agents nor the positions that constitute the field of pediatric cancer treatment are confined to the space of the hospital. A great deal of the labor of cancer treatment takes place in the private homes of patients, and health care professionals acquire specialized knowledge in a range of spaces beyond the hospital, such as medical schools, conferences, and continuing medical education courses held in various locations. There are many more possible examples.

When I speak of the *field of pediatric cancer*—a term I develop by building on and modifying Bourdieu's theory of fields—I am not referring to a single delimited site. The field of pediatric cancer treatment encompasses many delimited sites—many "physical plants," to use Bluebond-Langner's (1978) phrasing, but it is not reducible to any particular site or spatial configuration at any particular moment in time. Rather than a bounded, static space, the field of pediatric cancer refers to a set of historically unfolding relations through which pediatric cancers are diagnosed and individual people are made into cancer experts, professionals, patients, and caregivers.

Fields are composed of a range of hierarchically organized positions that shape how individual participants see themselves and each other. As new participants enter a field, a twofold process typically unfolds: 1) pre-existing participants deploy ideological models in attempts to position new participants at the same time as 2) new participants position themselves by engaging in *position-takings*. In the field of pediatric oncology, there are a number of generally recognizable positions that specific people inhabit/are made to inhabit and which call for certain role-based activities—e.g., physician, nurse, music therapist, patient, parent, etc. As Bourdieu makes clear, although position-takings can be performed in s variety of ways, they are never totally spontaneous or unconstrained. Rather, they are structured by at least two sets of processes—*habitus formation* and *capital distribution*. Habitus refers to a historically unfolding but relatively stable embodied set of dispositions structured by schemas of "vision and division" that are derived from the structure of the social world, which is composed of multiple fields. As bodies are conceived and born into the world, they emerge into regions of social space shaped by fields that existed before their birth and which are organized around specific forms of capital that drive social activity. Individual habituses are formed and capital is accumulated through dynamic interactions between bodies and social structures.[1] It should be remembered, however, that

capital accumulation begins from the ground of *inherited* capital. Furthermore, it should be pointed out that accumulation is not a linear process. In other words, capital can be gained and lost.

To take an example from the topic at hand, the general position of "pediatric oncologist" has existed for some time, and many people have taken it up. No one is born a cancer physician, but over time and through social interaction they acquire general models or schemas that allow them to identify the physician role and, perhaps, to imagine themselves carrying it out. A pediatric oncologist, in a very general sense, is a person who has moved through social space in a way that led them to pursue advanced training in the biomedical treatment of cancer. Entry into such training would have required the inheritance and accumulation of what Bourdieu (1986) refers to as social, cultural, and economic capital.[2]

In the normative structure of American medical education, the novice student is transformed into a resident, then a fellow, and then a physician. In going through this institutionalized set of positions, which is never as straightforward as it sounds, the habitus of the medical student changes. Through hours of participation in a broad range of pedagogical exercises, students gradually acquire the corporeal and mental schemas necessary to carry out the work of a professional oncologist. They learn to recognize and interact with cancer in ways that are opaque to many non-physicians, and they receive educational credentials and licensure to practice cancer medicine. Various institutional bodies and professional organizations uphold the value of these forms of capital, which provide cultural and legal guarantees that specific people have reasonable levels of oncological expertise to justify being placed in charge of the process of cancer treatment—a job which carries a tremendous amount of responsibility, as well as a great deal of cultural distinction and a high salary relative to many other careers, although it should be pointed out that pediatric hematologists/oncologists are one of the lowest paid groups of specialists (Hamblin 2015).

In drawing attention to the reproduction of physicians, or, for that matter, any other position in the field of pediatric cancer, it is important to point out that fields are neither frozen in place, nor do they mechanistically reproduce themselves in perpetuity. Given my reliance on Bourdieu's theory of fields, I might be accused of rendering the social world static. This is a critique that has frequently been lodged at Bourdieu and other theorists who rely on a notion of "social position." For example, although he does not name Bourdieu specifically, Brian Massumi (2002) objects to concepts of "position" or "positionality" on the grounds that they freeze the body and subjectivity in a particular location on an ideological grid, thus making it impossible to describe how bodies and subjectivities engage with the world and change over time. However, I think this critique only really holds if one treats the ideological grids, models, or schemas as fixed. If, instead, these are treated as "structuring structures," or *iterable constructs* that circulate widely, producing social life at the same time as they are produced and mutated by it, then Massumi's critique becomes much less of an issue. At the same time, while it would be a mistake to treat the ideologically constructed positions that constitute fields as frozen in space and time, it would also be a mistake to imply that all positions are easily changeable. Unfortunately, there are many people in the world who are arguably frozen—or perhaps "trapped" is a better word—into the ideological grids with which other people identify and control them.

Judith Butler, focusing on Bourdieu's ideas about language and performativity, also finds a troubling fixity:

Bourdieu's view…presupposes that the body is formed by the repetition and acculturation of norms, and that this forming is effective. What breaks down in the course of interpellation, opening up the possibility of a derailment from within, remains unaccounted for. Bodies are formed by social norms, but the process of that formation runs its risk. Thus, the situation of constrained contingency that governs the discursive and social formation of the body and its (re)productions remains unacknowledged by Bourdieu. This oversight has consequences for his account of the condition and possibility of discursive agency. By claiming that performative utterances are only effective when they are spoken by those who are (already) in a position of social power to exercise words as deeds, Bourdieu inadvertently forecloses the possibility of an agency that emerges from the margins of power (Butler 1997, 156).

Butler finds Bourdieu's account problematic in its repetitive fixity. By implying that the forms of capital always function in expected ways, essentially securing the efficacy of the powerful and the inefficacy of the less powerful, Bourdieu seems to foreclose the possibility of resistance. But, in my reading, Bourdieu's account of social fields and the role of capital and performative speech in social (re)production is much more dynamic than Butler suggests. Still, it is perhaps easy to see why Bourdieu has been criticized in this manner. Despite his disavowal of mechanistic explanations of social life (Bourdieu and Wacquant 1992, 108), there is a definite systematicity to his account that can easily be read as implying a fixed reproductivity. But I interpret Bourdieu's account as one of *relative historical stability*, not fixity. For example, in their study of the French educational system, Bourdieu and Passeron (1977) show how the schemas that enable the production of distinctions between "good" and "bad" students reflect the values of the dominant classes, and most teachers reproduce those values in their pedagogical and evaluative activity. Since students who come from families who belong to the dominant class *tend* to reproduce dominant values in their classroom behavior and schoolwork, they *tend* to be recognized by teachers as the brightest and most promising students, a recognition that results in their admission into the best universities, and, later, to the most highly compensated and regarded careers.

Of course, there are always instances in which common tendencies do not occur—for example, when a member of a population not associated with high levels of capital is recognized for their abilities, and, through this recognition, manages to break into the highest ranks of a field. But the fact that this *happens relatively infrequently* ensures that the structure of existing social formations and the distributions of capital that undergird them are usually not fundamentally altered by these events. While change can certainly occur, existing distributions of capital create powerful forms of social inertia that act as barriers to change, especially changes proposed or enacted "from the margins of power," as Butler puts it. This is not to deny that resistance can occur, or that it can lead to major change in a particular field. Rather, it is to say that such change is extremely difficult to achieve, as it requires challenges to existing forms of authority, as well as sufficient capital and energy to sustain such challenges to the point of having an impact on institutionalized practices.

The positions that constitute any given field are not fixed, but they also do not change in totally spontaneous ways. A certain amount of historical stability can be attributed to the structure of particular fields, although this stability should not be understood as naturally occurring, but rather maintained by interested human agents, endowed with particular habituses that lead them to value and pursue certain forms of capital and to conform to certain naturalized,

or *doxic*, schemas of thought and behavior. Positions can be made to endure for very long periods of time, and when fields do change, they do so in ways that are constrained, though not totally determined, by existing distributions of capital. The history of oncology demonstrates this. In the following section, I take a brief detour into this history, focusing particularly on the work of American oncologist Sidney Farber as a way of thinking with the concepts of field, habitus, and capital. This will also set the stage for the ethnographically oriented chapters that follow by describing some of the central historical transformations that have shaped the field of pediatric cancer treatment.

Disneyfying the Field of Pediatric Oncology: Sidney Farber's Vision of "Total Care"

> Every evening, Farber came to the wards, forcefully driving his own sailless boat through this rough and uncharted sea. He paused at each bed, taking notes and discussing the case, often barking out characteristically brusque instructions. A retinue followed him: medical residents, nurses, social workers, psychiatrists, nutritionists, and pharmacists. Cancer, he insisted, was a total disease—an illness that gripped patients not just physically, but psychically, socially, and emotionally. Only a multipronged, multidisciplinary attack would stand any chance of battling this disease. He called the concept "total care."

> -Siddhartha Mukherjee, *The Emperor of All Maladies* (2010:125)

Sidney Farber, who is often remembered in patriarchal fashion as the "father of modern chemotherapy" (Miller 2006), was born in Buffalo, New York in 1903 to a Jewish family who had migrated to the United States from Poland. Farber, one of fourteen children, grew up in an environment of high educational aspiration. As Mukherjee describes:

> The [Farber] family lived in modest circumstances at the eastern edge of town, in a tight-knit, insular, and often economically precarious Jewish community of shop owners, factory workers, book-keepers, and peddlers. Pushed relentlessly to succeed, the Farber children were held to high academic standards. Yiddish was spoken upstairs, but only German and English were allowed downstairs. The elder Farber often brought home textbooks and scattered them across the dinner table, expecting each child to select and master one book, then provide a detailed report for him (Mukherjee 2010, 18).

Farber excelled in school and eventually attended the University of Buffalo, where he studied biology and philosophy, graduating in 1923. After completing his undergraduate education, Farber went overseas to Germany to study medicine, and he later returned to the United States to complete his medical education at Harvard. As Mukherjee (2010) points out, it was a common pattern among Jewish American students to have to go to a medical school in Europe prior to securing a spot as a student at an American medical school, as the anti-Semitism of the time prevented even the most talented Jewish students from the ease of institutional entry that was enjoyed by many of their WASP counterparts. As they continue to be today, barriers to educational recognition in the United States were, in Farber's time, shaped by conditions of racial domination that prevented, or at least hindered, various forms of capital accumulation by members of non-white populations,[3] particularly African Americans, who have arguably been

the racial group most violently and persistently excluded from participation in higher education in the United States (Duster 2009). Of course, gender "intersects" (Collins and Bilge 2016; Crenshaw 1990) with race in producing forms of educational exclusion and privilege, and the fact that Farber inhabited a male identity no doubt worked in his favor.

Farber completed his medical training in pathology in the late 1920s and was able to secure a full-time position at Children's Hospital in Boston. By the 1940s, he had chosen to focus his attention on the treatment of childhood leukemia—a disease that, at the time, was considered a death sentence. Farber had taken note of the research of an English physician named Lucy Wills, who in 1928 had discovered that folic acid was effective in curing severe anemia in malnourished women who worked in cloth factories in Bombay. Wills discovered that folic acid is essential to bone marrow function and the production of healthy blood cells, and Farber extrapolated from these findings that perhaps folic acid could restore the normal production of blood cells in pediatric leukemia patients. Following his hunch, Farber designed a small clinical experiment to inject leukemic children with folic acid (Mukherjee 2010).

Unfortunately, Farber's initial experiment backfired terribly. The folic acid he injected into his patients, instead of halting the production of leukemia cells, actually exacerbated it. Farber was judged harshly by his colleagues, who accused him of hastening the death of his patients with reckless experimentation. But Farber was undeterred. He reasoned that if folate hastened the progression of leukemia, then perhaps an *anti*folate could halt it. Farber eventually acquired an antifolate substance, aminopterin, from the chemist Yella Subbarao. In late 1947, Farber began injecting leukemic children with the chemical, and, to everyone's surprise, aminopterin produced short-term remissions in 10 of 16 patients (Mukherjee 2010).

Farber had discovered the potential efficacy of chemotherapy as a cancer treatment strategy. However, he was not well liked among his colleagues, and his findings were initially met with fierce resistance and skepticism from other members of the field, who accused him of falsifying his data and exaggerating the success of his approach. Over time, however, Farber and others produced firmly established findings that demonstrated the promise of chemotherapy in treating pediatric leukemia, and this concretized Farber's reputation as a leading thinker in the field of pediatric cancer treatment. Farber's work laid the foundation for future discoveries (particularly those made by the coincidentally named researchers Emil Frei and Emil Freireich) that led to the model of high-dose multidrug chemotherapy regimens. These regimens produced the first long-term remissions in childhood leukemia, and their various iterations continue to be in wide use today (Mukherjee 2010).

At the same time as Farber was discovering and promoting advancements in the biomedical treatment of cancer, he was also advocating for the improved psychosocial care of cancer patients and their family members. Prior to the 1950s, most pediatric cancer wards were austere and solemn places. The bright colors and child-directed amenities of contemporary American children's hospitals had not yet become the cultural norm. Through the efforts of a number of influential people, including Farber, however, this all changed. Farber teamed up with the millionaires Mary and Albert Lasker to raise funds for the development of a state of the art cancer treatment center, where patients would have access to the most advanced forms of biomedical and psychosocial care. Farber and the Laskers, who made their millions in advertising, developed cancer fundraising ads using the image of a young cancer patient, Einar Gustafson, who was renamed "Jimmy" to make him more palatable to white Americans. Einar/Jimmy became an icon of the fight against pediatric cancer treatment, compelling millions of Americans to donate their spare change to the cause. Eventually, they raised enough money to

build the Jimmy Fund Clinic, which, unlike other pediatric facilities, was designed to emotionally uplift patients and their family members.

       The Jimmy Fund Clinic was designed and administered according to a model that Farber described as "total care." This approach marshaled all of the resources available to biomedical and psychosocial professionals in order to prolong the lives of children with cancer and to bring about as much comfort and peace of mind as possible throughout the difficult treatment process.[4] Over time, the total care model of the Jimmy Fund Clinic became a global standard in pediatric cancer care. In addition to incorporating new methods of treatment, such as chemotherapy, into their institutional repertoires, major cancer treatment centers throughout the world began to create new professional positions, particularly psychosocial professions, as it was acknowledged that pediatric cancer is almost always a psychologically traumatizing and socially damaging experience for young people and their families (Krueger 2008).

       I point to the transformations induced by Farber and his colleagues to demonstrate that the major biomedical discoveries that have enabled contemporary pediatric cancer treatment have emerged alongside a process that can be described as the Disneyfication of cancer care. Although I don't want to suggest that Farber was directly and consciously influenced by Disney's practices, there are similar dynamics at play. As Giroux (1999, 1994) describes, the Walt Disney Company combines an ideology of childhood innocence and fantasy with corporate practices of branding and advertising. Much like Disney, Farber and the Laskers relied on mass branding and advertising practices in their Jimmy Fund Campaign, and, also like Disney, the ads drew on ideologies of childhood innocence, pleasure, and fantasy. In widely circulated radio, television, and print media, Einar/Jimmy was represented as an innocent victim of a terrible disease, and the act of donating to the Jimmy Fund was represented as a way to contribute to curing cancer *and* helping victims like Einar/Jimmy cope with the disease by providing them with gifts and pleasurable experiences. In one iconic radio broadcast, millions of people listened to Einar/Jimmy visit with members of his favorite baseball team, the Boston Braves, and this led to a flood of donations from the public in order to buy him a television for his hospital room so he could watch the Braves games. Of course, most of the money actually went toward cancer research and developing the Jimmy Fund Clinic (Krueger 2008).

       In addition to branding and advertising practices, Farber and the Laskers also enacted the Disneyfication of cancer care by designing the Jimmy Fund Clinic as a child-directed environment emphasizing play, imagination, and lightheartedness. As historian Gretchen Krueger describes:

> The clinic's waiting room contained a television set and toys to entertain the young patients, painted murals depicting images from familiar children's stories adorned the walls, a merry-go-round provided distraction before appointments, and tricycles provided kid-sized transportation from the waiting room to the laboratory for blood work (Krueger 2008, 87-88).

       Today, the transformations that Farber and his colleagues introduced into the field of pediatric cancer treatment remain strong. The Jimmy Fund Clinic is still in operation at the Dana-Farber Cancer Institute in Boston, and it continues to serve as a model for pediatric cancer treatment centers throughout the country. What Farber dubbed "total care" is now a standard feature of major cancer treatment centers in the United States, including the hospital where I carried out fieldwork, which I will describe in the following chapter. Not only do pediatric

cancer treatment centers offer biomedical practices like chemotherapy and radiation; they also offer various entertainment technologies, child-directed aesthetics, and a range of professional- and volunteer-led activities intended to alleviate boredom, sadness, loneliness, and other emotional difficulties that are common among hospitalized cancer patients and their family members.

As the discovery of chemotherapy and the development of the "total care" model make clear, the field of pediatric cancer treatment is not frozen in time, and the agents who take up positions within it have both reproductive and transformative effects. Farber, the Laskers, and Einar/Jimmy are primary examples of this. In their dogged attempts to find better ways to treat cancer and care for cancer patients, Farber and the Laskers, alongside many other people, including patients like Einar/Jimmy, helped to create the conditions for a new set of professional positions, practices, and environments to emerge in the field of pediatric cancer treatment.

The Iterability of Models of Care within the Field of Pediatric Oncology

To say that the total care model—or, for that matter, any model—has had a broad influence on the field of pediatric oncology is to suggest that it has undergone what Bauman and Briggs (1990) refer to as "entextualization," "decontextualization," and "recontextualization." Before models can be circulated and exert productive effects, they must first be discursively rendered, or entextualized. Entextualization need not refer only to the production of written text, but can also refer to the production of images, verbal utterances, video, audio, etc. Once a model has been entextualized via some modality of discursive/semiotic production, it can be extracted, or "decontextualized," from the original context of its production, and then placed into circulation across various networks, leading to its "recontextualization" in new settings.

Bauman and Briggs' (1990) observations build on Derrida's notion of "iterability," or "citationality," which Derrida suggests is a property of all signs (Briggs 2005).[5] For Derrida, iterability emphasizes "the necessity that for every sign to be construed as a sign it must conform to some 'code'…, a principle of identity which regiments every iteration of it…as 'the same'" (Nakassis 2013, 66). While common codes regiment the iteration of signs, citational acts of "grafting" together chains of signs can also give rise to new semiotic possibilities (Derrida 1988, 9). As Briggs and Bauman (1990) show, however, acts of decontextualization and recontextualization (which involve citational grafting) are constrained by various social inequalities and forms of power. From their perspective, discourses should be viewed "neither as free-floating ions of power or signification, nor as tied inexorably to contexts" (Briggs 2005, 273). Discourse circulates, but its circulation is shaped by relations of power, which, as I have argued, following Bourdieu (1986), are structured by the distribution of the three fundamental species of capital. Due to inequalities in capital, not all individuals or groups are granted the same rights or resources to produce models that become widely influential and "grafted" into the institutionalized fields that structure everyday life. This does not mean that agents or groups with relatively less access to capital will never have an impact—that their grafting is never effective, as Butler alleges against Bourdieu's account—but rather that such individuals or groups will likely face major barriers to accumulating the capital needed to enact a widely influential transformation in a given field.

But beyond matters of capital, what is involved in the de- and recontextualization of a model of care, and how might such processes play out in the field of pediatric oncology? As Krueger describes, Farber's model of "total care" came to be seen as the gold standard among

cancer experts, and, by the 1970s, many major medical centers, including Duke University Medical Center and Stanford Children's Hospital, had taken up this model. Obviously, however, as the model is decontextualized, mobilized, and recontextualized, novel effects are produced. Duke's "total care" program is not exactly the same as Stanford's, which is not exactly the same as the Jimmy Fund Clinic's. Recontextualization produces variation, and no two organizations will have grafted a model of total care into their operational structure in the exact same way. Furthermore, dominant models, formally ratified or not, do not totally dictate individual activity, and there will always be variation in the ways in which particular professionals cite and hybridize models in thought, speech, and practice.

And yet, despite the variation that iterable models produce, there are certain general characteristics that are shared by all major treatment centers in the field of pediatric oncology in the United States. In all of these settings, professionals are grouped under two umbrellas: biomedical and psychosocial. The biomedical team is the more standardized of the two across contexts. In every organizational setting, the biomedical team will be composed of physicians, nurses, technicians, etc., and they will carry out the process of delivering and monitoring treatment. The psychosocial team, however, is more variable across treatment centers. While virtually all organizations will offer some form of psychotherapy to their patients, they may vary in other kinds of professions and services. For example, some organizations may have a robust music therapy program, while others may not have one at all.

Biomedicalization, Psychosocialization, Pharmaceuticalization and Total Care

In addition to the novel effects produced by the iterative institutionalization of total care, the model has also been transformed by processes that scholars have described in terms of "biomedicalization" (Clarke et al. 2010) and "psychologization" (Rose 1996). While total care has always been a biopsychosocial undertaking, both biomedical and psychosocial practices have been thoroughly elaborated upon, and new professional strategies have emerged and been incorporated into models of total care. On the psychosocial side, a vast array of "psy-technologies" (Rose 1996) have been incorporated into the process of cancer treatment. This includes various standardized instruments that psychosocial professionals use to judge the severity of psychosocial distress and to make diagnostic judgments. It also includes the development of new psychosocial strategies in professional contexts such as music and art therapy. The development of new musical and audiovisual technologies have altered the manner in which music and art therapists engage with pediatric cancer patients.

As Clarke et al. (2010) describe, the process of biomedicalization has entailed the spread of new forms of "technoscience" that shape the project of health care and biomedical research. Such transformations have certainly affected the model of total care. Since Farber's time, a massive cancer research apparatus has developed that is constantly churning out statistics and experimental therapies that affect the decisions made by frontline clinicians. Biomedicalization is linked to processes of "pharmaceuticalization" (Abraham 2010; Bell and Figert 2012; Biehl 2007), or the development and spread of a vast array of mass-produced pharmaceutical drugs. In the context of cancer treatment, this includes a number of drugs that help control the iatrogenic effects of dominant modes of cancer treatment. While all of these processes—biomedicalization, psychosocialization, and phamaceuticalization—have produced the potential for positive benefits for patients, they have also produced the potential for various forms of *iatrogenesis*—a concept

which emerged in relation to studies of medicalization, but which has has been less emphasized in studies of biomedicalization.

The term *biomedicalization* builds on the notion of *medicalization*, which generally refers to the expansion of biomedical authority (Metzl and Herzig 2007; Rose 2007). Joan Busfield (2017) claims the first use of the concept is frequently attributed to a 1968 encyclopedia entry on the topic of "social control" by the sociologist Jesse Pitts, a student of Talcott Parsons. Drawing on the ideas of his teacher, Pitts saw the practice of medicine as a mode of social control in that it had the power to define the norms that governed the "sick role." Zola (1972) similarly viewed medicine as "an institution of social control." While Zola did not want his analysis to be taken as an attack on medicine or medical practitioners, he nevertheless lamented that medicalization tended to have a depoliticizing effect. Once a problem was placed within the purview of professional medicine, Zola suggested, non-medical interventions were often foreclosed (Busfield 2017).

Compared to Pitts and Zola, the philosopher and Catholic priest Ivan Illich took a much more decidedly anti-medical stance in his book *Medical Nemesis: The Expropriation of Health* (1982), which was another early attempt to describe processes of medicalization. Among the book's primary contributions were the intertwined concepts of *clinical, social, and cultural iatrogenesis*, which attempted to highlight the harmful effects caused by the spread of medicine. Illich's goal was to demonstrate how the apparently "natural" events of birth, healing, and death had become objects of biomedical definition, surveillance, and control, and how, in the process, many people had lost their capacity for self-care and the endurance of pain and suffering. In response, Illich called for widespread liberation from the authority of medicine, which he metaphorically represented with the Greek mythological figure of Nemesis, the goddess who retaliated against human hubris.

Feminist scholars and activists also began to criticize the expansion of medical authority in the 1970s. Barbara Ehrenreich and Deirdre English (1973) discussed the ways in which medical experts undermined women's roles as healers and reinforced the idea that women should be primarily confined to the roles of wives and mothers. As anthropologist Margaret Lock recounts, the anti-medical thrust of this early feminist literature led to the assumption "that enlightened individuals should resist medicalization and that one function of the social sciences was to raise consciousness about the inappropriateness of, for example, a medicalized childbirth or menopause" (Lock 2001, 481).

Several decades after these calls for liberation from and resistance to the authority of the medical establishment, the concept of medicalization has lost much of its critical appeal for some scholars. Nikolas Rose suggests that the concept has become "a cliché of critical social analysis" (2007:300). The anti-medical stance proposed by thinkers such as Illich, Ehrenreich, and English now appears to some scholars as an overzealous and naïve way of viewing the world—what Paul Farmer and Gastineau Campos (2004) might refer to as a "Luddite trap." The introduction to the edited volume *Against Health* (Metzl and Kirkland 2010)—a collection of critical essays exploring the limits of contemporary health discourses—is also indicative of a growing distaste for anti-medical modes of critique. The introduction begins in the following manner:

> How can anyone take a stand against health? What could be wrong with health? Shouldn't we be for health?

On behalf of the authors, let me reply to these questions by proclaiming that we believe that anyone who feels ill before, during, or after reading this book should seek immediate medical attention (Metzl 2010, 1).

Although the authors set out to criticize health discourses, the introduction immediately qualifies this project as not mounting a full-scale attack on biomedicine or public health measures. The book begins by warning readers not to misinterpret the authors' critical stance as anti-medical. To do otherwise, the introduction implies, would be reckless and unnecessarily risky—the kind of risk that might be taken by someone caught up in a Luddite trap. The introduction continues:

We believe in the germ theory of infectious illness. We believe in penicillin. We believe that physicians should wash their hands between patient visits. We are optimistic about the promise of stem cell research. We believe that the transition from the rigid sigmoidoscope to the lower abdominal MRI represents indisputable progress. We are for bike helmets, sunscreen, and enteric-coated tablets, and we are against the swine flu. Perhaps most of all, we believe that disparities in incidence and prevalence of disease are closely linked to disparities in income and social support. We believe that documents such as the Department of Health and Human Services' "Healthy People 2010" prove beyond doubt that access to health care and availability of adequate health insurance remain unattainable goals for many Americans. We believe that such disparities need to be rectified, and we stand firmly behind recent expansions in healthcare coverage (Metzl 2010, 1).

Illich, who passed away in 2002 of cancer for which he refused oncological treatment, would perhaps be dismayed to see the current state of critical theories of health and medicine. But there are arguably understandable reasons for the emergence of more medically apologetic rhetoric within critical social theories of medicine. For one thing, doctors and other biomedical practitioners, once treated by some critics as the primary power-holders within a burgeoning healthcare empire, are increasingly constrained by various regulatory apparatuses, corporate ideologies, and economic and political interests. Insurance and pharmaceutical companies, ideologies of evidence-based medicine, patient advocacy groups, and laws intended to protect patients' rights are among the factors that constrain clinician authority. In this context, it makes less sense to rail against biomedicine as if it were a unitary project controlled by clinicians. The fragmented character of the contemporary "medical-industrial complex"—a term I borrow from Kaufman (2015)—challenges Illich's image of Medical Nemesis as a monolithic force destroying the health and coping capacities of people throughout the world. In its place, it suggests a vast complex of organizational nodes, each populated by heterogeneous actors, technologies, and practices and animated by a variety of affectively charged narratives and interests.

Despite the complexity of the task, there is without a doubt still value in criticizing biomedicine—not out of a sense of animus, but rather out of desire to mitigate the modes of iatrogenesis that biomedical technologies and practices continue to enact. Of course, to some extent, medical practices will always produce iatrogenic effects. As Illich pointed out long ago:

To defuse the issue and to protect their reputation, some physicians insist on the obvious: namely, that medicine cannot be practiced without the iatrogenic creation of disease… Disease takes its features from the physician who casts the actors into one of the available roles. To make people legitimately sick is as implicit in the physician's power as the poisonous potential of the remedy that works. The medicine man commands poisons and charms. The Greeks' only word for "drug"— *pharmakon*— did not distinguish between the power to cure and the power to kill (1982, 15).

But in making this point, it is important not to fall into a position of biomedical fatalism. Although the potential for harm may always be implicit in medical practice, iatrogenic effects exist on a very broad spectrum, and it is a worthwhile project to attend to different modes of iatrogenesis. By better understanding how various modes of iatrogenesis are enacted, we may be able to lessen the severity of their effects.

Beyond Social and Cultural/Symbolic Iatrogenesis

The "total care" model that dominates the field of pediatric cancer treatment provides a dynamic site for exploring the production of various forms of iatrogenesis. Cancer treatment technologies and practices obviously produce a tremendous amount of what Illich refers to as clinical iatrogenesis (or physical harms that directly result from biomedical treatments and practices). But, as Illich pointed out, iatrogenesis is not confined to its clinical manifestations. In order to better understand multiple modes of iatrogenesis in the context of pediatric cancer treatment, however, it is useful to dispense with Illich's notions of social and cultural/symbolic iatrogenesis, and, in their place, to develop the concepts of *structural* and *moral iatrogenesis.*

Let me begin by stating my objection to Illich's concepts. I will start with social iatrogenesis, which Illich defines as "a term designating all impairments to health that are due precisely to those socio-economic transformations which have been made attractive, possible, or necessary by the institutional shape health care has taken" (Illich 1982, 10). Illich offers many examples of such transformations. To name a few: the stress-inducing expansion of medical bureaucracies; the commodification of healthcare; and the labeling of various forms of suffering, pain, and mourning as deviance, etc. The target of his critique is what he refers to as "industrial medicine," by which he means the biomedically oriented healthcare systems that emerged in tandem with industrial capitalism in wealthy societies over the course of the twentieth century. According to Illich, biomedicine transforms "the doctor from an artisan exercising a skill on personally known individuals into a technician applying scientific rules to classes of patients" (1982, 9).

For Illich, the re-organization of social life around biomedical technologies and practices is correlated with a shift in symbolic frameworks for dealing with illness, pain, suffering, and death. This is what Illich means by *cultural/symbolic iatrogenesis*, or "the paralysis of healthy responses to suffering, impairment, and death." This mode of iatrogenesis "occurs when people accept health management designed on the engineering model, when they conspire in an attempt to produce, as if it were a commodity, something called 'better health'" (Illich 1982, 11). Within such an arrangement, patients become dependent on medical authority, thus losing the ability to confront suffering and death in an autonomous fashion: "The patient's unwillingness to die on his own makes him pathetically dependent. He has now lost his faith in his ability to die...and has made the right to be professionally killed into a major issue" (Illich 1982, 35).

There are several problems with Illich's conceptualizations of social and cultural/symbolic iatrogenesis that I want to raise here. First, by implying that the social and cultural organization of biomedicine enacts a destruction of the ill person's ability to confront suffering and death, Illich implies that the social and cultural worlds which preceded the emergence of biomedicine enabled people to confront death in an apparently more noble, less "pathetic" way that he characterizes in terms of "self-care" and "autonomy." This argument relies on a demonization of biomedicine juxtaposed with a romanticization of an apparently superior medical past, when doctors operated like artisans and individuals confronted death with courage and acceptance. Although I am not a historian, I am not convinced that such an idyllic state of medical affairs has ever existed on a large scale anywhere in the world. Beyond the questionable historical implications of Illich's claims, the second issue I want to raise here is that Illich relies on an uncritical deployment of the concept of autonomy, which he frames as a universal good, although he does not describe precisely why it is good. Perhaps ironically, Illich's argument for autonomy resonates with the discourse of contemporary bioethics, which has made "patient autonomy" into one of the primary ethical concerns that structures professional practice in the medical-industrial complex (Traphagan 2013).

Another problem with Illich's notions of social and cultural/symbolic iatrogenesis is that they seem to rely on an essentializing and homogenizing notion of culture, which anthropologists have long since criticized. According to Illich, "each culture has its own characteristic perception of disease and thus its unique hygienic mask" (1982, 15). This implies that all people who identify with a particular culture share the same conceptions of health, illness, and hygiene, which is clearly untrue. Of course, Illich was writing well before the emergence of academic discourses of globalization, which would lead many scholars to abandon the concept of culture, or to argue for understanding of culture as a hybrid and emergent process, as opposed to a stable object.

There are at least two ways to deal with conceptual inadequacies: resignification or abandonment. In this case, I choose to abandon the terms social and cultural/symbolic iatrogenesis. Yet I do not want to abandon all of the insights Illich provides. Most importantly, I follow Illich in emphasizing that iatrogenesis can occur via biomedicine's impact on social structure: biomedical knowledge, technologies, and practices now circulate through virtually all the nations of the world, and there are many ways in which certain populations are systematically more harmed than others by these processes. In order to avoid the problems I've raised with Illich's notion of social iatrogenesis, however, I follow Stonington and Coffa (2019) in terming this process "structural iatrogenesis." Structural iatrogenesis can be understood as biomedically induced manifestations of what medical anthropologists refer to as structural violence (Farmer 2004; Scheper-Hughes and Bourgois 2004). Furthermore, unlike Illich, I do not deny that structural iatrogenesis can coexist with therapeutic benefit. Social groups who are systematically harmed by biomedical technologies and practices can also benefit from them. I am less interested in declaring the structural impact of biomedicine as either harmful or beneficial, and instead opt to ethnographically explore the structurally produced ratios of benefit and harm that people inhabit in their everyday lives.

Another insight of Illich's that I would like to preserve is that iatrogenic effects can occur via the impact of biomedical knowledge and practices on the symbolic/cultural models people use to evaluate their embodied existence and their relations to others. But unlike Illich, I do not insist that medicalization entails the wholesale destruction of an original culture or worldview. Rather, I examine the ways in which biomedical knowledge and practice interact and become

hybridized with other forms of knowledge and practice, producing a multiplicity of effects that can be described as both destructive and constructive. Biomedical knowledge and practices can be incorporated into peoples' lives in ways that they view as positive, or they can have harmful effects by contradicting or delegitimizing knowledges, practices, and identities to which people are morally attached. I refer to this latter possibility as *moral iatrogenesis*. Yet, unlike Illich's notion of cultural/symbolic iatrogenesis, moral iatrogenesis does not posit the destruction of some totally idyllic cultural/symbolic framework that preceded the process of medicalization. I assume that problems of health and illness have always produced dependencies, anxieties, and obsessions, and that people have always had a difficult time confronting sickness and death.

Inhabiting the Promise of Total Care

As I hope to demonstrate in the chapters that follow, as young people and their family members become positioned as patients and caregivers in the field of pediatric oncology, their lives become fundamentally shaped by iterable models of care that produce both therapeutic and iatrogenic effects. According to Bourdieu, all fields are characterized by certain forms of *doxa*, or naturalized assumptions about the world that are so taken for granted that questioning them would be seen as foolish and irrational. In the field of pediatric oncology, a prevailing form of *doxa* is the idea that young people who are diagnosed with cancer, often even those with very negative prognoses, are in undeniable need of the poisonous but potentially healing practices carried out by the biomedical side of the total care team. Young people who are pulled into taking up a patient position in the field of pediatric cancer treatment are subjected to this *doxa*, which many of them reiterate in their own utterances and practices.

Because cancer treatment requires a sudden and terrifying disruption of young people's lives, and because it entails the endurance of iatrogenic biomedical processes, most professionals also assume that patients will benefit from one or more forms of professional psychosocial care, which are intended to mitigate the emotional and social difficulties of treatment. Psychosocial care can involve many different activities—for example, talking to a psychotherapist, attending a support group with other patients, participating in art and music therapy, or engaging in group and individual activities with professionals who are known in the pediatric field as "child life specialists," whose work I will describe in more detail in chapter four. Despite widespread recognition of the benefits of psychosocial care among cancer treatment professionals, however, it is not viewed as imperative. There are patients and families who use the services of psychosocial professionals much less than others, and while members of the care team may disagree with a particular family's decision not to engage with psychosocial professionals, they would not treat it with the same concern as they would in the case of a family who opts not to pursue biomedical treatment. In the latter case, the family may even be charged with child abuse and have custody of their child legally taken away (Burke 2019).

The doxic framing of pediatric oncological treatment as imperative in the overwhelming majority of cases is no doubt related to the process of "biomedicalization" discussed in the preceding section. The emergence of chemotherapy and radiation, as well as more recent developments, such as the use of autologous stem cell transplantation, has made pediatric cancer treatment a much more optimistic endeavor in many cases. As Del Vecchio Good (2001) points out, engagement with the scientific and technological products of biomedicalization, particularly in life-threatening situations, can lure people into what she calls the "biotechnical embrace," or an affective state in which a deep faith is placed in biotechnological solutions to illness and

death. In the context of pediatric oncology, professionals, patients, and family members alike can be prone to falling into this embrace, and this can lead them to express disapproval toward any attempt to question its logic.

However, as Del Vecchio Good (2001) also points out, biomedical professionals and patients do not always fall into the biotechnical embrace in the same way. While patients and their family members may desperately hold out hope that science and biotechnology will solve *their particular case*, biomedical professionals are more likely to express faith in biomedicine *on a populational and historical level.* While professionals realize that many young people with cancer in the present historical moment will die from the disease, they hold out hope that the percentage of young people who survive will only continue to increase and that, at some point in the future, treatment technology will progress to the point that cancer will be looked at as no more troublesome to treat than a common infection.

In describing different styles of attachment to the promise of biomedical technologies and practices, it is useful to draw attention to multiple senses of the word "promise," which can be used in at least the following two ways:

a) *I promise to cure your cancer.*
b) *This particular treatment has shown great promise in previous cases.*

As much as physicians may wish they could in good faith utter a statement like the one in example b), and as much as patients and families may want them to, they are more likely to utter something closer to statement b). Even in the most optimistic cases, few, if any, oncologists would make the kind of promise articulated in statement a). It is widely accepted among oncologists that, although statistics and clinical experience provide useful guides, no physician knows in advance exactly how a particular treatment trajectory will unfold. The promise of pediatric cancer treatment, as in all "evidence-based" biomedicine, is probabilistic, not guaranteed. Biomedical professionals know that long-term remission will certainly not occur in every case, but they feel the project of oncology continues to hold promise because it will occur in some cases, and most oncologists believe that the number of successful cases will only continue to grow.

Here I draw on anthropological discussions of promises as phenomena that shape social relationships and engagements with the world. In doing so, however, I depart from J.L. Austin's (1962) influential theory of promises as speech acts that either succeed or fail. Rather than considering how people make and subsequently keep or break individual promises, I explore how the various activities that constitute the field of pediatric oncology can produce embodied feelings of optimistic future possibility that are expressed in a range of ways by people taking up specific positions in the field. I draw inspiration from Angela Garcia, who also moves away from an understanding of the promise in terms of "codified rules or law-like morality." Instead, Garcia suggests that promises can be viewed as "modes of living" that vary across time and space (2014:53). Drawing on and adapting Garcia's analysis, I argue that the promise of pediatric oncology is constituted over time via the ideologically mediated, relational positions and practices that can be seen as modes of living within the field of pediatric cancer treatment.

Intersecting Models of Care and Communication

Although the promise of total care cannot be reduced to any specific utterance and instead must be seen as an ideologically mediated mode of living, this does not mean that utterances or other forms of communication do not play a role in the production and maintenance of the feelings of promise that energize the field. Previous anthropological studies have emphasized the central role of communicative interaction in shaping cancer treatment, particularly in helping patients and their family members to maintain a sense of optimism throughout the treatment process. These studies rely on the notion of "disclosure practices" (Clemente 2015; Del Vecchio Good et al. 1990; Gordon and Paci 1997; Hunt 1994; Luxardo 2015).

Early studies of disclosure focused on the question of how oncologists in different societies approached the issue of whether or not to tell patients they had cancer. Comparing Italian and Japanese oncologists to Americans, for example, Del Vecchio Good et al. found that American physicians saw it as necessary to disclose the diagnosis to the patient in order to preserve their sense of autonomy, while Italian and Japanese oncologists thought otherwise: "American styles of disclosure of diagnosis and prognosis are largely considered by observers from these countries to be cruel or to have the potential to lead to 'social death'" (1990, 59). In a similar finding, Gordon and Paci (1997) note that Italian oncologists viewed American practices of frank disclosure as harmful to patients. They attribute the difference to "cultural narratives," suggesting that a "social-embeddedness" narrative was dominant in Italy, whereas in the United States a more individualistic "autonomy-control" narrative was dominant.

It is important to note that most studies of disclosure have focused on adults. Studies conducted among children, on the other hand, have found different dynamics surrounding questions of disclosure. In one of the few long-term ethnographic studies of pediatric cancer patients in the United States, Myra Bluebond-Langner (1978) found that most parents and medical professionals avoided talking openly about cancer with sick children. According to Bluebond-Langner, the decision not to discuss cancer with children was rooted in beliefs about the nature of children as irrational and innocent and thus particularly in need of protection from suffering and awareness of death. Bluebond-Langner shows that, despite these attempts at protection, children were in fact aware of their conditions, although they often did not express this awareness in a way that most adults recognized. Instead, children tended to engage in "mutual pretense" (Glaser and Strauss 1965) with adults. In other words, although both adults and children realized that the children were dying, when interacting with each other, they avoided open acknowledgment of this fact. As Bluebond-Langner notes, studies of mutual pretense among adult patients tended to rely on the explanation that death is taboo and interactions must therefore be sanitized of its presence (Fulton 1966; Glaser and Strauss 1965; Kalish 1969; Hendin 1973). But she argues that this explanation is not sufficient and instead suggests that mutual pretense is better explained by concerns about continued social membership:

> The leukemic children, their parents, and the staff that attended them…practiced mutual pretense because it offered each of them a way to fulfill the roles and responsibilities necessary for maintaining membership in the society, in the face of that which threatened the fulfillment of social obligations and continued membership (1978, 210).

Of course, Bluebond-Langner was writing at a time when far fewer cancer patients survived treatment. As treatment practices have grown more effective, attitudes around sharing information about the treatment process with young people have shifted. At the same time, it is important not to imply that improvements in cancer treatment outcomes have led to the total displacement of one style of disclosure for another. Although there are shifting tendencies, there is not only one style of disclosure that emerges in the field of pediatric cancer. The anthropologist Ignasi Clemente (2015) demonstrates this point in Spain: "disclosure has not replaced non-disclosure in Spain, but they have coexisted, evolved, and influenced each other" (Clemente 2015, 34). Rather than viewing disclosure and non-disclosure as binary, mutually exclusive strategies, Clemente argues for the utility of the concept of communication regulation that views complete disclosure and complete non-disclosure as two possible strategies among many. Clemente argues that "information disclosure (or non-disclosure) is not a one-time event but a process that extends over entire cancer trajectories, and it involves highly variable and diverse communication strategies" (2015, 1).

Another possible takeaway from studies of disclosure is that models of how best to care for patients and families and models of how best to communicate with them intersect to a large degree. In many ways, these studies show that many participants in the field of oncology see communication as a process through which certain aspects of cancer care are realized. However, all of these studies focus overwhelmingly on interactions between patients, parents, and biomedical professionals, while the psychosocial arm of the total care team has been eclipsed. While the presence of psychosocial professionals is briefly noted at certain points, none of these studies provide an in-depth discussion of psychosocial care and communication. This dissertation attempts to address this omission, particularly in chapter five. In addition to pointing out this empirical omission, in the following section I want to raise a more fundamental conceptual issue regarding studies of disclosure practices, which do not account for the manner in which iterable models of communication and care participate in producing what I have been describing thus far as the positions and embodied habituses that constitute the field of pediatric oncology.

From Disclosure Practices to Pediatric Communicability

Although these studies of disclosure have provided valuable insights into communicative practices in the field of oncology, they all seem to take the existence of social positions for granted. The "disclosure practices" framework shows how doctors, parents, and patients interact with each other, but it fails to note how iterable models of communication and care help to produce the very positions of doctor, parent/guardian, and patient in the first place. Rather than reified, pre-existing positions, the positions that compose any field, including the field of pediatric cancer treatment, must be actively (re)produced. Social positions and subjectivities do not exist prior to embodied, physical relations and interactions, but emerge through them. As participants take up positions in any given field, they cite, implicitly and explicitly, various ideological models that play a role in producing the very contexts and positions they seem merely to describe. Furthermore, such models are inscribed in the "physical plant" of the cancer treatment center—in the built environment and the various material objects that populate it. As participants spend time in the hospital environment, they learn to interpret and use the physical plant in a variety of ways—sometimes in ways that do not conform to expertly and professionally dominant models.[6]

In order to move beyond the disclosure practices framework, this dissertation develops the concept of *pediatric communicability,* which builds on the work of Charles Briggs and colleagues (Briggs and Hallin 2016; Briggs and Nichter 2009). Briggs (2005) initially developed the concept of communicability in part to emphasize the ways in which ideologies of communication produce social positions and guide the circulation of knowledge. The related notion of *biocommunicability* makes a similar point specifically in relation to health communication. Biocommunicability challenges dominant models of health communication that portray a simple, linear transfer of information from scientists to health professionals to laypeople—social positions which all apparently exist prior to and independently of communicative processes. Building on the work of media theorist Jesús Martín Barbero (1987), Briggs and Hallin (2016) suggest that it is important to show how communication is ideologically modeled in specific instances. Instead of viewing circuits and positions as fixed sites through which health information unproblematically circulates, biocommunicability emphasizes the productive effects of ideological models of communication in producing communicative circuits, subjectivities, and roles. As Briggs observes, "Rather than regulating preestablished social categories and groups, [bio]communicability helps create and structure them" (2005, 275).

For the purposes of this study, *pediatric communicability* can be seen as a variant of biocommunicability. It refers to the processes through which ideological models of pediatric communication help to produce the intertwined, hierarchically arranged positions that they seem to merely describe. As Briggs and Hallin (2016) show in a study of representations of health communication in media sources, one of the most common models of health communication is the "biomedical authority" model, in which doctors are seen as expert disseminators of scientific knowledge about health, and "good" patients are seen as those who make rational and obedient use of this knowledge. But this is not the only model in wide circulation, and its dominance has significantly decreased in recent decades. The neoliberal restructuring of the U.S. health care system has also given rise to what Briggs and Hallin (2016) describe as the "patient-consumer model" of health communication that circulates in the media and many other sources. This model casts patients as making difficult, life-altering choices in the context of overworked doctors, competing information, various profit motives, and a plethora of treatment options. The "good" patient in this model is one who arrives to the healthcare interaction equipped with information and willingness to self-advocate. As Briggs and Hallin note, models of health communication are not mutually exclusive, and they can be hybridized in practice.

While the models that Briggs and Hallin (2016) describe can be found circulating and guiding circulation in pediatric contexts, they nevertheless take on a modified form that introduces an intermediary "parent/guardian" position between the physician and the patient. As historian Sydney Halpern (1988) observes, over the twentieth century in the United States, pediatric knowledge and practices became widely implanted in social space, resulting in the institutionalization of a set of relationships among pediatric professionals, parents (particularly mothers), and children. Over time, many parents and children have become positioned as participants in the field of pediatric biomedicine. Through various media—from books, to magazines, to television shows, to posters and billboards—authorities began to warn parents to take pediatric authority seriously in order to ensure the health and optimal development of their children (Halpern 1988).

The pediatric injunctions described by Halpern project a relatively simple model of hierarchical pediatric communication between physicians and mothers as ideal for the production

of healthy and well-adjusted children. Halpern's account resonates with what Briggs and Hallin (2007) describe as the "biomedical authority" model of health communication, although the inclusion of "mother" or "parent" as a communicative intermediary between patients and health professionals complicates the model. Given that children and adolescents are often presumed to be "irrational" or "incompetent" actors and communicators—two assumptions that the anthropology of childhood and youth has vociferously opposed (Lancy 2008; Montgomery 2009)—pediatric authority constructs an alliance between physicians and parents. In "biomedical authority" models of pediatric communication, the ideal parent is constructed as not questioning doctor's orders, but instead carrying them out, performing prescribed health surveillance and care functions. But the neoliberal restructuring of health care has affected the fields of pediatric and adult medicine alike, and "patient-consumer models" of pediatric communication also circulate. In neoliberal models, "good" parents/guardians are cast as informed, rational, and responsible consumers of pediatric knowledge that they apply judiciously to the care of their child.

But as I will discuss in more detail in subsequent chapters, the model of total care transforms standard notions of pediatric communication, and although the "biomedical authority" and the "parent/guardian/patient-consumer" models certainly shape the field of pediatric cancer treatment in a number of ways, they are hybridized with ideologies of cancer communication and care that position patients and families as in the throes of a biomedical and psychosocial crisis that must be addressed via the patient and empathetic communication of a multidisciplinary team of professionals. In part, this is the inheritance of Farber's vision of "total care" at work. In attempts to keep families invested in the promise of pediatric oncology, the field is organized around models of communication and care that presuppose not a doctor-patient dyad, or even a doctor-parent-patient triad, but a whole team of professionals who communicate different kinds of information and provide distinct forms of care to both parents and children.

Conclusion

As I hope to show in the chapters that follow, the models of care and communication that are grafted into institutional policies and professional cancer care practices have a multitude of productive and destructive effects upon specific individuals who, voluntarily and involuntarily, take up positions within the field of pediatric cancer treatment. For individuals who are positioned as patients or as parents/guardians, this process involves not just an act of naming or ideological framing, but the grafting of new modes of living onto existing ones. Cancer treatment requires patients and their familial caregivers to incorporate new technologies, practices, and social relationships into their lives, spending extended periods of time in biomedical environments. This process is mediated by established models of care and communication that iterate in a range of mediums—medical school curriculum, organizational policies, written documents, biomedical and psychosocial technologies, social interactions between families and professionals, websites, the built environment of the hospital, professional habituses, etc.—and that locate individuals in specific social positions and roles, allocating them with different levels of capital. It is important to note that these models can be resisted and creatively hybridized, although distributions of capital affect the ability of specific individuals and groups to create and circulate models widely in ways that result in institutionalization.

As I've described in this chapter, the field of pediatric oncology in the United States today continues to be organized around the model of total care, which Sidney Farber developed

at the Jimmy Fund Clinic over a half century ago. In a very general sense, total care envisions the ideal cancer treatment center as one that provides patients and families with access to the technologies, knowledge, and services of both biomedical and psychosocial professionals in hopes of making cancer treatment as effective and comfortable as possible. In many situations, comfort can be extremely difficult to achieve, as patients and families are dealing not only with the difficulties of the disease itself, but also with the iatrogenic effects of treatment. While the iatrogenic effects of biomedical treatment modalities such as chemotherapy and radiation are widely recognized by professionals in the field, it is much less common to hear professionals discuss the possibility of psychosocial care producing iatrogenic effects. As I will argue in chapter five, however, such effects do occur, particularly among patients whose experiences and preferences do not resonate with what I earlier referred to as Disneyfied environments and practices.

Now that I have described the concepts that guide this dissertation and discussed major historical transformations that have shaped the field of pediatric oncology, in the following chapter I will describe how I gained access to Bay Area Children's Hospital, or BACH. I will also describe the methods I used to carry out my fieldwork.

End Notes

[1] Although a number of commentators have accused Bourdieu's conceptual repertoire of perpetuating determinism, I find this a misplaced critique. Bourdieu's ideas allow for the possibility of resistance to existing social structures, but the point I take away is that resistance too must make reference to dominant structures. To take a prominent example related to pediatric concerns, there are many people in the United States today who engage in resistance to legally mandatory vaccinations for their children, which they view as a violation of their rights as parents who believe that vaccinations are dangerous and unnecessary. Through a series of experiences, many of these people have formed a habitus that issues forth negative reactions to social structures that seek to impose vaccination. Although they may be working to destroy, or at least reform, these structures, they must simultaneously live in relation to them, referencing them in the words and actions they deploy. The exact form these words and actions take in particular situations matters little for the point Bourdieu makes about the relation between habitus and the fields that constitute social space. Regardless of the affective, ethical, and/or political valence that any particular agent's relation to any particular structure takes, the fact that the relation produces *some* set of structuring effects is indisputable.

[2] Here capital should not be understood only in the economic sense of material property or investments that generate profit. Bourdieu (1986) claims that there are "three fundamental species" of capital (each of which can be broken down into a number of subtypes): economic, social, and cultural capital. Economic capital refers to material property, money, and investments. Social capital refers to the totality of resources available to a person by virtue of the network of social relations at their disposal. Cultural capital refers to knowledge, credentials, and other characteristics that confer prestige and authority. In addition to the three species of capital, Bourdieu uses the concept of symbolic capital, "which is the form that one or another of these species takes when it is grasped through categories of perception that *recognize* its specific logic" (Bourdieu and Wacquant 1992, 119).

[3] Of course, Jewish people in the United States are now considered members of the white population. But, as Karen Brodkin (1998) demonstrates, this was not always the case. Jewish people became seen as white over the course of the twentieth century.

[4] As Krueger (2008) points out, Farber did not pioneer the notion of comprehensive care in hospital settings. For this, Krueger gives credit to the physician Richard Cabot, who, at the beginning of the twentieth century, advocated for creating an in-house social service department at Massachusetts General Hospital. Only a decade later, around 200 other U.S. hospitals had developed social work programs.

[5] I take the terms "discourse," "model," and "schema" to refer to signs or assemblages of signs that both emerge within and structure human thought, practice, and social interaction.

[6] Here this should not be taken as a contradiction of the fact that fields (and thus the positions that constitute them) pre-exist the entry of individual participants. This is only possible because participants pre-exist each other, and groups of individuals keep up positions prior to the entrance of any given individual. Of course, to put it this way is to bracket the question of the field of pediatric oncology's historical genesis. Thus far I have only discussed historical transformations, but I have elided questions of origins. These are important questions, but they are beyond the scope of this study. Although I've drawn on existing historical accounts of the field of pediatric cancer in this chapter, this study is not primarily a work of history, but of anthropology, and subsequent chapters will therefore focus less on historical issues and more on ethnographic descriptions of the contemporary field of pediatric cancer.

Chapter 3
Doing Fieldwork at Bay Area Children's Hospital

[Anthropology requires an] open-mindedness with which one must look and listen, record in astonishment and wonder that which one would not have been able to guess.

-Margaret Mead, *Sex and Temperament in Three Primitive Societies*, (1950, xxvi)

All knowledge, and in particular all knowledge of the social world, is an act of construction implementing schemes of thought and expression…Between conditions of existence and practices or representations there intervenes the structuring activity of the agents, who, far from reacting mechanically to mechanical stimulations, respond to the invitations or threats of a world whose meaning they have helped to produce.

-Pierre Bourdieu, *Distinction* (1984, 407)

Introduction

This study, like most anthropological studies, is based on long-term fieldwork. In this chapter, I will describe in more detail what my fieldwork entailed and how my methods shaped the relationships I was able to form at the hospital, and thus the narratives and descriptions I am now able to relay. I will begin by first describing the setting of BACH in more detail, paying particular attention to the oncology program and its supporting psychosocial programs. I will then move into a discussion of my own entry into the hospital, describing the IRB review process, the volunteer certification process, and the participant recruitment process.

I close this chapter with a reflection on my analytic strategy, which is to show how intersecting ideological models of care, communication, and childhood/youth circulate in the field of pediatric oncology, playing a role in the production and recognition of the social positions that constitute the field. In doing so, I pay attention not only to the ideological models that circulate among pediatric professionals, but also among patients, family members, and anthropologists. I emphasize that none of us can live without ideologies and the models of the world they help us to construct, but only certain ideological models become widely iterated throughout social space and naturalized by the people with whom they exist in a relationship of mutual construction.

Oncology at Bay Area Children's Hospital (BACH)

BACH was founded in the early 1900s as a small hospital for the care of infants and very young children. Over time, it has grown into a large, nationally recognized pediatric hospital that offers access to all major medical and surgical subspecialties. The hospital is also home to a major research institute that hosts visiting clinicians and scientists. In addition to offering patients access to experimental therapies, the research institute also serves as an important site of medical education, as BACH is a teaching hospital where many young physicians complete their internship and residency requirements.

BACH is located in the San Francisco Bay Area, which is one of the wealthiest regions in the United States. According to a 2018 Bureau of Economic Analysis report, economic growth in the Bay Area far outpaced the rest of the country in 2017, making it the world's 18th largest economy (Bay Area Council 2019). To place the scale of Bay Area wealth in perspective, one journalist notes the immense amounts of money being poured into construction: "The Bay Area's largest construction projects cost $22 billion collectively, which is more than the gross domestic product of Cyprus. Per the International Monetary Fund, 79 other countries also have a GDP smaller than this region's $22 billion construction tab" (Procter, 2018).

Of course, extreme wealth tends to generate extreme inequality. The living conditions fostered by the global political and economic arrangements that many scholars have described in terms of "neoliberalism" (Ong 2006; Richland 2009; Wacquant 2012), "late capitalism" (Han 2004; Gupta 1992), and "late liberalism" (Comaroff 2011; Povinelli 2016), have produced a relatively small number of global billionaires and millionaires, while trapping ever greater numbers of people into conditions of precarity. According to a Brookings Institution analysis from 2016, the Bay Area has the third highest level of economic inequality of all U.S. metropolitan areas. Families on the uppermost end of the income spectrum earn almost 11 times more than families on the lowest end (Kendall 2018).

In addition to its fabulous wealth, the Bay Area is also often recognized as one of the most culturally diverse regions in the world. Many different migrant communities and a complex mix of racial and ethnic groups have established a presence in the region. While this diversity is often celebrated in discourses of liberal multiculturalism, such discourses obscure the racialized nature of economic inequality. As is commonly noted among Bay Area residents, recent influxes of cash into the Bay Area economy have not benefitted all residents alike, and some have been harmed by economic growth. Sharp increases in housing costs have facilitated the gentrification of traditionally non-white and low-income neighborhoods, displacing residents of those areas, some of whom have been pushed into the large population of houseless people dwelling in public spaces throughout the Bay Area (Ghaffary 2019). Those who are able to maintain housing are often pushed further out to surrounding suburbs, although many remain employed in urban centers, such as San Francisco and Oakland, to which they must commute (Keller 2019). African Americans have been the primary victims of gentrification, with one estimate suggesting that almost half of Oakland's African American population has been pushed out, going from 140,000 in 2000 to 70,000 in 2018 (BondGraham 2018).

Throughout their history, capitalist economic systems have produced many actors and institutions that represent themselves as benevolent stewards to those who inhabit the poorest and most disenfranchised and stigmatized regions of social space (Friedman and McGarvie 2003; Hanson 2016). Urban and public hospitals, such as BACH, often describe themselves in such terms (Waitzkin 2005). In response to the extreme inequality that characterizes life in the Bay Area, BACH is designed as a "safety net" hospital for children in two counties in the region. What this means is that BACH will turn no patient away, regardless of insurance status or ability to pay. If patients come to BACH uninsured, they will be referred to BACH's social workers, who will help them enroll in the state's child health insurance program. In addition to helping patients and families access limited forms of state assistance, the hospital also sustains its mission through gifts from various charitable organizations and individuals, as well as through the unpaid labor of a large network of volunteers.

In addition to the economic aspects of its mission, there are also sociocultural aspects. Like many urban children's hospitals, BACH has adopted an institutional ethics of liberal

multiculturalism—an ethics that has been codified in discourses and practices of "cultural competence" (Willen and Carpenter-Song 2013). BACH providers often talk about having pride in serving a "diverse" patient population, and official hospital materials often portray patients who exhibit a range of culturally and racially coded characteristics. By portraying diverse families in their promotional materials, the hospital administration presumably wants to make patients of various backgrounds feel welcome and to signal that hospital provides "culturally competent care," which, as recent discussions of "structural competency" and "structural vulnerability" have pointed out, became widely circulated in problematic ways that, at their worst, led to the blatant professional stereotyping of non-white patients, as well as a systematic professional misrecognition of structural inequalities as problems of culture and belief (Metzl and Hansen 2014; Metzl and Roberts 2014). Beyond a desire to demonstrate cultural competency, the rhetoric and imagery of liberal inclusion at BACH is also likely intended to signal the biomedical virtue of "serving all patients," which is rooted in the idea of a universal human right to health care.

Despite the visions of social welfare and liberal inclusion that are core aspects of BACH's mission, the hospital is consistently threatened by the shifting political economic landscape of the Bay Area. The hospital has long operated on a budget deficit, and, despite a merger with a larger and wealthier university hospital system, BACH is still being subjected to major budget cuts, which many BACH employees feel will fundamentally threaten their ability to effectively carry out the mission of a "safety net" hospital. Oncologists at BACH were particularly concerned that the blood and marrow transplant clinic would be closed and moved to the bigger hospital. Despite fears about the future solvency of BACH, during the period of my fieldwork, the oncology program continued to hum along, providing care to patients at various stages in the treatment process.

Total Care at BACH

As I described in the previous chapter, the general model of "total care," which Sidney Farber introduced at the Jimmy Fund Clinic in the 1950s, has fundamentally shaped the field of pediatric oncology. To reiterate, total care refers to the provision of multidisciplinary biomedical and psychosocial care in the context of a single treatment setting. The model has since been used to guide the development of cancer treatment centers throughout the world, and BACH is no exception to this. In this section, I will describe the general positions and roles taken up by each side of the total care team, and then I will describe the entanglement of the two teams, which should not be viewed as working in total isolation from each other.

The Biomedical Team

BACH is a nationally recognized children's hospital, and it is highly ranked in a number of pediatric specialties, including oncology. The oncology program prides itself on providing comprehensive biomedical treatment to hundreds of children and teenagers with cancer each year. BACH is staffed by highly specialized physicians with knowledge of the most recent advances in cancer medicine. Collectively, BACH physicians embody what professionals in pediatric oncology consider the field's "cutting edge." In addition to treating cancer patients, members of the oncology faculty at BACH have designed major clinical trials in conjunction with the Children's Oncology Group, a national organization of pediatric oncologists. BACH

oncologists have also published many articles in medical research journals, as well as a textbook on pediatric oncology. The work of BACH oncologists is facilitated by the oncology program's connection to BACH's research institute, which is connected to national and regional clinical trial networks.

The work of the biomedical team is carried out in many different spaces throughout the hospital, but the majority of cancer patient care at the hospital takes place in the oncology clinic, the blood and marrow transplant clinic, and the immune-compromised ward. The oncology and blood and marrow transplant clinics are adjacent to each other on the same floor of the day hospital, which is located across the street from the main hospital. Patients come to these clinics for regular exams during and after treatment. The blood and marrow transplant clinic, which serves not only cancer patients, but also many patients with hematologic diseases, is for patients who have recently undergone a bone marrow transplant, which is now a common form of cancer treatment, particularly for patients with leukemia.

Both clinics include a number of exam rooms, some of which have brightly painted walls decorated with cartoonish art. The exam rooms are equipped with an exam table, several chairs, and a computer that physicians and nurses use to review and input the details of the patient's record. In addition to exam rooms, the blood and marrow transplant clinic also has a number of beds in an open-air area where outpatients receive care. The clinic facilities also include physician's offices, a scheduler's office, and nurse's stations.

The immune-compromised ward is on the top floor of the main hospital. The unit lies behind a set of two large double doors, which are separated by a small room. Since the unit is equipped with special air filtration, it is important that the two sets of double doors not be opened at the same time. People coming in and out of the unit are taught to peek through the window to the doors on the other side in order to ensure that only one set is open at a time. When someone absentmindedly forgets to check, or when a newcomer fails to check out of ignorance, and both doors are opened at the same time, a high-pitched alarm is activated, alerting nearby employees to come correct the situation.

Upon entering the small room that separates the immune-compromised ward from the rest of the hospital, one finds it equipped with a sink, soap dispensers, hand sanitizer dispensers, paper towels, and a metal tray and sanitary wipes with which to sanitize any belongings being brought in from outside. There are signs on the walls noting the importance of handwashing and sanitization before entering the unit. Many of the patients inside have severely compromised immune systems that render them susceptible to common infections, which can be deadly in this context. As patients go through the most intense phases of treatment, they are often confined for extended periods of time to the immune-compromised unit. Patients undergoing stem cell transplantation are often hospitalized for the longest periods of time. During my fieldwork, the longest hospital stay I witnessed was over 100 days.

Inside the immune-compromised ward, there are patient rooms, a playroom, a kitchenette, a small common room for family members to congregate, and a nurse's station. The patient rooms are equipped with a patient bed, a bathroom, a faucet and sink, padded chairs, a television, and a Playstation 2 video game system. The rooms also have large windows with padded window seat areas. While in the ward, many patients are also attached to an IV pole that nurses use to deliver chemo, medicine, saline, and nutrients. Over time, most patients become very adept at maneuvering these poles, which are set on casters and can be moved from room to room.

The biomedical teams that work in the clinics and the ward include physicians, physician's assistants, physicians-in-training, nurses, and nurse's assistants. While these are the "frontline" members of the team, their labor is also dependent on other members who do not usually participate directly in the everyday life of the clinic or ward—for example, laboratory technicians, radiologists, and pathologists, all of whom are essential to the process of diagnosing the disease and monitoring the effects of treatment. In the ethnographic descriptions that follow, I emphasize the activities of the frontline staff, but I want to insist on the importance of remembering that the field of oncology is never reducible to what happens in clinic and hospital settings, as these settings are dependent on multiple other settings—particularly laboratories and other scientific settings.

Among all of the professional positions available in the field of pediatric cancer treatment, oncologists occupy the high seat of authority. Physicians ratify the process of treatment, making decisions about how to proceed in individual cases. Much of this is guided by established treatment protocols, but such protocols often call for translation and amendment, as patients vary in their response to particular models of care.

While nurses inhabit a lower position than physicians in the formal hospital hierarchy, they nevertheless have a great deal of control over the care process. This is particularly true in the context of the ward, as ward nurses carry out much of the actual day-to-day labor of biomedical care—administering medicines, changing wound dressings, attending to IV malfunctions, etc. Head nurses also to some extent have an influence on the care-related decisions oncologists make, as they report on the details of particular cases to oncologists in regular "rounds" meetings.

Despite the level of authority enjoyed by any profession in the field of pediatric cancer treatment, no individual profession exercises complete authority. All of the professions are bound by formally and informally articulated models of care and communication that guide professional conduct. If any of the professionals involved in cancer treatment were to deviate too far from these models, they would likely be subject to professional sanction, perhaps even losing their jobs. In short, while there is variation in the ways in which professionals perform, or take up, any given position in the field, not all variations are accepted, and some constitute grounds for rebuke or removal from the field.

The Psychosocial Team

In addition to the biomedical services that the oncology program offers, cancer patients at BACH are offered access to a wide range of psychosocial services as they go through the process of cancer diagnosis and treatment. The psychosocial staff at BACH is comprised of many different kinds of professionals who carry out many different functions. These include social workers, music therapists, artists-in-residence,[1] child life specialists, hospital schoolteachers, and a spiritual care team. The primary intended purpose of the psychosocial staff is to help patients and family members process difficult emotions, but also to provide opportunities for respite and entertainment in an environment that is often simultaneously full of dread and monotony.

Social workers carry out many different roles, but their primary role is to connect families to various resources to help them financially and practically manage the treatment process. Social workers also act as conflict mediators in a variety of situations—for example, when there is conflict between parents, or between the family and the medical staff. While families and the care team are able to work through most conflicts, there are certain instances in

which the hospital is required to make a report to Child Protective Services (CPS), thus triggering the direct involvement of state authorities. In such instances, social workers handle filing reports and communicating with CPS. In addition to connecting patients to resources and acting as conflict mediators, social workers also offer emotional support to patients and families in the form of counseling and support groups.

The hospital school program is staffed by certified teachers who act as intermediaries between patients and their schools while they are in the hospital. School program teachers work with patients' outside teachers to establish a learning plan and, as much as possible, to prevent major setbacks in patients' educational trajectories. The school program also has a schoolroom where patients who are not immune-compromised can go to participate in various group activities or to work on school assignments with the aid of a teacher. School program teachers also carry out bedside instruction and activities with patients who cannot leave the immune-compromised unit.

Another integral component of the psychosocial care team is the child life program, which is closely allied with the music therapy and art programs. Many people who have not spent time in children's hospitals will likely not have heard of this profession. Child life specialists are equipped with a wide variety of skills and techniques that are intended to alleviate the difficulties of hospitalization. They perform many kinds of labor, from providing families and patients with a compassionate ear during the most difficult phases of treatment, to conducting individual and group play sessions, to sitting by a patient's side and attempting to console them through painful procedures.

The child life program has an office on the fourth floor of the hospital that doubles as the hospital's "Teen Lounge." However, the vast majority of teenage cancer patients are confined to the immune-compromised ward and thus unable to visit the lounge. For patients on the ward, child life specialists carry out activities in the playroom, which is stocked with various toys and art supplies. Child life specialists also visit patients in their rooms with bedside activities, such as board games and art projects. In addition to these activities, the child life program occasionally organizes special events, such as holiday parties and celebrity visits, for patients on the ward. For example, when I was conducting fieldwork, several members of the local professional football team visited the hospital.

Three music therapists staff the music therapy program. One of these therapists is assigned to the oncology ward. The program provides mostly percussion musical instruments for younger patients to play. For older patients, the music therapy program also offers access to guitars and keyboards that they can borrow while in the hospital. There is also a laptop with digital music software that older patients are permitted to use during music therapy sessions. The oncology music therapist holds weekly group sessions in the playroom, and she also carries out bedside sessions in patients' rooms. In addition to working with patients at the hospital, the music therapists also perform music at special events, such as patient memorials.

The art program, like music therapy, also provides individual and group sessions to patients on the ward. The "artist in residence" who runs the program in oncology designs various art projects, such as spin art, collages, stop-motion animation, watercolor painting, etc. Oftentimes, the art program will also organize public showings of patient art or arrange for it to be displayed in the hospital. All of these programs—art, music, and child life—may provide potential sources of therapeutic engagement for young people and their families, but professionals are also aware that this may not occur. Still, at the very least, professionals hope that these activities will provide a distraction, no matter how brief, from the boredom and

monotony that can characterize life in the hospital. These activities also offer opportunities to socialize with other patients, which, as anthropologists have shown, can serve a powerful learning function for patients. By interacting with other young people with cancer, these studies suggest that patients are often able to better make sense of their own condition (Bluebond-Langner 1978; Clemente 2015).

The spiritual care program is staffed by an ordained Christian reverend who acts as the hospital chaplain, providing pastoral counseling to patients and families of all faiths. Beyond directly providing counseling, the chaplain may coordinate spiritual care with religious providers outside of the hospital. The chaplain also speaks at memorial events in honor of patients who have passed away. In addition to the services of the chaplain, the spiritual care program also provides families with access to a meditation room, where they can go for a moment of silence, contemplation, or prayer.

Finally, it should be noted that the hospital relies on a large number of volunteers to carry out various forms of labor and care. Staff members of the volunteer program coordinate the assignments of all of these volunteers, many of whom are undergraduate students who hope to pursue a career in the health care professions. As I will describe below, as part of my fieldwork, I served as a volunteer in the child life program, which provided me with a in-depth look at how psychosocial care is performed in these contexts.

The Entanglement of Biomedical and Psychosocial Care

While the biomedical and psychosocial teams carry out different roles and are organizationally separate in the sense that they have separate team meetings and office spaces, their work is entangled in multiple ways. Most importantly, they work with the same patients and thus play a role in molding the same cancer treatment trajectories. While biomedical professionals deal with the details of the treatment process—for example, dosing and administering chemotherapy—psychosocial professionals try to help patients cope with the emotional and social difficulties of this process. To a certain extent, this requires collaboration and communication between the two arms of the treatment team, although much of this communication happens through patients' charts. For example, the chart will tell psychosocial professionals whether a patient is "on precaution" or not. Those who are on precaution are unable to leave their rooms to participate in playroom activities, usually because they have an infection that poses a risk to other patients.

In addition to the fact that the biomedical and psychosocial care teams work with the same patients, their work is also entangled in the sense that their respective models of care and communication draw on common assumptions about 1) the nature of cancer as a disease, 2) the intense difficulties associated with the treatment process, and 3) the role of different professionals. All professionals on the care team would likely agree that cancer is a biological disease characterized by the proliferation of cells that have undergone harmful genetic mutations. They will also likely agree that this biological process has profound psychosocial consequences in almost every area of the patient and family's life. This common understanding is an artifact of common socialization into the biopsychosocial models of illness dominant in the United States (Borrell-Carrió et al. 2004; Engel 1980). All professionals will also likely recognize common difficulties faced by cancer patients and families, and they will assume that certain professional positions will be best able to address particular problems. In other words, there is a certain acceptance of role division rooted in a common understanding of the disease and treatment

process.

In sharing patients, biomedical and psychosocial professionals also share spaces. While each care team has its own dedicated administrative space in the hospital, the actual work of care unfolds in spaces that are shared between the biomedical and psychosocial teams. The cancer ward is designed to accommodate the work of both sets of professionals. It is equipped not only with medical equipment, but also with toys, instruments, video games, etc. At the same time, it is very common for the psychosocial team to repurpose medical equipment as toys or art and music supplies. For example, patients learn to do spin art with plastic syringes used for dosing medicine, or they may experiment in music therapy with a stethoscope that has been repurposed as a microphone in order to record heartbeats.

Finally, the biomedical and the psychosocial care team are also entangled in the sense that there are several professional positions that seem to traverse the boundary between biomedical and psychosocial care. The psycho-oncology team, which is comprised of psychotherapists who have specialized training in the neuro-psychological and cognitive impact of cancer treatment on young people, is perhaps the most blatant example of this. These professionals provide talk therapy, but they also perform a number of neuropsychological tests that are rooted in notions of the objectivity of evidence-based medicine, and this gives them a level of biomedical and scientific authority that is not equally attributed to other members of the psychosocial care team. There is a similar dynamic with members of the nutrition team, who do not clearly fall on either the biomedical or psychosocial side of total care.

My Role at BACH

During my eighteen months at BACH, I positioned myself as both a researcher and a volunteer, which proved to be a difficult balancing act at times. My primary volunteer position was with Child Life Services, and my role was to facilitate play sessions on my own, as well as to assist music and art therapists in facilitating their group sessions in the playroom. Throughout my 18 months of fieldwork, I regularly volunteered at the hospital three days a week. My shifts usually lasted three to four hours and were carried out primarily in the immune-compromised ward, although I also worked with patients who were not immune-comprised and who thus occupied rooms outside of the ward. Although the activities performed during my volunteer shifts changed from time to time, in general, I would spend one day of the week volunteering with the art program, one day with the music program, and one day doing play sessions.

On a typical play session day, I would arrive to the hospital and report to the child life office, located on the fourth floor in the aforementioned "Teen Lounge." One or both of my two volunteer supervisors, the head child life specialists in oncology, would be there to greet me with an assignment, which was usually to check in with individual patients and families to see if they needed any assistance or if the patient wanted to engage in a play activity, such as board games or video games. They would provide me with a list of patients who they thought could benefit from some extra attention, as well as with details about specific patients' interests and play preferences. I would then go up to the fifth floor and check in with each patient on the list. Usually, a good percentage of these patients would be asleep or feeling too ill to play, but there were almost always at least a couple who were restless and bored and who expressed interest in a play session. On days when many patients wanted to participate, I would set up an activity in the playroom and turn it into a group session.

On other days—for example, special event days—I would be asked to perform different tasks. For example, the hospital has parties around every major holiday. For Halloween, the hospital usually receives a large donation of costumes from a well-known costume shop. These costumes are handed out to patients and their family members free of charge, which requires a great deal of coordination by the child life team and their volunteers. For Halloween 2017, I helped sort the costumes by size and then went from room to room checking to see who wanted a costume and taking down the sizes of those who did. On days when there were no special events or when few patients wanted to engage in a play session, my role was to clean the playroom toys, which had to be regularly sanitized with alcohol wipes. Although mundane and thankless, this is a crucial task given the high susceptibility of many cancer patients to infection.

On art and music group days, I would report directly to the immune-compromised ward, where the artist-in-residence or the music therapist would meet me in the playroom. We would usually debrief for a few minutes, going over the plan for the day, and then we would set up the activity and go around the ward to invite patients to the session. Usually, two or three patients attended the sessions, but there were also days when we had very large sessions, with over five patients and several parents present. On such days, the playroom could become a loud and jovial space, drawing the attention of the ward nurses, who would occasionally walk by smiling at the sight of patients and their family members engaged in a moment of levity. In chapter five, I will provide more detailed descriptions of these activities, analyzing the ways in which they draw on models of care and communication that are shaped by notions of child appropriateness, and which may cause what I describe in the previous chapter as *moral iatrogenesis* for some patients.

In addition to volunteering at BACH, I also conducted interviews with patients, families, and members of all of the above named professional groups. I will describe the themes that guided these interviews in more detail below. Beyond interviewing, I carried out participant observation by "shadowing" oncologists in the day clinic and immune-compromised ward, which I will also describe in more detail below. First, however, I want to describe how I went about gaining access to BACH as a volunteer and a researcher.

Gaining Access to BACH

As with many research projects, this one was facilitated by professional networks, and my first point of contact with BACH was a physician who I met through participating in a working group known as "Experiments in Radical Medicine," which was composed of scholars, healthcare providers, and patient activists who were working to develop ideas for introducing radical change in methods of medical education and community-based health care delivery. I met this physician at a coffee shop and described my project to her. She agreed to put me in touch with one of her colleagues, an oncologist who she thought would be receptive to my work.

The oncologist was indeed receptive, and he instructed me to contact the hospital ethics review board (or "the IRB," as such boards are often called) about submitting an application, which he agreed to sponsor. Anthropologists often lament that IRBs were not designed with ethnographic fieldwork and other forms of qualitative research in mind, but that they instead impose inappropriate ethical frameworks developed in the context of biomedical and behaviorist research. It is also common to hear these scholars comment that the IRB, which is sometimes seen as a manifestation of "audit culture" (Amit 2000; Strathern 2000), does a better job of protecting institutions and researchers than it does research subjects. Despite these critiques, which certainly have merit, IRBs are unavoidable for researchers who want to conduct studies

with human subjects, especially in biomedical institutions. My study was no exception to this rule.

So, as the oncologist suggested, I contacted the hospital IRB. The representative who I spoke to referred me to their website, where the procedures for getting a study approved were laid out in detail. I drafted an application based on the template provided on the website. After submitting, I heard back relatively quickly from an IRB representative who had performed a preliminary review of my application and noted a number of issues that struck her as "red flags." First, I had originally planned to conduct this study using methods that have been branded as "youth participatory action research" (Cammarota and Fine 2008; Mirra, Garcia, and Morrell 2015). I had proposed to recruit a small team of patient-researchers who would help design and carry out the research. The IRB representative, however, informed me that there was no way this would get approved. There were two reasons for this: First, cancer patients are considered a highly vulnerable population, and the labor involved in the research would be seen as asking too much of them. Second, health care environments in the United States are strictly regulated by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which enacts strict protections of private health information. The IRB representative informed me that the inclusion of patient researchers could run the risk of violating HIPAA by granting young patients access to the private health information of other young patients.

Although I did not entirely agree with the representative's initial assessment, she seemed quite adamant, and my primary goal was to get the study approved, so I decided to remove the participatory element. This appeased the representative, and she agreed to send the study to the board for full review. This would require me to attend the monthly IRB meeting and present my research to a board of IRB specialists, physicians, health researchers, and community representatives. Knowing that medical anthropology's particular brand of qualitative methods would be looked upon with suspicion by many members of the board, who had been trained in very different approaches to research, I was quite nervous leading up to the meeting. As it turned out, this was not an irrational reaction. At the meeting, when it was my turn to present, I briefly explained the goals of my study and how I planned to carry it out. At the end of my spiel, I was met with a blank stare by the board member who was moderating the meeting. "Okay…" She said in a somewhat sarcastic tone.

The board had two concerns about my revised protocol, only one of which would be widely recognized as ethical. First, they suggested that the study was still asking a great deal of families who were going through an extremely difficult situation, as it requested families to commit to six interviews, each an hour long, over the course of a year. The study thus risked adding to the difficulties of cancer treatment by asking families to donate extra time. Furthermore, as a graduate student, I had minimal research funds and was unable to offer support in the event that the study triggered intense emotions in patients and family members. Fortunately, Dr. Bhandari, the oncologist who sponsored the application was on speakerphone at the meeting, and he responded that he did not think the interviews would be asking too much, as they would conducted during normal clinic appointments, where patients often had to wait for significant periods of time to be seen by physicians or to undergo procedures. He also assured the board that, as the first point of contact in the recruitment process, he would select only patients and families who struck him as "resilient" enough to endure the research process. Although he didn't offer any criteria of resilience, his professional authority appeased the board, and they agreed that this sounded like a reasonable approach.

The second issue that the board had with my study is arguably more appropriately categorized as methodological than ethical. One of the board members expressed concern that the study lacked an obvious focus: "You're trying to talk to so many different groups of people about so many different topics," she pointed out. I tried to explain that this was a common way of doing ethnographic research in anthropology, as the goal of anthropology is not to generate statistically representative results that lead to generalizable knowledge, but rather in-depth accounts that problematize commonly taken for granted logics and social arrangements. She was unimpressed by this response, and another board member commented: "You know, you're not going to be able to publish this anywhere if you're not using any standardized instruments or statistics." I responded that I respectfully disagreed, as there are many journals and other outlets that publish non-statistical research that does not rely on the deployment of standardized instruments.

It is unlikely that this person was actually totally unaware of these outlets. In order to become a health care professional in the United States, one has to go through the university system, and all majors require courses in the humanities and social sciences. At some point in her educational trajectory, it is likely that she came into contact with forms of research that do not rely on standardized instruments or statistical analysis. Rather than evidence of a lack of familiarity with the kind of research I was proposing, I read her comment more as a judgment about the practical value and likelihood of institutional uptake. In saying I wouldn't be able to publish this work anywhere, she likely did not mean this literally. I think what she actually meant was something more like: "You know, you're not going to be able to publish this anywhere [that most biomedical experts take seriously] if you're not using any standardized instruments or statistical analysis."

In the end, the board decided that I would need to revise my application, responding to their concerns and resubmitting for another review. I left the meeting feeling discouraged, but Dr. Bhandari assured me that we would get the study approved. He expressed surprise at some of the board's comments, since, like me, he did not perceive them all as obviously related to ethical issues, but more to issues of study design. Although Dr. Bhandari was also trained in biomedical research and thus had less familiarity with anthropology and other critical social sciences, he nevertheless took the project seriously, even if he saw it as limited in its ability to produce generalizable knowledge. "This strikes me as a totally reasonable descriptive study," he said. In referring to it as "descriptive," he was marking its limitations, but he did so without denying its value. Feeling more confident after talking to Dr. Bhandari, I revised and resubmitted the application. After another full review, the board decided to approve the application, pending some minor changes to the protocol. After making the minor changes, I was officially allowed to conduct research at BACH.

In addition to gaining IRB clearance, I was also required to gain clearance through the volunteer office, which performed a background check and verified that I had all relevant vaccinations and a recent negative tuberculosis test. Once they verified all of this, I was assigned a date for volunteer orientation. Although most volunteers are required to go through 100 hours of probationary service in a relatively simple assignment, Dr. Bhandari requested that the Volunteer Office bypass this requirement in my case, and they permitted me to begin a more advanced volunteer position with the child life program in the oncology unit. Because I would be working directly with patients and helping facilitate psychosocial care, I was required to go through a separate child life orientation and training session. This involved training on a broad range of issues—proper sanitation procedures, rules and guidelines around communicating and

forming relationships with patients and families, information about the various emergencies that can occur in a hospital setting and how to respond, information about developmentally appropriate activities for different age groups, etc. After completing all of these requirements, I was provided with a light blue smock and a photo ID that marked me as a volunteer and enabled me to come and go from the hospital without checking in at the front desk.

Doing Fieldwork at BACH

After receiving IRB approval and going through all required volunteer orientations, Dr. Bhandari and I began recruiting patients and families. Dr. Bhandari selected potential participants who he thought would be receptive and could handle the demands of the study. It was unclear what exact criteria he used to make these determinations, and I was initially concerned that he would inadvertently select only more socioeconomically privileged families. However, this did not happen, and the pool of patient and family participants ended up being racially and socioeconomically diverse. Dr. Bhandari initially approached participants at their clinic appointments and inquired about their level of interest. If families expressed interest, he would arrange for me to meet with them to go over the details of the projects and sign consent forms. Written consent was obtained from all parents and guardians, as well as from patients ages 13 and over. Patients younger than 13 provided verbal assent.

Carrying out fieldwork at BACH involved three general activities: interviews, shadowing, and volunteering. Initially, all of my inquiry was focused on five themes: 1) iatrogenesis and the body of the patient; 2) ideas about disease causation; 3) the relationship between cancer treatment and other major problems families face; 4) the impact of cancer on social relationships inside and outside of the hospital; and 5) the exchange of medical information between patients, families, and professionals.

As the study progressed, I became interested in how ideological models of care and communication help to produce the social positions individuals take up, as well as how such models guide the circulation of health-related knowledge and practice in ways the produce a spectrum of harmful and beneficial effects in the lives of patients and their families. Although my focus changed as I spent time in the field, in many ways, the information gathered in my initial interviews and fieldnotes continued to provide insights about questions they were not originally intended to answer. For example, in asking patients and families about how they have been affected by iatrogenesis, or medically induced harm, I received a number of responses that provided insights into the ways in which respondents cited existing models of care, positioning themselves and each other as certain kinds of caregivers and receivers. And questions and observations about the exchange of medical information provided insights into the manner in which participants take up models of health communication.

Interviews

Interviews were carried out with patients, family members (mostly parents), and the various professionals described above. With patients and family members, interviews were conducted either in the clinic during appointments or in the cancer ward during hospitalization. Interviews focused on the themes listed above, as well as on diagnosis and treatment narratives.

As is usually the case in interview-based research, some participants were more responsive to my questions than others. Some of the interviews I conducted fell entirely flat,

while others produced rich and dynamic accounts. There are many possible reasons for the variation. One is the power dynamic of the standard interview, which places the interviewer in a position to extract knowledge from patients who are treated as sources of data. Initially, I had hoped to mitigate this dynamic by collaborating with youth researchers. But, given the IRB's concerns, I was unable to conduct the study in this way. In the end, I conducted the interviews with the help of two undergraduate research assistants, one of whom had previously been treated for leukemia as a young child. However, it was extremely difficult to schedule interviews around the students' hectic schedules, and I ended up conducting the bulk of the interviews myself. Given the fact that I am a straight, white, adult male, with an affiliation at a university, my self-presentation surely had unavoidable effects on the interactions that constituted specific interviews.

Interviews with professionals were carried out at the hospital, usually in the office of the professional being interviewed or in the café on the first floor of the outpatient center. These interviews also focused on the themes listed above, but from the perspective of health care providers, and often in reference to the cases of specific patients who had agreed to participate in the study. In addition, I also asked interviewees about their professional philosophies and how they found their way into a career in health care. Another theme that I explored with professionals but not with patients was the role of professional and organizational hierarchies in shaping the provision of cancer care.

All interviews were audio recorded and then transcribed shortly after. In relying on interview data in the accounts that follow, I have necessarily selected and edited particular bits of content, although I have attempted to do so in a way that does not entirely erase the conditions within which these interviews were carried out. I will say more about this below.

Shadowing

As most pre-med students and health care professionals will know, "shadowing" is an established practice in biomedical contexts, and it refers to the process through which interested newcomers "get their foot in the door" to biomedical institutions. To shadow a physician is to attend clinic appointments alongside that physician, acting as their "shadow"—in other words, quietly observing and receding into the background. Of course, as anthropologists have long known, it is impossible for a human participant to actually function as shadow, or a "fly on the wall."

While no participant can actually observe a situation without having an effect on it, there is a way in which shadowees blend into the everyday routines of the hospital, especially in the immune-compromised ward, where it is common for large teams of biomedical professionals to enter patients' rooms at one time. As patients and families become familiarized with the hospital, most of them come to expect the intrusion of various professionals, volunteers, and trainees. This is not to say that these intrusions ever cease being bothersome or annoying to some families, but they are predictably bothersome and annoying.

While shadowing, I paid particular attention to the ways individuals interacted with each other, implicitly and explicitly citing models of communication and care that placed themselves and others into specific positions as physicians, patients, and family members with particular sets of knowledge, roles, and concerns. I also paid attention to the manner in which technologies and various aspects of the built environment mediated processes of positioning. Although I could not document all of the interactions between professionals and patients that I witnessed while

shadowing, I took fieldnotes on any interactions that occurred between professionals and families who had provided informed consent. And even those interactions that I could only observe but not document helped to orient my understanding.

Volunteering

While shadowing provided an in-depth look at the biomedical side of the treatment process, in order to witness the work of psychosocial care professionals, I positioned myself as a volunteer, which enabled me to participate in the work of child life specialists, the music therapist, and the artist-in-residence. I decided not to attempt to participate directly in the everyday activities carried out by social workers and psychotherapists, as I did not think it would be appropriate to ask to intrude on conflict mediation, counseling, or psychotherapy sessions in this context, and I doubt the IRB or the professionals would have allowed it even if I had asked. Like with shadowing, while volunteering in the context of child life, music, and art, I was also not able to document all interactions, as I worked with many patients who were not participants in the study. However, I also did volunteer work with a number of patients who had provided consent, and I was able to document these interactions.

When I proposed acting as both a researcher and a volunteer, the child life specialists who served as my volunteer supervisors were initially concerned that having a dual role would have a negative impact on my relationships with patients. They were worried that the research would take precedence over the volunteering, or that families might see me as "just in it for the research." One way I addressed these concerns was by only recruiting participants in the clinic. During volunteer sessions, I did not attempt to recruit any patients, and I only documented interactions with patients who I had met and obtained informed consent from in the clinic. This prevented me from compromising potentially therapeutic interactions with patients by disrupting play sessions to obtain informed consent. Another way I addressed the concerns of the child life specialists was to refrain from taking any notes during volunteer sessions with study participants. Instead, I would generally take fieldnotes in the hospital cafeteria after my volunteer shift ended.

Documenting and Analyzing the Iteration of Ideological Models

The chapters that follow rely on an interpretive analysis of data collected during fieldwork, with an attention to the ideological construction of communication and care and to the productive effects, both harmful and beneficial, of these constructions. My analysis also attends to how these constructions rely on values articulated in ideologies of youth, a term which I take to encompass notions of both childhood and adolescence, as well as specific kinds of intergenerational relations. Finally, my analysis explores how the distribution of fundamental species of capital (see chapter 2) enables and constrains the iteration of models of communication and care that play a role in placing individuals into the social positions of patient, family member, and health care professional.

But several important caveats are in order here. First, I have discussed this study as one in which I document and explore the ways in which ideological models of youth, communication, and care circulate and intersect. But this begs an important question that I have thus far avoided: what do I mean by *ideological models*, and how do such models relate to the embodied position-takings of individuals engaged in particular field of practice? My use of the term "ideological model" is primarily informed by linguistic anthropological work on "language ideologies."

Despite being informed by this literature, in the chapters that follow, I do not restrict my analytical focus to ideologies of language, but instead consider how ideological models of care, communication, and youth intersect in the production of social positions and the embodied persons who take up these positions.

As Woolard and Schieffelin (1994) note in their review of this work, anthropologists have defined language ideologies in multiple ways.[2] According to Woolard and Schiefflin, one major division that characterizes studies that rely on anthropological concepts of language ideologies is "between neutral and critical values of the term [ideology]" (1994, 57). Critical uses of ideology rely on a notion of *mystification*. From such perspectives, ideology can be seen as a tool of social domination that helps to produce the dominated individuals' complicity in their own domination, which they view as natural. In other words, critical understandings stress the relationship between ideology and social power. It is useful here to connect this discussion to Bourdieu's theory of fields, upon which I drew in the previous chapter. For Bourdieu, *illusio* (akin to *mystification*) arises when agents misrecognize the structure of the social world and their position in it as natural, or inevitable. This misrecognition is related to agents' failure to see the arbitrariness of dominant sets of cultural distinctions (ideologies), including those distinctions made via language (Bourdieu 2009). While some agents inevitably challenge naturalized distinctions, the distributions of capital that drive activity in the various fields that constitute the social world compel social reproduction more often than transformation.

A more neutral usage of ideology, on the other hand, does not necessarily view ideological distortion as arising primarily from processes of social domination, but rather from "inherent limitations on awareness of semiotic process and from the fact that speech is formulated by its users as purposive activity in the sphere of interested human social action" (Woolard and Schieffelin 1994, 58). Distortion arises here because humans are unable to take in and consciously comprehend all aspects of a situation, but can only take the world in from particular, interested positions, which entail ideological frameworks into which we have been socialized and through which we position ourselves and are positioned by others. Here "interested" need not imply a desire to dominate others for personal gain, although it could. To say that social activity is "interested," is simply to note that it is guided by a set of affectively charged values and desires. For example, a person can be "interested" in fulfilling ideals of benevolence, charity, or self-sacrifice. Of course, the most cynical analysis could find a way to tie such interests back to a desire for social recognition, and there may be some truth to the idea that such desires are almost always operative, although I would question any reduction of human interests to *purely* self-serving motivations.

While Woolard and Schieffelin's (1994) analysis seems to place neutral and critical understandings of ideology in opposition, I do not think they are wholly incompatible. My view of ideology, linguistic or otherwise, is a mix of the two perspectives. From the neutral perspective, I take the point that all of human social activity is ideologically mediated, by which I mean it is partially produced by shared, circulating sets of ideas that commonly cluster around each other. Social activity would hardly be possible without ideologies. No person, including scholars and other social critics, has access to a position that totally transcends all ideology. In noting this, I draw inspiration from Rosa and Burdick's "rejection of the notion that some perspectives on language are objective while others are ideological" (2016, 2), which I see as a logical extension of the neutral approach. All perspectives on language and communication, or any other aspect of social life, are mediated by sets of interconnected ideas and are therefore ideological.

At the same time, from the critical perspective, I take the point that certain ideologies are made dominant in certain times and places by individuals and groups who are affectively and practically attached to those ideologies, which are "loaded" with moral and political interests, as Irvine (1989) puts it. Over time, and with the help of various forms of capital, ideas are made to iterate through social space, leading many people to see them as "self-evident" or "commonsensical," as Heath (1977) and Rumsey (1990) respectively put it. However, I want to be careful here about overstating ideology's blinding force. Although the forms of naturalization that ideology enacts can encourage people not to question the underlying assumptions upon which they operate, this does not mean that they lack the intelligence or ability to engage in critical questioning, but rather that the distribution of capital that structures the social fields in which they participate creates barriers and incentives against doing so.

Ideologies have complex relationships to forms of capital, which can be gained, maintained, or lost as a partial function of how one iterates an ideology. For the iteration of some aspect of an ideology to become converted into symbolic capital that accrues benefits to an individual, others who participate in a given social field must recognize the iterative performance as legitimate. Failed attempts at iteration—that is, attempts at ideological performance that are not recognized by others as legitimate—may result in sanction or expulsion from one's position in the field and the loss of all the benefits that accrue to someone inhabiting that position. It is in part the widely held desire to avoid sanction and to be recognized as legitimate by select others that drives ideological reproduction, which is always inextricably linked to the reproduction of capital.

So, if ideologies can be understood as sets of ideas entangled with certain forms of capital that play a role in driving people's attachment to them, then what is a *model*, and how do ideologies and models come to intersect? Models, according to Duranti, are "entities that are good to think-with" (2005, 419). In a way, though, this doesn't take us very far from the term "idea," which could arguably be conceived in the same way. (Of course, some would perhaps object to calling ideas "entities," but I see no problem with it.)[3] In my use, a model isn't only an entity that facilitates thought, but an entity that represents the structure and functioning of some aspect of the world, or that provides directions as to how to carry out a particular activity in the world. In using this definition, I draw on Geertz's (1973) classic distinction between two types of models: "models of" and "models for." This distinguishes models from ideas in that ideas can be imaginary constructions that have very little to do with the actual structure of the world, despite the fact that they emerge within that structure. Furthermore, imaginative constructions that initially have little to do with the world can be realized through ingenuity and serendipity. For example, there was a point in time when it would have struck the average person as bizarre to think that much of humanity be walking around with blocks made of plastic, silicone, glass, and metal that allow us to almost instantaneously see and hear people on the other side of the planet.

In summary, *ideological models* can be understood as representational entities that project how things are, or how some process is to be carried out, and which are dependent on some prevailing set of ideas that have become entangled with the forms of capital that enable and constrain the practices through which social fields are produced and maintained. To take an example from my account of the IRB review process, the board member who commented on the lack of standardized instruments and statistical analytic strategies in my IRB proposal was drawing on ideological models of research that currently dominate the biomedical field. Such models rely on an ideology of scientific investigation that some anthropologists would refer to (disparagingly) as "positivism," or an approach that refuses to acknowledge the legitimacy of

knowledge claims other than those inferred from scientific data sets constructed by experts. Of course, as I will discuss in the following section, biomedical experts are not the only ones who traffic in ideological models.

The Ideological Models of Patients, Families, and Anthropologists

Thus far, I have primarily relied on examples of ideological models of youth, care, and communication produced and taken up by cancer professionals. In doing so, I could be accused of obscuring the fact that not only biomedical experts and professionals produce and iteratively cite such models. As they take up positions in the field of pediatric cancer, patients and family members also cite ideological models that are not restricted to professional models of care and communication, or that may even entail resistance to professional models. Or, as I found to be more commonly the case, they may attempt to hybridize professional models with other models derived from outside the biomedical field.

The observation that patients and family members also participate in the iteration of ideological models can be taken as another extension of the neutral view discussed above, which views *all* social life as ideologically mediated. This leads me to a second caveat before I move onto an analysis of material I gathered during fieldwork: I do not exempt my profession or myself from the analytical gaze. As Briggs (2011) points out, anthropologists too cite ideological models of communication (which he refers to as "communicable models") that we use to situate ourselves in relation to research participants, who we have historically referred to in various stilted terms, such as "interlocutor" or "informant." Much like physicians and other health care professionals, we use communicable models to produce and circulate various narratives and other bits of data, but, also much like physicians and health care professionals, our models often reduce complex pragmatics to oversimplified metapragmatic maps.[4]

As Briggs (1986) has pointed out in his earlier work, anthropological interviews are a primary example of this. Often, interviews are represented as a simple process of extracting information and narratives from participants who have all the relevant content available to conscious reflection and articulation. This model treats the interviewee as a font of discourse that the anthropologist simply taps into and documents. Yet things are never so straightforward, and the information and narratives collected during any research project, anthropological or otherwise, are always co-produced by participants and researchers (Briggs 2011). But this does not mean that participants and researchers are on equal footing. The process of documenting and circulating material collected through interviews and participant observation is always shaped by social hierarchies and forms of capital that ultimately tend to place the anthropologist in the authoritative position to select and edit narratives for circulation. In the process of selection and editing, information and narratives about illness and health care are often stripped of various aspects of their "indexical histories," which, Briggs suggests, "represent patients' efforts to place themselves vis-à-vis the production and circulation of knowledge" (2011, 464).

Of course, to some degree, selection and editing are involved in the production of any article or book, and an anthropological work that removes none of the indexical histories associated with specific narratives or strands of speech or description is not possible. Under the influence of the communicable models that dominate the academic field, the anthropologist and their professional reviewers and editors make final decisions about what goes into the publication. While collaborative research with participants is one way to address unequal power dynamics in the production and circulation of knowledge, I think most anthropologists who do

this kind of work would admit that such methods, while certainly a step in the right direction, do not totally neutralize existing communicative inequalities.

For good reasons, anthropologists tend to be very self-conscious about exercising power over research participants' words, images, and stories. This self-consciousness stems in part from the fact of anthropology's emergence in the colonial era, and the accompanying recognition that anthropologists have often served as agents of colonial power, whether consciously or unwittingly.[5] It also stems from critiques that anthropologists have lodged at other professions' and scholarly disciplines' methods of observing and representing the world, which anthropologists often attempt to avoid reproducing or mimicking at all costs. For example, Kleinman and Kleinman (1991) describe how medical anthropologists have often accused physicians of acts of professional transformation that reduce the complexities of human illness to cold and dehumanizing models of disease. But Kleinman and Kleinman argue that anthropologists are caught in a similar dilemma:

> The anthropologists' interpretive dilemma is that they participate in the same process of professional transformation. The interpretation of some person's or group's suffering as the reproduction of oppressive relationships of production, or the symbolization of dynamic conflicts in the interior of the self, or as resistance to authority, is a transformation of everyday experience of the same order as those pathologizing reconstructions within biomedicine. Nor is it morally superior to anthropologize distress, rather than to medicalize it (1991, 276).

While I wouldn't equate the processes of transformation in which anthropologists and biomedical professionals respectively engage, and while not all anthropologists view suffering or oppression as their primary object of study, I take Kleinman and Kleinman's (1991) overall point: writing up an anthropological manuscript about one's fieldwork-based interactions with a group of people is inevitably to transform the complex processes and relationships that can be found in any social field into a particular text, which necessarily says some things and excludes others. Furthermore, our texts virtually always introduce interpretive frames that did not arise in the field under study, but in the academic field. For example, many anthropologists throughout the twentieth century developed the academic concept of culture to make sense of non-Western peoples, many of who did not employ an equivalent concept. As the culture concept came under more intense scrutiny in the 1980s and 1990s, particularly by members of what Allen and Jobson (2016) refer to as the "decolonizing generation" (e.g., Abu-Lughod 1991; Bolles 1996; Harrison 1997; Trouillot 1991), many anthropologists eventually turned away from the study of culture entirely. More recently, anthropologists have called for a move beyond other fundamental concepts—humanity (Dubal 2018) and society (Rees 2011), for example. But even anthropologists who have assumed a new area or object of inquiry nevertheless continue to write and, in doing so, to transform selected aspects of the fields they study into specific texts.

By taking up a position as an anthropologist in the academic field, which is produced and driven by its own ideological models and forms of capital, we always run certain risks. We run the risk of erasure—of failing to represent in our written accounts important contextual details or aspects of a situation. We run the risk of distortion, whether as a consequence of erroneous documentation, or of introducing our own projections, or of circulating texts to audiences who introduce their own projections. And, most importantly, we run the risk of causing more harm

than good to the people whose lives our texts portray. There are many dangers inherent in any act of professional transformation, and the anthropological profession is no exception.

Yet while it is important to develop measures to mitigate these risks—for example, participatory research methods—I'm afraid the only way to avoid them entirely would be to avoid the practice of fieldwork entirely. As Scheper-Hughes observes:

> The anthropologist is an instrument of cultural translation that is necessarily flawed and biased. We cannot rid ourselves of the cultural self we bring with us into the field any more than we can disown the eyes, ears, and skin through which we take in our intuitive perceptions about the new and strange world we have entered. Nonetheless, like every other master artisan (and I dare say that at our best we are this), we struggle to do the best we can with the limited resources we have at hand—our ability to listen and observe carefully, empathically, and compassionately (Scheper-Hughes 1992, 28).

To translate what Scheper-Hughes is saying into the terms I have used thus far, in taking up a position in some field that is relatively foreign to them, anthropologists necessarily use their existing habitus, which is infused with various ideological models (schemas of vision and division), to make sense of that field, or at least some aspect of it. By the time an anthropologist carries out formal fieldwork, their habitus will have been shaped by the rituals of anthropological training—e.g., taking seminars, writing papers, completing qualifying exams, etc.—and it will issue forth ideologically mediated reactions derived from that training. These reactions shape the acts of professional transformation that result in the production of anthropological texts, with all their problems.

At the same time, the abilities of listening and observation that Scheper-Hughes (1992) identifies as among our limited anthropological resources can play a role in short-circuiting these reactions and thus further transforming the habitus of the investigator. Most anthropologists have some level of expectation that fieldwork will change them—that acts of listening, observing, and writing have the potential to dislodge our ideological assumptions and the models of the world they uphold. In the early twentieth century, some anthropologists described such experiences in terms of "culture shock" (Oberg 1960). More recently, having dispensed with the culture concept, Tobias Rees (2010) has described such experiences as moments of "derailment." For Rees, these moments are central to fieldwork as a model of knowledge production:

> This derailment - this noise - is at the methodological core of fieldwork. It is at the core of it because it (at least potentially) invalidates the preconceived, robs the ethnographer of the conceptual framework with which she arrived in the field. The effect of derailment is a loss of orientation that creates the conditions for the fieldworker to learn to reorient herself in the field; to find, amidst a bewildering, seemingly chaotic perplexity, a way of bringing the field site (or elements of it) in its specificity into view; to learn ways of thinking it through in its own terms (all the while reflecting on the conceptual presuppositions one makes) (2010, 896).

While we come into the field with our own ideologies, anthropologists are perhaps unique among researchers insofar as we are trained to expect even our most fundamental assumptions to be challenged by the process of fieldwork. If we come into the field with ideological models of how the world works, we often do so in hopes that the field may provide

us with counter-models that we can place in productive tension with our own, which we may eventually discard. This was the approach I used throughout this study.

Conclusion

In short, through interviewing, shadowing, and volunteering at BACH, I conducted 18 months of fieldwork focused on the description and analysis of ideological models of communication, care, and youth that intersect and play productive roles in the field of pediatric cancer treatment. In doing so, I engaged in acts of anthropological transformation through which I converted a series of situated experiences and social interactions into textual material that I then analyzed, selected, and edited into the dissertation you are now reading. There were many ethical dangers inherent in these acts—and not always the dangers presaged by the IRB. In engaging in anthropological transformation, I inevitably took certain risks, but I did so carefully, often with the help of a digital audio recorder.

While I don't have any final solution to the problems that pervade our existing models of anthropological inquiry and writing, I take several cues from my forebears in attempting to convey the social interactions and observations that made up my research in the field of pediatric oncology. From Kleinman and Kleinman, I take the observation that this text, like all anthropological texts, is an act of professional transformation, and it is not a perfect copy of experiences or situations that unfolded in the field. Following Briggs, I note that the material that serves as the basis of this text was not simply extracted from participants and installed into this text. In inhabiting the position of researcher, I played a powerful role in co-producing this material and selecting the descriptions and narratives that made it into the final product. In doing so, I have tried to convey important aspects of this material's indexical histories and to represent participants' voices and actions as faithfully as possible, although I follow Scheper-Hughes (1992) in acknowledging that I have almost certainly introduced biases and contradictions that are the very basis of my social existence as an embodied person in the world.

End Notes

[1] Although one of the officially stated goals of the art program are to provide potentially therapeutic artistic activities to patients, the professionals who staffed this program did not refer to themselves as "art therapists," but "artists-in-residence."

[2] My understanding of the term *idea* is informed by Ian Hacking's critical analysis of social constructionism. Hacking situates ideas as emergent within specific social matrices, which have a distinct materiality. As Hacking puts it: "Ideas do not exist in a vacuum. They inhabit a social setting. Let us call that the *matrix* within which an idea, a concept or kind, is formed" (1999, 10, emphasis in original). In this view, ideas are not immaterial forms that exist in a Platonic realm beyond the material world. Instead, ideas emerge through material interactions, and they do not have an existence independent of their physical articulations in thought, language, practice, and various media.

[3] They offer four different anthropologist's definitions of the term:

1. Michael Silverstein's: "sets of beliefs about language articulated by users as a rationalization or justification of perceived language structure and use" (1979, 193).
2. Shirley Brice Heath's: "self-evident ideas and objectives a group holds concerning roles of language in the social experiences of members as they contribute to the expression of the group" (1977, 53).

3. Judith Irvine's: "the cultural system of ideas about social and linguistic relationships, together with their loading of moral and political interests" (1989, 255).
4. And, finally, Rumsey's: "shared bodies of commonsense notions about the nature of language in the world" (1990, 346).

[4] In using the distinction between pragmatics and metapragmatics, Briggs draws on the work of Michael Silverstein (1976):

> Pragmatics refers to the use of signs in particular contexts. In a conversation, for example, how people take turns, build on each others words, shift topics, display attentiveness, and attempt to dominate their interlocutors are issues of pragmatics. At the same time, however, co-conversationalists are constantly commenting on what is being said, framing particular utterances as authoritative, hesitant, or humorous, registering their agreement or disagreement with what the other has said, and pointing to where they think the conversation should go. Metapragmatic dimensions are no less important in other types of discourse (Briggs 2011, 467).

[5] For accounts of attempts to decolonize anthropology from within the discipline, see Allen and Jobson (2016) and Harrison (1997).

Chapter 4
Cancer Treatment and the Moral Force of Developmentalist Ideologies of Youth

"You have lymphoma."

In June of 2016, Rachel Phipps, a 17 year old from Tracy, California, began having trouble breathing. At first, she thought nothing of it, since she has a history of asthma. But then she began to notice tightness in her neck and shoulders, and eventually it became difficult to lie flat on her back. At this point, she and her mother decided to go to her family doctor, who speculated that her issues were being caused by heartburn. She was prescribed heartburn medication and sent on her way.

The heartburn medicine didn't help. One weekend after the doctor's appointment, while in Los Angeles for her sister's softball tournament, Rachel was pulling a cart of folding chairs, and she became so out of breath that she had to be rushed to the emergency room. The ER doctors prescribed her an inhaler and an antibiotic.

Rachel went home to Tracy, but her symptoms kept getting worse. Her neck and cheeks had begun swelling. Thinking she was having an allergic reaction, her mother gave her Benadryl, but the swelling wouldn't subside. They decided to go to the local hospital, where a chest x-ray was performed. The x-ray showed fluid in the lungs. Rachel was put in an ambulance and transported to Bay Area Children's Hospital (BACH), where they performed blood work and a CT scan around 9pm. Then, around 3:30am, the doctor informed Rachel's family that she had lymphoma. At first, when she received the diagnosis, Rachel wasn't really sure what it would mean for her. "It's funny," she recounts, "'cause when they said 'lymphoma'—like they didn't say 'You have cancer.' They just said 'You have lymphoma.' But I didn't know what lymphoma was, so it took me a couple days to figure out 'oh, that's cancer'… It was really shocking and sudden."

The diagnosis was shocking for Rachel's parents, as well. They hadn't expected something so serious, and they felt guilty for having downplayed the significance of Rachel's symptoms. Rachel's mother, Sharon, describes the experience:

> Of course we thought, as parents, we're like, it's dramatic, y'know, 'cause teenagers… Rachel normally is, y'know, very sensitive. She kinda takes things to the next level and really overdramatizes things... like really. So at first I'm like, "Knock it off, you're fine…" I mean, you think back, and you just think "God, what an idiot I was." But you don't think of something like this, right? And for her to have some sort of allergy… I wasn't even thinking twice, because there were fires going on in LA at the time, and so that's what the ER had said, "It could be the fires, maybe the fire and the air." So maybe that's why it kind of triggered something… and again, you know you're not really even thinking."

Cancer Diagnosis as a Collision in Modes of Time: The Role of Developmentalist Ideologies

Rachel and her mother, like virtually all of the patients and family members I met, described cancer diagnosis and treatment as shocking and emotionally painful experiences. Once patients and family members realize the diagnosis is cancer, their thoughts and feelings often go

into overdrive. They replay past events, attend to worst case scenarios, and confront the potential loss of previously taken for granted futures.

In her book *Malignant*, the anthropologist S. Lochlann Jain describes such experiences as stemming from a "collision in modes of time" (2013, 97). Cancer patients go through feelings of extreme fear and disorientation as their relationship to dominant institutions and the temporal projections on which they rely is suddenly thrown into question. On the one hand, there is the time of individual biographies, which often project a series of normative events: birth, high school graduation, marriage, parenthood, retirement, etc. On the other hand, there is what Jain refers to as the "immortal time" of various institutions, such as states, schools, banks, and employers. As individual persons flicker in and out of existence, these systems hum along in seeming perpetuity, promoting future-oriented models of investment and accumulation. For those affected by cancer or any other terminal illness, the perpetual pulsations of institutional time can serve as a reminder that they may be forced out of their particular position in the dramas of social life before they are ready to leave.

Building on Jain's observations, I point out that the ways in which people experience and describe this "collision in modes of time" enacted by pediatric cancer diagnosis is influenced by the life stage categories embedded in developmentalist ideologies that structure institutionalized practices of temporalization. Through the positioning effects of these ideologically modeled practices—these "modes of time," as Jain calls them—people often come to see themselves and others as inhabiting specific life stages. Yet this is not to say that cancer patients passively accept the ways in which others attempt to position them, and they may engage in active resistance to particular positionings.

Many patients, family members, and professionals at BACH relied on some version of the distinction between childhood and adolescence. This distinction is widely distributed throughout American society, and it is in part a product of biomedical practices, which rely on developmentalist ideologies of the human as a biological organism and psychosocial being that advances through a series of stages that roughly correspond to chronological age. These categories structure biomedical institutions, which are often divided between pediatric and adult medicine. As a consequence of this distinction, many young people under age 18 who are diagnosed with cancer are treated in children's hospitals, such as BACH. But the correlation between chronological age and institutional placement is not perfect, and, during the period of my fieldwork, I met a number of BACH patients who were over the age of 18. Many of these patients began treatment prior to turning 18, but since cancer treatment often takes years, some of them legally became adults during treatment.

As anthropologists and other scholars have pointed out, racialized, gendered, and sexualized constructions of childhood and adolescence are ubiquitous in many spaces (Lancy 2008; Jones 2009; Mead 1928; Mendoza-Denton 2008; Montgomery 2008; Lesko 2012). The field of pediatric cancer treatment is no exception to this general trend. To take an example from the narrative of Rachel's diagnosis recounted above, we can see how her parents originally interpreted her complaints as a product of the overly dramatic manner of being in the world commonly associated with teenage girls. In hindsight, Sharon feels guilty for having viewed the situation this way, as it delayed Rachel's diagnosis. Despite Sharon's guilt, she can hardly be blamed for the delay. Rachel's doctors also made the assumption that her symptoms were caused by something less serious—something more common among people in her age group. Such stories of diagnostic delay are incredibly common among cancer patients, and they are usually partially related to the fact that general practitioners deploy a model of care that relies on the

practice of "differential diagnosis," which leads many of them to assume that symptoms with which most of their patients present are caused by common ailments, as opposed to relatively rare diseases like pediatric cancer. This is especially true in the cases of younger patients, who, according to developmentalist epidemiological models, are generally assumed to have a very low risk of cancer (American Cancer Society 2018).

As I will show in the next section, once pediatric patients actually receive a diagnosis, they are very likely to experience the "collision in modes of time" described by Jain, albeit in a different key. Like Jain, the patients who I met at BACH were indeed concerned about how cancer diagnosis and treatment might negatively affect their lives and foreclose possible futures. But these general concerns were oriented differently given the child/adolescent social positionalities they inhabited. No patients I met expressed the exact concerns that Jain associates with young adult patients—for example, the effect that cancer treatment could have on one's ability to save money for a home (2013, 90). However, many described themselves as having experienced intense anxiety about missing school, losing friends and significant others, and making it to college. And some feared the impact that cancer and the treatment process would have on their ability to realize careers they had been dreaming about for years. In other words, they feared how cancer would negatively affect their transition into adulthood, or even rob them of that transition entirely.

In the following section, I return to Rachel's story in order to explore how she and her parents describe her entrance into the treatment phase, which involved the re-temporalization of her life around a cancer treatment protocol in hopes of repairing the rupture in her biographical timeline. After starting treatment, Rachel went through a phase in which she could not help but fixate on worst case scenarios, which in turn led her to experience hallucinations related to her own death. As I will describe, Rachel, her parents, and her professional caregivers' response to this situation were mediated by developmentalist ideologies of the human that project a movement from childhood to adolescence to adulthood. In this context, care is often constructed as a practice of maintaining an attitude of optimism and protecting patients from emotionally charged forms of communication. Although limiting certain forms of communication is often framed as "for the patient's own good," it is also arguably a way for adult caregivers to avoid distressing thoughts and conversations.

"Am I gonna die?"

The initial moment of shock that Rachel and her mother describe above continued to reverberate throughout their lives for some time, negatively affecting their emotions and thought processes. For Rachel, the negative thoughts and emotions generated by diagnosis were compounded by the physical difficulties and social isolation of treatment, which required her to stop going to school during the most intensive phases. All of the stress, uncertainty, fear, and isolation amplified thoughts of death that began to overpower Rachel's consciousness. As Rachel and her mother explained in an interview at the oncology clinic one morning:

> Rachel: All I could think about was, like, my friend's dad had lymphoma and he passed away, so I was just thinking, "Am I gonna die?"
>
> Sharon: I remember her saying that and thinking that, and I thought, "Oh my god, really, you thought that?!" It's like… the TV was on, remember, you thought we were just

playing family videos on the TV even though there weren't any videos?" During the course of chemo, she was given prednisone, and that was part of the mix to shrink the tumor… 60mg twice a day. Lots of prednisone.

Rachel: I had this manic stage…

Anthony: So you had a hallucination where you thought there were family videos on TV?

Sharon: Yeah and no one's in the room, so she thought we had left the room and were playing family videos so she could see her life how it was before she died. Like her life passing before her eyes. I'm like Really?! Oh my god, you really thought that?

Rachel: Yeah, I had a lot of weird thoughts. Like all of the medicine, it just all got in my head.

Sharon: I would videotape her, and she would be like [imitating a monotone, barely audible voice]: "Mom… I hear noises. There are kids crying in the other room. They need help."

Rachel: [laughing]

Sharon: It was pretty weird… I was like "Okay…"

Rachel: Yeah, and there was also this point where I wasn't sleeping. I went like 2 days without sleeping at all. And they were trying to get me to go to sleep.

Sharon: Because she was afraid to go to sleep because she thought she was gonna die. I was like: YOU ARE NOT DYING! YOU NEED REST!

Rachel: Yeah, I thought when they were saying, "You need to go to sleep," they were actually saying it was time to die. It was all just messing with my head [laughing].

Anthony: Well, it's kind of understandable… You were going through a lot.

Rachel: Yeah…

Sharon: Seriously… It was a lot… A lot. And I think we, as parents, at some points felt delirious too because we were up as long as she was.

As Rachel and Sharon describe, this particular period in the treatment process was the most difficult part, even if it produced some moments that are now laughable to them in hindsight. At the time, however, Rachel was struggling to hold onto hope, and her parents didn't know exactly how to help her. Like Rachel and her mother, Rachel's stepfather, Robert, also recounted this as one of the most difficult periods of treatment.

Robert: When someone would walk in she'd ask "What are they doing here? They're not gonna hurt me right?!" We just had to insist to her that everyone's here to help. She was in her own little world there for a while.

Sharon: I mean, she wasn't violent at all, but it was just like certain colors… mainly red. Just don't have on a red shirt!

Robert: And she would talk about dying a lot and scare us.

Sharon: But finally the psychiatrist gave her an antipsychotic—well, some combination of medications… Lithium, Zyprexa, and Ativan. And it helped…They hadn't really witnessed anything like this. Just one episode… a girl who is now a junior at Berkeley.

In addition to pharmaceutical interventions, Robert and Sharon also intervened by taking Rachel's phone from her, as she was posting morbid social media content and worrying friends and family.

Rachel: One time, when they moved me to a room alone, I didn't have my phone with me, and I just wanted to know what time it was, and I was asking all my nurses, and they wouldn't tell me, and I felt like I didn't know what day it was. Everyone looked like zombies to me at that point…

Robert: Her phone was her big thing… But she starts getting on social media and telling everyone she's dying on this medicine, and now we're getting all this other feedback, so we took her phone away.

Rachel: And my friend told me I was texting her all these long things.

Robert: Yeah so we had to monitor that.

Anthony: So which friend was it?

Robert: I think it was her friend Brittany's family that called and told us. They were like "What's going on? How come Rachel's saying she's dying?"

Sharon: And we were like "What?!"

Robert: So that same day we made a trip down here and collected the phone.

Anthony: And how'd you react to that?

Rachel: I was just like "Why are you doing this to me?! I'm already going through all this…" [laughs] I was mad, but…

Sharon: It was just for your own safety.

Robert: We tried to replace it with games and interactive stuff.

Sharon: And you colored and painted a lot.

Rachel: Yeah, I was talking about painting one night, and then one of my friends bought me some canvasses and paints and stuff to do, and then I just started painting.

Repairing the Rupture: Fear and Optimism

When Rachel's parents found out about her morbid thoughts, they were taken aback. At first glance, this response struck me as unusual—to express surprise at the fact that a cancer patient would fear death. However, as Sharon points out, as parents of a young person with cancer, they were also emotionally and physically exhausted. Their response was no doubt mediated by their own fears, which prompted them to constantly remind themselves that their daughter had been given a very positive prognosis. During the patient and family education process, Sharon and Robert learned that Rachel was diagnosed with primary mediastinal B-cell lymphoma, a type of non-Hodgkin's lymphoma that oncologists view as having a relatively high survival rate. The oncologists and other members of the care team reassured the family that Rachel had a very good chance of living beyond treatment, and Sharon and Robert took refuge in this reassurance.

For example, during an interview with Dr. Bhandari, one of the oncologists, I asked him to describe Rachel's case, and he responded in the following way: "She had primary mediastinal B-cell lymphoma. Pretty rare tumor. I've had a few kids with it. Treatment's not super, super intensive." From Dr. Bhandari's perspective, Rachel's cancer was not her biggest problem. Rather, it was her fearful, manic reactions and hallucinations, which were likely exacerbated by heavy doses of prednisone, a kind of corticosteroid which is known to cause adverse psychiatric effects, although reactions as severe as Rachel experienced are less commonly reported (Warrington and Bostwick 2006). As Dr. Bhandari described it:

> The main issue for her was, I think, she came in not having the best coping skills, and she got on steroids as part of treatment, and she had a psychotic break. She kind of went into this mania afterward that was pretty challenging to control, so she was in the hospital a lot for the psych issues even more so than the therapy, so it took some time to really get on top of those things. The treatment itself is relatively manageable, and she did well with the chemo part, and the response rate is actually very, very high for that tumor type, and the chance of relapse is very low. So it was more managing some of these other psychosocial issues… She got really uninhibited and was saying a ton of stuff to everybody… But from a cancer standpoint she's done fine, and she'll do fine. It's just kind of overcoming some of these other things.

From the perspective of Dr. Bhandari and the other oncologists, Rachel's particular diagnosis was highly treatable and thus not cause for panic. Although oncologists never make definite promises about treatment efficacy, they reassured Rachel and her family that she would very likely be okay in the long run, and her parents took comfort in their expertise, which seemed to suggest that Rachel's relationship to dominant modes of time would be restored.

For Rachel, however, the reassurance that oncologists offered was, at times, difficult to inhabit optimistically. While her parents and the care team assured her that her prognosis was good, she couldn't shake the fact that the only other person she had actually known with lymphoma had passed away. On top of that, her life had been put on hold as her body was put through an aggressive treatment regimen that involved chemotherapy, radiotherapy, and prednisone. While everyone wanted Rachel to have faith in the possibility that she was currently on a path back toward health, Rachel was fixated on the possibility that the temporal rupture that cancer introduced into her life could be permanent.

Although there was no question that Rachel was going through a life-altering event that caused her a tremendous amount of suffering and stress, the oncologists suggested that it wasn't common for patients to have such severe reactions to treatment. Because of this, Rachel's parents were left wondering why her reaction was so pronounced:

> Sharon: They had only seen one other case similar to what Rachel experienced: Rachel's age, another female. It kinda makes you wonder… Was it was hormone induced? They really didn't know. But apparently this other girl is now a 3rd year university student, and she's doing really well. You just never know.

Dr. Bhandari and Sharon both locate the cause of Rachel's distress in her personal characteristics. Dr. Bhandari describes Rachel's issues as related to her limited "coping skills" and her extremely negative reaction to prednisone. Having watched hundreds of adolescent patients pass through the cancer ward over the years, Dr. Bhandari couldn't help but observe that not all of them responded like Rachel, and this led him to believe that perhaps the response had to do with Rachel's individual characteristics. Sharon also wondered what caused Rachel's issues, speculating that it could have something to do with Rachel's gender and the high levels of hormones commonly associated with adolescence. Ultimately, though, despite Sharon and Dr. Bhandari's best guesses, no one could be sure what precisely caused Rachel's hallucinations. Regardless of what caused them, everyone's top priority was to stop them from occurring.

The Limits of Unmasking: Affective Attachments to Developmentalist Time

Thus far I have considered the particular ways in which Rachel's reactions to treatment, as well as her parents' and doctors' reactions to her reactions, were shaped by figures of adolescence associated with developmentalist models of the human that commonly circulate in the contemporary United States. In doing so, I want to question a scholarly orthodoxy commonly reiterated in the field of childhood and youth studies, which insists on viewing young people as "beings" as opposed to "becomings."

First, let me say a bit more about this orthodoxy. As many scholars in childhood and youth studies have noted, children and adolescents are often viewed through developmentalist theoretical frameworks. In other words, they are seen as embryonic adults who lack rationality and are in formation toward a hopefully productive end. Beginning in the 1990s with the emergence of the "new sociology of childhood" many scholars began to criticize this view, arguing that it does violence to young people, who we must see as "beings" as opposed "becomings" (Arneil 2002; James and Prout 1997; Jenks 1996; Lesko 2012; Qvortrup 2009).

To take one example, Nancy Lesko (2012) offers an account that associates the devlopmentalist view of the human with the emergence of modernity. Citing the work of

Reinhart Koselleck (1985), Lesko suggests that a defining quality of the modern era is the "temporalization of experience." According to Lesko: "The temporalization of experience utilized clock time, standardized world time, active measurement, and counting of time. Time was tracked in order to use it…And productive use of time became a central measure of better, more valuable individuals and groups" (2012, 92).

It is unclear whether Lesko takes Kosselleck to mean that humans did not have modes of temporalizing their lives prior to the emergence of modernity. This would be an odd claim, as time-keeping devices existed well before the clocks, calendars, and models of world time that Lesko associates with modernity (Hannah 2008). As anthropologist Nancy Munn argues, time is "an inescapable dimension of all aspects of social experience and practice" (1992, 93). Temporalization is a panhuman phenomenon, and it arguably goes beyond the human, as there is a temporal order to life on Earth, which depends on predictable, repetitive processes, such as sunrise and sundown (Gell 1992; Gingrich, Ochs, and Swedlund 2002).

Although temporalization is not unique to modernity, I take Lesko's point that the modern era saw a linking of the passage of time to ideas of rational, scientifically driven progress and betterment, which are often articulated in gendered and racialized ways. Within this context, human individuals and the populations within which they live become the objects of what Lesko, borrowing from Anne McClintock (1995), refers to as "panoptical time." Panoptical time refers to the ways in which colonial powers produced an image of a racialized, classed, and gendered humanity moving along a universal evolutionary track—most vividly represented in the figure of the "Family Tree of Man"—that portrayed European societies as the height of civilization and European patriarchs as the masters of order and rationality.

As Lesko describes, scientific theorists of child and adolescent development, such as G. Stanley Hall (1904), the notable opponent of Margaret Mead (1928), projected this colonial temporality onto the process of individual human development through the theory of recapitulation, which argued that the stages of individual development recapitulated the stages of sociocultural evolution. Young children became analogous to "savages," and each individual was seen as a being caught up in the struggle of climbing the developmental tree towards the ideal of adult maturity and rationality. In this model, adolescence was viewed as a metaphor of the boundary between civilization and savagery, and each individual developmental trajectory ran the risk of getting stuck, or arrested, in the adolescent phase. According to Lesko, "the teenager regularly called forth the underbelly of the colonizers' evolutionary narrative: worries over degeneration and contamination and the anxious scrutiny of physical characteristics, behavior, and morals for signs of decay" (2012, 96).

Of course, there have been significant transformations in discourses of human development since the colonial era. The theory of recapitulation has long fallen out of fashion and been displaced by newer forms of racialized thinking. Despite important historical changes in developmentalism, though, Lesko suggests that it continues to compel adults to monitor young people for signs of "progress, precocity, arrest, or decline" (2012, 96). While certain developmentalist ideas may have shifted significantly, young people are today no less the objects of developmentalist observation and control than they were over a century ago at the time of Hall's writing.

Here I want to raise several points about Lesko's analysis in order to help make sense of the descriptions that Rachel, her family, and her physicians offer—descriptions which are highly unique in certain respects, but which also exhibit elements that commonly occur in the context of cancer care. First, I want to focus on the fact that Lesko, like other critics of developmentalism,

is offering a social/cultural constructionist account. As Ian Hacking has pointed out in regards to such accounts, rather than trying to define what precisely is meant by social/cultural construction, it is more productive to first ask "What's the point?" What do social/cultural constructionist accounts attempt to achieve? As Hacking argues: "A primary use of ''social construction'' has been for raising consciousness" (1999, 6). Such accounts usually present themselves as unmasking some taken for granted "fact" in order to liberate the people who live under the weight of that fact. The unmasking effort is a move "against inevitability" (Hacking 1999, 6). It is to demonstrate that things could be otherwise, and that humans play a greater role than is often recognized in designing and producing worlds. As Hacking describes:

> Social construction work is critical of the status quo. Social constructionists about X tend to hold that:
> (1) X need not have existed, or need not be at all as it is. X, or X as it is at present, is not determined by the nature of things; it is not inevitable.
> Very often they go further, and urge that:
> (2) X is quite bad as it is.
> (3) We would be much better off if X were done away with, or at least radically transformed (1999, 6).

Hacking's assessment would seem to hold up in regard to Lesko's account. As she describes in the conclusion, the desire to unmask certainly played a role in the production of her account:

> This book is the result of my efforts to think in "untimely" ways about youth. My interest in doing so arose from many interactions with "real" teenagers, social science research on youth, and theories of adolescence and from my own dissatisfaction with how youth were represented in scientific and popular cultural texts. Youth were usually presumed to be deficient, a little crazy, controlled by hormones, and educators and parents were warned that their actions and effectiveness were always broadly circumscribed by teenagers' immaturity, by their being in transition. Thus it seemed that a circular reasoning was in place, and I went from hormones to peers to self-esteem to age and back again in attempting to get out of the loop of common sense (2012, 178).

According to Lesko and many other thinkers in childhood and youth studies, developmentalist ideas, images, and narratives have colonized commonsense thinking about adolescence, which has been imagined as a way station between childhood and adulthood. It is reasonable enough to speak of developmentalist theories of the human as comprising a set of ideological models that have had broad influence on the ways in which people think about childhood and adolescence, but Lesko goes onto argue as if these models have been widely circulated in ways that have not introduced mutations, fractures, or hybridities. According to Lesko, the discourse of adolescence comprises "a sealed system of reasoning" that blinds educators, parents, and other adults, who suffer from an "inability to talk and think about youth outside the discourse of 'adolescent development'" (2012, 178).

If we were to rely on Lesko's account as a model for thinking through Rachel's case, we might come to the conclusion that part of the problem is that all of the adults around Rachel are cognitively and practically locked into the logic of developmentalist time, which is associated

with specific regimes of observing, disciplining, and controlling young people in the interest of transforming them into valued adults. True, the primary concern of Rachel's parents and health care providers was that she make it through the treatment process so that she could continue living and growing into a healthy and productive adult. Sharon's comments about the other young woman who is now a third year university student hint at this. In these comments, Sharon cites a gendered model of adolescence, wondering if perhaps Rachel was exhibiting a kind of horomonally induced psychosis. While she realizes that this is probably an unanswerable question, she is happy to note that the one other person to whom this happened has successfully restored her relationship to developmentalist time and its typical milestones. For Sharon, this person functions as an optimistic metaphor for Rachel, who will also hopefully soon be done with the suffering of cancer treatment and on her way to college.

It is also true that, in the descriptions Sharon offers, she seems unable to acknowledge the possibility of Rachel's death at a young age, which would run entirely counter to the logic of developmentalist time. Instead of expressing fears of death, Sharon and Robert placed their trust in the model of care offered by oncologists, who suggested that all of this could just be a brief detour in Rachel's biography. As the oncologists assured Sharon and Robert, if they were willing to subject themselves to the rituals of cancer treatment, Rachel had a very high chance of living beyond the disease.

Despite all of this, it is debatable if Sharon or Robert—or, for that matter, any parents I met at BACH—were *unable* to imagine or speak about their child's biography outside of developmentalist models. Judging from my experiences with them and many other parents of cancer patients, nothing could be further from the truth. It was not that Robert and Sharon were literally unable to think or speak about the possibility of Rachel's death, or that they had not had their own fears that treatment might not work. But, in the face of so much fear, Robert and Sharon, as well as many other parents I met at BACH, attempted to place their trust in the model of care offered by the treatment team, which was described to them as very likely to bring about an optimistic outcome. As I discussed in chapter two, the models of care that play a role in producing the field of pediatric cancer treatment intersect with models of health communication. Oncologists and other health care providers often view it as a form of care to communicate with patients in the most optimistic manner possible, and this view is often also shared by parents, who often attempt to keep their children's spirits up by emphasizing optimism.

Still, many parents, including Sharon and Robert, also admitted that there were numerous moments when their ability to remain optimistic started to break down, even if only temporarily.[1] This suggests that parents were capable of questioning the optimistic logic of developmentalist time, although most of them preferred not to. The issue for Sharon and Robert wasn't that they were unable to think or speak about the possibility that Rachel's life might not conform to a normative timeline, but rather that it pained them to do so. Pediatric oncology offered a way of repairing their potentially ruptured relationship to the dominant timelines that structured their existence up to this point, and they preferred to hang onto the possibility of repair as opposed to accepting the loss of those timelines.

I point this out in order to draw attention to certain difficulties implicit in advancing social/cultural constructionist accounts of childhood and adolescence, especially in the context of life-threatening illness. The unmasking function that such accounts attempt to perform would seem to imply that people only need to be made aware of two things in order to transform oppressive conditions of adolescence: 1) adolescence is not a naturally occurring stage of life and 2) alternative, non-developmentalist models of human life trajectories are possible. In raising

consciousness about these points in books and essays, authors who advance social constructionist arguments exhibit some level of hope in the idea that the circulation of critical discourses about developmental conceptions of adolescence might lead to the formation of new ways of thinking about and treating young people. This is not a naïve hope in itself, but it must contend with the existence of affectively charged attachments to currently dominant frameworks for ordering young lives and enacting the passage into adulthood. Even in the presence of alternatives less dismal than death, many people are likely to remain attached to developmentalist models of the life course, which seem to promise health, wealth, happiness, and fulfillment.

It is not that cancer patients and their families are unaware that non-developmentalist ways of envisioning young lives are possible, but rather that they are affectively and morally attached to developmentalist models.[2] This is as true for many young people as it is for many adults. Rachel was no less attached to dominant modes of temporalizing the life course than her parents. She too wanted to go to college, and she dreamed of pursuing a career in fashion. Perhaps because she was so profoundly afraid of losing the normative life trajectory she envisioned for herself, Rachel found oncological reassurance difficult to inhabit, and she couldn't help but worry that these people who claimed to offer a reliable pathway back to her desired future were actually there to hurt her. Nurses and doctors, far from obviously benevolent actors, began to resemble "zombies" who carried out painful procedures, withheld information, and stole cell phones. Even her parents' motives began to seem questionable for a brief moment. They too stole cell phones, and their constant insistence that she needed to rest started to seem like covert attempts to ease her into death. Eventually, however, with the help of psychiatric medicines, Rachel was able to see the treatment process to its optimistic conclusion. As she and her parents had hoped, Rachel is currently cancer free and attending college.

Rather than a problem of being cognitively trapped in developmentalist models of adolescence, pediatric cancer and other life threatening illnesses draw our attention to a different phenomenon: the pain that some adolescents and families may feel when illness threatens to sunder their relationships to ideological modes of temporalizing and living the transition from adolescence to adulthood. At the same time, I do not mean to imply that such pain is homogeneous. It should be pointed out that that the ways in which people articulate their relationship to developmentalist time are shaped by processes of race, class, and gender formation. Rachel inhabits a white and middle-class positionality, and her attachment to a normative vision of the future—a future in which she goes to college and develops a successful career—was no doubt facilitated by socioeconomic and racial privilege. Obviously, this is not to say that non-white and/or economically impoverished young people cannot have aspirations similar to their white, middle-class counterparts, but they experience greater barriers to access, and cancer is just one more barrier for patients who already face significant challenges to building desired futures.

In addition to these socioeconomic and racial privileges, many patients are also biomedically "privileged" to be diagnosed with a type of cancer that oncologists associate with very high survival and low relapse rate. Although it sounds odd to use the term privilege here, many parents I met at BACH described the experience of going from being devastated as they learned of their child's cancer diagnosis, to feeling relatively grateful as they learned that their child had been diagnosed with one of the more treatable cancers. Still, as Rachel's case shows, even in the most optimistic cases, cancer diagnosis and treatment invariably produce anxiety, fear, and other forms of suffering in patients and family members, as cancer treatment protocols can never offer total certainty, and they rely on an extremely iatrogenic series of procedures. The

combination of negative factors can lead some patients to question whether or not they will make it to adulthood, and, in a small number of cases, such as Rachel's, these fears can fuel symptoms that get marked psychiatrically as hallucination and delusion.

Although Rachel and many other patients have recovered from the most severe phase of treatment, it is debatable to what extent any patient will ever be "cancer free" in all senses of the term. Even when patients achieve long-term remission, the fact of having gone through treatment increases their risk of developing cancer years later. Unfortunately, in some instances, this does happen. As I will show in the following section with the case of a young man named Jun, even after a person is declared cancer free, there is always a chance, however slight, that the disease will recur, or that a new cancer will form, and one will be thrust back into miserable conditions of patienthood.

"Well, no, they didn't say I was cured."

Jun was born in São Paulo, Brazil to a family who migrated there from China to open a restaurant. Jun's mother and father were the proprietors of the restaurant, and his grandparents acted as the children's caretakers. Jun had two siblings—one sister, Liang, and one brother, Jian—and he was the youngest of the three children. When Jun was four years old, he was diagnosed with renal cell carcinoma, a form of kidney cancer, and he underwent treatment in Brazil. As Liang and Jun recounted in an interview:[3]

> Liang: I guess it was like stage 3 or 4, but we were so young that I didn't know what was going on with him. But I remember our parents rushing back and forth from the hospital, and our dad just told us he was sick. They didn't tell us he had cancer. But he had surgery, and they took out one of his kidneys. That's where it started. He survived through it, and then he got chemo and radiation, and then the doctor said he was cured…

> Jun: Well, no, they didn't say I was cured. They said that I had a 60% chance of it coming back in the next 10 years, and they said once that 10 year time period passed, I was pretty much "cancer free." But they said there was always gonna be a small chance. My parents knew there was a very slight chance it would come back.

As Jun points out, correcting Liang's optimistic gloss of the situation, oncologists rarely use the term "cure." It is only after many years of a patient being cancer free that some oncologists are willing to utter that word. Rather than cured, oncologists view most patients who no longer have active cancer as "in remission."

This can be a very difficult point for family members and patients to accept, as it requires recognition of a high level of uncertainty. Most people, like Liang, would rather think of their family members or themselves as "cured" than "in remission." Cure implies total liberation. Remission implies living in the disease's shadow, dreading the possibility of its reemergence.

Despite the fears associated with living in remission, life does not stop, and parents and guardians must continue to make decisions about how best to care for their children and prepare them for the future, where they will have to fend for themselves. When Jun was around seven years old, his parents decided that their children would have better educational opportunities in the United States, and they therefore moved Jun, his siblings, and his grandparents to California:

"I didn't know I was moving. I had only visited [California] one time during summer vacation," Jun recalls.

For over 10 years, Jun's life in California continued uninterrupted by cancer. But then, about 13 years after his initial diagnosis, he began to have some distressing symptoms:

> It was the summer after 10th grade. End of August. Grandma wanted some help moving some boxes. When I went to help, when I went to pick up the box, I lifted it wrong. I didn't use my legs. I bent over and used my back instead of my legs. It was like a light box, not particularly heavy at all. So I thought it would be fine to just pick it up. But then, as I was coming up, I felt my spine pop. At first, it didn't hurt. I thought it was just some tension or something. But then the pain came like two seconds after. It was really bad. I couldn't stand up. Sitting down hurt too, so I had to go lay down. And then that was like the whole day. Just me laying down in pain. I thought I just twisted a muscle or something, so we didn't go to the hospital or anything. We just used some ointments and rest. And after two weeks, it kind of went away, the constant pain went away, but it would still be sore when I sat down a lot. It kinda continued that way for about three months. I think it was November that it started getting really bad again, and then we started looking for more options. We went to these people that my family knew. I went and got massages. I was taking herbal medicines to help with the pain. Taking Tylenol sometimes. It was all just temporary relief. All of it.

Over time, Jun's symptoms became more severe. After a family trip to Disneyland, they got so bad that his parents decided to take him to the hospital:

> We went to Disneyland for Christmas break, and that's when it started getting really bad again. Like almost near the level it was when I hurt my back in the first place, back in the summer. So when we went to Disneyland I barely got on any rides. I had to take frequent breaks, and then, on the last day there, I think I didn't go at all. Or halfway through I went back to the hotel room because it was just getting too bad. So when we went back, I think it was in January, we decided to go to the hospital one night…They took x-ray images of my back, and they noticed that in the scan one of the bones looked deformed. It looked squished, kinda caved in. They thought: "This might be something serious, so we're gonna transfer you to the children's hospital." 'Cause I was 17 I think... or 16. Once they transferred me in there, they took an x-ray, they took a CT, and they made me stay there for, I think, a week. Then, they said they needed to take a biopsy of it to get a clearer picture because it could have been a mutated bone from previous radiation I had when I was younger.

The biopsy revealed that Jun had renal cell carcinoma—the same cancer he had been diagnosed with as a child, the same cancer that was very unlikely to return after ten years of remission. Unfortunately, for Jun, the cancer reappeared in his 13th year of remission:

> They think that it came back a little bit after the ten-year mark because when they did the biopsy, it was the same type of cancer. So, either it was there from the very beginning and never became a problem, or it just recently came back. It just deteriorated the bone, and all the stress I put on it when I was picking up the box made it crack. And they said

they had to remove most of the bone because they couldn't just use radiation anymore. So they had to prep me for surgery, and that's when I took the second semester off. I just didn't feel like going to school. And there was still pain… And then I think in March was when they did the first part of the surgery to take out the bone, and then they waited until April to do the second part of the surgery, where they used bone graft from my right rib. They used it as bone graft for the new spinal bone. And that was the surgery. I stayed in the hospital for like two more weeks, and then I had to wear a brace to let it set so it didn't grow weirdly. But I did that for three, four months. It was right before 12th grade started.

Jun's life was again radically disrupted. According to the optimistic temporal projections of oncology, Jun had reached a safety point—a point at which he could rest assured that the cancer was highly unlikely to recur. But this is not what actually transpired. Despite oncologists' emphasis on probability, sometimes the improbable occurs. Not even biomedicine can totally protect the idealistic projections of developmentalist time from the ravages of cancer. But this doesn't stop biomedical practitioners from trying.

Quickly after diagnosis, Jun began chemotherapy. Unfortunately, he experienced a wide range of side effects that were apparently atypical. Again, Jun found himself in an improbable position:

I started taking the first chemo drug, Sutent. It was pretty bad. They gave us a list of all possible side effects from people who have taken it. But then they're all older, like in their 30s and 40s. I wasn't even 19 yet. So when they gave us this list, there were low chance, medium chance, and normal side effects from taking Sutent. And when we looked at it, it wasn't that bad—it was like headache, diarrhea, fevers. Nothing too bad. But then when I started taking it, I think there was… I was losing my sense of taste, and I don't think that was on the list at all…But when that started happening I started eating less because there was no taste. Everything was bland. I couldn't swallow. I could swallow soft foods, but it tasted like gruel. I would eat stuff that was really salty or really sweet, but I couldn't handle spice at all. It actually enhanced my sensitivity to spice. Even the mildest things would taste like fire. And the first week of taking the Sutent, that's when I started getting headaches. Two weeks in I started getting fevers, and then three weeks in I had to come back to the hospital because it was just too much for me. I couldn't go to school. I think I took like a whole week off. That's when they lowered the dose by half.

As Jun describes it, being on Sutent was miserable. He was exhausted all the time, and he could barely eat. Because of this, he lost a great deal of weight, and his oncologists became concerned that he wasn't getting adequate nutrition. By the end of his final semester of high school, Jun decided that he could no longer handle going to school full time. He began a part-time program where he was going half a day to school and then doing some extra credit work at home. This allowed Jun to stay on track and graduate high school on time, although he didn't get to go to the graduation because he was too sick.

Although Jun's side effects decreased when his doctors lowered the dosage of Sutent, the decreased dosage also led to decreased efficacy. After running a series of imaging tests, the doctors found that the Sutent was not having an effect on the cancer cells in Jun's lungs, where

the disease was concentrated. The doctors decided to try one more round of Sutent, but the next scan showed the cancers had just kept growing. At that point, the doctors gave Jun the option to switch to a different medicine, Cabozantinib, or Cabo.

When his doctor suggested the possibility of a different treatment with a more optimistic outlook, Jun was quite skeptical, but he was pleasantly surprised to find that the Cabo did actually offer an improvement, at least in terms of side effects:

> For the past year and a half, optimism wasn't really an option for me. I mean, the cancer coming back after it shouldn't have… And then having a crappy surgery, and then having a crappy three months after because I couldn't walk normally, and then when I could finally walk normally and do stuff on my own, I had to start taking the Sutent, which made my life hell for a year and a half. So you can hopefully understand my skepticism when they said it was going to be better. But it was actually pretty better. There were no side effects that made me feel too horrible, and I'm pretty sure the side effects in the beginning that showed up was just me adjusting to the Cabo. It wasn't anything severe. It was like, just a little bit more tired. A little bit less appetite. I could finish my meals though. And no loss of taste. Which was the best thing. The best thing. I could eat and not feel horrible…I don't think I've had any side effects except loss of appetite, and that could easily have been because of the radiation. Apparently, the cancer on my back was acting up, and it started pushing the growth into one of my nerves, which gave me severe pain, and they had to do radiation on it, which fixed it. But yeah, Cabo hasn't been a problem. I still get a little bit tired and feel like I need more sleep than normal. But nowhere near like before with the Sutent.

Prognosis and the Ideal Temporalizations of Oncology

As I have described with the cases of Rachel and Jun, cancer diagnosis enacts what Lochlann Jain refers to as a "collision in modes of time." Cancer ruptures relationships to previously taken for granted futures and the modes of time on which they rely. To enter the field of pediatric cancer treatment as a patient is to have one's life re-temporalized around established protocols that prescribe particular sequences of care. Many families enter into this arrangement in hopes that these sequences will provide a path back toward developmentalist time—in other words, that patients will be able to resume a relatively normative life trajectory that includes finishing school, entering adulthood, and building a family and/or career.

However, as Jun's case demonstrates, the ideal temporalities projected in treatment protocols do not always materialize in practice. Although there are many different treatment protocols that rely on a diversity of tools and strategies, the generalized, ideal temporality projected in them all goes something like: multiple rounds of treatment→remission with frequent (usually monthly) check-ups→long-term remission with annual check-ups. Many parents and family members cling to the ideal temporalities that treatment protocols project, particularly when patients are going through treatment for the first time (i.e., they haven't relapsed). It is often hoped, even against the odds, that treatment will go smoothly and patients will be able to go on with their lives. As I learned in my time at BACH, this does indeed happen. I met a number of people, including a nurse on the cancer ward, who had gone through cancer treatment as children and survived well into adulthood. But all of these people had cancers that oncologists consider highly treatable.

Other people, such as Jun, were diagnosed with cancers with lower probabilities of treatment success. Despite the lower probability, the ideal temporality projected in the protocol was still hoped for, and Jun's family even thought for several years after his first bout of treatment that the ideal had come into fruition. Tragically, however, this was not the case, and Jun and his family found themselves inhabiting another nightmare, another period of subjection to the well-intentioned tortures of treatment. And, this time, available statistics suggested that Jun had a lower chance of achieving long-term remission, as relapsed cancers are generally considered less responsive to treatment. Knowing this, Jun couldn't help but be skeptical that treatment would save his life.

Still, despite the low odds of remission, Jun's oncologists continued in their attempts to treat him. In cases of relapsed cancers, oncologists tend not to have high hopes for long-term remission, although most of them refrain as much as possible from conveying pessimism to families. In such situations, oncologists often follow a model of care that focuses on two goals: 1) extending life as long as possible and 2) decreasing suffering as much as possible. In telling Jun that the Cabo presented a more optimistic option for him than Sutent, the oncologist did not necessarily mean that he thought Cabo was likely to bring about long-term remission, although he wouldn't have ruled this out as a possibility. His decision to switch Jun's chemo drugs was driven less by the superior efficacy of Cabo and more by the fact that Jun could not tolerate a large enough dose of Sutent for the drug to have the desired effect.

It is unclear from my conversations with Jun if he expected Cabo to bring him into remission or if he was just thrilled after spending so much time suffering to simply be able to carry out everyday tasks again. Although he admits that he had a difficult time staying hopeful given the improbability of his situation, he also seemed to exhibit some level of optimism by continuing to go to school part-time, thus partially maintaining his relationship to developmentalist time. After graduating high school, Jun enrolled in a community college and was taking classes in computer engineering, as he had long been interested in computer hardware and planned to design computers for a living. Eventually, however, Jun's treatment stopped working, and the oncologists had no more treatment options to offer him. Jun grew too ill to continue attending college, and, very rapidly, he was placed in hospice, where he passed away in July 2018. In a social media post announcing her brother's death and soliciting funds for his funeral, Liang wrote the following:

> Jun was the most genuine, caring, loving, selfless, and fearless 19-year old. Throughout his battle with cancer, he never once complained or blamed any of us for his misfortune. He always had a smile on his face like he was living the best life he could ever ask for. He was so social, always having conversations with strangers, nurses that took care of him, and doctors. He was truly loved by many, even loved by strangers that met him once or twice. He left a big impact in everyone's lives that he came across…It's cruel that they took him away from us so soon, but we know he's in a better place now and pain free. The heavens gained a beautiful angel. Jun will always be remembered and stay close to our hearts. Throughout the battle that he was going through, all he wished was for us to be happy and not to be sad about his condition. His dream was to be a computer engineer and to be able to go to college and live a normal life like any of us.

Cancer Treatment as a Mode of Living: Supplementation and Extension

Like Rachel and many of the other young people I met at BACH, Jun was also attached to a developmentalist model of his own life course. Jun imagined becoming a computer engineer, and he made active attempts to stay connected to this possible future until it became physically impossible for him to do so. All of this would seem to present a further challenge to the argument that young people must be seen as beings as opposed to becomings. For one thing, this argument relies on the idea that adults impose developmentalist models onto young people and that this imposition constitutes an oppressive act. But here we see that young people also position themselves according to developmentalist models. Furthermore, rather than the imposition of such models causing them harm, it seems more accurate to say that it was the sudden threat which cancer posed to their ability to see the model into fruition that acted as the greater source of harm in these cases.

In thinking through the beings/becomings debate, I want to raise the question of how scholars in childhood and youth studies imagine our relationship to the young people and ways of life we study. On the one hand, many of us clearly see our role as chroniclers—people who empirically document the lives of young people. But few scholars are satisfied with simply amassing stories or other forms of data—"butterfly collecting," as the anthropologist Edmund Leach (1961) mockingly referred to it. Most of us want to use the data we collect to produce some kind of theory or conceptual repertoire. But then the question becomes: What do we hope to achieve with theories and concepts? Do they function primarily as devices of thought that we circulate among other scholars? Do we hope to make normative claims about the way we should behave or the way the world should be? Do we provide blueprints for solving some social or political problem? Perhaps all of the above?

It seems to me that one way the argument that all young people must be seen as "beings in their own right" tends to function is as a normative claim. That is, it seeks to establish an ethical norm that calls people to respect of the "full humanity" of all young people. It expresses righteous indignation at the situation of adults treating young people as incomplete, proto-adults, or as sites of investment toward a productive future, and it calls for an end to such practices. The cases of Rachel and Jun, however, raise a problem here. If we accept this framework, what are we to do with the fact that young people often position themselves according to developmentalist models, and the potential loss of those models can cause young people great distress?

Of course, one way out of this problem would be to take up an extreme version of the critical concept of ideology I discussed in chapter two. One could say that young people only position themselves according to such models because their habitus has been ideologically conditioned to misrecognize those models as naturally desirable. They are underneath the spell, caught up in the *illusio*, as Bourdieu would put it, of the *doxa* that constitutes social life in a given place and time. According to this logic, Jun may really have experienced himself as wanting to go to college and become a computer engineer, but this was not an unmediated desire. It was a mere epiphenomenon of his racialized, classed, and gendered position in social space.

While I clearly still find much of value in Bourdieu's theoretical framework, I find this aspect troubling. As critics of scholarly critique (Fassin 2012a; Ferguson 2010; Latour 2004) have pointed out, critical positions such as Bourdieu's rest on the elitist notion that scholars are uniquely situated to see through misrecognition, while everyone else falls for it. Furthermore, it seems to suggest that, if only one could discover the master code, one could transcend misrecognition once and for all and bask in the truth of enlightened recognition. In this context, it

would seem to imply that, if only one could convince professionals, parents, and young people themselves that young people are full human beings, not simply becomings on the way to adulthood, then they could all stop fixating on the future and live in the here and now, and they would all be better off for it. This strikes me as a naïve proposition.

Nick Lee (2001) has also questioned the childhood studies orthodoxy that all young people must be seen as "beings." Drawing on Derrida (1978) and Deleuze and Guattari (1988), Lee argues that all of human life exists within assemblages that alter the properties and abilities of the human body via various forms of supplementation and extension. Various technologies (including ideologies) and non-human forms always and everywhere mediate human life, which exists in fluctuating states of stability and instability. This allows Lee to challenge a fundamental view that undergirds the being/becoming distinction: namely, the view that adults are complete, independent human beings. If all life is lived via supplementation and extension, then not even adults can be said to enjoy the totally complete and autonomous status: "No matter how complete humans may seem, we constantly "borrow" from each other, from media including speech and writing, and from the powers and properties of all the world's resources, animal, vegetable, and mineral…[H]umans, regardless of age, are constitutionally unfinished" (Lee 2001, 113).

This view has serious consequences for theories of misrecognition, such as Bourdieu's (1984). If we accept that our existence is always mediated—that we are always indebted to and enabled by various forms of supplementation and extension—then it would seem to follow that no process of recognition is unmediated. As I argued in chapter two, iterative ideologies and forms of capital mediate all acts of recognition, even those of scholars. There can be no recognition that completely transcends ideology and capital—in other words, that does not rely on some set of ideas and images that are valued in certain ways and that orient embodied cognition. If ideology and capital are the source of misrecognition, and if we accept that ideology and capital mediate the "schemes of vision and division" available to scholars, then the claim that scholars are uniquely equipped to root out misrecognition starts to feel rather shaky.

In this study, I do not cast myself in the unmasking role of the critic, such as Lesko or Bourdieu, who roots out the forms of misrecognition through which people are oppressed. I do not deny that there may be a time and place for strategically performing this role, but it is not here. Rather than delegitimizing cancer patients' and their family members' attachments to developmentalist models by unmasking them as products of capitalist misrecognition, here I build on Lee's argument—which I take as empirical, not normative—about childhood as a process of becoming in order to point out that patients and families engage with pediatric cancer treatment as an optimistic form of supplementation and extension. In other words, they participate in it as a mode of living in attempts to supplement the patient's ability to heal and extend existence into the future, hopefully into adulthood.

Of course, as Jun's case shows, these processes are fraught with uncertainty and iatrogenic harm. There is no guarantee that treatment will work as intended, and, even when it does, it comes at the cost of excruciating pain and other harsh side effects. No one knows for sure if the temporal rupture caused by cancer diagnosis will ever be entirely repaired.

Complicating the Lived/Died Binary

In juxtaposing Rachel and Jun's cases, I want to be careful about reproducing the lived/died binary that Lochlann Jain associates with prognostic cancer statistics. As Jain

observes, "A prognosis seems like a fact, if only a scrap of flotsam frenziedly bobbing in the rapids of cancer treatment. But its stunning specificity ("34.7%") shields the bloodlessly vague platitude: in five years, you, yourself, will be either dead or alive" (2013, 59). The vagueness obscures that there are not only two possible outcomes. Instead, there are many ways to survive cancer, and there are many ways to die from it. In part due to the heterogeneity of human bodies and cancers, there are always cases that do not conform to statistically informed expectations.

As I've emphasized thus far, existing pediatric cancer treatments have become much more effective at extending many patients' lives, yet the technologies of oncology are nevertheless some of the most harmful biomedical tools in existence. Although these tools can produce amazing results, bringing about long-term remission in some patients, they can also cause a wide range of temporary and permanent forms of injury that are not registered in survival statistics. And even for those who were affected by no obvious, long-term forms of biomedically induced harm, there is still a great deal of concern among oncologists about the possible "late effects" of pediatric cancer treatment—in other words, the negative health effects that may take many years to manifest.

Finally, there are small numbers of more ambiguous cases where patients are not technically in remission, but their cancers have remained stable, even in the face of very poor prognoses. In such cases, the temporal rupture induced by cancer diagnosis can remain open for very long periods of time, leaving patients to find ways to go on living within the rupture. In the following section, I describe such a case, recounting the experiences of Jared, who, twelve years ago, was told he would die in six months from bone cancer.

"You're gonna be fine afterward."

Jared is an African American man who was born in the San Francisco Bay Area in 1990. For most of his life, he lived with his mother and stepfather. By the time he started high school, he became very passionate about basketball. Inspired by a neighbor who played regularly, Jared decided that his ultimate goal was to play professionally. He joined the basketball team at school and played as much as possible in his free time. As he retells it, he had complete faith that he would make it to the NBA.

But in 2004, Jared's life changed completely. At the age of 14 he was diagnosed with osteosarcoma, a form of bone cancer, in his left arm. The cancer was discovered on an X-ray that Jared's doctor ordered when Jared came to him complaining of pain in his elbow. As Jared remembers it, when he discovered he had cancer and would have to go through nine months of chemotherapy and radiation, he initially underestimated the gravity of the situation:

> I didn't know what cancer was because I was the first person in my family this generation to get it…I didn't think it was as big of deal as I found out it would be. So I pretty much just looked at it as, okay I'll go knock out chemo and go back to school then be on my way to the NBA…

As Jared remembers it, at the beginning of treatment he optimistically assumed that doctors could cure him of his condition. And why wouldn't he? Healing and cure were the outcomes prior times he had gone to the doctor. As Jared describes, his family nurtured his faith in oncology, as they sought to keep him as comfortable and as hopeful as possible throughout the difficult treatment process:

I believe there was more to it than I was told. I think my family felt like it was their job to keep me calm and happy, so they didn't wanna tell me really bad news. I remember them saying: All you have to do is this nine months of chemo and you're gonna be fine afterwards. I was gonna have to have a bone replacement three months into chemo, but after that I'd be fine. I'd do physical therapy and get my body the way it should be. That's pretty much how I intended it to be—to do 9 months of chemo. I was gonna be really sick, which they informed me. But I didn't know it was gonna be as bad as it was.

Jared began chemotherapy very soon after diagnosis. This involved three different drugs: doxorubicin, methotrexate, and cisplatin. Like most chemotherapy drugs, these are known to cause intense side effects. According to Jared, these are some of the worst chemo drugs a patient can receive. This sentiment is echoed in the fact that Doxorubicin is colloquially known among cancer patients and professionals as "the red devil" or "red death," due to its red color and violent side effects (Livingston 2012).

Jared's chemotherapy protocol required five days a week in the hospital. At the beginning of each week, he would go through 24 hours of chemotherapy, and then during the remaining four days his blood would be flushed with IV fluids to reduce toxicity. Ideally, he would go home on weekends, but sometimes his cell counts were too low, and he had to remain in the hospital over the weekend to prevent complications, such as an infection. Throughout this phase of treatment, Jared tried as hard as he could to focus on basketball and his future goals:

Through the whole process I just focused on getting back to playing basketball—y'know, doing what made me happy. Being in the hospital doesn't make you happy at all, so you have to think about things that do make you happy. And y'know, I was really young at the time, so I knew I wasn't gonna let this beat me. I had too many goals to let cancer get in the way of that.

After enduring three months of chemo, Jared's treatment proceeded as planned, and he underwent a bone replacement surgery. The surgery was successful, and Jared soon re-started chemo treatments, which he underwent for six more months. At the end of the sixth month, PET-CT scans and bloodwork indicated that Jared was in remission.

"I didn't feel how they said I would feel."

By June of 2005, Jared was focused on getting his life back to normal before his sophomore year of high school. He started back at school in August, and things were going well. But then one day in November he fell down the stairs at his house and landed on his arm. The next morning, his arm was swollen and in pain, so his mother called the hospital, and Jared's oncologist asked him to come in for an x-ray. That day, Jared and his family received the news that his cancer had returned, and they would need to amputate his arm. Jared was devastated, as the need for amputation was a clear signal that this was not just a detour on the way to the NBA. Cancer had fundamentally altered his life. Still, there seemed to be few other options. Jared and his family decided to continue pursuing oncological treatment, as doctors advised them that Jared's condition would rapidly decline without it.

In February 2006, Jared's arm was amputated in hopes that the relapsed cancer could be eliminated before spreading to other sites in his body. Four months later, a PET-CT scan showed

three tumors had metastasized on his lungs, and surgery was performed to remove them. Two more months later eight tumors appeared, one of which was attached to Jared's trachea, affecting his ability to breathe. The doctors tried to remove it, but there were complications during the surgery, and, in the end, they had to cauterize the tumor without fully resecting it.

At this point, things were not looking good, and medical professionals had begun to take a much less optimistic tone when discussing treatment options. His family was informed that the only options left were to continue with chemotherapy and radiation in hopes of slowing the disease's progression and controlling symptoms. At this point, the oncology team no longer mentioned the possibility of long-term remission, as their evidence base of clinical experience, randomized controlled trials, and various other kinds of biomedical studies suggested the odds were not good.

By September of 2007, a tumor came back, this time on Jared's head. After discussing it with his parents, Jared decided not to do chemotherapy. He couldn't stand the idea of missing any more school, and he just wanted to enjoy what time he had left. With the odds of long-term remission being so low, Jared decided he had experienced enough chemo-induced suffering for one lifetime. Since radiation tends to cause fewer side effects than chemo, however, he decided to do another round of radiotherapy. The radiation shrunk the tumor on his head, but not on his lungs.

By December 2007, Jared's oncologist, Dr. Carden, told his parents that, without further chemotherapeutic treatment, Jared would likely have about six months to live. The cancer was spreading rapidly, and it would result in organ failure. It would just be a matter of time. After hearing this news, Jared chose to stop all treatment and just live his life. "If I'm gonna go out, I'm gonna go out happy," he told himself. In the span of three years, the oncological promise had shifted from possible remission to impending death. Recognizing this, Jared embraced what seemed like the inevitable. But then six months went by, and he was still feeling relatively healthy and attending school. Eventually a year went by, then two years, and so on…

To the surprise of Jared, his family, and his oncologists, the tumors have remained stable, staying the same size for almost eleven years. Jared described the experience to me one afternoon in an interview:

> I didn't feel how they said I would feel. I didn't lose my vision. I didn't lose my hearing. I was still playing basketball everyday. I couldn't play on the school team because for so long I was always in and out of the hospital, but I was able to become the team manager, so I was able to travel with the team and just be a part of it, which was enough.

Since then, Jared has graduated high school and started a career as a personal trainer, youth basketball coach, and motivational speaker. Jared has also formed a non-profit organization focused on telling his story and spreading awareness about cancer-related issues. Although Jared's relationship to institutional time is extremely ambiguous given the fact that he still has cancer, he has found ways to go on living in the midst of the uncertainty.

Statistical Deletion

Jared's case may have proceeded very differently if he had not been a cancer patient in the United States in the 2000s. As I described in chapter two, prior to the emergence of contemporary models of cancer care, pediatric cancer was usually considered a death sentence,

and pediatric cancer wards were generally very austere and solemn places. Over time, however, certain cancers have become much more treatable, although a "cure" is still often elusive in many cases. As cancer specialists commonly point out, particularly dramatic improvements have been made in the treatment of childhood acute lymphoblastic leukemia (ALL). For example, in the 1960's, the 5-year survival rate for children diagnosed with ALL was about 10%, but by 2013 it had risen to over 85% (Pui and Evans 2013).

While improvements in treatment outcomes are encouraging, it is important to also note that the outcomes of all types of cancer have not improved at the same pace. Young people diagnosed with ALL have a relatively high chance of survival beyond five years in most cases, but outcome statistics are generally not as optimistic for osteosarcoma patients, such as Jared, although they have certainly improved over time. Until the 1980s, 5-year survival rates for osteosarcoma patients in the United States hovered around 20% (Mirabello et al. 2009). But this number shot up rapidly after a series of clinical trials demonstrated the efficacy of administering specific combinations of chemotherapeutic drugs before and after the surgical resection of tumors. However, this strategy is most effective when the cancer has not spread. For osteosarcoma patients whose cancer is still localized, the 5-year survival rate is currently 70 to 75%. For patients' with metastasized osteosarcoma, however, that number plummets to under 30% (St. Jude 2018).

Of course, as I pointed out above drawing on Jain (2013), prognostic statistics can obscure more than they reveal insofar as they reduce complex treatment processes to a lived/died binary. As Joan Fujimura (1996) describes in her book *Crafting Science: A Sociohistory of the Quest for the Genetics of Cancer*, contemporary cancer research is collective work that relies on standardized experimental systems. In addition to experimental procedures, cancer research also involves epidemiological practices of counting and producing population level survival statistics, such as those quoted in the paragraph above. The emergence of national cancer registries has facilitated this project, and practitioners in the United States have built up decades of statistical data on cancer treatment outcomes. The combination of data from experimental trials and cancer registries provide a wealth of statistical figures that can inform prognosis in individual contexts. While these numbers are no doubt useful in certain ways to physicians, what I want to point out here is how their production involves something similar to what Fujimura (1996, 45) refers to as "theoretical deletion," which describes the process through which contextual information is erased in favor of producing abstract theoretical statements. Statistics are not themselves theories in the scientific sense, even if they play a powerful role in informing theories. Yet their production and circulation nevertheless involves the erasure of important contextual details. Survival statistics describe what are inevitably complex treatment processes in terms of the binary outcome of "lived" or "died." Drawing on Fujimura, we can refer to these processes as *statistical deletion*. In using this term, I don't want to imply that it necessarily refers to a sinister process of concealing information or of violently reducing human lives to numbers. Although statistics can indeed be put to sinister uses, they can also serve as incredibly useful biomedical guides when employed judiciously with knowledge of their limitations.

But I don't only want to point out how outcome statistics can obscure the details of individual cases that they represent in aggregates. I also want to note how they play a productive role in the development and selection of cancer treatment protocols, which provide models for how care and communication proceed. Since Jared's cancer was still localized upon diagnosis, his physicians treated him with a protocol designed for such cases. Yet the practices prescribed by this protocol did not get rid of Jared's cancer, and he had to move on to second line treatment

options. In most cases, Jared's oncologist told me, patients with such aggressively relapsed osteosarcoma pass away in a short period of time. But, as Jared is living proof, this is sometimes not the case. Sometimes evidence-based prognoses are blatantly wrong, and patients must find ways to live within the temporal rupture that cancer diagnosis has created.[4] As we see in Jared's case, for some, this can entail entering adulthood with cancer.

Conclusion

As I argued above, and as these three cases demonstrate, developmentalist ideologies of the life course shape dominant institutions, which have a powerful influence on the ways in which patients imagine the temporal order of their lives. Cancer diagnosis creates a temporal rupture in that order, inducing a sense of shock in the present and threatening the possibility of desired futures coming into fruition. Pediatric oncology, equipped with treatment protocols and an array of biomedical technologies, offers the possibility of repairing the rupture and restoring the patients' relation to previously taken-for-granted life trajectories. However, given the intractability of many cancers, the toxic nature of oncological technologies, the heterogeneity of human bodies, and the probabilistic nature of treatment strategies, a great deal of uncertainty characterizes all cancer treatment trajectories.

For patients socially identified as adolescents, cancer treatment commonly threatens to undermine plans to pursue educational and career opportunities. That said, as a number of studies on youth educational and vocational aspirations have shown, the future opportunities in which young people express interest are influenced by various aspects of social positionality, particularly race/ethnicity, class, and gender (Howard et al. 2011; Riegle-Crumb et al. 2011; Signer and Saldana 2001). Yet, in the context of this chapter, which presents only three cases, I hesitate to make generalizations about the specific nature of this influence.

From the perspective of the critique of developmentalism and related arguments about the importance of seeing children and youth as "beings," Rachel, Jun, and Jared's desires to go to college and enter into future careers would seem to render them complicit in reproducing developmentalism. One problem with this critique, though, is that it seems to stem from a desire to freeze time, denying the fact that all beings are simultaneously becomings whose existence is unfolding in time and space and with the assistance of various technologies of supplementation and extension. While I applaud Lesko's attempts to demonstrate the ways in which an unceasing emphasis on progress and betterment can harm young people, particularly young people who inhabit non-white and working class positionalities, I do not think this requires a general critique of future-oriented temporalizations. Virtually all people dwell on pasts and anticipate futures, as life is in motion. This is as true for young people as it is for adults. In my mind, the tragedy is not developmentalist temporalization, but rather that the forms of supplementation and extension that oncology offers frequently fail to work as desired, and illness and treatment prevent so many young people from realizing futures to which they were once passionately attached. Although oncology attempts to prevent this tragedy, it cannot successfully do so for all patients.

In the following chapter, I will move away from a focus on the ways in which models of care and the developmental life course shape practices of temporalization in order to explore how patients who are positioned as adolescents are affected by the child-directed practices that take place in the context of pediatric institutions.

End Notes

[1] However, many parents attempted at all costs to conceal moments of fear and pessimism from their sick children, as they believed that pessimism could rub off on patients and lead to worse treatment outcomes.

[2] What I mean here is that they are attached to future-oriented models in which they project themselves as transitioning to some version of adulthood organized around career and/or family, which can take many different forms. As I hope is obvious, I do not mean that cancer patients and their family members are avid proponents of Piaget or some other developmental theorist, although I do not rule this out as a possibility.

[3] I met Jun and his family in 2017, when he was undergoing treatment for relapsed renal cell carcinoma. All interviews were conducted with Jun and his siblings. I could not interview his parents due to language barriers.

[4] This is not scandalous from the perspective of biomedical professionals, who tend to exhibit a probabilistic understanding of disease and treatment efficacy. Evidence-based prognoses are always produced via clinical judgments and statistical calculations, and it is widely accepted that the available evidence and modes of judgment can lead to wrong conclusions in individual cases, although it is also stressed that this is unlikely to be the case.

Chapter 5
Child Appropriateness as a Source of Stigma and Moral Iatrogenesis

As I've described thus far, the field of pediatric cancer treatment in the United States is produced through a model of total care that positions professionals in two distinct but entangled spheres of caregiving activity: the biomedical and the psychosocial. In the previous chapter, I described how cancer diagnosis enacts a temporal rupture that virtually all patients and family members describe as shocking and terrifying. As the narratives I shared demonstrate, the difficulties of cancer diagnosis and treatment are exacerbated by the intensely iatrogenic nature of biomedical cancer treatment technologies. Patients going through chemo and radiotherapy often must endure intense pain, rapid weight loss, hair loss, loss of appetite, and many other side effects that the biomedical team views as a necessary evil.

In this chapter, I turn to a different but related problem. While the blatant forms of iatrogenesis associated with the biomedical side of the project of total care are widely recognized by professionals, there are less injurious but nevertheless consequential forms of iatrogenesis that professionals tend to overlook. Building on the work (bio)medicalization theorists, I argue that practices of cancer care can produce *moral iatrogenesis* (see chapter two), particularly among older patients. In many instances, moral iatrogenesis is related to the ideological models of child appropriateness that saturate pediatric environments and practices. Although it is common to refer to pediatric hospitals such as BACH as "children's hospitals," this classification obscures the fact that these institutions serve many patients who are not viewed as children, but as adolescents or teenagers. Yet, as anyone who has spent time in a children's hospital can attest, these spaces tend to be designed in ways that cater more blatantly to sensibilities and interests more commonly associated with younger children. Furthermore, these spaces are regulated by professionals who perform their authority in ways that draw on dominant standards of child appropriateness that derive from bourgeois, Euro-American understandings of children as innocent and fragile beings who must be protected from the corrupting influences of the adult world.[1] I argue that the deployment of such models can enact moral iatrogenesis via the alienation, infantilization, and censorship of patients who do not identify with them. Furthermore, I show how models of child appropriateness are ideologically linked to models of parental responsibility in ways that can result in the stigmatization and increased professional surveillance of parents who are seen as behaving inappropriately.

Music Therapy at BACH

The currently existing music therapy program at BACH was founded in 2008. Three music therapists, one of whom is the full time director of the music therapy program, run it. Another music therapist, a black woman in her mid-thirties who I will refer to here as Jennifer, was the primary provider of music therapy to patients in the hospital's immune compromised unit, where cancer patients endure the most intensive phases of treatment.

In addition to professionals with expertise in techniques of music therapy, the music therapy program at BACH is equipped with a mix of digital and acoustic instruments. These include an acoustic guitar, shakers, tambourines, hand drums, xylophones, a digital keyboard, a laptop computer, and an iPad with music software and Internet access. Jennifer transports these instruments around the hospital on a large, grey cart. In addition to serving patients in the oncology ward, Jennifer also works with patients in other units of the hospital as needed.

However, her time is greatly limited by the *per diem* nature of her employment contract, which offered no employee benefits and allowed for only 19 hours a week of labor.

As part of my fieldwork, I volunteered with the music therapy program, helping Jennifer facilitate weekly groups with patients of various ages and at different stages in their treatment process. These sessions generally lasted around two hours, and I attended them regularly throughout 16 of the 18 months I conducted fieldwork. I also helped Jennifer provide music therapy to individual patients on many different occasions. My role in facilitation generally involved playing instruments, helping to address patient needs, and sanitizing instruments at the end of sessions. In the following section, I will describe a session that is typical of the sessions I observed during fieldwork.

From Moana to 2pac

One day in April 2017, I was helping Jennifer, one of BACH's music therapists, facilitate a music therapy group with two patients present—one five year old, Anna, and one twelve year old, Rashad. Jennifer began by encouraging each of us to pick an instrument off the table. Anna and I chose hand drums, and Rashad selected some chimes and a mallet.

"Okay, let's do a little warmup… Let's see how many of you know this song. I already happen to know this is one of Anna's favorites," she said, smiling warmly at Anna, who smiled sheepishly back. Jennifer took her guitar and began strumming the chords to "How Far I'll Go" from the Disney movie *Moana*. Anna's eyes lit up, and she sang the opening lines with Jennifer:

> *I've been staring at the edge of the water / long as I can remember / never really knowing why / I wish I could be the perfect daughter / but I come back to the water / no matter how hard I try* (Miranda 2016).

I kept the beat with the hand drum as Anna and Jennifer sang together. Rashad looked bored and randomly hit the chimes, adding a dissonant quality to the song. After the song ended, Jennifer turned her attention to Rashad, asking him what kind of music he liked.

"I don't know… I like a lot of music," Rashad said in a disengaged tone.

"Who are some of your favorites?" Jennifer asked.

"I like 2pac," Rashad responded.

"Okay," Jennifer said. "I can appreciate that. I can't say I know any 2pac songs off the top of my head, but how about I learn one and we can sing it together next time?"

"Sounds good," he said.

"Just in case I need more options, is there anything else you like? How about songs from cartoons or movies?"

"I like Naruto," Rashad responded, referring to the popular Japanese animated series.

"Okay, well, we'll see what we can come up with for next time,"

Jennifer played a few more songs, and then Rashad's father, Malachi, showed up. He greeted us all. At this point, Rashad had grown visibly tired, and he started nodding off. Malachi asked him if he was ready to go back to his room. Rashad nodded yes, and Malachi helped him maneuver his IV pole as he got up slowly out of his chair. Jennifer, Anna, and I said goodbye to Rashad and Malachi.

Later that Day

After the session that afternoon, I stopped by Rashad's room to check in with Malachi. I had known the family for a few months at this point. Malachi and I had earlier bonded over our mutual love of playing music. We had since started meeting weekly for jam sessions at my apartment. As Malachi described it, these meetings functioned as his own form of music therapy. Over time, we began writing and recording songs. Some were instrumentals. On others, Malachi rapped and sang.

"What's up, Ant?" Malachi greeted me, shaking my hand. "How was music group?"

"It was good," I responded.

I smiled and gestured toward the closed door of the restroom where I could hear Rashad running the faucet and said, "I'm not sure how much he liked it though."

Malachi chuckled. "Yeah, he's not too crazy about that campfire, kumbaya stuff she does," referring to Jennifer. "She should do something more for older kids," he suggested.

I thought this was a good idea, and I ran it by Jennifer a few days later. She also thought it was a good idea, but she was concerned that she would not have enough time to execute it well, as her schedule only permitted her to spend two hours a week on group sessions. I asked her if maybe I could facilitate a session on my own, offering to bring in some of my musical equipment. She seemed a bit uneasy and responded that the hospital usually asks volunteers not to bring in outside items. I didn't push the issue, and we decided that instead we would split the next week's group into two distinct sessions—one for very young children, and another for older children and teens.

The Iatrogenic Effects of Children's Culture

As Cheryl Mattingly, who has carried out decades of ethnographic research in American pediatric contexts, points out, "Pediatric clinicians routinely draw upon children's popular culture to connect with children" (2010, 177). I also found this to be true at BACH, particularly among psychosocial professionals who engage in art, music, and play therapy sessions with patients. It was very common for professionals to cite popular children's movies, television shows, books, and songs in attempts to draw young people into potentially therapeutic and entertaining forms of play, artistic/musical engagement, and social interaction. In short, in addition to actual children, various fictional child characters also populate pediatric hospitals in ways that can have a profound impact on the manner in which caregiving interactions unfold.

In her analysis, Mattingly emphasizes how various forms of "popular children's culture" that circulate in pediatric environments can act as a source of hope that transcends lines of difference. As she describes:

> Children's popular films and television shows provide familiar figures across a vast array of national, ethnic, class, religious, gender, disability, and racial borders. Stories from children's popular culture serve as fertile ground for the imagination, for identity play. They even offer a resource for expressive resistance or defiance in the face of grim prognoses and stigmatized identities. These tales are woven into clinic life and into interactions with home health professionals. They become part of stories acted out or referred to, especially during rehabilitation therapies that try to incorporate treatment into some form of child play. Families and health professionals draw upon globally popular narratives to develop a shared story of hope and to counter the stigma of disability (Mattingly 2010, 176).

While conducting fieldwork at BACH, I certainly witnessed the kinds of hope-inducing interactions and forms of play that Mattingly describes. In particular, psychosocial professionals, such as Jennifer, often deployed what Mattingly refers to as "children's popular culture" in attempts to create social connections with patients and to draw them into various forms of play, ideally in a manner that produces a therapeutic response. As we see in the vignette above, this strategy works well with Anna, who is immediately drawn in to the Moana song. In pointing out that the song was one of Anna's favorites, Jennifer signals that she has already discussed this with Anna, which reveals a central strategy used by psychosocial professionals. To a large extent, psychosocial care is viewed as dependent on personal relationships and connections. Therefore, professionals attempt to get to know patients personally in order to foster relationships that are conducive to therapeutic engagement. In the context of music and art therapy, this often involves getting to know patients' cultural preferences in order to cite them in caregiving interactions. The Moana song speaks to Anna because she has heard it before. She has watched the movie countless times, knows the words, and takes great pleasure in singing them loudly. In other words, the music therapy session is effective for Anna partly because it taps into her experience outside of the hospital.

However, as the descriptions above also show, not all patients have the same cultural preferences, and this can make it very difficult to facilitate group psychosocial sessions in ways that benefit all patients equally. I witnessed many interactions where professionals tried to wield children's culture to no avail, and, in some instances, these practices arguably produced morally iatrogenic effects by making certain patients feel alienated and infantilized. To some extent, these dynamics were produced by age and life-stage categories. While patients who were positioned as young children, such as Anna, often responded positively when Jennifer performed songs from popular children's shows and movies, those who were positioned as older children and teenagers, such as Rashad, were often alienated by certain styles of child-directed music. Yet this was not always the case. I met a small number of older patients who seemed to enjoy child-directed therapy sessions for a variety of reasons. Some seemed to take great pleasure in watching the younger children attempt to play musical instruments. Others seemed to engage nostalgically, deriving joy from singing songs they first heard when they were younger.

Of course, age and life-stage are only two ideological elements of identity and positionality. The awkward dynamic with Rashad in the session described above was also

mediated by the ways in which ideologies of race and class inflect dominant models of child appropriateness, marking many non-white and economically impoverished young people's cultural preferences as inappropriate. For example, Jennifer blames her inability to connect with Rashad on the limitations of her repertoire, and she proposes expanding it to accommodate him. What I want to point out here, though, is that her repertoire is not limited because she has never heard of 2pac or because she was not a fan of rap music. On the contrary, Jennifer knew a lot about rap music and about 2pac in particular. Despite her knowledge of this music, it did not find its way into her music therapy repertoire. Rather than a lack of knowledge, this omission of 2pac and other rappers was more related to the ways in which professional practices are regulated by standards of "child appropriateness" that reflect sanitized notions of child health and wellbeing. The musical forms considered appropriate for young patients were those that refrained from using profane words or making explicit reference to violence, sex, or substance use. Even if Jennifer would have learned and performed a 2pac song—which I never personally saw her do—she would have likely had to edit it to meet the moral standards of the professionalized, child-directed environment, and it is difficult to say how this would have been received by participants.

All of this complicates our understanding of the role of "popular children's culture" in the production of hope and social connections between young people and their professional caregivers. While professional strategies of deploying children's culture seemed to be very effective in drawing patients into psychosocial activities, at other times these strategies failed miserably. As I will describe, there are a number of reasons why such strategies failed, but one reason was that some patients were averse to what Giroux describes as "Disneyfied" forms of children's culture. Giroux argues that Disneyfied culture combines "an ideology of enchantment and aura of innocence in narrating stories that help children understand who they are, what societies are about, and what it means to construct a world of play and fantasy in an adult environment" (1994, 66). Giroux suggests that such forms do not only exist as representations, but as "teaching machines" (1994, 66), which shape how people view particular children and childhoods and how they position themselves and others as children. Furthermore, they shape the ways in which people make distinctions between morally good and bad children and childhoods.

While my intention is not to totally negate Mattingly's observation that children's culture is often used as a tool to counter the stigmas of disability and chronic illness, it is important to remember that many patients are affected not only by health- and disability-related stigmas, but also by stigmas that empower race, class, and gender hierarchies. In many cases, these same hierarchies are present in children's culture. Giroux offers the example of how good and evil forms of femininity are represented in Disney's *The Little Mermaid*:

> Ursula the large, oozing, black and purple squid in The Little Mermaid gushes with evil and irony, the heroine and mermaid, Ariel, appears as a cross between a typical rebellious teenager and a Southern California fashion model. Disney's representations of evil women and good women appear to have been fashioned in the editorial office of Vogue. The array of animated objects and animals in these films is of the highest artistic standards, but they do not exist in some ideologically free comfort zone. Their characters are tied to larger narratives about freedom, rites of passage, intolerance, choices, and the brutalities of male chauvinism (1994, 70).

For patients who are sensitized to the ways in which dominant understandings of race and gender are encoded in such representations, this can render the deployment of Disneyfied cultural forms more harmful than beneficial. And even in the absence of conscious sensitivities to race and gender dynamics, young people may reject a cultural form because it does not resonate with the particularities of their life experience. In other words, they cannot see themselves in it and thus do not identify with it.

Beyond the problem of patients not seeing themselves reflected in Disneyfied cultural forms, the issue is exacerbated by the fact that the cultural forms with which many patients do identify are viewed as inappropriate, as I've pointed out with the example of Jennifer's omission of 2pac. In many cases, young people identify with and take pleasure in cultural forms, such as rap music, that are stigmatized as inappropriate from the perspective of the formalized professional ideology of the institution, which is dominated by Euro-American, bourgeois understandings of childhood, even if staff members as individuals may question those understandings. At times, professional ideologies result in a stigmatization of the manner in which young people articulate their identities and cultural preferences. Such ideologies mark indulgence in "inappropriate" youth cultures as psychosocially pathological. More often, however, professionals do not overtly stigmatize any particular cultural preference, but instead maintain the boundaries of child appropriateness by selecting and deploying "Disneyfied" cultural forms and by re-directing young people's conversations and behaviors when they veer in "inappropriate" directions. To a large extent, though, overt professional behavioral interventions are often unnecessary, as many young people actually police their own behavior according to standards of child appropriateness, which play a productive role not only in pediatric environments, but also in other institutional settings in which young people have spent significant amounts of time, such as daycares and schools.

Now I turn to an ethnographic description of the teen group Jennifer and I tried to organize one afternoon. As I will describe, even in contexts where professionals tried to create teen-directed groups, dominant child-directed standards maintained a recalcitrant presence.

Heartbeat Recordings, GarageBand, and 90s Rap

When I arrived at the hospital on the day we planned to do the teen group, there was an older, black, male patient who I didn't recognize sitting in the playroom. I later found out that his name was Haamid, and he was an 18 year old who had migrated from Sudan at the age of 10.[2] I said hello and introduced myself as a volunteer. I told him that we were about to hold a music therapy group that he was invited to, and he smiled and nodded his head: "Yeah, that's what they told me," he responded. "I'm gonna check it out."

At this point, Jennifer showed up with the instrument cart. "Hey Anthony! Hey Haamid!" She greeted us both, signaling that she and Haamid had already met.

"Anthony, do you want to go ahead and start setting up while I do invites?"

"Sure, no problem," I responded and began taking instruments off the cart and placing them on the two tables in the room—one standard sized, and one child-sized. Jennifer left the playroom to go around the ward and invite families to the session, which was scheduled to start in half an hour.

"So you a musician?" Haamid asked me.

"I'm not a professional," I said. "But I've been playing guitar and writing and recording songs since I was a kid. It's my main hobby. How about you?" I asked.

"I'm a rapper." He told me. "My friend Chris produces my beats. He's here with me as my caretaker. I'm sure you'll meet him."

"Cool," I told him. "Looking forward to it. What program does he use to make beats?"

"He's got FruityLoops," he responded. (FruityLoops is a popular computer program for making digitally synthesized and sampled music. It's used most widely among hip hop and electronic music artists.)

"So you know Malachi?"

"Yeah, I do," I said. "You've met him?"

"Yeah, he's hella cool," Haamid responded. "He told me y'all have been making beats too."

"Yeah, we have. He's really talented."

"You got any of y'all's stuff you can show me?" Haamid asked.

"Actually, yeah, I have some on my phone." I pulled out my phone and scrolled through my files. I played him a sample of a track we'd recently recorded.

He smiled and nodded along with the beat.

"Y'all wrote this?"

"Yeah," I said. "I played guitar and bass, and Malachi did the drums and vocals."

He chuckled. "Y'all keep it old school, huh?"

I laughed. "I guess so… We are kinda old…"

"I don't mean it in a bad way." He said. "I'd listen to it. It just sounds more like 90s rap or something."

"No offense taken." I told him. "I love 90s rap."

At that point, Jennifer came back to playroom.

"Looks like we have a few takers," She said. "They were mainly younger, so I think we'll start with a more child-focused group, and then in the second hour we can do something more

teen-focused. Haamid, if you want to hang out during the children's group we'd love to have you, but it's also totally cool if you want to just come back for the teen group."

"I'll hang out," Haamid said.

A few minutes later, a black, male three-year-old patient named William came in. His mother walked behind him, pushing his IV pole. She was making a great effort to keep up with him as he lurched in random directions, as three-year-olds will do.

"Hey William!" Jennifer greeted him.

He looked at her momentarily, but his attention quickly shifted to a large, rideable, plastic car that sat in the corner. "Car!" He exclaimed, lurching toward it.

"He loves that car," his mom told us.

"Hey buddy, come over here, and let's sit at the table," she said to William, picking him up and placing him in her lap as she sat down in front of a small, colorful hand drum. William lunged in the direction of the drum.

"You like the drum?" Jennifer asked him? "Here ya go, why don't you play this one?" She handed him the drum, and he held it tightly, inspecting it with a tense gaze. His mom tapped the drum a few times, breaking his concentration and prompting him to mimic her. He hit the drum several times and laughed.

At this point Anna and her father arrived. Anna looked tired and glum. She and her father took a seat at the table.

"Hey Anna!" Jennifer greeted her. "You ready to make some music?"

Anna looked deliberately away from Jennifer, offering no verbal response.

"She's a little out of sorts today," her father apologized. Jennifer nodded and gave Anna's father a look of compassionate concern.

"Hey, that's no problem," Jennifer said. "We all get a little out of sorts sometimes."

Jennifer then addressed the group, beginning the session. "Alright, let's make some music!" She said enthusiastically. She strummed through a chord progression on her guitar.

"Anthony, how about you give us some rhythm?" I picked up the hand drum in front of me and began to play. William watched me, intrigued for a moment, and then began to bang on his drum.

"William, my man!" Jennifer said. "I like your style,"

Anna's father had picked up a shaker and was trying to coax her into taking it, but she sat with her arms crossed, staring at the floor. Haamid played a hand drum and watched entertained as William thrashed about in his mother's lap.

After three or four minutes, Jennifer brought the improvisation to a close, and shifted to playing songs from popular children's shows and movies. We continued for about forty-five minutes, and then Jennifer announced to the group that we would be shifting to a session for teens and older children where we would experiment with some digital music software. Anna, William, and their parents left at this point, and Haamid stuck around. A few minutes later, a sixteen-year old, Latinx patient named Juan came into the playroom with his mother.

"Hey Juan," Jennifer greeted him. "Cómo estás, señora?" She asked Juan's mother, whose primary language was Spanish. "Bien." his mother replied. She explained that she had to leave to run an errand, but she would be back in an hour or so.

At this point, Jennifer was ready to start the group. "Okay guys, so we're gonna try something a little new today and have teen group where we experiment with some music software. How many of you guys have ever used GarageBand?"

Chris responded quickly: "I've used it before, but, honestly, now I prefer to use FruityLoops and Cubase in combination. Cubase is better for really crafting unique tones."

"Well, I'm not sure we'll be able to get that fancy today," Jennifer said, "But I thought it would be fun to do some heartbeat recordings. Have you guys ever heard of a heartbeat recording?"

Everyone shook their heads no.

"Well, it's a really simple technique that we use all the time in music therapy. You've all seen one of these things before, right?" She asked, holding up the stethoscope. "Basically, we cut the stethoscope, and then we put a little microphone inside of it so we can record your heart beat. Anyone wanna try it?" Juan raised his hand.

Juan placed the stethoscope-microphone against his chest, and Jennifer plugged it into the computer. We suddenly heard the booming and whooshing sound of Juan's heart. The sound meter on the computer began to move up and down with the rhythm. Jennifer pressed record and captured twenty to thirty seconds of audio.

"Okay, now we can loop this if we want," she said, copying and pasting the audio several more times. "And now it can be kind of like the drum beat for a song. Does anyone want to try to add something to it?"

"I'll try," Haamid said, amused.

Haamid turned on the keyboard and started shuffling through the sounds. He settled on ethereal sounding synthesizer, and began playing a simple melody along to the heartbeat.

"Nice!" Jennifer said. "Keep playing that!"

"Anthony, how about you try to add some drums to it?" She asked, sliding the iPad toward me.

I opened up the GarageBand app on the iPad and selected a drum kit, and then began to tap a beat along with Haamid and the heartbeat. Jennifer began strumming slowly along with Haamid's melody on her guitar.

"Juan, Chris, why don't you guys jump on some hand drums or shakers? Or if anyone wants to try some singing or rapping, feel free!" She said.

"Freestyle!" Chris urged Haamid, who laughed and shook his head no in response.

Eventually we lost our steam, and the song tumbled to an end. Jennifer had us all switch roles, and this time Haamid recorded his heartbeat and Juan played the keyboard. Chris took the iPad, Jennifer took the hand drum, and I took the acoustic guitar. We rotated like this two more times, and then it was time to end the session. Chris, Haamid, and Juan all said goodbye and went back to their rooms, while Jennifer and I donned latex gloves and began sanitizing the instruments with alcohol wipes.

The Omnipresence of Children in Pediatric Settings

The teen group we conducted provides a contrast to the more child-directed group carried out with Rashad and Anna. In this group, Jennifer used a different set of instruments and techniques. She attempts to draw the three young men in by showing them how to use a novel piece of equipment—the stethoscope-microphone. In many ways, this was an effective strategy, as Haamid, Chris, and Juan quickly engaged with the process. However, when the energy begins to reach a climax and Chris urges Haamid to freestyle—in other words, to improvise a rap over the beat—Haamid quickly refuses the opportunity. Wondering why he chose to limit his engagement, I asked Haamid afterward why he reacted this way. He explained that he was afraid he might say something inappropriate in front of Jennifer and me.

Haamid's response attests to the power of standards of "child appropriateness" that produce and regulate pediatric settings. In attempting to better understand the processes through which child appropriateness exerts effects, I find it useful to build on Ochs, Solomon, and Sterponi's (2005) model of "child-directed communication" (CDC).[3] CDC is similar to the notion of "child-directed speech" (Blount 1972; Fernald et al. 1989; Snow et al. 1995) in that it focuses on communication with all people classified as children and youth. Unlike child-directed speech, though, CDC does not only focus on speech, but on multiple communicative modalities, or *semiotic repertoires*, including "gesture, gaze, touch, writing, and music" (Ochs, Solomon, and Sterponi 2005, 553). CDC also differs from linguistic anthropological notions of "motherese" (Fernald 1985) and "parentese" (Chafetz et al. 1992) in that it does not restrict the focus on adult speakers to those positioned as mothers or parents, but rather expands it to include any adult.

As Ochs, Solomon, and Sterponi (2005) acknowledge, one drawback of the term CDC is that it may give the impression that children are not active participants in communication. However, they argue that this would be a misinterpretation, as the CDC model acknowledges young people's capacities to participate in and exert influence over communicative interactions. One other thing I want to note about the CDC model is that, although it incorporates the term "child" into its name, it also recognizes the communicative participation of young people positioned as teenagers or adolescents. The CDC model proposes six analytic dimensions: habitats, artifacts, ideologies, participation frameworks, activities, and semiotic repertoires. Here I will briefly consider the teen music therapy session described above through the lens of each of these dimensions.

For Ochs, Solomon, and Sterponi, *CDC ideologies* refer to "implicit and explicit beliefs and values linked to codes, modalities, and social positionings of persons involved in a communicative exchange" (2005, 554). Here I want bring the notion of CDC ideologies into conversation with my earlier discussion of ideological models and biocommunicability. CDC

ideologies provide pediatric biocommunicable models that serve as technologies through which the social positions and communicative practices of health care professionals, patients, and parents/guardians are produced. For example, the notion of "child appropriateness" discussed above can be seen as an element of CDC ideology that is implicitly and explicitly cited in interactions between participants. We can see that Jennifer selects certain songs and activities that do not deviate from this ideology, and patients often also conduct themselves in child appropriate ways.

In noting the role of citational acts and the iterative models on which they rely, I want to stress that it is not only through the citational activity of corporeally present participants that ideological models come to mediate interactions. A number of non-present people arguably also influence interactions between caregivers and patients insofar as they play or have played a role in the design and administration of the hospital as a physical and social structure through which various discourses and objects circulate. The analytic dimensions of *CDC habitat* and *CDC artifacts* are useful here. CDC habitat draws our attention to the role of "macro-niches," such as landscapes and architectural structures, and "micro-niches," such as beds, infant slings, chairs, and strollers, in shaping child and youth corporeal orientations that affect communicative exchanges. The habitat of the BACH playroom, for example, featured brightly painted walls with a wallpaper border depicting a jungle scene. The playroom also included a vinyl couch and two tables, one standard sized and one miniature, which were accompanied by matching chairs. The CDC habitat of the playroom was also populated with *CDC artifacts*, or material/discursive objects—videos, writing tools, educational diagrams, etc.—that play a role in producing different styles of CDC. In the context of pediatric music therapy, digital and analog musical instruments, music software, and audio recordings function as CDC artifacts.

What I want to stress here is that the micro- and macro-niches that constituted BACH as a space of corporeal engagement were consciously designed and arranged and thus contain ideological traces that play a role in producing social positions and interactions. Entangled CDC ideologies, habitats, and artifacts give rise to the *CDC participation frameworks* through which specific participants take up positions associated with particular *CDC activities.* As we can see in the music therapy session described above, individual persons enter into the habitat of the BACH playroom, which is equipped with furniture and various artifacts designed to facilitate the specific CDC activity of music therapy. These activities rely on the entanglement of diverse *CDC semiotic repertoires*, primarily speech, bodily gesture, and musical production.

Of course, the effects of such music therapy activities and the ideologically and artifactually mediated semiotic repertoires they deploy are partly dependent on the manner in which participants interpret them, which is partially related to how they interpret the setting, or habitat, in which such activities unfold. Here I want to note the similarities between the children's hospital and other institutions that are designed for children—especially schools. All of the young people in the group had spent time in such settings before, and these experiences shaped their sensibilities and habits. The closest thing to the playroom many young people had probably experienced before cancer diagnosis was an elementary school classroom or a daycare setting. The resonance between these spaces likely reinforced a perception of the playroom as child-directed and thus calling for child appropriate forms of expression. In this way, it isn't only non-present designers and administrators who can have an influence on CDC habitats and artifacts, but also non-present, imaginary children with which they are ideologically associated. In other words, no actual child has to be immediately present in order to exert an effect on interactions that occur between hospital professionals and patients. Ideologies of childhood were

inscribed into the BACH habitat, as well as into the artifacts used to facilitate care and communication, and young people had been conditioned to respond to these ideological traces in specific ways. We see this in Haamid's decision not to freestyle for fear of saying something inappropriate.

Beyond the fact that BACH was designed and administered as a CDC habitat populated with CDC artifacts, there are several other ways in which the ideology of child appropriateness exerts effects. One factor to which Haamid alluded in his response to my question about why he did not freestyle was that Jennifer and I, whether we wanted to or not, were acting as representatives of the hospital professional culture. Our self-presentation certainly contributed to our professional aura, as Jennifer and other adults at the hospital had a habit of speaking in a different tone to young people than they did to each other. As a volunteer, I occasionally found myself falling into these speech patterns. I realized over time that I was subconsciously mimicking the communicative style of the professionals who supervised my activities, as my habitus was not initially attuned to child-directed environments, and I was searching for ways to more comfortably perform the role of hospital volunteer. In doing so, however, I unwittingly played a role in reproducing a style of child-directed communication.

In addition to the widespread habit of child-directed speech, my self-presentation probably affected Haamid's perceptions of the group. As a volunteer, I was required to wear a light blue smock and a photo nametag that said "VOLUNTEER." This likely signaled that I was acting as a representative of the institution and its child-directed technologies. The fact that I am a white male with an affiliation to a university also probably had an effect on our interactions, as Haamid may have interepreted me as likely to hold dominant standards of professional decorum, which, in the pediatric hospital environment, entails standards of child appropriateness.

The overt child-directedness of the BACH habitat and the forms of social interaction that occur within it is not lost on pediatric professionals. This is why Jennifer was initially receptive to the idea of a regular teen group, as she was aware of the fact that older patients might benefit from less child-directed programming. But after the first attempt, Jennifer decided that she did not want to continue splitting groups into two separate hours. This was partly related to the limitations of her employment contract. Planning two separate groups would add to her labor and limit the amount of time she was able to spend with patients. Another reason was that the immune compromised ward had limited facilities, and the playroom was the only space where patients could spend time outside of their rooms. Doing a separate teen group required her to close off the playroom to younger children, which she preferred not to do. Jennifer also did not think splitting the groups up was the most practical option, since there was a great deal of variation in the demographic composition of the ward from week to week. It was very difficult to predict in advance if there would be a significant enough number of teens interested in music therapy to warrant a teen group every week, and there were often weeks when no teens participated. While Jennifer recognized the need for teen-centered activities, the structural conditions of her work prevented her from regularly offering them.

In the following section, I consider other attempts that hospital professionals made to create teen-directed psychosocial activities, showing how the habitat of the BACH immune-compromised ward was spatially isolated from the hospital "Teen Lounge" in ways that prevented cancer patients' direct participation in certain psychosocial activities. However, the hospital's closed circuit television system and internal phone lines, which can be seen as CDC artifacts, enabled cancer patients to participate remotely in certain Teen Lounge activities, such as the weekly BINGO session held on Thursday nights. In very special cases—for example,

during a special event like the annual hospital prom—teens could also request their physician's permission to leave the ward in order to participate in an activity in the Teen Lounge.

The Teen Lounge

Jennifer was not the only professional who recognized a need for teen-centered activities at the hospital. Child Life professionals have tried to address the needs of teen patients by creating a "Teen Lounge" on the fourth floor, one floor below the cancer ward. This space regularly holds activities designed specifically for teens, such as art projects, group music therapy sessions, and holiday parties. The Teen Lounge is also the site of a daily television show called *Good Morning BACH* that is produced by teens and older children with the assistance of professionals. Finally, the Teen Lounge holds Thursday night BINGO sessions where patients can win prizes that range from small toys to Xbox games.

Despite the presence of the Teen Lounge and its teen-oriented services, it was not directly accessible to patients who were confined within the immune-compromised ward, which is where virtually all cancer patients are placed. There was no dedicated space for teens in the ward, and, in most cases, they could not leave the unit without risk to their health, as patients going through cancer treatment have a dramatically increased susceptibility to infections. Teen cancer patients could, however, participate televisually and telephonically in Thursday night BINGO and *Good Morning BACH*.

For BINGO, participation from the ward involved watching a live-stream of the event on the hospital's closed-circuit television system. Prior to the event, volunteers would take BINGO cards and crayons around to patients' rooms and remind them that the game was on channel 3 and would start at 6 p.m. Those who were interested in playing could tune in and watch as patients and professionals carried out the game in the Teen Lounge. Usually, five or six patients sat around a table playing the game with one or two volunteers, while another volunteer operated the camera. Yet another volunteer assumed the role of calling out numbers and writing them on a whiteboard. For the duration of my fieldwork, the primary BINGO caller was an older, white, male volunteer who had adopted a "Patch Adams" style of self-presentation and referred to himself as Pun, in reference to his penchant for speaking in puns. The first time I met him, he introduced himself in the following way: "Hey, they call me Pun because I love puns, except for insect puns… Those bug me." He wore a blue smock like all volunteers, but his was decked out in colorful buttons and other pieces of flair. While Pun called and wrote down the numbers, another volunteer and two Child Life employees handled the phones and prize distribution.

As patients from the cancer ward called in to report their BINGOs, the volunteer and employees would answer the phones and ask the patients what item they wanted off of the prize table, which the camera operator zoomed in on intermittently for patients to see what was available. Once patients selected a prize, it would be set aside, and a volunteer would keep a list of where each prize was supposed to go. At the end of the BINGO session, volunteers would deliver the prizes to patients' rooms. Often, this worked smoothly, but there were also many times when patients would call and request a prize that had already been taken. Although patients were generally good sports about choosing a different prize, at times they expressed disappointment at not receiving the prize they initially selected, particularly when the prize in question was a bigger ticket item, such as an Xbox game.

Good Morning BACH was also directly inaccessible to patients, although, like with BINGO, they could watch the closed-circuit television in their room. The show was hosted by

one of the Child Life employees and teen patients who were not isolated to the immune-compromised unit. Often, the show involved a special segment designed by patients. For example, once they aired a fashion show where patients had designed clothing using various art supplies and hospital scrubs, and the clothes were modeled by one of the social workers. In addition to special segments, the show also had regular segments where patients could call in to give shout outs, tell jokes, or answer trivia questions.

Although the BACH employees' attempts to offer teen-centered psychosocial services were commendable in many ways, and although there were a number of patients who clearly enjoyed participating in them, the services were arguably much less effective for cancer patients who could not directly participate. Furthermore, although participation in BINGO and *Good Morning BACH* was restricted to patients 11 and up, child-directed technologies and practices continued to exert effects, much like they did in the teen music therapy group described above. In the context of BINGO, one of the primary sources of child-directedness was Pun, who some patients loved, but who others reacted to with annoyance or puzzlement. Pun's loud self-presentation and endless inventory of puns and corny jokes were clearly designed for young children, and the fact that he was the primary BINGO caller had an infantilizing effect on the game. As for *Good Morning BACH*, also like music therapy, its content was constrained by the standards of child appropriateness.

In the rest of this chapter, I will move away from the issue of how ideologies of childhood mediate the practices of child-directed communication that constitute psychosocial care during hospitalization. I shift to the issue of how these ideologies fuel the stigmatization of patients and families who do not conform to them. As I will show, stigmatization can involve the circulation of racist, classist, and gendered stereotypes of "inappropriate" young people and families who are viewed as attached to cultures and behaviors that are pathogenic to valued forms of childhood and youth.

Racism, Racial Stigma, and the Diminishment of Suffering

One day, a few weeks after his second stem cell transplant, Rashad was hanging out in the playroom with his dad and a nurse. Rashad was not particularly fond of this nurse, as she had previously hurt his feelings by jokingly calling him a "bed bum" one day when he slept until noon. In doing so, she had overstepped the boundaries of her relationship with Rashad, attempting to joke in a moment when he didn't feel like joking, especially at his own expense. On this day, the nurse was talking to Malachi and Rashad about another patient who they all knew, another African American boy named Devon, who had a reputation among professionals as being tough and untalkative. The nurse, a white woman, referred to Devon as a "little street thug." In inhabiting a white subject position and using the term "thug" in a pejorative manner, the nurse triggered intense emotions in Rashad and Malachi, who both, as black males, identified with Devon on a personal level. After the fact, Rashad reflected on the situation, suggesting that the nurse had racialized Devon's intensely negative reaction to cancer diagnosis and treatment:

> [Devon] was sad, disappointed, and enraged with his situation. So I think it's uncalled for for a nurse to go to another patient and be like "Oh my goodness there's this patient..." She said he was a "thug" or "ghetto" or something like that, and that's upsetting because it's an emotional experience and everybody deals with it differently, so I don't think it's right for her to judge him like that, when this might just be his reaction to having a life-

threatening disease… I mean, there's other kids who respond that way, and she doesn't call them thugs…

Malachi was also taken aback by the nurse's choice of words. He reflected on the situation: "How are you gonna call a kid with cancer 'a little street thug,' especially right to the faces of two black males?!" He asked indignantly. "I mean, the kid is hard, but I would have chosen different words. Something like, 'Oh, yeah, that Devon, he's pretty stoic.'" Despite Malachi's frustration, he decided to let the interaction slide, and he said nothing to the nurse. "I think she's just got a fucked up sense of humor," he said. "She's good people though." But then, afterward, Rashad expressed anger at Malachi. "Dad, why didn't you say something to her?" he asked. "What if it was me she was calling a thug?" Malachi later decided to report the nurse to her superior.

In many ways, Rashad's diagnosis of the situation echoes the work of historian Keith Wailoo (2011), who shows how ideas about who is affected by cancer and how have changed dramatically over time in the United States. In the early twentieth century, many scientists and medical professionals viewed cancer as a disease of modernity that primarily affected wealthy, white women. African Americans, on the other hand, were viewed as immune to the disease due to a supposedly primitive biological constitution. Cancer awareness campaigns reflected this racialized, gendered, and classed view, often focusing on the experiences, worries, and concerns of wealthy, white women. By the 1950's, ideas changed, and cancer became seen as a democratic disease that affected all races, classes, and genders. Yet it would be two more decades until the rhythm and blues singer Minnie Riperton became one of the first widely recognized African American cancer awareness advocates and a broad public was exposed to the cancer narrative of an African American person for the first time. As Wailoo points out, even as cancer awareness discourses began to recognize the fact of African American cancer, they nevertheless portrayed African Americans as "the colored multitudes," lacking in the kind of individual psychological depth and complex inner experiences that were often attributed to white people (Wailoo 2011, 179).

Although Rashad was likely not aware of the particular history of cancer as a racialized disease, he was certainly aware of the general historical and cultural pattern in which white Americans diminish non-white suffering and stigmatize the coping strategies upon which non-white people rely. This is precisely what Rashad felt the nurse had done to Devon by racializing his negative emotions and reducing him to a "thug" with a bad attitude, as opposed to recognizing the complexity of his situation as a terrified young person with a life-threatening disease. Of course, as Malachi generously observed, the nurse may have been joking. In fact, after he reported her to her superior, she apologized, telling him that she didn't mean anything by it and that she has African American family members. Neither Malichi nor Rashad found this a convincing defense of her remark. Whatever she intended, my aim here is not to condemn her, but to recognize the morally harmful impact of her words on Rashad and Malachi, and to show how such statements, joking or not, resonate with the dynamics of racism in the United States. The delegitimization of African American emotional experience in the context of life-threatening illness is not a new cultural pattern, and it continues to shape institutions, social interactions, and subjectivities in both overt and covert ways. By citing the figure of the "thug" in a stigmatizing manner, the nurse only perpetuated this pattern.

But I also want to note how the nurse's comment can be read as relying on ideologies of child appropriateness. In this case, however, the focus isn't on the ways in which CDC habitats,

artifacts, and activities are designed according to models of child appropriateness, but rather on the ways in which professionals interpret specific young people's appearance, speech, and behavior as appropriate or inappropriate. These interpretations are just as mediated by ideological models of childhood and child appropriateness as are the CDC activities of music therapy and BINGO described above. In all of these examples, we can see the ways in which ideological models of childhood and child appropriateness that shape cancer care and communication are racialized and classed. As we saw in the music therapy sessions, the cultural forms deemed most appropriate for children are those that have been "Disneyfied" (Giroux 1994), or articulated in ways that do not threaten bourgeois, Euro-American norms of childhood as a site of innocence and enchantment. I argue that cultural forms that many older children and teenagers prefer—particularly rap music, an African American cultural phenomenon that has since been appropriated by people of many other races—are often stigmatized as inappropriate precisely because they tend to negate Euro-American models of childhood by conveying in vivid terms the pain and suffering that characterizes life for Black people, including many children and youth, in the United States. Furthermore, rap music often conveys "illicit" pleasures, particularly promiscuous sex and substance use, as methods of coping with pain and suffering. From the perspective of the Euro-American models of childhood, such representations are likely to have pathological effects on children. In other words, rather than viewing rap as an expression of the pain of living as a Black person within the pathological conditions and relations of American poverty and racism, rap and hip hop culture get re-signified as the cause of social pathology. This is arguably the interpretive lens that the nurse employed in calling Devon a "thug," regardless of whether or not the reader is convinced by the justification that she was just kidding around.

Of course, as I have demonstrated with the case of Jennifer, who is an African American woman and a fan of rap music, hospital professionals did not necessarily have to agree with such ideologies in order to effectively reproduce them. Jennifer was constrained by the institutionalized ideological models used to reproduce the BACH music therapy program and thus her position as a music therapist. Regardless of her personal perspective on the legitimacy of these models, to a large extent, they mediated the CDC activities that she carried out with patients.

In the following section, I describe how professionals also judge parental behavior as appropriate or inappropriate and how these judgments rely on ideas about how to properly care for young people.

The Oncology Clinic at BACH

During my fieldwork at BACH, I shadowed physicians and nurse practitioners in the oncology clinic for over a period of three months. I also regularly attended the appointments of eight patients whose cases I followed most closely throughout the study. The clinic is in a building across the street from the immune-compromised ward. Upon entering the building, there is an information desk and a small café with a mix of large and small tables and chairs. The area is designed to evoke a tropical setting, with models of palm trees and large, colorful birds flying overhead. There are also cartoon-illustrated signs posted on the walls informing parents and other caregivers about the importance of talking, singing, and reading to their children, noting the positive effects of such practices on child brain development. The sign is written in several different languages, including English, Spanish, Arabic, and Cantonese.

The oncology clinic is on the second floor of the hospital. For the duration of my fieldwork, the inside of the elevator to the clinic displayed a sign advertising the BACH Research Institute's role in the developing CRISPR, the gene editing technology that has been heralded in the media as holding great potential for the treatment of complex diseases, including cancer, sickle cell anemia, and a number of other ailments that affect young people (Begley 2018; Davis 2018; Fernández 2018). Upon reaching the second floor, the doors of the elevator open into a standard pediatric clinic waiting room, with rows of chairs, and a few toys, magazines, and books. A receptionist checks patients in to their appointments, after which they are eventually called into the clinic by the nurse's assistant, who first records their "vitals" (blood pressure, temperature, and weight) before taking them to an exam room to wait for the nurse practitioner or oncologist.

As the oncology program treats patients with many different diagnoses using many different protocols, patients who visit the clinic are enduring a wide range of treatment regimens (however most involve some combination of chemo- and radiotherapy) and are at various stages in their treatment process. Some are in the midst of the most intensive phases of treatment and are going through intermittent periods of hospitalization and home-based isolation. Others are in less intensive phases of treatment and have returned to school. Others are in remission and only come to the clinic for yearly checkups, which can be a source of great anxiety, but also an opportunity for families and medical professionals whose lives have become intimately intertwined to see each other and visit about life beyond treatment. These interactions often involve the exchange of stories, photos, videos, and gifts—for example, one patient who was a painter gave her favorite nurse an original acrylic portrait of the nurse's terrier in a regal pose against a hot pink background. Often, these appointments also served as a chance for oncologists to gauge patients' and families' "psychosocial situation," which can prompt moral judgment, stigma, and formal and informal referrals to psychosocial professionals.

In the following section, I describe how these appointments commonly unfold, and I provide an example of an interaction that was tinged simultaneously with intimate camraderie, stigma, and moral judgment. In doing so, I also emphasize how patients' and families' imaginative projections of themselves are at times viewed by health professionals as pathogenic.

Big Girls Don't Cry

One day, I arrived at the clinic to shadow one of the neuro-oncologists, Dr. Sherman. I got there a bit early, and she had not yet arrived. I sat waiting in the tiny room known by employees as the "doc box," listening to the nurses and oncologists talk about their weekend: "I finally figured out what brand of veggie dogs they use at the baseball stadium—took me forever, but I found out!" One of the oncologists excitedly told us. The doc box often functioned in this manner, as a space for small talk while professionals waited for patients to arrive. It also served as a place for professionals to check in with each other about issues that arise during appointments. Finally, it served as a record-keeping room, where nurses, nurse practitioners, and physicians would sit staring intently at computer screens, fleshing out their notes and reviewing information between patients' appointments. The room was particularly crowded on this morning—eight healthcare professionals and one anthropologist—as two patients had canceled their appointments. "Geez, we have more providers than patients right now," the veggie dog enthusiast/oncologist commented. A few moments later, the nurse's assistant came in and asked

if someone could check on a parent who had just arrived and was nervously pacing in and out of the exam room.

About ten minutes later, Dr. Sherman arrived, and we went to see the first patient of the day. Her name was Elena, a fifteen-year old Latinx girl who was in remission from brain cancer and was at the clinic for her yearly checkup. On our way to the room, we bumped into Elena's father, who was standing in the hall outside the exam room. Dr. Sherman greeted him warmly with a hug. She introduced me briefly, and I shook hands with him. Dr. Sherman then asked him how he was doing, and he told her excitedly that they had just recently bought a new house. She congratulated him and asked about his sons. He immediately produced pictures of his children, who ranged in age from toddler to teenager. Dr. Sherman commented that she couldn't believe how much they had grown.

After Dr. Sherman finished looking at the photos, Elena's father led us into the exam room where Elena and her mother were waiting. Elena was sitting on the exam table scrolling on her cellphone, and her mother was sitting in a chair against the wall. Dr. Sherman greeted them and asked how they were doing. "We're okay," her mom replied. "It's been kind of a rough month. She's been having lots of pain in her head and neck," Elena's mom said. Elena looked up from her phone and seconded her mother's comment. The treatment process had caused her to develop growth problems and severe scoliosis, or a sideways curvature of the spine. As a consequence, Elena suffered from a great deal of musculoskeletal pain. The treatment process had also caused an issue with her vocal cords that gave her voice a high-pitched and strained quality.

"I'm sorry to hear that," Dr. Sherman said, as she pulled up Elena's chart. "Everything here looks good," she said. "Have you still been seeing the physical therapist?" Elena nodded yes.

"How is everything otherwise?" Dr. Sherman asked. "How is school?"

"I hate it." Elena responded.

Elena's mom interjected, "She thinks the boys don't like her. I told her that's not even it. She thinks it's her looks, but I told her it has nothing to do with her. The problem is that two of her older brothers go to the same school! The boys like you; they're just scared of your brothers!" She looked at Elena and said emphatically. "That's why when I was in high school I didn't even date the boys at my school. I was a player, but all my boyfriends went to other schools," her mother said, laughing and elbowing Elena's father in jest.

"Yeah, right," Elena said sarcastically, rolling her eyes at her mother.

"I have something I wanna show you!" Elena said to Dr. Sherman, changing the subject quickly. "It's a music video I made from my quinceañera!" She said, scrolling through her phone to find the video.

"A music video from your quinceañera?!" Dr. Sherman asked, sounding intrigued.

"Yeah, it only cost us our life savings," Elena's father joked.

"She really wanted one," Elena's mother said. "Honestly, we don't even speak a word of Spanish, and I didn't have one when I was a kid, but she just loves the culture."

Elena pulled up the video and pressed play. The video was extremely high quality, and they had clearly hired a professional to shoot it. It opened with a shot of Elena in a large, fancy red dress and tiara. She was surrounded by other young people in tuxedos and fancy dresses. The song "Big Girls Don't Cry" by the pop star Fergie began to play as a fleet of sleek muscle cars pulled up. One of the boys in a tuxedo opened a car door for Elena as two of her female friends helped her gather the train of her dress and enter the car. The video then shifted to a series of scenes of Elena and her friends enjoying themselves on the car ride, singing along to the song with their hair fluttering in the wind. As the video played, Elena sang along, and her eyes began to tear up as she watched.

"You know why I chose this song?" Elena asked Dr. Sherman. "It's because this was the song I woke up to after surgery," Elena explained, referring to the surgery Dr. Sherman had performed to remove her tumor. Her mother explained that after surgery Elena wouldn't wake up, but then she played this song, and Elena's eyes opened.

"That's really special," Dr. Sherman told them, smiling warmly.

After the appointment, Dr. Sherman and I went back to the doc box, and I noticed she had a concerned look on her face. She told me that, although Elena's family was lovely, she was worried about some of their choices, particularly the music video. "This is not a family that has the resources to be spending on that kind of thing," she lamented. She also expressed concern at the way Elena's mother speaks in front her daughter, pointing out that she didn't think it was appropriate for her to be describing her high school self as "a player."

Capital and the Politics of Fantasy: Biomedicine and Hollywood

Dr. Sherman's response to Elena's music video relied on ideologically mediated standards of child appropriateness and connected them to standards of parental responsibility. In judging the family's use of resources on a quinceañera and a music video, Dr. Sherman was criticizing what she saw as the financial irresponsibility of Elena's parents. Furthermore, in judging Elena's mother's description of her teenage self as a "player," Dr. Sherman was criticizing her for representing herself as sexually promiscuous in front of her daughter. The subtext of Dr. Sherman's comment was that she thought Elena's mother was not acting as a proper role model. In other words, she was performing her parental role in ways that Dr. Sherman deemed pathological.

In pointing out Dr. Sherman's criticism of Elena's mother, I do not mean to negate the warmth and concern that existed between Dr. Sherman and Elena's family. It was clear that Dr. Sherman found the family endearing and that she cared deeply about them. But the race- and class-based tensions of their relationship remained. Dr. Sherman is a white woman with the highest possible level of education in her field and a specialist physician's income. Elena and her family, on the other hand, are Latinx and working class, and cancer treatment for them was not a source of income and prestige, but of economic loss and traumatic memories. Of course, it was also the source of Elena's extended corporeal presence in their lives—a presence that they were no doubt eternally grateful to Dr. Sherman for making possible. At the same time, treatment had permanently affected Elena's embodied existence. She was not the teenager her and her family

had once hoped she would grow into, and the loss of this previously taken-for-granted trajectory created problems and difficult emotions for Elena and her family. Her parents' decision to give her an extravagant quinceañera and a beautifully produced music video can be seen as an attempt to compensate for this loss, and from Elena's perspective, the video was clearly worth every penny.

From Dr. Sherman's perspective, however, the video and quinceañera, although "special," were not a wise use of money. Her judgment is clearly rooted in common standards of parental responsibility that cast "good" parents as those who engage in future-oriented forms of investment for their children, who will ideally grow into healthy, happy, and successful adults. In other words, good parents are those who adequately prepare their children for the demands of developmentalist time, which I analyzed in the previous chapter. As I argued, most young people and their families are attached to some form of developmentalist time. As we can see in the case of Elena and her family, health care professionals sometimes view the ways in which patients and families articulate their relationships to developmentalist time as evidence of psychosocial pathology. Dr. Sherman did not approve of the way in which Elena's parents enabled her to perform her transition into young womanhood with an extravagant ceremony and music video.

Of course, Dr. Sherman's moral judgment did not necessarily have a negative impact on the family, as Dr. Sherman only voiced her critique to me, most likely because she thought that I, a white, middle class researcher, would agree with her assessment. Still, while Dr. Sherman did not raise her critique in front of the family in a way that would directly cause insult or some other form of moral iatrogenesis, I recount this interaction because it is indicative of the subtle ways in which practices of cancer care also function as practices of moral surveillance. Throughout the treatment process, professionals monitor parents and patients for signs of dysfunction, and, in many cases, the identification of such signs can result in increased professional assistance, which also functions as professional surveillance, particularly by social workers. In such cases, if social workers judge families to be unsustainably dysfunctional, they may report the family to child protective services, although they are extremely careful about taking this step, and every effort is made to avoid it.

From the perspective articulated by Dr. Sherman, rather than spending scare resources on things that bring temporary joy, such as music videos and extravagant parties, parents should save money for things their children "really" need, particularly education and health care, as it is often assumed these are necessary ingredients to a healthy and economically successful life. Of course, this perspective would seem to assume that it is possible for families to save enough money to cover such expenditures. Yet it appears that many families simply cannot save the amount of money they would need to cover the costs of care in a neoliberalized health care system, as biomedical expenditures are the biggest source of family debt and bankruptcy in the United States (Himmelstein et al. 2019). Regardless of what Elena's family spent on her music video and party, saving that money would have likely made a small dent in the cost of her treatment. To put things in perspective, the average cost of just one hospital stay for pediatric cancer patients is around $40,000 (National Pediatric Cancer Foundation 2019). Of course, in California, uninsured cancer patients immediately qualify for MediCal, the state-funded health insurance program, but this still leaves many out of pocket costs that families must cover, and caring for a child with cancer often affects parental employment and income.

The tragedy of this situation, however, is not necessarily the high cost of treatment or the fact of bankruptcy. Rather, it is that, for a significant number of families, the hope produced by cancer treatment technologies is no less temporary than the joy that Elena's music video and

quinceañera produced for her. Although oncology saves many young lives, cancer remains the leading cause of disease-related death for people ages 0-19 in the United States (National Pediatric Cancer Foundation 2019). And even for those who survive, life is often irrevocably transformed. As we see in Elena's case, sometimes the iatrogenic effects of treatment permanently changes one's appearance and even one's voice. It also often leads to infertility and an increased risk of developing subsequent cancers. Regardless of whether one agrees with the claim that oncology has the most effective tools currently available for treating cancer, there is no debating the fact that these tools are by no means failsafe or free of costs to those who are subjected to them.

In juxtaposing these points with the story of Elena's music video and Dr. Sherman's reaction to it, my intention is not to simplistically articulate the obverse of Dr. Sherman's critique—in other words, that cancer treatment is a "waste of money" for some patients, who would do better to spend their resources on producing joy with what time they have left on Earth. This is not my call to make. Rather, my goal is to draw attention to the relationship between ideologies of child appropriateness and parental responsibility, on the one hand, and ideologies of hope and judicious investment, on the other. In doing so, it is useful to quote a question raised by Cheryl Mattingly in her analysis of the use of popular children's culture in pediatric settings: "In light of the relentless onslaught of trouble most of these families face, how might Hollywood's happy endings offer a vehicle for hope that is not sheer escapism?" Here I want to note that the way in which Mattingly formulates the question stigmatizes activities that she refers to as "sheer escapism" and locates the potential for their emergence in relation to the fictional stories that circulate in popular youth culture. However, Mattingly suggests that the practices she observed offered patients and families legitimate sources of hope, which she marks as superior to the foolish dangers of escapism.

Here I take a slightly different tack. Rather than defending pediatric uses of children's culture from accusations of escapism, I want to note that certain pediatric uses of biotechnologies could also be seen as escapist and rooted in fantasies of scientific progress—fantasies that I certainly do not mean to demonize, but which I also do not want to uncritically celebrate. Mary-Jo Del Vecchio Good's concept of the "biotechnical embrace" is useful here. As she points out, biomedicine and biotechnologies are tied to what she refers to as "the medical imaginary," which she describes as "that which energizes medicine and makes it a fun and intriguing enterprise" (2001, 397). The medical imaginary gives life to the kinds of experimental research that has produced promising (and extremely expensive) discoveries such as CRISPR, the technology advertised in the elevator at BACH. Such research can result in amazing discoveries that revolutionize human life. But, more often than not, this doesn't happen. As most scientists will admit, true discoveries are extremely hard to come by, and many experimental treatments offer little benefit to the patients who endure them. Yet, much like movie characters, popular songs, music videos, and other forms of children's culture, experimental therapies too often act as powerful sources of fantasy for patients with dismal prognoses.

In this way, we might say that science, biotechnology, and biomedicine, like Hollywood, produce their fair share of escapism. But rather than stigmatizing the practices of either biomedicine or Hollywood, I want to acknowledge the legitimacy of desiring, even fantasizing about, an escape from the ravages of cancer and other life-threatening illnesses. To demonize imaginative practices as no more than deluded retreats from reality is to rob people of one of their most crucial resources for dealing with illness, suffering, and death. Here I reiterate Scheper-Hughes and Lock's observation, which I discussed in the introduction: "it is impossible

to rid powerful human experiences of metaphor, of cultural representation [or of other imaginative elements]" (1986, 138). At the same time, it is important to be realistic about the heterogeneous effects of all manner of imaginative practices, which produce hope, joy, and practical solutions, but also debt, loss, alienation, and stigmatization.

End Notes

[1] Many scholars have argued that this particular understanding of childhood is an invention of Western modernity (e.g., Ariès 1965; Malkii 2010; Mead 1928; Scheper-Hughes and Sargent 1998; Stephens 1995). While this is a contentious area of debate, I do not have space here to describe the various positions that have emerged. Here I take the position that the dominant ideologies of childhood that play a productive role in pediatric contexts have been introduced and enforced by bourgeois, Euro-American populations, but they have since become globalized and appropriated by many people who do not identify as bourgeois or Euro-American. Of course, this begs the question of whether ideologies should be identified with their originating group once they have been widely circulated and taken up by many groups. It also begs questions of power and the extent to which the adoption of an ideology is voluntarily undertaken or externally imposed. This question is also beyond the scope of this chapter, but I hope to explore it in later work.

[2] I later discovered that Haamid was a sickle cell anemia patient who was preparing to undergo a stem cell transplant in attempts to cure his disease. I ultimately included him in the study because he received the same psychosocial services as cancer patients, he was hospitalized in a space that was primarily populated with cancer patients, and stem cell transplantation is also commonly used in cancer treatment.

[3] In light of my discussion of ideological models, I want to stress that the CDC model is no less ideological than any of the non-academic models discussed here. What makes it unique is that it derives from *anthropological* ideologies, which are arguably very useful tools, although, like any ideologies, they enable one to see some things and not others.

Chapter 6
Conclusion

In this dissertation, I have attempted to demonstrate how ideologies of youth, communication, and care intersect in producing the field of pediatric cancer treatment and the individual cancer treatment trajectories that unfold within it. In doing so, I hope to have shed light on issues that negatively affect young cancer patients, particularly those identified as teenagers, and their families. As with most dissertations, this one has raised more questions than it has answered, and I do not purport to have solutions to these problems. As a number of trusted advisors have reminded me, this is only the beginning of my research, not the end. I hope that this dissertation will serve as a point of departure for more work in the field of pediatric cancer treatment.

In order to conclude, I want to briefly review what I see as the four main takeaways of this work, particularly for scholars in anthropology and childhood studies, although these findings may also be of interest to people who work in the field of pediatric cancer treatment. In my time at BACH, I found that many professionals were open to critical analysis of their work, and many were actively seeking out new ways of thinking about pediatric care. For example, my pediatrician colleague who connected me to the BACH oncology program was actively involved in attempts to circulate the emerging model of "structural competency" (Metzl and Hansen 2014) among BACH professionals. This is just one example. Many BACH professionals regularly hosted and attended events to foster critical discussions about issues that affect their patients. In the future, I would like to condense the findings of this dissertation into a talk or workshop designed for cancer treatment professionals.

After discussing the major takeaways of this work, I will then briefly discuss its limitations. I will then close with a discussion of possible directions for my own future work in the field of pediatric cancer treatment.

1. The ideological model of multidisciplinary pediatric cancer care—which Sidney Farber and his colleagues famously developed as "total care" at the Jimmy Fund Clinic—has taken on many iterations, playing a profound role in producing the field of pediatric cancer treatment.

Through historical and ethnographic analysis, I have attempted to show how the ideological model of "total care" has been institutionalized in cancer treatment centers throughout the world, including BACH. Of course, the iterative circulation of any model gives rise to transformations—some subtle, some drastic—and the model of total care is no exception. To say that total care has shaped the institutionalization of care in multiple sites is not to say that the model has been carbon-copied and installed in identical form at each site. Rather, it is to say that the general model, which emphasizes the necessity not only of biomedical care, but also of psychosocial care for patients *and* their family members, has served as a source of inspiration in the institutional development of many pediatric cancer treatment centers.

While virtually all pediatric cancer treatment centers in the United States offer both biomedical and psychosocial care, they do not do so in the same ways. For example, the extent to which smaller cancer treatment centers can mimic world-renowned centers like the Jimmy Fund Clinic is limited by the capital they are able to generate in support of their institution. As I reviewed in chapter two, part of the reason the Jimmy Fund Clinic was initially so successful at

developing its total care program is because of the cultural, social, and economic capital generated through the activity of Sidney Farber, his colleagues, and his wealthy friends. Farber and "the Laskerites" were the first to mobilize images and narratives of young cancer patients within a vast advertising apparatus that enabled them to raise unprecedented amounts of money for cancer research and care programs.

Since that time, such advertising and fundraising practices have become standard features of the field of pediatric cancer treatment in the United States. Most of us have seen ads from organizations such as St. Jude's, which feature pictures of smiling, bald children beckoning us to donate money or participate in some kind of fundraising activity, like head shaving or running a marathon. National and local advertising and fundraising apparatuses enable the project of total care, and those institutions that have the greatest ability to tap into donor streams are able to develop their programs to the fullest extent.

As I described in chapter three, BACH is a "safety net" hospital and thus did not have the same level of resources as other local hospitals. For example, one of the private hospitals in the area offered a dedicated program for adolescent cancer patients. Given BACH's relatively limited resources, hospital professionals were unable to offer such a program, even though they did offer the "Teen Lounge" for the general patient population, and they made efforts to design activities and services that would speak to the interests of adolescent cancer patients. Although BACH struggles to stay afloat economically, it is nevertheless located in one of the wealthiest regions in the world, and professionals and hospital administrators are often able to cobble together enough support to maintain a range of psychosocial care programs for cancer patients. These include art therapy, music therapy, and play therapy. As I have shown in the preceding chapters, this work is facilitated by professionals equipped with various instruments, techniques, and ideological models of care and child-directed communication.

2. Ideological models of pediatric cancer care intersect with models of communication and childhood/youth.

Building on previous studies of "disclosure" in the context of cancer treatment, I argue that ideologies of pediatric care intersect with ideologies of communication and youth. As other scholars have shown, professionals, patients, and families often view certain styles of communication about cancer as more caring than others. For example, earlier studies of disclosure in the United States found that professionals and family members often attempted to shield patients from the knowledge that they had cancer. In pediatric contexts, this was viewed as especially necessary in many cases, as it was assumed that young children would not comprehend death and that they should be protected from the negative emotions associated with it. However, as Bluebond-Langner argues, young people's awareness of events is not limited to what adults explicitly tell them, and most of the patients in her study demonstrated awareness that they had cancer and were dying. Despite this, they made attempts to conceal this awareness from their parents, leading to a situation in which both parties upheld "mutual pretense" (Glaser and Straus 1965). It would seem that children, too, were attempting to care for their parents by refraining from discussing the devastating topic of their illness.

Although I witnessed many attempts to avoid the discussion of uncertainty and to present information in the most optimistic manner possible, my fieldwork at BACH revealed that there has been a massive shift at the intersection of models of pediatric cancer care and communication among professionals and families in the United States. In contrast to Bluebond-

Langner's study, I found not only that the illness and treatment process were openly discussed in front of many children and young people, as most professionals now view such discussions as beneficial to the patient. It would seem that the dominant model described by Bluebond-Langner has flipped, and now, rather than viewing young people as in need of protection from knowledge of their illness, it is much more common for professionals to view them as entitled to information. Many professionals expressed very strongly that they believe patients have a right to know what is happening to them. Furthermore, they stressed that non-disclosure was always an ineffective approach insofar as most patients know something is terribly wrong with them. Regardless of what they are told, there are countless other ways in which young people gather information about their condition. Non-verbal sources of information include: the experience of excruciating symptoms and side effects, the observation of parents' and professionals' bodily gestures and facial expressions, and the fact of having one's life practically reoriented and re-temporalized around the prescribed activities of the treatment protocol. These are just a few examples.

While most families opt to follow the lead of professionals and tell their child about their diagnosis, some are reluctant to take this advice, which they view as potentially harmful to their child. In such cases, professionals make every attempt to respect the models of communication that the family wishes them to observe. However, difficulties often arise, as young people frequently ask questions about why they are in the hospital and why they are going through certain procedures. In cases where families do not want children to know about their diagnosis, professionals are often able to navigate such questions skillfully without mentioning cancer. However, a number of professionals also suggested that, while they were willing to try to avoid the topic of cancer when speaking with patients whose families opted for non-disclosure, they refused to outright lie to the patient. For example, if a patient blatantly asks "Do I have cancer?" some professionals see it as their duty to be honest. While I heard stories about such interactions in interviews, I did not personally work with any families who adopted a model of total non-disclosure.

As I've already emphasized, children's hospitals, despite their name, serve many patients who are not socially recognized as children, but rather as adolescents or teenagers. Developmentalist models of youth are in circulation, and the manner in which patients are positioned vis-á-vis such models has effects on the ways in which professionals enter into interactions with young people. At BACH, the care team attempted to design services for teenagers. These included the Teen Lounge, Thursday Night BINGO, *Good Morning BACH*, and teen-only art and music therapy group sessions, although these were not carried out on a regular schedule due to resource limitations.

Despite the recognition of a need for differentiated services, I argue that the field of pediatric cancer treatment, and perhaps pediatric biomedicine in general, is characterized by a kind of habituation that leads professionals to reproduce specific forms of "child-directed communication," even when working with young people who are not socially classified as children. This is in part related to the architectural design of the hospital as a "CDC habitat" equipped with a range of "CDC artifacts" that can create a kind of spectral child presence even in the absence of actual children (Ochs, Solomon, and Sterponi 2005). This is also related to the fact that the habituses of professionals, patients, and their family members are attuned in different ways to standards of "child appropriateness" that shape institutional policies and practices. As we saw in the music therapy sessions I recounted in chapter five, these standards can be seen as enacting forms of infantilization and leading certain patients to censor their self-

expression in ways that ultimately work against therapeutic engagement. Furthermore, standards of child appropriateness are often used as standards of moral judgment that can lead to the race- and class-based stigmatization of specific patients and families. For example, patients and families who were viewed by professionals as behaving inappropriately may become the subjects of gossip and increased professional surveillance. In a very few number of cases, professional surveillance can lead to state involvement—for example, in cases where parents are struggling with substance use issues that professionals believe have rendered them unable to care for their children in an appropriate manner. Although I did not witness any such cases at BACH, there are also documented cases in which parents have lost custody of their children for refusing treatments that professionals view as necessary (Burke 2019).

3. The iterative circulation of ideological models of care, communication, and youth do not merely regulate the field of pediatric cancer but play a role in actively producing it.

As I discussed in chapter two, studies of "disclosure practices" have relied on a conceptual framework of "communication regulation," which does not account for the role that ideological models of communication play in producing the very phenomena they seem only to describe. In contrast to these studies, I propose the concept of pediatric communicability, which stresses the (re)productive relationship between "biocommunicable models" (Briggs 2005) and the various material circuits and social positions through which knowledge and narratives about health are made to circulate. These circuits, positions, and circulatory processes do not exist independently of the ideological models that mediate them, but neither are they carbon copies of these models.

The point I am making here builds on decades of work on the "performative" function of language and communication in linguistic anthropology and sociolinguistics (Austin 1962). In contrast to "referentialist" ideologies, which view language as simply referring to objects that exist independently of it, concepts of performativity stress the manner in which linguistic and communicative practices produce worlds and objects, as opposed to merely describing or referring to them. Concepts of communicability draw on this understanding of performativity on both a pragmatic and metapragmatic level. In other words, communicative positions, roles, and processes are produced not only through the pragmatics of symbolic interaction, but also through the projection of metapragmatic models, which Briggs (2005) refers to as "biocommunicable models" when they pertain to biomedical contexts.

The actual circulatory processes that produce care and communication in the field of pediatric cancer, as in any field, are always more complex than they are made out to be in metapragmatic models, which I refer to as *pediatric communicable models* in this context. Ideologies and practices do not circulate freely, but neither do they obey the boundaries and hierarchies projected in pediatric communicable models. Rather, pragmatics and metapragmatics exist in productive tension. The actual unfolding of pragmatic processes is produced in part by attempts to metapragmatically model them. At the same time, the construction and citation of metapragmatic models is to some extent dependent on pragmatic processes. In a sense, metapragmatic models can be seen as "structuring structures," to use Bourdieu's term. As discursive structures that can be iteratively cited, ideological models of all kinds can exert productive effects in the settings in which they are deployed, but they are also structured by the pragmatic processes through which they emerge. In other words, pediatric communicable models exist in a kind of feedback loop with pragmatic processes.

It is through the productive effects of these models and processes that individual participants are positioned as professionals, patients, and family members in the field of pediatric cancer treatment. In chapter two, for example, I described Sidney Farber's biography, discussing the processes through which he received a medical education and became a pathologist. Farber, like all physicians, had to inhabit the role of "medical student" for years before he was permitted to participate as a physician in the field of pediatric cancer treatment. It was in part by submitting to the ideologically mediated pragmatics of medical education that Farber was able to secure the cultural capital necessary to enact the transformations he did in the field of pediatric cancer treatment.

To take the example of cancer patients, it is not simply the presence of the physiological process that we call cancer that makes an individual person into a cancer patient. As I show by recounting the diagnosis and treatment narratives I co-produced in interviews with Rachel, Jun, and Jared, individuals do not become cancer patients at the precise moment when the first cancer cell emerges in their body, but they instead must go through a series of social interactions with biomedical professionals. Patients or their loved ones must describe their symptoms, and professionals must run tests that reveal a cancer diagnosis and justify a referral to an oncologist. All of these processes are guided by various pediatric communicable models, which persist through both formal institutionalization and informal convention.

As I've already noted, pediatric communicable models intersect with ideological models of care and youth. The pragmatic hybridization of these ideologies endows them with unique forms of moral force that shape interactions among individuals who are positioned as health care professionals, patients, and family members. For example, in chapter four, I describe how cancer diagnosis produces a temporal rupture, or what Jain (2013) calls a "collision in modes of time" that is shocking and terrifying for patients and families, most of whom did not expect to confront a potentially terminal diagnosis at such a young age. As I argue, most patients and families tended to identify with developmentalist models of childhood/youth in ways that amplified the moral force of cancer diagnosis and treatment. By positioning themselves according to developmentalist models of time and the life course, patients and families had become attached to viewing certain forms of childhood, adolescence, and adulthood as expected and desirable. In threatening their relationship to those future projections, cancer diagnosis inevitably produced intensely negative emotions. However, cancer treatment provides a potential pathway back to developmentalist time, and many patients and families, at least initially, place their faith in the expertise of oncologists. Yet oncological expertise is notoriously uncertain, and a significant number of patients tragically never resume movement along the tracks of developmentalist time.

I argue that this raises questions about the commonly made distinction between being and becoming that characterizes a great deal of work in childhood and youth studies. By showing that young people themselves are attached to developmentalist frameworks, I question the claim that such frameworks are necessarily oppressively imposed by adults. In order to make such a claim, it seems that one would have to rely on a concept of misrecognition that views young people as ideologically blinded by developmentalist models. This strikes me as an elitist and dubious way out of the problem. While I do not wish to challenge all critiques of developmentalism, I nevertheless question what strikes me as a desire to freeze time and to demonize future-oriented projections of young people's lives as mere epiphenomena of projects of capitalist accumulation.

4. The total care model, like all models of biomedical care, carries the potential to produce both therapeutic benefits and iatrogenic harms, and intersecting ideologies of youth and communication shape the production of these harms.

As models of care are put into practice, they do not function exactly as planned. There are always mutations, unexpected events, and processes of hybridization that produce variation and uncertainty. The field of pediatric oncology is particularly rife with uncertainty, partially because the biomedical technologies upon which cancer treatment relies are intensely iatrogenic, and they cause patients many problems at the same time as they hold out the promise of therapeutic benefit. While the iatrogenic physical and psychiatric effects of treatment technologies such as chemo and radiotherapy are widely recognized by biomedical professionals, here I have attempted to draw attention to the *morally iatrogenic* effects of total care. In doing so, I do not mean to equate the severity of different forms of iatrogenesis. Some forms are certainly subtler and less harmful than others, but I think all forms warrant recognition.

One potential source of moral iatrogenesis that struck me as particularly common at BACH was the child-directed nature of the children's hospital habitat, as well as the artifacts that populated it and the ideologies and semiotic repertoires that constituted professional caregiving practices. The hospital, like most children's hospitals, was designed in a way that evoked the presence of children even in their absence. The aesthetics of the hospital décor, the children's toys, the miniature furniture—all of it contributed to the child-directed ambience of the hospital. Professionals and volunteers, including me on occasion, amplified this ambience even more by engaging in various forms of child-directed communication (Ochs, Solomon, Sterponi 2005). Sometimes this happened in the form of simplified speech patterns and tone alteration. Other times it happened via the citation of what I described, drawing on Giroux (1994), as "Disneyfied" children's songs, televisions shows, movies, etc. An ethic of child appropriateness shaped professional practices, and many patients' habituses were already attuned to this ethic for having spent time in other child-directed spaces, such as day cares and schools.

Another way that moral iatrogenesis can occur in cancer treatment is through the "collision in modes of time" enacted by diagnosis and treatment. For virtually all patients, to be suddenly removed from one's place in developmental time and to have one's life totally re-oriented around a treatment protocol is a shocking experience. As I described in chapter four with the case of Rachel, some patients responded much more intensely than others to the anxiety, isolation, and loneliness of being removed from everyday routines and modes of temporalization. Here I want to suggest that the concept of moral iatrogenesis might offer an alternative to more individualizing psychosocial interpretations of treatment related distress. Rather than drawing attention to factors like "coping skills," as Dr. Bhandari did in Rachel's case, an interpretation rooted in the concept of moral iatrogenesis would emphasize the myriad forms of harm and loss, both potential and actual, that weigh on patients and families throughout the treatment process. This is not to deny that individuals can possess or actively develop "coping skills," but rather it is to question the value of emphasizing perceived individual deficiencies in moments of intense suffering.

Another form of moral iatrogenesis that occurred less frequently at BACH was the stigmatization of certain patients and family members. However, this often happened in complex ways, and, for the most part, professionals avoided expressing negative opinions about patients in front of them. For example, in the previous chapter, Dr. Sherman did not voice her criticism to Elena's family, but only to me. This was a common approach—professionals kept blatant

criticism of patients contained to inter-professional dialogues. However, as we saw in the case of the nurse who referred to Devon in derogatory, racialized terms, the professional stigmatization of patients can happen in front of other patients. Such situations, even if the stigma was not directed at the patient involved in the interaction, can act as a source of moral iatrogenesis. Rashad, for example, identified with Devon on a personal level, and he was therefore angered and offended by the nurse's comment.

Although I am focusing on what clinicians might label "psychosocial" mechanisms of iatrogenesis, I also want to stress their entanglement with the more commonly recognized iatrogenic effects of biomedical cancer treatment technologies. Moral iatrogenesis does not only derive from having one's life spatially, temporally, and practically re-arranged, or from social processes like infantilization and stigmatization. It also derives from the changes in body image and capacity that accompany the violent processes of treatment. Sometimes these changes are only temporary, and patients eventually recover. Other times, as we saw in the case of Jared, who had to undergo the amputation of his arm, iatrogenic effects are permanent and can have profound consequences on the manner in which one is able to lives one's life.

Here I want to reiterate the reasoning behind the term moral iatrogenesis. The term may cause confusion in that the word "moral" is often associated with good and bad actions. In this usage, a person who behaves morally is someone who has done what is viewed as good from the perspective of a particular morality. But I have a broader meaning of the word "moral" in mind. Following anthropologists who have developed notions of "moral experience" (Kleinman 1999) and "critical moral anthropology" (Fassin 2012a), I use the term "moral" to refer not only to people's sense of right and wrong, but to encompass all of the values that animate their sense of "what matters most" in life, to use Kleinman's phrasing. Moral iatrogenesis occurs, then, when some form of biomedical or psychosocial care causes harm or insult to some highly valued element of existence. For example, when Jared lost his arm to cancer, this was not only an instance of physical iatrogenesis, but it was also moral in the sense that it did it harm to his future projections of himself as a professional basketball player.

In addition to the harms of clinical and moral iatrogenesis, I have also argued, following Stonington and Coffa (2019), that cancer patients and their family members are affected by structural iatrogenesis, which refers to the ways in which "structurally vulnerable" (Bourgois et al. 2017; Holmes 2011) populations are systematically harmed by biomedical and psychosocial ideologies and practices of care. For example, the high cost of cancer treatment in a neoliberalized health care system systematically harms low-income families who are underinsured. And the moral iatrogenesis that I argue is associated with subjection to child-directed ideologies and communicative practices is also arguably a form of structural iatrogenesis insofar as it may systematically affect teens.

Limitations

As I described in chapter three, this dissertation is based on 18 months of fieldwork at BACH. This involved participant observation in the form of volunteering and shadowing physicians, as well as interviews with professionals, patients, and parents. Twenty-four families and eighteen biomedical and psychosocial professionals participated in the study. With the exception of nutritionists, at least one professional from every discipline on the frontline care team participated in the study.

As my strategy was to recruit a variety of professional participants who could speak to different aspects of total care, I did not interview and shadow a large number of professionals in any single category. The small sample size and diversity of professional categories included in the sample makes it difficult to make generalizations about any specific profession. Although the small and heterogeneous sample presents limitations, I nevertheless want to stress the value of spending more time with a small group of people and getting to know them in a more in-depth way than a standardized interview or survey would permit. Furthermore, through volunteering, I was able to observe many things that I could not include in my formal record of data, but which nevertheless informed my analysis.

Another limitation of the sample was that it primarily included English speakers, although a very small number of Spanish speaking patients and family members were also interviewed. Initially, I had hoped to recruit and interview more Spanish speakers, but I was nervous about carrying out the interviews in a sensitive manner given that I am still in the process of developing my Spanish speaking abilities. I therefore recruited an undergraduate student who is a native Spanish speaker to help me conduct the interviews. However, it proved to be extremely difficult to work around her busy schedule, and we did not end up completing many interviews. I also had a somewhat difficult time recruiting Spanish-speaking families, and one of the social workers suggested to me that this may have had to do with anxieties related to the currently hostile political climate around undocumented migration, which strikes me as a reasonable explanation for not wanting to be unnecessarily interviewed.

Future Work

I do not see this project as the end of my work in the field of pediatric cancer, and, if anything, it has only opened up questions that I hope to continue exploring in settings beyond BACH. Here I will discuss several different issues that I want to explore in subsequent research. While my primary method will remain fieldwork, I am also interested in collaborating with researchers who do more survey-oriented work in order to explore questions at different scales and using a variety of techniques. At some point, I also hope to do as I had originally planned and develop a collaborative project with young people who have been directly affected by cancer, either as patients or as siblings of patients. Now that I have actually carried out fieldwork in a pediatric institution, I believe I will be better equipped to design a project that meets institutional standards of ethical review.

Cancer Genetics and Genetic Counseling

There is existing work in anthropology and related disciplines on the genetics of cancer (Fujimura 1996; Gibbon 2007). However, none of this work focuses on pediatric populations. In order to address this gap, I would like to carry out future work that looks at a number of questions related to this issue. First, I am interested in the ways in which cancer experts and professionals use genetic discourses to make sense of differences between pediatric and adult cancers. One thing that I heard multiple times among oncologists at BACH was that pediatric cancers are almost always genetic, while adult cancers are overwhelmingly related to "lifestyle factors." I would like to further interrogate this distinction, asking how it relies on ideas about the individual responsibility and thus culpability of adult patients in contrast to the innocent victimhood of child patients. I am also interested in exploring how the discourse of pediatric

cancers as genetic leads to a certain sense of inevitability, almost implying that there is nothing that would have prevented these particular children from getting cancer, as if it is their genetic fate.

Another genetics-related aspect of cancer care that I would like to explore is the role of genetic counseling in making treatment decisions. This was not something that I asked about it in interviews, and no patients or family members brought it up, although physicians mentioned it several times. In the future, I would like to consider the pediatric communicable models that guide these practices of genetic counseling, asking what assumptions they make about parents and patients and how those assumptions shape the manner in which genetic information is presented in specific instances.

Finally, another genetics-related aspect of pediatric cancer treatment that I would like to explore is the emergence of genetic editing as a potential tool in cancer treatment. Although there are currently no such treatments in use among pediatric oncologists, they have been widely touted as the potential future of cancer medicine, and I would like to explore how oncologists, patients, and families interpret these promises. Furthermore, as genetic editing potentially comes into fruition as a legitimate and widely used treatment strategy, I hope to document the process through which it is adopted.

The Politics of Pediatric Cancer Fundraising

As I described in the introduction with the vignette of the shave-a-thon and in chapter two with the account of Sidney Farber and the Laskerites' fundraising strategies for the Jimmy Fund Clinic, fundraising has a major impact on pediatric cancer in the United States, and many different organizations exist that raise money for various issues, such as cancer research and family assistance. A number of organizations, such as the Make-a-Wish Foundation, also exist, and they provide special gifts and trips to patients and families in attempts to bring them joy after going through a dismal process. I would like to explore in more detail how fundraising organizations of multiple kinds function and to consider how political and economic issues shape how they articulate their mission.

Another aspect of fundraising that I am interested in is the role of images and narratives of patients in mobilizing resources. What kinds of images and narratives circulate most widely, and how do fundraising organizations choose them? How are they received, and in what ways do they compel people to donate time or money? Upon what ideologies of youth do such images and narratives rely?

Programs Designed Specifically for Adolescent Patients

Cancer researchers have noted a disparity in cancer treatment outcomes among "AYAs," or adolescent and young adult patients (Smith et al. 2019). Out of pediatric patients, those who are diagnosed with cancer at the age of fifteen or over are seen as having significantly worse odds of survival. This has given rise to a number of debates as to what's the driving these disparities, and it has led professionals to develop models of care specifically for these patients. Although BACH did not have a dedicated adolescent oncology program, there are a number of cancer treatment centers throughout the US that do provide such services. In the future, I would like to identify such a program and study it ethnographically.

I am interested in two different aspects of adolescent cancer care programs. First, following from this study, how do professionals re-articulate ideologies of care and communication around figures of adolescence as opposed to childhood, and how might this require a reconstruction of the habitat of the average children's hospital, as well as the introduction of new artifacts that facilitate professional care and communication? What forms of youth culture do professionals draw upon, and how do the standards of "appropriateness" that guide their citations get re-configured in relation to ideologies of adolescence? Second, how do young people interpret such programs, and how do they shape individual cancer treatment trajectories? How do particular individuals take up the position of adolescent patient, and what forms of biosociality do such programs foster between patients?

The Intersection Between Cancer Stigma and Age, Race, Class, and Gender

Although the issue of stigma surrounding cancer was raised by Sontag (1978) decades ago, no anthropological study has systematically looked at the ways in which pediatric cancer patients are affected by various stigmas related to the disease and treatment. Stigmas related to altered appearance, diminished bodily function, and death at a young age often affect patients in different ways. In the future, I would like to explore how stigma shapes and is shaped by various elements of positionality, particularly race, class, gender, and age. How do stigmas related to these other categories intersect with the stigmas of cancer, and how do patients make sense of and cope with any negative emotions or other consequences of being subjected to stigma?

The Afterlife of Iatrogenesis

As I learned from the oncologists with whom I worked, "late effects" are one of the major issues that can affect patients even decades after treatment. In addition to the iatrogenic effects that accompany the most intensive phases of treatment, there are also many potential delayed iatrogenic effects that may arise years later—for example, cardiac problems or the development of another cancer. Furthermore, many patients are affected by intense memories of the treatment process that weigh on them well after the completion of treatment. In the future, I would like to consider how people who went through cancer treatment as children manage all of these potential "late effects," particularly those related to the emotional weight of treatment memories.

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